

OBSESSIVE COMPULSIVE HOARDING: AN EXAMINATION OF THE EFFECT
OF TRAUMA ON HOARDING BEHAVIOR

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OBSESSIVE COMPULSIVE HOARDING: AN EXAMINATION OF THE EFFECT
OF TRAUMA ON HOARDING BEHAVIOR

A Project

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Abstract

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Hoarding is a disorder that has recently gained public attention due to the disastrous effects the behavior can have on those who suffer from it, as well as on the community. Despite growing awareness, research on the topic is still somewhat limited. This qualitative study seeks out the voices of key informants in the community who come into contact with hoarders in a variety of different capacities in an effort to add to the research base and determine what effect trauma has on hoarding behavior. Seven respondents were interviewed for this study, which revealed the following themes: 1) budget cuts will reduce services to hoarders in the Sacramento Area, 2) no available mental health services for hoarders, 3) trauma leading to hoarding typically not addressed in assessment and treatment, 4) current intervention strategies promote relapse by not addressing behavioral causes, 5) gap between empirically proven treatment methods and actual practice in the Sacramento area. The project is concluded with a summary of findings, implications for social work practice, and recommendations for future research.

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Date

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Chapter 1

THE PROBLEM

Introduction

Growing up I have always known that my father is a pack rat. He loves to save tools, car parts and things that peak his interest. Being in construction, he is always bringing home building materials from job sites new and old which he claims are still of value and can be used again. Over the years, it seems that he has thrown very little away, and the forty five acres of property on which his house is located is littered with broken down vehicles, scrap metal, and all types of miscellaneous objects. He is not prone to being organized which lends itself to cluttered garage spaces and living areas that appear unkept. This has always been a source of contention in the family as other members wish to live a lifestyle with less seemingly useless clutter desecrating what would otherwise be a beautiful country landscape. While searching for a thesis topic that peaked my interest, my advisor recommended I look into hoarding as a potential project. Immediately I thought of my father and his unusual saving behaviors. I even thought that by gaining knowledge on the topic I might be able to help my dad make some lifestyle changes. Early on in my research I realized that there is a difference between a pack rat and a hoarder and that my father does not fall into the latter category.

In September of 2008, I began my second year Master of Social Work (MSW) internship with the UC Davis Linkages program. At this placement, my job was to provide targeted case management to the frail elderly and disabled population with the goal of preventing or delaying premature institutionalization. It was through this

internship that I met a client who fit the definition of hoarding. Because my supervisor knew that I was studying hoarding, a referral was sent my way for a client exhibiting hoarding behavior. Upon arriving at this client's home I immediately noticed the putrid smell of rotting garbage, animal urine, and feces. As I entered the home it became apparent that there were stacks of random items such as news papers, furniture, old computer parts, and clothing throughout the entire premises. The clutter was so profound that there was only enough room for a narrow walkway from room to room. The kitchen was filled with items to the point that it was unusable. The bathroom was in a similar state of uselessness, however the client stated that he removed the items that filled the tub twice a week in order to bath. Our assessment was completed on the edge to the client's bed which was the only place in the small condominium with enough room to sit down. Even the bed was piled with items leaving only enough room for myself, the client, and the client's large pit bull terrier. I left the assessment with the understanding that my father may not meet the definition of clinical hoarding and that it was clients like this one that have raised interest in the community about this fascinating disorder known as compulsive hoarding.

In the 1990's little was known about hoarding and there was very little research on the topic. However increased media attention on cases of hoarding that have led to tragic consequences has led to public awareness, more research, and even a show on the A&E channel entitled "Hoarders" that is dedicated to the syndrome.

Background of the Problem

Compulsive hoarding is mostly studied in the context of Obsessive – Compulsive Disorder (OCD). OCD, which is characterized by recurrent intrusive thoughts and ritualized actions, affects between 1% and 3% of the population (Wheaton, 2007). Hoarding symptoms occur in nearly one-third of obsessive-compulsive patients (Frost, Krause, & Steketee, 1996). However there is little research on hoarding that examines the prevalence of this problem outside the context of OCD. The acquiring and collecting of possessions, in humans, can be seen as a useful tool to ensure survival of the species in times when commodities are sparse (Grisham & Barlow,2005). When it is taken to the extreme, as in the case of compulsive hoarding, acquisition and collection are no longer helpful survival tools, but become the physical manifestation of a serious mental illness. Compulsive hoarding can be defined as “the acquisition of, and failure to discard, possessions which appear to be useless or of limited value” (Frost & Gross, 1993), and having living spaces that are so cluttered, the activity for which the space was originally designed is no longer possible (Frost & Hartl, 1996) (for example not being able to use the bedroom for sleeping, the kitchen for cooking and so on). Compulsive hoarders have such an excessive accumulation of goods, that their living conditions create serious fire, and health and safety hazards (Frost, Steketee & Williams,2000). These hazards affect not only the individual(s) living amongst the clutter, but also family, neighbors, and fire and rescue personnel who may have reason to enter the dwelling. Many basic home maintenance tasks go undone because repairmen either cannot physically access the item or because they are denied entry to the home due to the embarrassment felt by the

hoarder. This leads to unsafe homes and apartments in disrepair sometimes even leading to condemnation.

Additionally, one of the most common problems in the elderly population is falling. Unintentional falls affect at least thirty percent of the population of those aged sixty-five or over each year (CDC,2007). Compulsive hoarding has been discovered to be a significant problem in the elderly population, particularly those with dementia (Steketee, Frost, & Kim,2001). Living in a home filled with clutter greatly increases the likelihood of a fall.

It is estimated that 1 to 2 million Americans exhibit behavior that could be described as compulsive hoarding (Feusner & Saxena, 2005). We can only speculate as to how many family members and members of the general community are affected, but based on the above numbers a likely guess would put the number in the millions. Compulsive hoarding can have dramatic consequences on the individual and the community at large (Frost & Steketee,1999). The excessive accumulation of possessions can pose fire, health and safety hazards. The most commonly hoarded items are newspapers, magazines, lists, receipts, old clothes, letters, mail, bags and books (Frost et al., 1993, Kaplan & Hollander, 2004, Saxena et al., 2002, Winsberg & Koran, 1999). All of these are extremely flammable and are frequently piled near heat sources such as stoves or furnaces, making ignition possible. The means of egress from a dwelling that is congested with debris can be significantly restricted or, in extreme cases, blocked altogether making exiting in the case of an emergency difficult or impossible. In addition, excessive debris can also result in substantial hazards to anyone seeking access

in order to address an emergency situation. The sheer volume of material can make a fire harder to control (Frost et al., 2000). The excessive volume can also overstress joists and beams causing structural overload. When this occurs, floor systems crack, sag, or even collapse. When hoarding extends to the kitchen, the excessive grease, food, and trash add to the potential for a fire and can create severe insect and/or rodent infestation. In addition, the constant exposure to dust, pollen, bacteria and the unhygienic conditions created by the accumulation of excessive debris can pose significant health problems to both the hoarder and the surrounding community. If the hoarder lives in close proximity to other dwellings, the excessive amount of flammable materials makes the spread of fire to other inhabited residents much more likely. If vermin are attracted to the hoarders dwelling, they may spread to other areas of the community. However, most neighbors tend to complain about unpleasant smells emanating from a hoarders home or unsightly yards filled with clutter that may even encroach across property lines (Frost et al., 2000).

The monetary ramifications of hoarding are endless. From squandering inheritances, to creating situations where children must financially support parents who have spent their savings compulsively shopping, to the money it takes to clean a hoarder's home. A common problem among hoarding individuals is losing valuable items including money, jewelry, and family heirlooms. These items are mixed in and lost with rubbish because a hoarder attributes special value to everything. When everything is seen as precious, truly meaningful and valuable items are lost in heaps of trash. Finally, complaints about a hoarder usually involve multiple community agencies, resulting in significant monetary cost to the community (Frost et al., 2000).

Statement of the Research Problem

Understanding the causes of hoarding, especially the effect of trauma on hoarding behavior is crucial to appropriate treatment of this population. However, there is an obvious lack of focus on this aspect of the disease in actual practice in the Sacramento area. Although limited, research has outlined some best practices for dealing with hoarding clients, but in reality these practices are not utilized leading to the ongoing vulnerability of the hoarding population in this area.

Purpose of the Study

The purpose of this study is to qualitatively analyze issues surrounding the hoarding population in the Sacramento area, including actual practice with the population, and the effect of trauma on hoarding behavior. This project builds on a 2006 study of compulsive hoarding by California State University Sacramento Master of Social Work Student Kimberly Dochterman in an effort to understand hoarding as a disorder in Sacramento. Through a review of the literature and interviews with seven community professionals experienced in working with this population, this project will attempt to help foster understanding of a population that is gaining increased attention from the community and social work professionals.

Theoretical Framework

This research project is based on Cognitive Behavioral Theory (CBT). Cognitive Behavioral Theory attempts to explain human behavior by understanding thought processes. The assumption being that humans are logical beings that make the choices that make the most sense to them (Frost & Hartl, 1995). In CBT “information

processing” is a commonly used description of the mental process, comparing the human mind to a computer. Hoarding is a disorder that is largely based on decision making. Decisions to save and decisions to discard are the mental processes that create or prevent hoarding behavior. Cognitive Behavioral Theory describes in depth the information processing deficits that cause a person to hoard. Frost & Hartl (1995) provide a model for viewing hoarding through a Cognitive Behavioral lens that is used throughout this research project. This model includes examining a hoarder’s deficits in categorization/organization, difficulties with memory, emotional attachment problems, behavioral avoidance, and faulty beliefs about the nature of possessions. By focusing on these deficits, how they are created and how they can be treated, treatment methods based on CBT have proven to be useful. The theory posits that hoarding is not simply a bad habit of a lazy and messy person, instead, it is a behavior that is deeply ingrained in the thought processes of an individual.

Definition of Terms

Obsessive Compulsive Disorder: A psychological disorder whose essential features are recurrent obsessions or compulsions that are severe enough to be time consuming or cause marked distress or significant impairment (American Psychological Association, Diagnostic and Statistical Manual of Mental Disorders, 4th ED., Text revised, 2000, P. 456).

Compulsive Hoarding: The acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value; living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and

significant distress or impairment in functioning caused by the hoarding (Steketee & Frost, 2003).

Hoarding Behavior: Saving or collecting of items that may fit one or more of the three part definition above for compulsive hoarding, but that does not fit the diagnostic requirements for compulsive hoarding.

Pack Rat: An individual who exhibits hoarding behavior but does not meet the criteria for compulsive hoarding.

Activities of Daily Living (ADLs): Functions such as cooking, cleaning, dressing, grooming, and bathing. These things are referred to in the study as being affected by hoarding.

Assumptions

Hoarding is most often associated with and studied in the context of Obsessive compulsive disorder (OCD). The research design, including the questions asked in the interview guide, assume that hoarding is its own distinct OCD subtype that requires research outside the context of Obsessive compulsive disorder. This assumption is not supported by the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) in that hoarding is not addressed in this way, however, the research supports viewing hoarding as its own separate classification.

Justification

“The primary mission of the social work profession is to enhance human wellbeing and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty”

(NASW Code of Ethics, 2008, pg.1). Hoarders are a population in the community who live in the shadows. Their disorder is one that causes the basic functions for human well being to fall by the wayside. Without treatment and assistance their health and safety are at risk. They are vulnerable to medical problems, homelessness, social isolation, and even death. This project will attempt to uncover inconsistencies between empirically proven treatment methods and actual practice in the Sacramento area in an effort to benefit this vulnerable population. Additionally, the effect of trauma on hoarding behavior will be observed and analyzed in an effort to uncover the causes of the disorder so that practitioners can better serve the population.

Limitations

This research project is limited to interviews with members of the community who have experience working with hoarders. Unfortunately, it does not include information gathered from individuals who suffer from compulsive hoarding due to the potential risk that would be posed to clients as human subjects in this study. A study on hoarding not taking into account the voices of hoarding clients cannot be considered complete, however, effort was made to obtain information from key community players that would benefit the population itself.

Additionally, family often plays a large part in the life of a hoarding individual, however, in this study family issues are not addressed. Family support issues, isolation from family, family conflict as a result of hoarding, loss of children to child protective services could all be looked at in future studies.

Chapter 2

LITERATURE REVIEW

Although the body of research on hoarding is relatively limited compared to more established disorders, the following is a summary of the literature on hoarding including seven themes that emerged during the researcher's review of the available material.

Themes reviewed include: obsessive compulsive disorder, obsessive compulsive disorder and hoarding, historical context, current status of the research, reasons hoarders collect, theoretical context, treatment, and hoarding and trauma. Together, these themes provide an overview of hoarding as a disorder.

Obsessive Compulsive Disorder

Obsessive –compulsive disorder (OCD) is a mental disorder in which obsessive thoughts and compulsive behaviors replace functional behaviors (Wilhelm, Tolin & Steketee, 2004). Engaging in these compulsive behaviors allow the OCD individuals to use avoidance mechanisms against unpleasant thoughts or situations. Four principle OCD symptom factors exist. These features consist of (1) checking compulsions related to sexual, religious, or aggressive beliefs; (2) obsessions with symmetry/order causing ordering and organizing compulsions; (3) obsessions with contamination leading to compulsions of washing and cleaning; and lastly (4) saving or hoarding behaviors (Saxena & Maidment, 2004).

Individuals with OCD often feel a sense of “incompleteness” which initiates the practice of many compulsive behaviors, especially those related to exactness. Anxiety is one essential component of OCD and frequently occurs with depression in as much as

30% of individuals within the OCD population (Wu & Watson, 2004). The OCD population, which consists of only 3% of the general population, is approximately equal in its distribution between genders. The onset of OCD can occur as early as childhood, although symptoms typically develop during the adolescent years. Many compulsive behaviors are displayed across the OCD population with hand washing and compulsive checking as the most common. OCD patients frequently exhibit co-morbidity with several other disorders including many types of depressive disorders, eating disorders, anxiety disorders as well as neuropsychiatry disorders including schizophrenia, dementia, and mental retardation (Saxena & Maidment, 2004).

Obsessive Compulsive Disorder and Hoarding

The practice of hoarding is frequently seen in individuals with OCD. Frost & Hartl (1996) outlined the first widely accepted definition of hoarding identifying three characteristics: “(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” (Frost & Hartl, 1996, pg.341). Hoarding behavior is not considered pathological unless accompanied by extreme clutter (Frost & Steketee, 2003). In severe cases, hoarding and the subsequent clutter created can prevent the completion of basic activities of daily living (ADLs) such as cooking, cleaning, moving through the house, and even sleeping. Interference with these activities makes hoarding a dangerous problem, putting people at risk of fire, falling, poor sanitation, and health risks (Damecour & Charron, 1998; Frost, Steketee, &

Williams, 2000). Hoarding's harmful consequences range from failure to pay bills, to injury, and even death when a pile of refuse falls over. Severe self-neglect in elderly persons can also accompany hoarding behavior, resulting in nutritional deficiency and other health problems. Named Diogenes syndrome, after the Greek philosopher who lived in a barrel, this condition represents the most clinically severe end of the hoarding spectrum (Brown & Meszaros, 2007).

Although it is possible to solely be affected by hoarding, compulsive hoarding is only listed in *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* (American Psychiatric Association, 2000) as a symptom of obsessive compulsive personality disorder (OCPD). Hoarding is thought to be linked to the perfectionism criterion level used in diagnosing OCPD (Seedat & Stein, 2001). Hoarding has been viewed as a possible link connecting it to psychotic, emotional, and obsessive-compulsive disorders (Greenberg, Witztum & Levy, 1990). It is important to note that the DSM-IV does not list hoarding behavior in the diagnostic criterion for OCD despite the frequent occurrence of hoarding in OCD. For this reason, many researchers have difficulty in describing hoarding in relation to OCD. However, simply put hoarders seem to be obsessed with being caught without a needed item and then compelled to save over and over beyond their needs (Steketee, Frost & Kim, 2001).

Hoarding has been described in many different ways in relation to OCD. Through previous literature published on this topic, hoarding has been referred to by a variety of titles including a symptom of OCD, a variant of OCD, and a manifestation of OCD (Wu & Watson, 2004). Individuals diagnosed with OCD who experience hoarding behaviors

as their predominant symptom dimension of OCD are said to be affected by “compulsive hoarding syndrome” (Saxena et al., 2002; Steketee & Frost, 2003). OCD compulsive hoarders exhibit more severe displays of symptoms as well as higher occurrences of functional impairment as opposed to their non hoarding OCD counterparts (Saxena & Maidment, 2004). Individual cases of hoarding can range from mild displays of hoarding behaviors to life-threatening severity (Frost & Gross, 2003). Hoarding compulsions and obsessions develop independently from each other (Baer, 1994; Leckman et al., 1997). Previous research in determining the prevalence of hoarding behaviors in the OCD population has indicated that between 18-42% of adults diagnosed with OCD exhibit hoarding practices (Frost et al., 2000) and between 11-42% of children and adolescents suffering from OCD display hoarding tendencies (Seedat & Stein, 2001). Evidence that gender does seem to play a role in hoarding practices has also surfaced through research studies (Samuels, et al., 2002). Hoarding was seen twice as frequently in males than in females. It is also important to note that although most researchers presume that hoarding is a symptom of OCD, this remains an unanswered question. In fact, a substantial number of those who hoard display no other OCD symptoms. Whether hoarding in these cases is actually OCD or a separate or co-occurring disorder is not clear (Steketee & Frost, 2003).

This researcher feels it is important to note the distinctiveness of compulsive hoarding from obsessive-compulsive disorder. While previous research has interpreted the comorbidity between OCD and hoarding to suggest that hoarding is a subtype of OCD, one study conducted by Grisham and colleagues (2004) suggests that hoarding lies

on the spectrum of OCD-related disorders such as Tourette's syndrome, trichotillomania, and body dysmorphic disorder. The study provides evidence that hoarding may be a compulsion for some OCD individuals, however, hoarding in the absence of other OCD symptoms may be a clinically distinct syndrome (Grisham, et.al.,2004). These findings support the notion that hoarding may be better conceptualized as an impulse control disorder, because many individuals appear to derive pleasure from hoarding behavior. Hoarding has been associated with the spectrum of impulse control disorders (ICDs), including trichotillomania and skin picking (Samuels et.al.,2002), compulsive buying (Frost et.al.,1998), and gambling (Frost,et.al.,2001). Hoarding behavior, like ICDs, is positively reinforcing to the individual and is associated with a wide variety of emotional states, including pleasure or gratification. In these cases, hoarding behavior would not be accompanied by the distress and anxiety associated with symptoms of OCD (Grisham et.al.,2004).

Historical Context

Historically, hoarding has been discussed in the works of many psychoanalysts. The term "hoarding" was originally coined by Rapoport (as cited in Frost & Gross, 1993) in order to discuss animal behaviors regarding the storage of food. Other studies on hoarding in animals show that hoarding throughout time has been highly conserved across species. Animal research normally focuses on food hoarding, however, birds and other animals also collect foil, beads and other brightly colored objects (Brown & Meszaros, 2007). The concept of hoarding was first used to describe this collective behavior in humans in a 1966 study conducted by Bolman and Katz (Maier, 2004). In

this study, Bolman and Katz used the term compulsive hoarding to discuss their findings in an anecdotic case report. From an evolutionary perspective, the propensity for humans to collect or hoard could have been extremely beneficial during times of crisis and need (Leckman & Mayes, 1998). Hoarding has been linked to Sigmund Freud's anal stage of development (Freud, 1908). Freud suggested that hoarding was related to the infant's anal fixation, and that it symbolized fecal retention. Freud also linked hoarding to orderliness, parsimony/miserliness and obstinacy which he observed in hoarding and other obsessive-compulsive behaviors (Frost & Gross, 1993; Greenberg, 1987; Kyrios, Steketee, Frost & Oh, 2002).

There have also been theories suggested regarding hoarding that are not supported by empirical evidence. The idea that hoarding behavior is somehow linked with an individual experiencing material deprivation at some point in their lives such as in the case of a survivor of the great depression is not supported by the research (Frost & Gross, 1993; Greenberg, 1987). However, Fromm (1947) theorized that individuals who hoard relate to the world around them by forming attachments to possessions rather than other people. From this perspective, hoarding beliefs and emotional attachments to possessions may develop as an attempt to compensate for an impoverished or problematic social environment. Due to this long standing development of the notion of hoarding, it is surprising that so little research on hoarding behaviors has actually been conducted. Empirical research on hoarding was not completed until the early 1990's. Hoarding has been seen in a variety of other disorders including schizophrenia, primary degenerative

dementia, and eating disorders and has historically been studied within these contexts (Greenberg et al., 1990).

Current Status of the Research

In recent years, the issue of compulsive hoarding has gained increased attention due largely to increased media coverage of extraordinary tales of compulsive hoarders. Of particular interest to this researcher was the discovery that up until the 1990's there had been virtually no research done on the subject whatsoever. Randy Frost and colleagues have since led the effort in investigating compulsive hoarding. They have discovered specific character traits common to hoarders (Frost et al., 1996), developed a measure for hoarding behavior (Frost, Steketee & Grisham, 2003), made a link with compulsive hoarding and compulsive buying (Frost, Steketee & Williams, 2002) and illustrated how compulsive hoarding extends into the community (Frost et al., 2000). Saxena and colleagues (2004) are leading the current effort in the investigation of whether hoarding behavior might be related to specific neurological characteristics by identifying what a hoarder's brain activity looks like. Finally, compulsive hoarding is most frequently considered to be a component of OCD, although it is actually listed in the DSM-IV-TR as a component of obsessive compulsive personality disorder (OCPD) and absent in OCD (American Psychiatric Association, 2000). Compulsive hoarding is not typically presented for therapy by itself. It is more frequently associated with Obsessive Compulsive Disorder (OCD) (Frost et al., 1993) and Obsessive Compulsive Personality Disorder (OCPD) (American Psychiatric Association, 2000), as well as Anorexia, Schizophrenia, Dementia, Autism, Schizotypal Disorder (Kaplan & Hollander, 2004),

PTSD, Major Depression (Frost et al., 1996) and Attention Deficit/Hyperactivity Disorder (Hartl, Duffany, Allen, Steketee & Frost, 2005). Research on hoarding in this decade and the one past make clear that there are many questions left unanswered (Steketee & Frost, 2003). It is not known whether hoarding warrants its own classification in future editions of the DSM-IV-TR, or whether it should continue to be considered merely a symptom of other disorders such as OCD and OCPD. One thing is for sure, hoarding is gaining attention in the community. One cable television channel (A&E) has recently created a weekly, hour long, documentary style program dedicated solely to hoarding. The show is entitled *Hoarders*, and will begin airing in the summer of 2009.

Reasons Hoarders Collect

Within compulsive hoarding, two distinct tendencies, instrumental saving and sentimental saving, have been classified as separate issues (Frost & Gross, 1993). Instrumental saving occurs when individuals save items in order to fulfill a projected specific need sometime in the future. Compulsive hoarders often feel they are being resourceful and thrifty by saving items that they perceive themselves using at some point in the future. Sentimental saving, on the other hand, has little to do with the functioning purpose of a specific item. Rather the accumulation of these items surround the emotional attachment that compulsive hoarders associate with all of their inanimate possessions (Frost, et al., 1998).

Based on the research done by Frost and Hartl (1996), there is evidence supporting the concept that compulsive hoarders use the clutter they collect as a form of

comfort and security. Frost and Hartl (1996) went on to coin the term “hypersentimentality” to discuss the deep emotional investment compulsive hoarders place on their clutter. In a study performed by Coles, Frost, Heimberg & Steketee (2001), a strong relationship was displayed between anxiety sensitivity and hoarding behaviors. Since compulsive hoarders experience heightened levels of anxiety when discarding their belongings, these individuals fear the grief-like emotions that would come with the disposal of clutter. Because of this, anxiety sensitivity may increase the likelihood of developing hoarding tendencies.

In early studies on hoarding, Furby (1978), suggests that the value an individual places on a possession is directly related to their personal beliefs regarding power. For example, Furby states that one major reason that hoarders decide to hold onto these items is their concept that each object will provide them with some sense of control over their environment in the future. As seen in the work of Frost and Gross (1993), compulsive hoarders do exhibit a need for control over their lives just as Furby had predicted years earlier.

Theoretical Context

Throughout the research, Cognitive Behavior Theory is used to frame hoarding behavior. Using this Cognitive-Behavioral Model, Frost and colleagues have discovered several character traits common to individuals exhibiting hoarding behavior. They appear to suffer from large deficits in the ability to process information, this trait manifesting itself as a lack of organizational skills and chronic indecisiveness (Frost et al., 1996). They exhibit a great deal of behavioral avoidance usually in the form of

avoiding any acknowledgement of a problem altogether. They have difficulties in forming emotional attachments (to people) and harbor faulty beliefs about the nature of possessions (Frost et al., 1998). They become so emotionally attached to their possessions that they appear to have no room in their lives for emotional attachments to people. They appear to take great comfort from and experience an unaccountable degree of safety with regards to their possessions, feelings that are normally derived from relationships with other people. They also report problems with memory and great difficulty organizing and/or categorizing things and information (Frost et al., 1996). Compulsive hoarders have great difficulty parting with their collection of useless items due to many erroneous beliefs they have regarding the future usefulness of their clutter. This is partially due to the compulsive hoarder's commonly experienced desire to conserve and waste as little as possible. Ironically, hoarders often are perfectionists holding on to these useless objects in order to be better prepared if they need such an item in the future (Frost, et al., 1998).

Information Processing and Perfectionism

Deficits in information processing are a distinguishing feature of compulsive hoarding. Frost and Gross (1993) state that hoarding is an avoidance behavior tied to indecisiveness and perfectionism. They suggest that saving allows the hoarder to avoid the decision required when discarding a possession, and to avoid the worry that a mistake had been made when something is discarded. Hoarders go to great lengths to avoid making decisions for fear of making a mistake (Frost et al., 1996). Hoarders attempt to limit if not eliminate the potential for making mistakes by saving practically everything.

By doing so, they avoid potential regret for having discarded something they later discover a need for. Akin to aspects of OCPD, hoarders tend to be overly concerned with perfectionism (Frost et al., 2002). They can become so consumed by it that they fail to complete important tasks and can even lose touch with the initial pertinent activity. When faced with the task of sorting through possessions and making decisions as to what to save and what to discard, compulsive hoarders can become so preoccupied with ensuring that piles line up and are appropriate for each item, they forget all about the initial task of discarding. The consequence of years and years of avoidance leads to an entirely new obstacle. The immense effort required to sort through decades of collecting is enough to make even a well adjusted person want to avoid it (Greenberg, 1987).

Emotional Attachment and Lack of Insight

Compulsive hoarders have a tendency to become extremely emotionally attached to their possessions (Frost et al., 1996). They frequently feel their possessions to be an extension of themselves (Frost et al., 1996). When other people touch, move or use their possessions without permission, compulsive hoarders report feelings of excessive anxiety, loss of control and a sense of having been violated (Frost et al., 1993). Compulsive hoarders have reported inexplicable feelings of safety and security simply by being in the presence of their possessions (Frost et al., 1996). When faced with the challenge of discarding such items, hoarders have compared the resulting sensation to that of losing a close friend or loved one. These emotional attachments are what well adjusted people strive to achieve in their relationships with other people. It has been noted that most hoarders are single (Feusner et al., 2005) which would seem to

substantiate the preceding data. Two types of emotional attachment exist. Pure sentimentality exists when a possession is seen as a part of the self and getting rid of it would be like losing a close friend (Frost & Hartl, 1995). The second type of attachment is related to items being seen by a hoarder as a sense of comfort and indicating of a safe environment (Frost & Hartl, 2005).

Compulsive hoarders are unable to grasp the fact that they are hindering the functioning of their own life by refusing to part with such a large quantity of possessions. They are preoccupied by their hoarding to the detriment of other areas of their lives. Hoarders may be unemployed or unmarried as a result of their condition (Hartl & Frost, 1998), and women sometimes let their children fend for themselves sometimes to the point that Child Protective Services becomes involved or physically removes children from the home (Wheaton, et. al.,2007). Hoarders are often secretive about their behavior and attribute it to external factors and seek salvation through manipulation of their environment rather than changing themselves. These behaviors highlight the extreme lack of insight common to hoarders (Greenberg, 1987).

Frost and colleagues (2002) have also discovered an interesting link between compulsive hoarding and compulsive shopping. Compulsive hoarders and compulsive shoppers share excessive emotional attachment to possessions as well as a sensation of excitement experienced during the acquisition of things, particularly the acquisition of free things. Compulsive shoppers exhibit great difficulty in resisting a bargain. The result being that they acquire an inordinate amount of things for which they have no need

simply because said things were “too good to pass up” (Frost et al., 2002). For hoarders, this is just one more way to increase the amount of their possessions.

Problems with Memory and Organization

Compulsive hoarders tend to believe that they have weaker memories than non-hoarders (Saxena & Maidment, 2004). In a study conducted by Hartl et al. (2005), hoarders have reported significantly less confidence in their memory than non-hoarders. Interestingly, the results of this same empirical test show that compulsive hoarders do in fact seem to recall less than their non-hoarding counterparts on both visual and verbal assignments. Though the results of this study are limited, this research provides evidence that compulsive hoarders do in fact have weaker memories than non-hoarders.

Furthermore, OCD has been associated with memory problems independently of the research regarding memory strength and hoarding (MacDonald, Antony, Macleod, & Richter, 1997). Due to these memory deficits, compulsive hoarders reinforce their need to have so many possessions; they fear that they may forget where they have put specific items so they deem it a necessity to keep all of their clutter out in plain view in order to avoid losing the items.

Due to their perception of junk as potentially useful, compulsive hoarders have tremendous difficulty in the organization of their possessions. This is in view of the fact that compulsive hoarders tend to attach so much sentiment to their belongings that each item becomes irreplaceable and unique in their eyes (Saxena & Maidment, 2004). Since each item is seen as unique, when organizing, a hoarder usually ends up with far too many categories that are too narrowly defined also referred to as under-inclusiveness

(Frost & Gross, 1993). For example, when organizing paperwork a hoarder might try to create a filing system with a filing cabinet. However, since each individual piece of paperwork is seen as unique and important, every scrap would be thought to need its own file. The result would be a house full of filing cabinets with far too many files (categories) and no real organization (Maier, 2004). Another consequence of under-inclusiveness is that all attributes of a possession must be considered before discarding it. Because each possession is unique and complex, it is not possible to decide that a class of objects, like old newspapers, is unimportant and can be thrown out without close examination (Frost & Hartl, 1995).

As opposed to non-hoarders, compulsive hoarders also tend to be more easily distracted and have difficulty concentrating for a long period of time. Not only are compulsive hoarders unable to sort their possessions, they tend to avoid daily tasks that would seem trivial to non-hoarders. For example, many compulsive hoarders have reported avoiding activities including regular correspondence such as returning a call, going through junk mail, or even paying their bills on time (Neziroglu & Tobias, 2004). When compulsive hoarders finally decide to attempt organization, it takes significantly longer to complete such tasks. Instead of immediately dealing with the issue at hand, compulsive hoarders are known to spend a great deal of time partaking in an activity known as “churning” (Saxena & Maidment, 2004). Churning involves constant movement of items from pile to pile with very few items actually being thrown away.

Treatment

Compulsive hoarding is notoriously resistant to treatment and family members', therapist, and other outsiders attempts to intervene have a tendency to worsen relationships and further the hoarder's social withdrawal (Feusner et al., 2005). Interestingly, few OCD compulsive hoarders have a grasp on the severity of their disorder or just how much clutter they have accumulated over the years of hoarding (Greenberg, 1987). Compulsive hoarders tend to minimize both the frequency of their hoarding behaviors as well as the excessive amount of items in their possession. A hoarder rarely admits to being anything more than a bit messy or disorganized and they feel that they could manage all of their belongings if they chose to do so. Furthermore, hoarders believe that the most effective way to help them deal with their problem would be to provide them with more monetary funding or the availability of more space for their items (Greenberg, 1987). Individuals suffering from compulsive hoarding rarely seek out help for themselves. This may be due to the fact that compulsive hoarders believe that their behaviors are greatly attributed to external factors (Feusner et al., 2005).

Since hoarding is so closely linked with Obsessive-Compulsive Disorder (OCD), many of the treatment modalities applied to hoarders were intended for use on OCD individuals. However, many possible treatment procedures that have been at least somewhat effective for non-hoarding OCD individuals have been ineffective for hoarding OCD individuals. For example, serotonin reuptake inhibitor treatment (SRI) has been used for both OCD hoarders and non-hoarders. Although this procedure has been shown to be effectual for OCD non-hoarders, OCD hoarders demonstrated little to no

responsiveness to SRI treatment. This may be reflective of the typical lack of insight, perfectionist behaviors and magical thinking related to discarding objects that is experienced by most hoarders (Saxena & Maidment, 2004). Strong associations have been made between hoarding and saving compulsions and poor response rates to SRIs (Black et al., 1998; Mataix-Cols et al., 1999; Winsberg et al., 1999). In a study conducted by Mataix-Cols (1999), the higher an OCD patient scored on a scale of hoarding symptoms, the less likely they would respond to SRI treatment methods. Similar results were found when observing the effectiveness of cognitive behavioral therapy for hoarding and non-hoarding OCD patients. Non-hoarders were much more likely to be receptive to treatment than those with compulsive hoarding tendencies (Black et al., 1998). Since OCD hoarders do not seem to benefit from the more typical treatment procedures used for OCD, research has been done in an attempt to isolate hoarding as a 'subtype' of OCD with different physiology or microanatomy instead of merely a diagnostic indicator for OCD (Brown & Meszaros, 2007).

For effective treatment of hoarding, research strongly suggests examining several aspects of the individual. Such features include: (1) the amount of clutter accumulated; (2) beliefs regarding their possessions; (3) deficits in information processing; (4) avoidance behaviors; (5) daily functioning; (6) medication compliance; (7) levels and reliability of insight; and (8) social and occupational functioning (Saxema & Maidment, 2004). Frost and colleagues have developed a new CBT treatment plan that has shown some effectiveness based on four main issues faced by compulsive hoarders (Hartl & Frost, 1999; Steketee & Frost, 2000). These four areas are (1) deficits in information

processing, (2) emotional attachment issues, (3) avoidance behaviors, and (4) false beliefs regarding their possessions. The goals of this treatment plan are threefold. The plan involves trying to remove a large percent of the clutter from the home to the point of returned functioning within the space, helping the individual strengthen their decision making ability as well as their organizational skills, and teaching each compulsive hoarder how to successfully resist their future urges to accumulate new clutter. This is accomplished through specialized CBT for hoarding behavior including training in decision making, categorizing possessions, exposure to discarding, and cognitive restructuring. These components should be combined in “de-cluttering” therapy sessions followed by homework assignments to practice learned techniques. The client should make all decisions and be made to feel in control while the therapists role is to assist in decision making skills, provide feedback on normal saving behaviors, and identify and challenge distorted thinking (Frost & Hartl, 1996). Above all any person assisting with de-cluttering, organizing, or cleaning of any kind must not allow their own personal bias toward cleanliness disrupt the process. It is important to remember that not all possessions or clutter need to be removed, just enough to reduce fire and health hazards (Brown, 2007).

Hoarding and Trauma

In her 2008 study on compulsive hoarding, Dochterman indicates that more research is needed regarding the effect of trauma on hoarding behavior. Throughout the research there is little material available on the correlation between the two. However, in one study, compared to individuals with OCD who did not meet the criteria for hoarding,

participants classified as hoarders were significantly more likely to have reported at least one Traumatic Life Event (TLE) in their lifetime (Cromer, et al., 2007). Frost and Hartl (1996) remarked on a number of clinical cases where compulsive hoarding was reported immediately following a trauma. Another hypothesis is that in response to a threatening environment, possessions acquire an association with safety and security (Hartl, et al., 2005). Interestingly, Frost and colleagues (2005) found that traumatic events were reported more frequently in a general sample of hoarders (not evaluated for OCD or other psychiatric diagnoses) compared with a non-hoarding community control sample.

In a 2004 study Hartl and colleagues studied aspects of post-traumatic stress disorder and attention deficit/hyperactivity disorder (ADHD) among hoarders. Compared to a sample of 36 controls, hoarding patients (28) reported a significantly greater number of different types of trauma, more frequent traumatic experiences, more symptoms of hyperactivity, inattention, and greater comfort derived from possessions. Types of trauma included natural disasters, accidents, sexual and physical abuse, assault, serving in combat, illness, rape, and tragic death of a loved one. This data suggests a strong link between traumatic experiences and compulsive hoarding. PTSD diagnosis were reported more frequently in the hoarding group, and hoarders reported significantly greater number and frequency of different types of trauma. Interestingly, hoarders tended to differ from controls in the frequencies of traumas that reflected physical and sexual abuse. It may be that hoarders come to trust the safety of objects as opposed to people due to histories of abuse. Participants in the study also reported having stronger feelings of attachment, security, and comfort in their possessions (Hartl, et.al., 2005).

The onset of hoarding in patients with traumatic brain injury, stroke, and neurodegenerative diseases also points to the possibly critical role of brain trauma or injury in hoarding clients (Brown & Meszaros, 2007). Recent studies have begun to pinpoint the specific brain circuits involved. Saxena and colleagues (2004) found that persistent hoarding behavior developed in 13 of 87 patients with brain lesions. Frost (1998) pointed out that patients with certain types of dementia seem especially prone to hoarding. This suggests that trauma to circuits in the brain that normally inhibit hoarding behavior are interrupted.

Age of onset might also be relevant to trauma as it relates to hoarding behavior. Grisham and colleagues (2005) investigated the age of onset of compulsive hoarding. Individuals with a later age of onset were more likely to report a traumatic event directly prior to the onset of symptoms, compared with those with an earlier age of onset. In the study some patients reported that the behavior began in response to a stressful life event, while others describe a slow and steady progression throughout their lives (Grisham, et.al.,2005).

The current literature provides support for a link between trauma and hoarding, however, more empirical research is needed. Studies evaluating the presence of hoarding symptoms in relationship to the experience of trauma, the influence of trauma on the severity of hoarding symptoms, and the association between trauma and the three facets of hoarding: clutter, difficulty discarding, and acquisitioning is needed (Cromer, et al., 2007).

Summary

Although hoarding is a disorder that has been identified and studied since the eighteenth hundreds, only recently has increased attention to the phenomena in the media created a desire for new understanding. Hoarding does not have its own clear cut spot in the scientific literature and much debate remains regarding whether or not hoarding should be lumped in with OCD or be considered a diagnosis on its own. Hoarding can be serious and even life threatening; however, the behavior is resistant to treatment. With more research being done on the topic than ever, new treatments are being developed that utilize the cognitive behavioral model that is often used to frame hoarding as a basis that have shown some effectiveness. Some evidence has been uncovered that may lead to a possible link between trauma and hoarding, however more research is needed. This project will seek to explore this need.

Chapter 3

METHODS

Research Design

The design for this study is based on a 2007 CSUS Thesis project on hoarding by Kimberly Dochterman. It utilizes a similar qualitative research strategy and attempts to build on her indications for future research. Qualitative research was selected for this particular topic due to the researchers belief that hoarding can best be understood by studying the human experience of this behavior from the perspective of those who have experienced it (Yegidis,2002). The project is exploratory in nature in that it seeks to add information to an area of social work research that has previously received little attention (Steinberg, 2004). As the literature review illustrates Hoarding has only recently gained the public attention necessary to prompt scholarly research on the topic. An exploratory research design is appropriate for a project on hoarding because the behavior has been identified as a problem, however, understanding of the problem is quite limited. Thus, this project intends to build on the groundwork laid by the project before it and hopes to set the stage for other knowledge building that will follow.

Grounded theory was selected as the research theory base for the project. Grounded theory is based on the premise that the meanings people give to their experiences are very important in understanding behaviors and events. It holds that people construct their own meanings for behavior based, in part, on their interactions with others. Grounded theory research thus lends itself particularly well to social work research (Yegidis, 2002). Seven community agents were interviewed in an effort to

analyze the meaning that they have attributed to their experience dealing with clients who hoard. The information collected was then used by the researcher to generate a hypothesis.

Data Analysis

Each interview was transcribed by the researcher at which time open coding was used to conceptualize and categorize the data. Coding is a crucial part of qualitative data analysis in that it assists with the discovery of patterns in the data. These patterns point to theoretical understanding of social life (Rubin & Babbie, 2005). In this project, the researcher focused on uncovering themes within the data related to the effect of trauma on hoarding behavior. Each interview was closely examined for similarities and differences, broken down into parts, and questions were asked about hoarding as it was reflected in the data. Phenomena that stood out in the data were then categorized and named. Four overlaying themes were identified as the result of this process (Rubin & Babbie, 2005).

Subjects

Seven community agents were located who have come into contact with hoarders in a variety of different capacities. Participants were recruited using two types of nonprobability sampling. The first five interviewees were located via purposive sampling and included three geriatric case managers, one mental health professional, and one code enforcement agent. These subjects were selected based on the researchers knowledge of the population and the specific aims of the project (Rubin & Babbie,2005). The hoarding population is small as is the number of key informants in the community who have come

into contact with them. Seeking out appropriate interviews using the researchers' judgment along with the purpose of the study represented the most efficient sampling procedure.

The researchers' internship at the UC Davis Linkages Program allowed for an introduction to the phenomena of hoarding as well as to community agents that have worked with hoarders. The researcher was allowed to review files of hoarding clients and request participation in the project from agents identified from the files. During these interviews the researcher utilized a snowball sampling technique by asking subjects for referrals to other community agents who may have information relevant to the project. Snowball sampling is useful when members of a special population are difficult to locate as is the case with hoarding clients and those who have worked with them (Rubin & Babbie, 2005). Data was collected from the interviewees the researcher identified and located. These individuals were then asked to provide information on other potential subjects relevant to the project. Two more interviews were scheduled based on the information gained with a Sacramento Sheriff's deputy and an Adult Protective Services case manager.

Instrumentation

The instrument used during subject interviews was created by the researcher. An interview guide was utilized featuring open ended questions in two sections. Open ended questions were used due to the high likelihood that the range of responses would be too great for the researcher to anticipate, to avoid suggesting possible responses to participants, and also to allow the researcher to collect data in the form of direct

quotations. Direct quotations were important in this project as they proved to be very meaningful in presenting participants' attitudes and opinions (Yegidis, 2002). The sections included experience working with hoarders (six questions) and causes of hoarding behavior (3 questions). This type of instrument allowed the researcher the flexibility to ask follow up questions depending on the subjects experience and answers to the guide questions in an attempt to elicit information pertinent to the research project. A structured approach was used when creating the interview guide, meaning that all respondents were asked the same questions in the same sequence, in order to increase the comparability of responses and to ensure that complete data was gathered from each person on all relevant questions (Rubin & Babbie, 2005). However, an attempt was made by the researcher to remain conversational during the interviews thus remaining free to probe into unexpected responses. The questions were derived from the review of the literature as well as the findings from Kimberly Dochterman's 2007 CSUS thesis project. The questions were designed to gain as much information as possible on hoarding and with attention to the effect of trauma on hoarding behavior.

Data Gathering Procedures

The Data in this study was gathered through interviews with community agents who have come into contact with hoarding behavior in the course of their work duties. Face to face interviews were conducted, each lasting 45-60 minutes. Written permission was obtained from the agency director to use a conference room at the UC Davis Linkages facility to conduct the interviews. The conference room is secluded and the doors were closed during all interviews to protect subjects' confidentiality. Six of seven interviews

were conducted in this conference room while the seventh was conducted in an office at the Sacramento County Sheriff's station. All interviews were tape recorded with permission of the subjects so that the researcher could later transcribe and analyze the data. Notes were also taken by the researcher during the interviews on answers to questions that were thought to be of extreme importance. Upon completion of data analysis all tapes and notes were destroyed in order to further preserve subject confidentiality.

Protection of Human Subjects

The Protocol for the Protection of Human Subjects was submitted and approved by both the university's Graduate Studies Department and the CSUS Division of Social Work as posing minimal risk. At the beginning of each interview, both researcher and participant signed the informed consent form. The form indicates that interviews are voluntary and explains that if any discomfort is experienced by the interviewee as a result of the questions asked or the interview process, the interview could be terminated at any time. Before beginning the interview process, the researcher asked each subject if they anticipated any negative feelings or reactions as a result of reliving some of their experiences working with clients who hoard. If there were none, the interview commenced after the researcher advised each participant to be aware of their emotional state during the process and to terminate the meeting if they became uncomfortable.

Participants were informed on the consent form as well as verbally that their anonymity would be protected by assigning a number to their interview that would be used instead of their name in data analysis and the final project. Participants were also

reminded not to provide any identifying data on the hoarders that were discussed during the meeting so as to protect client confidentiality. All tapes and subject contact information was destroyed upon completion of data analysis to further protect confidentiality. The interview guide, informed consent form, and Protocol for Protection of Human Subjects can be found in Appendix B of this project.

Chapter 4

OUTCOMES

Upon completion of the interviews, the data was analyzed by the researcher and five overlaying themes were drawn from the data. Those themes included 1) California's budget crisis will severely affect services to local hoarders 2) There is a lack of mental health services specific to hoarders 3) The trauma and behavioral problems that lead to hoarding are typically not addressed in assessment and treatment 4) Current intervention strategies promote relapse by not addressing the behavioral causes of hoarding and 5) There is a gap between empirically proven treatment methods and actual practice in the Sacramento area. What follows is a description of the subjects who participated in the study followed by a discussion of the five themes that resulted from the subject interviews.

Description of Participants

A total of seven interviews were conducted to complete this project. Each interview was conducted with a community agent who has worked with hoarding clients during the performance of his or her job. Each subject has had experience working with hoarding clients in different capacities and thus each was able to lend a unique perspective to the project.

The first two interviewees were geriatric case managers from the UC Davis Linkages program. The UC Davis Linkages program provides targeted case management to the frail elderly and disabled population with the goal being to prevent or delay premature institutionalization. The first subject was this researcher's field instructor, a

forty-five year old Caucasian male with nineteen years experience as a case manager. Subject number one stated that he has come into contact with more than ten hoarding clients during the course of his work with UC Davis and has personally case managed seven of those individuals. Subject one made it a point to mention that he feels Linkages is one of the community's main assets in terms of assisting hoarding clients. He stated that:

We know that this type of consumer rarely comes into contact with social services. Often times they don't want help or don't feel they have a problem. And when they are forced by APS or code enforcement to address their hoarding problem, there really is nowhere for them to turn. Our client's are low income, mostly Medi-Cal so they usually can't afford treatment or professional organizers. That's where we (Linkages) come in. APS refers to us and we can offer no cost or sliding scale case management to address the issue.

Subject number two also works as a case manager for the UC Davis Linkages program. Subject two is a thirty-eight year old Caucasian female who has been with Linkages for five years and is a recent graduate from Sacramento State University. She has case managed four hoarding clients total and at the time of the interview had one client exhibiting hoarding behavior on her caseload.

Subject three is also a geriatric case manager but from a different program. Subject three is thirty-five year old Hispanic female who has worked as a case manager with the Geriatric Network for eight years. She has worked with fifteen plus hoarding clients and is the self proclaimed Geriatric Network hoarding specialist.

Whenever the agency gets a referral for a hoarder it comes to me. I'm not sure how it happened but I guess I am just intrigued by the behavior and have had some success working with these types of clients.

Subject four is an LCSW specializing in the elderly as well as substance abuse. He is a forty-eight year old Caucasian male and was located while this researcher was sifting through UC Davis Linkages files of past hoarding clients. Two clients were referred to subject four by subject one for treatment. This professional estimates that he has worked with more than fifty hoarders during his twenty year tenure as an LCSW.

I've developed a reputation as a geriatric therapist. I get referrals from APS, Linkages, Geriatric Network, the Sacramento Older Adult Network of Care, and Senior Legal Services to name a few. When you work with so many elderly clients you are bound to run into a few who hoard. It seems to be gaining more attention now, but twenty years ago there wasn't much precedent for treating a hoarder, we just did the best we could.

Subject five is a Sacramento County Code Enforcement officer with fifteen years experience in the field. This thirty-nine years old respondent has come into contact with approximately eight individuals who he felt were "true" hoarders.

Some people are just messy. Their yards are cluttered and unkept and their neighbors will complain to the city and we (code enforcement) will be called in to make sure the mess is cleaned up and to levy fines. But I have come to recognize right away when we have a real hoarder on our hands. It's tough because I just

know its going to be an ongoing problem with this person and they definitely don't want to hear from us.

Subject six is a thirty-seven year old Sacramento Sheriff's deputy who has seen three individuals in the community who were hoarders. This subject was referred to this researcher by subject number five as they had worked together on a case.

I've had to forcibly evict two of these types of individuals after they had plenty of chances to clean up their act. Other agencies do their best to help them out but in the end, we are the guys who have to enforce the rules if things don't change.

You never want to put somebody on the street but it's an issue of safety for the individuals and for the community.

Subject seven is an Adult Protective Services (APS) worker who has had more than twenty referrals for hoarders come across her desk. She is a Twenty-nine year old African American female who wishes there was more she could do for these clients. She stated:

It breaks my heart. We (APS) are so swamped that hoarders are just not seen as a priority until the problem is so bad that they are close to eviction and homelessness. Usually we just make referrals, but even the referrals that we can make are limited because the services for them just aren't out there.

Table 4.1

Themes

Subjects	1	2	3	4	5	6	7
Budget cuts will reduce available services	X	X	X	X	X		X
No available mental health services for hoarders	X	X	X	X	X	X	X
Trauma and behavioral problems leading to hoarding typically not addressed	X	X	X	X			X
Current intervention strategies promote relapse by not addressing behavioral causes.	X	X			X	X	X
Gap between empirically proven treatment methods and actual practice	X	X	X	X			X

Budget Cuts Will Reduce Available Services to Hoarders

A common theme among respondents is their concern over how California's budget crisis will negatively affect hoarders in the area. During the time the interviews were conducted, budget cuts threatened to close Linkages, the agency where subjects one and two are employed, close Geriatric Network where subject number three is employed, and severely limit services APS is able to provide. Five of the seven respondents in this project shared this concern. Subject one shared his concern about this issue, he states,

We are in real jeopardy here. It is a very real possibility that Linkages will be closed before the year is out. On top of that, Geriatric Network has already been shut down and other programs that would be serving hoarders are being cut left

and right. So where do they go for help or treatment? I can say almost without exception that the clients I have had who were hoarders would be unwilling or unable to pay out of pocket for help with this problem. It's going to create a real gap in available services for individuals who have difficulty with hoarding.

Subject one goes on to state that, "After the dust around the new budget has settled, if Linkages is closed I won't even have a program to refer my hoarding clients to because there won't be any left. We were their last line of defense." Subject two who works at the same agency as subject one in the same capacity asserts that,

I'm preparing my hoarding clients right now for the worst. They can't afford to pay for services and they can't afford to have their mess cleaned up for them nor would they want that. When we are shut down, I fear that the progress we have made will be lost and there will be no one available to pick up the slack.

Subject three illustrates this theme in a very personal way when he states, "I'm sure you have heard the news that our program has received official word that we will be closed." Later he goes on to say "This is very relevant to your project I think because as I make referrals for all my clients my hoarders come to mind. Normally I would refer them to Linkages but I just spoke with [subject one] and you guys are not taking referrals due to the high likelihood that you may too be closed by year's end. I really don't know where to send them. Services to assist hoarders are limited as things are. Soon it will be worse."

Subject four postulates that cuts to Medi-Cal in the upcoming budget may negatively affect hoarders in this way,

You know with the new cuts proposed to Medi-Cal all mental health services will be done away with. So a Medi-Cal client with hoarding behavior who might otherwise have sought treatment for the behavior through counseling will no longer have that option covered through their only means of insurance.

Subject four also states, “Over the years I have counseled many hoarders. Some are referred to me to solely address their hoarding. But more often than not, hoarding is only one of many issues that we address. Unfortunately, I am in private practice so I have also had to turn away potential clients who did not have the means to pay for service.” Later in the interview after being probed further by the researcher about what should be done with clients unable to pay without services such as Linkages and the Geriatric Network he simply replied, “truthfully, I don’t have an answer for that.” Subject five, the code enforcement worker voiced a strong opinion on what would happen when services to hoarders are limited due to budget cuts,

I have to go to people I use when I work with a hoarder. Your agency (Linkages) is one of them. If you are telling me that Linkages and other similar services are in serious danger of being shut down, we are going to see a lot more evictions. It’s tough because that’s not what we want. We would love to see places cleaned to alleviate dangerous situations. I will be interested to speak with you and (subject one) after this interview about what I can do when I encounter these situations.

Subject seven, the adult protective services worker interviewed had this to say,

I’m sure we’ll (APS) be seeing a lot more hoarders. With the budget cuts and program closures it is inevitable. A lot of hoarders are elderly, and with no other

options, cases tend to get dumped on APS. The trouble is we are suffering from cuts too. Workers are going to have higher caseloads meaning less time for individual clients. On top of that we'll have less agencies to refer hoarders to. I'm afraid only extreme cases will warrant a home visit. The rest will be lost in the shuffle.

Subjects one, two, three, four, and seven all work with the hoarding population in the Sacramento area and have had experience with the services available to these clients. These respondents felt that the established service network that these clients have been able to utilize in the past is in jeopardy. A common thread among all of their responses was that there are currently very few services available to the hoarding population. With looming budget cuts threatening to eliminate these services, this population could be left with less options for intervention and treatment than they have had previously.

No Available Mental Health Services for Hoarders

The idea that there is a lack of services for the hoarding population was one shared by all the subjects interviewed for this project. Earlier in this chapter the idea that budget cuts will reduce available services for hoarders in the Sacramento area was outlined. This second theme is different in that each respondent touched on the fact that there are not services that treat hoarding specifically. Subject four put it clearly,

There are many different types of mental disorders. There are thousands of types of OCD alone. It seems that each has a treatment specific to it. But with hoarding it is different. I don't know of a treatment center, a retreat, or an outpatient program that works with hoarders.

Subjects one, two, and three all work specifically with the geriatric population and each made similar comments regarding their services and hoarding clients. Subject one stated, “Our target population is the frail elderly and disabled. Hoarders fit into this population sometimes but not always. We are not geared to work with hoarding specifically, but when they come across our desk we do our best.” Subject two said, “We are case managers for low income seniors mostly. Of course that is simply put, but that’s basically what we do. We aren’t case managers for hoarders. We will case manage a hoarder that fits in with our agency. I don’t think there is case management for just hoarding.” Subject three claimed, “Working with the elderly population is my specialty. Working with hoarders is not. Hoarding happens to be prominent among elderly clients and that is how I come into contact with hoarders.” Each of these three subjects was clear in stating that the agencies they work for are not tailored specifically to hoarders. In the theme outlined above, it was made clear that the agencies these three subjects work for are the only local agencies that service hoarding clients. This means that there are no local agencies that are set up to deal specifically with hoarding. Subject five agreed with this notion when he said, “We try to make referrals even though that’s not what we do. I just don’t know where to send someone to be treated for this thing.” And subject six hoped that specific treatment for hoarding would be available in the future. “If there was a place we could send a hoarder for help we would. Maybe you should start a clinic.” Subject seven summed up this theme when she said,

I refer my hoarders to places whose target population encompasses hoarders. But I can't refer hoarders to an agency whose target population is hoarders because I don't know of any.

Trauma Typically Not Addressed in Assessment and Treatment

Another common theme among respondents was the idea that trauma leading to hoarding is not typically addressed in assessment and treatment. Several respondents recognized that the research states that traumatic events can lead to hoarding. And that trauma should be addressed in assessment so that it can be addressed in treatment.

Respondent number one had this to say:

I believe that each of my client's stories is important in the helping process. As a clinician I need to have an understanding of each consumer's life story. So I have an idea of the traumas my hoarding clients have lived through. But since inquiring about trauma in relation to hoarding is not a part of our agencies process, it ends up being left up to the clinician. This leads to inconsistencies.

At this point in the interview the researcher shared some findings from this project's literature review regarding trauma and its relation to hoarding. Specifically that traumatic experiences (especially the death of a spouse in the elderly hoarding population) can be a trigger for hoarding behavior and should be a focus of treatment.

Respondent one then asserted:

It's definitely an idea I am familiar with. In fact, I'm reviewing my cases in my head and it makes sense intellectually. But in reality, especially as a case manager trying to assist clients with this disorder, I spend a lot of time helping

them gain control over their lives. It seems like we don't have time to really get into what really created the mess we are cleaning up.

Subject two has had a similar experience. She too works as a case manager in the same agency.

I have an idea of what best practice with my hoarding clients would look like.

We know that this is a difficult problem to get under control, but we also know that there are some treatment methods out there that can be successful with hoarders. In a best case scenario I would be spending time delving into the traumatic experiences that may have lead to each client's difficulties, but that is just not reality. Is this a focus of our work here? No. that's just the honest truth.

There is a lot I would like to do with and for my clients that I know would benefit them but here we are just trying to keep them in their homes living independently.

Both subject one and subject two felt that agency change in this area would benefit hoarders. Subject one stated, "talking about this now I'm realizing that there are some things we could do differently.....looking into trauma and how it creates hoarding is one thing." Subject two made a similar statement, "Even though we are case managers and not therapists for our hoarders, in some cases we are the only treatment they will get, so looking into the trauma thing is something we should be doing."

Subject three also made a comment consistent with this theme when she claimed:

I can see why you would want to elicit information in regards to trauma and hoarding. The more we learn about hoarding, the more we find out that this is not just the behavior of messy individuals. Instead, it is a disorder that has root

causes. Experiencing trauma is one of these causes isn't it? To be truthful, it isn't something I typically look at in the assessment process.

Subject four felt like he personally addressed trauma in his practice, but agreed that typically this is not the case:

I really appreciate the importance of looking at trauma in my hoarding clients.

But I also understand that I have a somewhat rare opportunity to do this. First of all, many hoarders never receive treatment of any kind. Oftentimes when they do, it is not individual therapy as it is in my cases. Many of the referrals I receive are from people who don't have the opportunity to work with their clients in this capacity and that's why they are referred to me. In a lot of cases clients who would benefit from therapy for hoarding cannot afford it. I do look at trauma extensively, and many times there is a direct correlation between a traumatic experience and hoarding which tells me that it should be a point of interest for all clinicians working with hoarders. It's unfortunate that it is not.

Subject seven, the Adult Protective Services worker interviewed had the most to say about trauma and hoarding of all the interviewees. This is what she said that was in line with the theme that hoarding is not addressed in the assessment and treatment of hoarding clients in this area:

In APS we deal with a ton of trauma. Some clients come to us as a result of trauma and we deal with it. Some clients we see have been through traumatic experiences that are hard to even comprehend. We are talking abuse, neglect, war, and these things lead to PTSD in some cases. But here is the interesting

thing. When a hoarder comes across our desk, what is addressed is the mess. Not what caused the creation of the mess. It's not that way with other types of OCD. With other OCD clients you wouldn't just address the checking, you would try to solve the problem that is causing the checking. But with hoarders, if trauma or whatever else is the cause it is overlooked in favor of cleaning up a mess to keep a client from being evicted or to appease neighbors, family, or the city.

The idea presented in the theme above that trauma is not typically addressed in assessment and treatment of hoarders is an important one to this project. During the interviews, the researcher had to continually redirect the focus of the questions back to the effect of trauma on hoarding clients. Although, the respondents were aware that there may be a relationship between the two, they lacked education on the subject.

Current Intervention Strategies Promote Relapse

A key aspect of hoarding behavior is the mess that it creates. Subjects seemed to agree that a main barrier to successful treatment of hoarders is that the underlying behavioral causes of the disorder are not typically addressed. This project attempts to focus on trauma as a cause for hoarding behavior. This theme identifies that not addressing trauma and other behavioral causes that lead to hoarding, promotes relapse. This means that even when a hoarder's mess or clutter is cleaned, it returns quickly because the issues that cause the client to hoard are not remedied. Cleaning up the mess created by a hoarding client tends to be the focus of intervention. Subject one stated this theme in this way:

What I have noticed is the fact that the chaos created by a hoarding client is what we work on as case managers. We are not therapists, we are case managers. It's fairly obvious that we are missing something when you assist a client in cleaning up a mess just for the mess to return in short order.

Subject one went on to state, "I have had some luck cleaning up after a hoarder, but it is usually short lived. And although the clutter may not come back as bad, it comes back none the less." Subject two had a similar experience, "In one case it seemed that clutter grew from clutter. We did a major clean up, but of course when you are working with a hoarder, you are not going to get rid of everything. So there was some papers stacked in a corner and with each home visit I noticed the stack getting bigger and bigger until it was encompassing the living room again." For subjects one and two, it is their agencies mission to keep their elderly clients living safely and independently in their homes. For hoarders this means cleaning up the mess to prevent eviction. Subject one felt that given the time they are allotted to work with each client, it is not possible to do anything but get things cleaned up. He stated, "It can be time consuming to treat a hoarder correctly. It takes constant supervision. When we are trying to keep someone in a safe home, there isn't the time. Hoarders are four of my eighty five clients." It was interesting to note the different point of view on this theme shared by both subject five and six. Subject five being the sheriff's deputy and subject six being the code enforcement officer. Subject five was clear in stating:

When we get a call to an individual like this, we can be certain it is going to be an ongoing situation. It's usually not a onetime thing. We may be called back time

and time again by neighbors or the city. One time maybe the mess in the front yard will be cleaned up, then sure enough you get called back again because the mess has returned. Maybe you can tell me why that is because I don't know.

Subject six had a similar experience:

You know how the clutter gets cleaned up? The person is evicted. It's sad but true. If they are left in their own place the stuff just comes back even if we send in a crew to clean it up. You can talk till your blue in the face explaining that if it gets out of hand again they face being evicted but it doesn't seem to sink in. Of course these are the extreme cases I'm sure, but law enforcement is only called in on extreme cases. It's like domestic violence. There are bad cases, and there are worse cases. Law enforcement isn't called for every instance. So there are probably lots of hoarders that never have to deal with us, but in extreme cases, they do.

Subject seven stated,

In APS we get a lot of repeat referrals. You get to know your clients because even if you close the case there is a good chance you might open it again. This is especially true with hoarders. Relapse is a big issue with them it seems. It's pretty obvious to me why this is. We get the mess cleaned up because we have to. But we don't have to address other issues. And it's the other issues that create the mess. If a hoarder has been reported to APS it usually means they are a danger to themselves or in danger of being evicted. So we must assist them in getting the mess cleaned up. But they have other issues. Almost without fail I always see

my hoarders again even after the mess is cleaned up once. It always comes back.

The reading I have done supports this as well. There is very low treatment success and what we are doing isn't even treatment, it's just clean up. So what we do really doesn't work.

Gap Between Empirically Proven Intervention Strategies and Actual Practice

Several of the subjects interviewed felt that there is a gap between treatment methods that have been proven to work for hoarders and what is actually put into practice. This is consistent with what was outlined in chapter two of this project. Although hoarding is notoriously difficult to treat, there have been some treatments created that have shown some effectiveness. Subject one believed this to be the case. "It comes down to money. Since I started working with clients who hoard, I have done some research. I have read about some treatments that work. But most of which take time and money that we just don't have here." At this point in the interview, the researcher presented subject one with a description of one such successful treatment that is outlined in chapter two of this project. The treatment involves extensive work between client and clinician during the cleanup process along with individual therapy. Subject two then stated, "I think I've come across something like that. But that is a good example of what we are talking about. We get one hour with our client per month on the phone and four home visits yearly. There just isn't the time available to be involved with a method like that." At one point in the interview with subject three she asked about treatment methods that this researcher had come across in researching for this project. Several treatments were explained to subject three including the use of a hoarding task force, and

the utilization of cognitive behavioral therapy during hands on “clean-up” sessions.

Subject three commented on these treatment methods,

I think it would take someone with a passion for working with this population in this agency to take the reins and implement something like you are explaining. Or someone to start an agency or a task force like you said. Geriatric Network is struggling we will probably be closed very soon so our focus is elsewhere. But as far as our work in the past, I could see using parts and pieces of these ideas to help our clients a little more. With us it’s more about dealing with crisis. But our mission statement includes improving the lives of clients. With hoarding clients improving their lives would be much more possible if we could implement some strategies specific to their needs.

It is clear from subject three’s statement that her agency does not implement a strategy like the ones presented to her by this researcher during the interview. She was asked a follow up question about what, if any, methods her agency uses when working with hoarding clients. She replied, “We don’t have a uniform practice for our work with hoarders. Each case manager has their own style and methods of working with clients on their case load.”

Subject four explained that he did feel like he utilized empirically proven treatment methods in that he sees himself as a Cognitive Behavioral Therapist and CBT has been used extensively with hoarders. However, he was unfamiliar with the widely accepted Cognitive Behavioral Model for working with hoarders created by Frost and Colleagues (1998) that is outlined in chapter two of this project. He stated

I have done quite a bit of research of my own on Cognitive Behavior Theory as it relates to hoarders. I am definitely a Cognitive Behavioral Therapist and I know that CBT has been widely used with hoarders with some success. The idea of addressing the thinking, the information processing deficits we talked about earlier is something that I feel like I have had some success with. As far as the complete CBT model, I would have to do further research and perhaps seek training to use it in practice.

Subject seven felt that the way hoarders are dealt with is “haphazard.” She became agitated when explaining that she wished hoarders and other client’s issues were handled differently at APS,

Its not just hoarders. In school we are trained to use interventions that have been proven to be successful in the research. But here we don’t. We are also trained to evaluate our practice. The evaluation we do participate in is not focused so much on successful treatment of clients, but instead on staff efficiency. Are we meeting our caseload numbers, completing our assessments on time, finishing progress notes on time, things like that. What we should be doing is assisting referral agencies with the implementation of treatment and evaluating whether or not a client was successfully treated as a result of their interaction with us. Closing a case does and getting it off the books does not constitute successful treatment. We might not do the treatment ourselves, but we should feel that the agencies we refer to are. I’m not sure I even feel comfortable with that.

Most of the subjects interviewed for this project shared an interest in the hoarding population. Subject one's comment that, "hoarders are some of the most intriguing populations we get to work with. I'm always interested when I get a referral for a possible hoarder," and subject two's statement that, "they (hoarders) tend to be extremely interesting people, it can be an adventure building rapport and working with them," capture the general feeling that this is a population of interest in the community. However, subjects were quick to note that they are not experts on the topic of hoarding and that projects like this one are needed to work more effectively with these clients. Subject three put it this way, "I have worked with several hoarders at this point and it's still a bit of mystery for me." Hopefully, this project will be another stepping stone to further understanding of hoarding.

Chapter 5

SUMMARY

Findings

Hoarding continues to be a topic that is as misunderstood as it is interesting. As the public gains awareness from increased media coverage, more professional research is needed to further understand this behavior. This project seeks to add to the knowledge base on working with hoarders. The findings from this project confirm the researcher's hypothesis that although trauma is a causal factor for hoarding behavior, it is not a focus of the treatment of hoarding. Additionally, best practices for treating hoarders have been identified in the research, however these interventions are not consistently utilized. The themes that emerged as a result of the interviews were also consistent with the literature review.

The first theme identified by this researcher was that California's current budget crisis will drastically effect the services available to hoarders. Six out of seven subjects interviewed felt that looming budget cuts will force agencies that work with hoarding clients to close. It was clear that this was an area of great concern for those who participated in this project. Three of the interviewees worked for agencies that were in danger of being closed and they worried that the hoarding clients they serve will be left without services.

The second theme outlined the fact that even before impending cuts to social services take effect, there has historically been a lack of mental health services available

to hoarders. Subjects felt that hoarding individuals tend to be low income and services for low income hoarders are limited.

The third theme uncovered from the research in this project is of particular interest as it confirms the researcher's hypothesis. During my work with several hoarding clients and after reviewing agency files of past hoarders, I hypothesized that trauma is a behavioral cause of hoarding that is not typically addressed when treating the population. It is clear from the literature review that trauma is an important factor that should be addressed in the assessment and treatment of hoarding. However, according to the research for this project, five of seven respondents stated that trauma is not addressed in actual practice.

Theme four describes the idea that current intervention strategies promote relapse by not addressing the behavioral causes of the disorder. This is important as five of seven subjects interviewed felt the main focus of intervention is cleaning up the mess created by hoarding behavior. Because the mess is the focus of treatment instead of the root causes of why the mess was created, hoarding clutter returns after it is cleaned up. This relates to the third theme identified, as trauma is a behavioral cause of hoarding that should be addressed to prevent relapse. This also confirms what was discovered in the literature review for this project. The literature clearly states that relapse is typical for hoarders. This research highlights the reason for this, namely, that clutter should be addressed while treating behavioral issues.

The last theme identified was that there is a gap between empirically proven treatment methods and actual practice. Although they are limited, there have been

interventions that have proven successful for working with hoarding clients. Five of seven subjects interviewed for this project were aware that such interventions exist, but were not implementing them in their practice. Several of these interventions are outlined in the literature review for this project and should be introduced to the hoarding community in the Sacramento area.

Implications for Social Work Practice

It is clear from the review of the literature done for this project that addressing the behavioral causes of hoarding such as trauma, is necessary for successful treatment. Simply cleaning up the clutter associated with hoarding is a temporary intervention that leads to relapse. Unfortunately, this project has shown that the mess is what is addressed when social work practitioners and other community agents come into contact with hoarding clients. This research indicates that this trend needs to change. Hoarding is a difficult disorder to treat, but there are empirically proven intervention strategies that have been shown to be successful. The subjects interviewed for this project seemed to be aware of these concepts but due to agency restrictions, budgetary constraints, lack of exposure to the research on hoarding, and subpar interagency collaboration, they have not been able to implement them.

It was discovered through the research process that the community of practitioners that work with hoarding clients in the Sacramento area is small. Most of the interviewees knew each other and had knowledge of the small number of resources available to local hoarders. I suggest a committee of social workers, therapists, law enforcement, Adult Protective Services workers, code enforcement agents, as well as any

other interested parties who interact with hoarders be formed to organize resources, disseminate information, and generally advocate for the proper treatment of hoarders. Panels of experts could be recruited to present best practices and intervention strategies for dealing with this population. Cases could be presented and discussed and collaboration between agencies dealing with hoarders could be promoted. Budgetary restrictions were identified in this project as a barrier to proper treatment. A hoarding committee would be useful in coming up with creative ways to circumvent these monetary difficulties. It will take a few individuals with a passion for the subject but given the level of interest that each subject in this project had in this topic, participation should not be an issue. A first step toward creating support for this idea will be taken on by this researcher. During an internship at the UC Davis Linkages Program I was introduced, and asked to participate in, the Sacramento area's Older Adult Collaborative. This is a committee of people who work with the older adult population who gather once per month to discuss issues relevant to the population. At some of these meetings, presentations are given that may benefit older adults or the professionals that work with them. The findings from this project along with the findings of Kimberly Dochterman's 2007 CSUS project on hoarding upon which this research was built, could be presented to the Older Adult Collaborative. The idea that assessing and treating trauma should be a focus of intervention along with the presentation of empirically proven treatment strategies intended to be used when working with hoarding clients could be presented. Finally, the creation of a task force or committee on hoarding could be brought up for

discussion. These would be good steps toward more effective treatment of hoarding in the Sacramento area and could be used as a model for communities around the country.

Implications for Social Work Research

There are several issues that deserve focus in future hoarding research. A focus on the creation of interventions that are cost effective should be of utmost concern. The respondents in this project all felt that budget constraints are a barrier to the utilization of proven treatment strategies. Treatments that include family members would benefit hoarders tremendously because they would utilize resources that may already be in place. Additionally, research on the effect of hoarding on family supports should be considered. This project revealed that many of the agencies working with hoarders in the Sacramento area are in danger of being closed due to California's looming budget cuts. Soon, family members of hoarders may be the most viable resource available for support.

Personal Reflections

I strongly believe that it is important for a researcher to critically analyze work upon completion. Although I am satisfied with the results of this project, there are things I would do differently if given the chance. If starting over, I would advocate for the opportunity to do a qualitative study of older adults who hoard compulsively. The research method used in this project is important in that I was able to look at the current methods used by professionals who work with hoarders, and thus I could identify areas of intervention that could be improved in order to better treat the population. However, interviewing hoarders themselves would offer the opportunity to record the experiences of these clients and give them a voice in the research. Theirs is a voice that is often

unheard and should be taken into consideration when attempting to improve social work practice with hoarders. Understandably, interviewing clients directly presents more of a risk to human subjects, however, it has been done. Future researchers studying this topic should consider the possibility of setting up interviews with hoarders themselves as well as their family members.

As a result of my experience researching hoarders for this project and my experience working with the population as a social work intern at the UC Davis Linkages program, I have become passionate about this topic. I intend to disseminate the information from this project informally to the subjects interviewed. Four of seven respondents expressed interest in viewing the final product and will be given an opportunity to read the project. I also intend to follow up on the implications for social work practice outlined in this chapter by presenting this project to the Sacramento Older Adult Collaborative. Hoarding has become a subject that will retain my interest throughout my career as social worker.

APPENDECES

APPENDIX A

Interview Subject Name:

Interview Date:

Research Guide

The Role of Trauma in Hoarding

I. Experience working with hoarder

1. What has been your experience working with hoarders?
2. What is your agency's role with hoarding clients?
3. How are these cases referred to your agency? Protocol for dealing with them?
4. How many cases have you worked on? What is the prevalence of such cases?
5. Have you noticed characteristics common to hoarding clients?
6. Please provide any case studies you feel may be relevant.

II. Causes for hoarding behaviors

1. With the hoarding clients that you have worked with, what is your perception of the reason for their hoarding?
2. Have clients shared their beliefs on the reasons why they hoard?
3. Can you recall any trauma suffered by the hoarders you have worked with (loss of a spouse or loved one, homelessness, etc.).

APPENDIX B

Consent to be in a Research Study

I _____ have been asked to be in a research study conducted by Wayne Cottle, an MSW student at California State University, Sacramento.

Name of the Study:

Compulsive Hoarding

Purpose of the Study:

I understand that the purpose of this study is to learn more about the ways that past experiences, especially trauma, relate to future hoarding behaviors.

Procedures:

During a one hour meeting with Wayne Cottle, I will be asked to answer questions about my experiences with hoarding clients.

Risks:

Some of the questions Wayne asks me could make me feel slight discomfort. If any of the questions that Wayne asks, make me feel uncomfortable, or are about subjects that I don't want to talk about, I may "pass" on the question.

Benefits:

As a result of participating in this study, my answers may add to the research on the causes of hoarding, and thus add to the body of social work research.

Confidentiality:

Wayne will assign me a false name to describe me or things I say in his notes, on recording, and in his final thesis paper.

A secured list will be kept by Wayne that connects my true first name with the assigned number. This information will only be used by Wayne if he needs to get more information from me after our meeting.

All of Wayne's notes, digital recordings of interviews, and any other personal information about me will be kept secure and private by Wayne.

When Wayne is not working on this research project, his notes, digital recordings of interviews, and any other personal information about me, will be stored in a locked filing cabinet.

I understand that in Wayne's final thesis paper, special care will be taken not to give details or information about me that would allow readers to easily identify me

I understand that when a final thesis grade has been given to Wayne, all of his field notes and any other personal information obtained about me will be properly shredded and destroyed, and all digital files of interview recordings, will be deleted.

Compensation:

I understand that there will be no compensation for participation in this study.

Right to Withdraw from Study:

I understand that I may stop the meeting with Wayne at any time during the hour, ask to be withdrawn from the study, and that there will be no penalty for doing this.

Wayne Cottle can be contacted by e-mail at: **waynecottle611@yahoo.com**, or by calling (916)-718-7008.

I understand that being in this study is completely voluntary. I understand that my signature below confirms that I have read both pages of this consent and agree to be in this study:

Signature of Participant

Date

Signature of Researcher

Date

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