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# The effectiveness of mental health services among individuals with hoarding syndrome

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# THE EFFECTIVENESS OF MENTAL HEALTH SERVICES AMONG INDIVIDUALS WITH HOARDING SYNDROME

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A Project

Presented to the

Faculty of

California State University,

San Bernardino

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In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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ABSTRACT

This study consisting of 35 participants examined the effectiveness of current mental health treatments for individuals with hoarding syndrome. The researchers compiled a questionnaire of both closed and open-ended questions that measured demographics and history of hoarding behaviors, as well as mental health history and treatment. The data results show that 68.6% of those who participated in this study were women and 86% were Caucasian. The percentage of trauma reported by the participants was 77.1% and 65.7% reported that their hoarding caused issues with their family or friends. Of the 35 participants, only eight reported to have received mental health services. Four of the eight participants reported an improvement in their hoarding behaviors. Cross tabulations revealed a strong relationship between the improvement in hoarding symptoms along with a combination of individual therapy, homework and medication.

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To our families and friends who have supported us throughout this journey, much love and many, many thanks. Last but not least, thank you to our wonderful cohort. These past two years were such an enjoyable and memorable ride. Each one of you has the potential and heart to make a difference in this world. Never forget GNDOPBIN and we social workers do it in the field!

# DEDICATION

I Yadira Cardenas, would like to dedicate this thesis project to my wonderful family. Without you, I could not have succeeded throughout my educational journey. Mom and Dad, gracias por todo el apoyo que me brindaron durante todos estos años. Su fe en mi me permitió llegar ha esta etapa de la vida. Nancy and David, thanks for all of your support and motivation along the way. Sis, thank you for introducing me to the wonderful field of social work. My little sister Mary, thank you for supporting and cheering me on each step of the way. My amazing nephew Luke, thank you for always pulling me away from my school work for a few moments of play. Luis, your unconditional support and encouragement these last four years helped me get through this difficult process. I love you all and thank you from the bottom of my heart.

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I, Girlyanne Lacson, dedicate this thesis project to the individuals who made me realize that a pursuit of a MSW is vital to making systematic changes in the world. To all those with mental illness who do not receive adequate services, I dedicate this to you. To consumers who refuse to be referred to by their diagnosis and to all the social workers who give them a voice, I dedicate this to you. And especially to the boys at the group home where I have worked with for five years, may you all find inspiration to change the paths of your lives, my work is dedicated to you.

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# CHAPTER ONE

## INTRODUCTION

This chapter will provide general background information about hoarding syndrome and how it fits within the specialization of mental health. It will also address how hoarding syndrome is viewed within the mental health field and by society. The chapter will focus on how this issue is relevant to the social work field and what role social workers play in regards to this mental illness. A brief outline of the type of research to be conducted on individuals with hoarding syndrome will be discussed.

### Problem Statement

Compulsive Hoarding Syndrome is considered a fairly new illness within mental health. The definition of this problem still remains unclear even for professionals within the mental health field. Hoarding syndrome is defined as the acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value, (Steketee & Frost, 2003). Compulsive hoarders have an "immense difficulty throwing anything away, from the oldest paperclip, to a used food

container, to an out-of-date newspaper, for fear that they might need those items in the future" (Maidment, 2007 p. 1).

This broad definition of hoarding syndrome contains other detailed information. For example, the living space of a hoarder is sufficiently cluttered that it prevents spaces in the home from being used for their intended purpose. An example of this would be a bedroom filled with boxes of collected items to the extent that the room can no longer be used as an area of sleep and relaxation. Daily activities such as cooking, cleaning, sleeping, and even moving from one part of the house to the other are disrupted by the immense clutter in the home. Significant distress or impairment in functioning for the individual is also caused by hoarding (Steketee & Frost, 2003, p. 910). This illness causes the person to feel overwhelmed and experience severe difficulties when it comes to decision making and completing tasks. They may even avoid doing certain tasks because everything is seen as tedious work with no end (Maidment, 2007 p. 2). The mere thought of attempting to clean and organize their home becomes too intense to handle.

Hoarding not only affects the individual's living conditions, it also creates a dangerous living environment. The hoarding of books, newspapers, old clothes, trash, food, and many other articles can put the individual at risk of falling, exposure to poor sanitation, and creates fire hazards throughout the home. As stated in Maidment, R. Frost, who has conducted much of the existing research on hoarding syndrome, explains that it does not take long for the clutter to spread throughout the home (2003). It also states that "items can be spread onto the floors, counter tops, hallways, stairwells, garages, and even cars" (Maidment, 2007 p. 1). It can get to such an extreme that the hoarder may only leave a small narrow path that leads them throughout their home. As stated by Claiborn (2008), "hoarding often creates situations that are considered dangerous or unsafe by local government officials responsible for the health and safety of the community" (p. 2).

Hoarding is considered a private illness that is generally hidden from others, including close friends and family. A person who is a hoarder may realize that they have a problem, but ultimately cannot stop their need to collect items (Melamed, Szor, Barak, & Elizur, 1998,

p. 400). These individuals are more likely to seek help in treating their behavior. Claiborn (2008) explains that in other cases, the hoarder may not acknowledge the absurdity of their ritual and may feel anxiety when their hoard is threatened in some way (p. 2). In ordinary circumstances, a person may keep something for a period of time because they feel they will need it someday. Melamed et al. (1998) explains that a severe hoarder, however, may stop finding excuses for their behaviors. They simply lose insight into the uselessness of the items that they insist on accumulating. Once this point is reached, they reject any attempt by family or friends to seek treatment and can even become hostile towards any interference with their behavior (Melamed et al., 1998, p. 400).

Outsiders, such as family members living outside of the home and neighbors may view this problem in a different manner. They may label the person as being dirty or simply a pack rat. They may also consider them as being lazy for not wanting to keep their home clean and organized. Most people do not understand the uncontrollable need of the hoarder to store things and the panic they face when attempts to discard these items

are suggested (Melamed et al., 1998, p. 400). Unfortunately, this creates a stigma towards this group because their behaviors are misunderstood and are criticized in a negative manner.

Hoarding syndrome affects an estimated 700,000 to 1.4 million people in the United States (Maidment, 2007 p. 1). It is common among the elderly, women, and those who may have experienced some sort of trauma or loss. Hoarding syndrome is prevalent among anyone ranging from the common person to educated professionals. Research shows that anyone can encounter this mental illness, which is why it is important for the social work field to address the problem.

It is important at this point to state that hoarding is most common among the elderly, and many social workers at Adult Protective Services are accustomed to seeing the illness first hand. Social workers must also keep in mind the rapid growth of the elderly population,

> Hooyman and Kiyak (2008) found the following:
>
> With the first baby boomer turning 60 in 2006, the population over 65 will again increase significantly after 2010. Thus, demographics predict that by 2030 the population age 65 and older may be as high as 72

million, representing a 100 percent increase over 30 years. (p. 13)

Therefore, the elderly population is growing at a much higher rate than that of the total population. Current, as well as, up and coming social workers must be aware of the illnesses of this population they may be serving within the next couple of years. Such understanding will help in developing new treatment and resources within the field of social work for those with hoarding syndrome.

Studying hoarding syndrome is important for the social work field because anyone within the profession can encounter a hoarder during their career. Melamed et al. (1998) explains that the phenomenon of hoarding involves many social agencies: welfare, health, mental health, and municipalities (p. 400). Adult Protective Services workers and other professionals often deal with elderly clients who have this problem and know little about what can be done to help them. Unfortunately, this creates a gap in services for this population.

On a macro level, hoarding syndrome is considered a societal problem for many reasons. If an individual is hoarding food or trash in their home, this can create a

potential problem on the community level. Unpleasant odors may be coming from the home, which creates a problem with the neighboring residents. Foul odors and poor home exteriors can create an unpleasant situation within the community. Once this begins to occur, neighbors may become involved by putting in complaints with the city's code enforcement division. Run down homes and lawns can create a dilemma for the hoarder if they are being pressured to clean their property by their landlord or code enforcement due to poor sanitation concerns. Claiborn (2008) explains that a pending visit from a landlord can be terrifying for the hoarder and can create fear and shame about how others will react to their hoard.

This illness is considered a societal problem that should be studied and addressed in order to prevent problems such as unnecessary falls, dangerous fumes, the accumulation of trash, feces, rodents, dangerous house fires, or even death. An individual's home should be a safe, nurturing environment that provides shelter and comfort for its residents rather than a prison secluded behind enormous amounts of clutter.

Although hoarding syndrome does not yet stand on its own in the DSM-IV as a mental illness, clinicians should take more consideration and be more aware of this problem. Clinical social workers may also encounter a client who has an obsession of collecting items and no longer knows what to do to change their behaviors. The clinician would need to have a clear understanding of this illness in order to provide adequate services and interventions to their client. As of now, hoarding syndrome is found as a primary type of obsessive-compulsive disorder (OCD), but distinctions must be made between OCD nonhoarders and OCD hoarders. It has been found that there are differences in characteristics between hoarders and nonhoarder patients with OCD.

> Compared to OCD nonhoarders, hoarders display an earlier age of onset, greater severity of comorbid anxiety disorders, higher rates of bipolar and eating disorders, and personality disorders. Higher rates of inattention and hyperactivity and frequency of traumatic events have been found. (Storch, Lack, Merlo, Geffken, Jacob, Murphy, et al., 2007, p. 313)

Mental health professionals will need to be informed about such characteristics and what treatments should be applied in assisting this unique population.

## Purpose of the Study

This research will look at hoarding syndrome outside of the realm of OCD, and in doing so hopefully instigate a movement to find more models of treatment, mental health interventions, and resources in general for individuals with this illness. Individuals with hoarding syndrome will be surveyed in hopes that they will provide clinicians with information on what type of treatment they feel is necessary to help them survive with this illness.

This sample will be obtained through an agency that deals with cleaning the homes of those with hoarding syndrome. Due to the fact that this population tends to be very private, data will be obtained through anonymous surveys. Addressing hoarding syndrome as a mental illness outside of OCD will help in targeting the population represented in the study. The research gives this population a voice, as well as giving clinicians a look

inside this illness that tends to be overlooked or simply misdiagnosed.

## Significance of the Project for Social Work

The proposed study is relevant to the social work profession because it provides valuable and educational information for clinicians to consider when dealing with this special population. The study contributes to the existing research on this topic and will explore the need for follow up and mental health services for hoarders in order to prevent regression and to control the behaviors of the illness. This study will provide necessary data that will ensure proper care and treatment for individuals and proper referrals to mental health professional by those who encounter clients who are hoarders.

This particular study addresses the assessing, planning, implementing, and evaluating phases of the generalist model. The results of the study can play a role in each of these phases in hopes of finding the best possible way to treat this illness. Overall, this study assesses the effectiveness of mental health services for individuals with hoarding syndrome.

# CHAPTER TWO

# LITERATURE REVIEW

## Introduction

This chapter will review current literature pertaining to hoarding syndrome as a mental illness, and the effectiveness of current interventions regarding this population. Characteristics, behaviors and general demographics of the hoarding population will be discussed, as well as the affects of these behaviors on the community and society as a whole. A general analysis of hoarding syndrome currently existing as a symptom of obsessive-compulsive disorder (OCD), and current interventions used by mental health professionals will also be outlined in this chapter. Cognitive behavioral theory will be addressed as the theory guiding this study.

## Demographics

Although there is limited research on hoarding syndrome, the studies that do exist demonstrate the population that is currently suffering with this problem. A study conducted by Samuels, Bienvenu, Grados, Cullen, Riddle, and Liang (2008) provides information on who is

affected by hoarding behaviors. This particular study examined sex-specific clinical correlations of hoarding in obsessive-compulsive disorder. The researchers wanted to identify the differences between male and female participants who were diagnosed with hoarding syndrome in obsessive-compulsive disorder. The sample of this study consisted of 509 adult participants, age 17 and older. The following indicators show basic characteristics about this specific group. Ninety-seven percent of the participants were Caucasian, 49% were college graduates, 29% had attended some college, and 42% were employed as higher executives, business managers, or administrative personnel (Samuels, Bienvenu, et al. 2008). The current household income among 33% of the participants was $50,000 to $100,000 and greater than $100,000 for 20 percent (Samuels, Bienvenu, et al. 2008). Demographic features and clinical characteristics of the participants were compared between those with or without hoarding behaviors among men and women.

The results of the study showed that women with hoarding syndrome had a later age of onset than men, which was 17 years of age compared to 13 for men. Out of the 358 women, 138 of them reported having hoarding

behaviors. Out of the 151 men who participated in the study, the researchers discovered that 61 had hoarding behaviors. Samuels, Bienvenu, et al. (2008) stated that among the male participants, several categories of obsessions and compulsions were significantly more prevalent among those with hoarding syndrome versus those without hoarding. These include "aggressive compulsions, sexual obsessions, religious obsessions, symmetry obsessions, checking compulsions, and ordering compulsions" (p. 1042). In both men and women, the odds of hoarding increased with the number of obsessive-compulsive personality disorder traits they presented. Another important factor that was found in this study was that the men were 53% less likely to have ever been married than the women, 70% of whom had been married (Samuels, Bienvenu, et al. 2008).

The findings in this study indicate that there are several clinical correlations of hoarding syndrome between men and women with obsessive-compulsive disorder. This study indicates that hoarding behaviors can affect both men and women and can also have an effect on people who are well educated and make a decent living.

As stated in Chapter One, some studies suggest that hoarding represents a distinct subtype of obsessive-compulsive disorder with differing clinical characteristics from non-hoarding OCD patients (Storch et al., 2007). The authors of this particular study stated that "hoarders displayed an earlier age of onset among the children and adolescents that were examined" (p. 313) Storch et al. (2007) stated that "patients with problematic hoarding behaviors have emerged as distinct from other OCD presentations in terms of clinical presentation, treatment prognosis, and possibly pathogenesis" (p. 313). Although symptoms among children who are hoarders seem to be similar to those of adults, hoarding in children has received very little attention by researchers and professionals. This study found that 21 out of the 80 participants presented significant hoarding symptoms. As shown, hoarding syndrome can occur not only in adults, but also in children and adolescents (Storch et al., 2007). The study also concluded that those with hoarding symptoms rated as having worse insight and displayed significant magical thinking obsessions, along with ordering and arranging compulsions (Storch et al, 2007). The youth participants with

hoarding behaviors presented more total obsessions overall.

Although little is known about hoarding among the elderly, a study conducted on an elderly population explained that hoarding is quite common in older adults. Here, the researchers conducted a telephone interview with 62-year-old individuals. They investigated hoarding behaviors and their impact on functional impairments and cognitive deficits, along with physical and psychological problems (Steketee, Frost, & Kim, 2001). The study found that most of the participants were females, unmarried, and lived alone. The information from this study also supports the claim that hoarders are not insightful about the severity of their collecting habits and are quite resistant to change (Steketee, Frost, & Kim, 2001).

The information found in these articles provides a general view of who can be affected by hoarding behaviors and what impairments they cause for the individuals. Hoarding can be found among children, adolescents, adults, and the elderly. Steketee, Frost, and Kim (2001) mentioned that studies have found hoarding individuals to be significantly older, possibly because hoarding problems increase in severity with age. This suggests

that hoarding symptoms are likely to worsen with age, placing the older population at a higher risk of developing these behaviors. The diverse studies attempting to narrow down general demographics of hoarding syndrome only suggest that hoarding symptoms can affect anyone regardless of age, gender, education and socioeconomic status.

## Theory Guiding Conceptualization

The current categorization of hoarding syndrome as a symptom of obsessive-compulsive disorder outlines the theoretical framework that will be discussed in this study. Cognitive-behavioral theory has been the guiding theory in explaining obsessive-compulsive behavior and interventions. This theory along with basic behavioral theory has outlined the methods clinicians have used in treating individuals with hoarding syndrome. In terms of obsessive-compulsive disorder, "the client's interpretation of the thought determines the level of obsession and the compulsive behavior would therefore be seen as a method of thought suppression, which ultimately results in more intrusive thoughts" (Fairfax, 2008, p. 55). Intrusive thoughts could encourage obsessive

fears and rituals, in which the feelings individuals hold of themselves, others, and the world around them determine the way one views everyday events. "Fearful core beliefs will lead to interpretations about danger, anxious mood, and over protective actions", which makes it more difficult to ignore intrusive, unpleasant thoughts (Wilhelm & Steketee, 2006, p. 7).

Cognitive theory suggests that, "behavior is affected by perception and interpretation of the environment during the process of learning" (Payne, 2005, p. 121). The negative behaviors of individuals with obsessive-compulsive disorder arise from misinterpretation and misconception.

Cognitive-behavioral theory outlines a deviation in the thought process that leads individuals to think negatively. These thoughts then alter the individual's perceptions of the world around them and their behavior. Using this theory, the professionals then attempt to reframe the thought process of the individuals. Reframing the misinterpreted thoughts helps the individual live appropriately in the environment around them (Payne, 2005). This process among OCD patients attempts to "directly target the patients' interpretations of

intrusive thoughts and long-standing negative beliefs to interrupt the negative spiral of obsessions and compulsions that disrupt functioning" (Wilhelm & Steketee, 2006, p. 13). There is a process of understanding the thoughts in order to refocus the negative thoughts to less intrusive ones that ultimately brings an end to rituals that tend to control the individual's life.

In terms of hoarding, the "basic deficits or problems in information processing, beliefs about and attachment to possessions" brings about emotional distress and avoidance behaviors (Anthony, Purdon, & Summerfeldt, 2007, p. 232). Hoarding involves a misconception of the items that cause the clutter, which adds to the already intrusive thoughts of obsessive-compulsive behavior.

Clinicians must be aware of cognitive behavioral theory in reference to treatments and interventions for individuals with hoarding syndrome. This theory explains the thought process these individuals go through, as it outlines how they perceive themselves, the world around them and their items.

## Causes of Behavior

There are many factors that are believed to increase a person's likelihood of developing hoarding behaviors. This is important to consider when determining the events that may cause a person to feel the desire to collect tremendous amounts of items in their home, while experiencing the inability to discard them. In order to determine what causes these behaviors to arise, it is important to consider traumatic life experiences of a hoarder. This can provide researchers and clinicians better insight as to what may have caused the behaviors in the first place.

A study that was conducted to examine whether traumatic events influenced the clinical expression of compulsive hoarding stated that, "traumatic experiences have been posited as one potential catalyst for the abrupt onset of compulsive hoarding" (Cromer, Schmidt, & Murphy, 2007, p. 2581). The researchers wanted to evaluate the presence of hoarding syndrome in regards to the experience of trauma, how that trauma influenced the severity of hoarding symptoms, and the relation between the trauma and the three facets of hoarding: clutter,

difficulty discarding, and acquisition (Cromer, Schmidt, & Murphy, 2007).

Out of 180 participants, approximately 54 percent stated that they had experienced at least one traumatic life event in their lifetime. Those who had experienced a traumatic life event also had greater hoarding symptom severity than hoarders who had not been exposed to any type of trauma (Cromer, Schmidt, & Murphy, 2007). Some of the traumatic life events reported by the participants included accidents, witnessing a non-violent death, witnessing a crime, sexual abuse, and illness of self or a loved one (Cromer, Schmidt, & Murphy, 2007). "In a cognitive-behavioral model of hoarding, Frost and Hartl (1996) remarked on a number of clinical cases where compulsive hoarding was reported immediately following a traumatic life event" (Cromer, Schmidt & Murphy, 2007, p. 2582). This shows that there is indeed a strong correlation between trauma and hoarding behaviors.

Other findings suggest that the possession of objects serves as a sense of safety and security in a threatening environment. A study by Cromer, Schmidt & Murphy (2007) mentioned that Hartl et al., who were among the first researchers to investigate the correlation

between hoarding and trauma, found that "traumatic events were reported more frequently among a general sample of hoarders" (p. 2582). A different study by Grisham, Frost, Steketee, Kim, and Hood (2006), found that "individuals with a later age of onset were more likely to report a stressful event directly prior to the onset of symptoms, compared to those with an earlier age of onset" (Cromer, Schmidt, & Murphy, 2007, p. 2583). The results of these studies indicated that the clutter factor of compulsive hoarding was most associated with having experienced a traumatic event in their life and that such events can influence the manifestation of hoarding syndrome.

One major behavior that was mentioned in the previous study was the acquisition of items. This can consist of acquiring purchased items, old belongings or free items that are accumulated over time. Such items can include books, newspapers, advertisements, promotional giveaways, and discarded items (Steketee & Frost, 2003). This particular behavior occurs when the hoarder places far more importance over their possessions than what is their true value. The authors of this particular article stated that certain beliefs about possessions suggest that some individuals acquire or save indiscriminately to

avoid emotional upset and/or prevent negative outcomes. Steketee and Frost (2003) also mentioned that emotional attachment to items is related to the belief that the objects provides emotional comfort, along with a fear of losing something important, and also experiencing a sense of loss of identity.

Various characteristics associated with compulsive hoarding suggest that a person suffering from a social phobia and depression may develop hoarding symptoms. A study by Samuels, Bienvenu, Pinto, et al. (2008) found that individuals with hoarding behaviors had more symptoms of anxiety and depression, especially generalized anxiety disorder and social phobia, along with poorer functioning. A different treatment study also had similar results. Here, researchers found that five out of seven hoarding patients presented social phobia and five of them had been diagnosed with major depression. The patients also reported feelings of anxiety (Steketee & Frost, 2003). This was also common among elderly hoarders who were experiencing isolation and limited social networks. These findings suggest that hoarding symptoms can be associated with a variety of Axis I disorders overall.

Another common behavior among individuals with hoarding syndrome is limited recognition of or insight into the severity and impairment caused by hoarding behaviors. Steketee and Frost (2003) indicate that research and case reports show that many hoarders do not consider their behaviors unreasonable. The authors also mention that there can be a delayed recognition of the problem at least a decade after onset of the illness. Social service providers within this study explained that most elderly clients with serious hoarding demonstrated a lack of insight into their problem, "despite the absence of observable cognitive impairment" (Steketee & Frost, 2003, p. 2).

The lack of insight creates a dilemma for the providers who are trying to help the individual by getting them the necessary resources that will address the clutter, health, and safety concerns. Although lack of insight is common among hoarders, those who do acknowledge their behaviors are ashamed of their hoarding and rationalize it (Melamed et al., 1998).

A hoarder may develop such an attachment to their possessions that they find it necessary to keep objects because they may find use for it one day. "When hoarding

becomes more severe, a hoarder may stop attempting to find excuses for their behavior. They become disorderly and lack insight into the uselessness of the items they save" (Melamed et al., 1998, p. 400). This particular article states that hoarders can reach a point where they have no desire to get help or treatment, and may even refuse any interference or treatment suggestions made by family and friends. The researchers stated that a pathological hoarder is disinterested in visits from mental health professionals, as they do not see themselves as a patient or admit to having a problem. It is also mentioned that to a hoarder, throwing out an item means giving up something that will no longer exist, and to save it brings them relief and comfort (Melamed et al., 1998).

## Treatments and Interventions

Due to the fact that hoarding syndrome is addressed as a symptom of obsessive-compulsive disorder, the treatments and interventions used within the mental health field in working with this population consist of cognitive behavioral therapy (CBT) and medication for obsessive-compulsive disorder. Basic treatment for

obsessive-compulsive disorder includes cognitive behavioral therapy, and serotonin reuptake inhibitor (SRI) medications (Saxena & Maidment, 2004). Studies have shown that individuals with hoarding syndrome have poor response to standard antiobsessional medication, such as SRI treatments. "A small study using open treatment with paroxetine with CBT for OCD patients found that nonresponders were significantly more likely to have hoarding/saving symptoms than responders" (Saxena & Maidment, 2004, p. 1146).

As stated earlier in this chapter, hoarders display a lack of insight into their illness, which causes them rarely to address their problem and usually to never seek help on their own.

> Many resist acknowledging that their hoarding is unreasonable or that it has an adverse effect on their lives. They are often reluctant to seeking treatment on their own, and they commonly cross the paths of clinicians only when relatives insist on their getting help. (Luchian, McNally, & Hooley, 2006, p. 1657)

It is important to educate this population along with their family to better treat their illness. This

suggests that clinicians should enter the hoarder's environment and witness first hand the connectedness to their items. The most common and effective types of interventions associated with hoarding include in-home visits. "Interventions typically include both office and in-home visits emphasizing motivational interviewing, decision making training, exposure, cognitive restructuring and efforts to reduce acquisition" (Tolin, Frost, & Steketee, 2007, p. 1463). This type of intervention is not typical for a general obsessive-compulsive disorder treatment. There appears to be more going on with individuals with hoarding than those with other obsessive-compulsive disorder symptoms. Studies suggest that clinicians should look outside the general interventions for obsessive-compulsive disorder in treating hoarders.

Studies outlining the use of cognitive-behavioral therapy without medication, but alongside in-home visits and homework, appears to be more effective than the use of cognitive behavioral therapy alongside serotonin reuptake inhibitor medication. Tolin, Frost, and Steketee (2007) composed a group of adults that had been identified as hoarders through intensive interviews, and

who were not receiving mental health treatment, to participate in a study of the effectiveness of cognitive behavioral therapy (CBT) in their hoarding. Treatment consisted of 26 individual sessions lasting over a period of seven to twelve months. This form of cognitive behavioral treatment for compulsive hoarding consisted of sessions in the clinic and in the patient's home. The interventions targeted the three manifestations of hoarding, "(1) skills training for organizing, decision making, problem solving, and reinforcement, (2) imagined and direct exposure to avoided situations, and (3) cognitive reconstructing of hoarding-related beliefs" (Tolin, Frost, & Steketee, 2007, p. 1464). Overall, this study indicated,

> a treatment protocol developed from the cognitive behavioral model for comprehensive hoarding can significantly reduce hoarding behaviors including clutter, excessive acquisition, and difficulty discarding. (Tolin, Frost, & Steketee, 2007, p. 1467)

It is important to state that within this treatment, clinicians conducted many off-site sessions along with distributing homework, which falls outside the basic

realm of CBT for patients with OCD. This study also suggests the importance of follow up, as the hoarders were reluctant to complete the homework, and had a tendency to stop treatment prematurely (Tolin, Frost, & Steketee, 2007). Clinicians must therefore be more persistent and attentive to these types of behaviors to intervene effectively. Interventions used within this study focused on specific behavioral patterns of hoarding individuals, and did not include any type of medication.

In a site-security model proposed by Kellett (2007) many interventions outside of cognitive behavioral therapy were proposed. Such interventions include challenging the hoarder's assumptions regarding their relationship to their object, understanding any losses and or traumas that the hoarder has gone through in order to address the way in which objects can act as a link to such losses, helping the hoarder separate from his or her physical environment, and understanding the hoarder's connection by keeping a diary of their daily input/output ratios, (Kellett, 2007). Overall, the hoarder must obtain some sort of insight into their illness and find ways to break the cycle of connectedness to unnecessary items.

These types of treatments imply a deeper understanding from the clinician of what the hoarder undergoes while acting out their behaviors. The importance of the items needs to be understood, along with the catastrophe that may come about once the item is taken away from the hoarder. The aim of treatment is to enable the hoarder to specify the form and content of the catastrophe they anticipate and to enable the hoarder to consider whether "(a) such a catastrophe is actually likely and (b) whether particular objects would actually prevent the imagined catastrophe from occurring" (Kellett, 2007, p. 419).

Cognitive behavioral therapy along with serotonin reuptake medication have not proved to be sufficient in helping the individual with hoarding syndrome to go through life with this illness. There is a lack of education, follow-up, support and empowerment for this population. The current methods may help address the problem in the present, but effectiveness is lacking in terms of helping the individual live with new behaviors.

This study of mental health services for individuals with hoarding syndrome hopes to contribute to the current interventions that are now being used to treat this

illness. Understanding what works, what does not work and what is needed is important in contributing to the overall effectiveness of mental health treatment of individuals with hoarding syndrome.

## Hoarding Syndrome Outside the Realm of Obsessive-Compulsive Disorder

Throughout the literature associated with hoarding syndrome, evidence has shown that patients with obsessive-compulsive disorder who report hoarding symptoms "have a distinct clinical profile compared to those who do not hoard" (Abramowitz, Wheaton, & Storch, 2008, p. 1027). Therefore, in addressing hoarding syndrome as a mental illness it has been suggested that hoarding be recognized as distinct from OCD, and be recognized as a stand alone psychiatric diagnosis (Cromer, Schmidt, & Murphy, 2007). The history, characteristics and behaviors of individuals with hoarding syndrome mentioned in this chapter make hoarders distinct from the general OCD population.

A main behavior among hoarders is the lack of insight. Many people with obsessive-compulsive disorder are aware of their illness, their constant counting, washing, checking and so on, but hoarders are unaware of

their illness as they view it as a normal part of their personality, (Grisham, Brown, Liverant, & Campbell-Sills, 2004). Individuals view their clutter as a connectedness to their items, in which they are unable to discard them. The connectedness to such items also differentiates hoarding syndrome from general obsessive-compulsive disorder. Kellett's site-security model states that the hoarder's inability to discard has a lot to do with a fear of losing information and their belief that the item is rare, or that they may need it later on (2007). The perceptions the hoarders have of the value of items is not the same as the constant repetitive behavior of the general OCD population.

A study conducted by Luchian, McNally, and Hooley (2006) investigated cognitive variables that may determine the likelihood of hoarding by an individual. Individuals who categorized themselves as "packrats" (non-clinical hoarders) were tested against a control group of non-hoarders. The individuals were asked to categorize objects as their emotional reactions were measured before and after the task (Luchian, McNally, & Hooley, 2006). Results indicated that the non-clinical hoarders had a more difficult time organizing the items

and also experienced more stress throughout the whole process. Although the non-clinical hoarders did experience more stress they did not experience other types of negative affects, such as being afraid, ashamed, guilty, hostile, and scared (Luchian, McNally, & Hooley, 2006). These negative affects are common with other individuals with OCD. This study indicated that the non-clinical hoarders did not experience more negative affects than the nonhoarders, therefore, there are some cognitive characteristics that are present in other OCD populations that are not present in individuals who hoard.

Another study of three groups (pure hoarders, non-hoarding OCD, and mixed OCD and hoarding) was conducted to investigate the relation of compulsive hoarding to other obsessive-compulsive disorders (Grisham, Brown, Liverant, & Campbell-Sills, 2004). The participants in this study completed many self-report questionnaires that measured anxiety, mood, and personality features.

> Individuals in the pure hoarding group reported significantly less negative affect, anxiety, worry and stress than the other two groups, as

> well as significantly more positive affect and less depression than the mixed group. (Grisham, Brown, Liverant, & Campbell-Sills, 2004, p. 775)

This study suggests that the lack of negative affect felt by pure hoarders distinguishes hoarding from OCD; therefore pure hoarding can exist outside of obsessive-compulsive disorder.

Although hoarding is only diagnosed as a symptom of OCD, there is literature that suggests ways in which individuals with hoarding syndrome do not hold common OCD cognitive characteristics. Studies like those stated above suggest that pure hoarding can exist outside of the obsessive-compulsive diagnosis.

## Effects on Family and the Community

Hoarding syndrome has many effects on the individual person. It keeps them secluded within their home, away from outside contacts such as family, friends, and their community. Although these behaviors affect the individual, they also cause a strain on those living in the home.

A recent study was conducted to see the effects of hoarding behaviors on family members living with a hoarder. The family members answered questions through an on-line survey and provided valuable insight into the dynamics of the home. They reported high levels of patient rejection attitudes toward treatment and suggested "high levels of family frustration and hostility" (Tolin, Frost, Steketee, & Fitch, 2008, p. 334). The family members also reported growing up in a cluttered home and emphasized the hoarder's lack of insight into their behaviors. Another study that was conducted among a community sample of hoarders mentioned that "more than three-quarters of the hoarders reported having at least one 'pack rat' among first-degree relatives" (Steketee & Frost, 2003, p. 912). Based on the information provided by family members of those with hoarding syndrome, it can be determined that "compulsive hoarding adversely impacts not only the hoarding individual, but also those living with them" (Tolin, Frost, Steketee, & Fitch, 2008, p. 334).

The studies mentioned above explain how hoarding behaviors can cause problems within the family structure and their living environment. The problems, however,

extend beyond the home itself, eventually making it a concern within the community. Hoarding can become so extreme that it can potentially become a social burden.

Tolin, Frost, Steketee, Gray, and Fitch (2007) conducted a study to determine the economic and social burden caused by compulsive hoarding. The study was done among self-identified hoarding participants, which provided insight into the impairments of hoarding within their lives. The participants reported that their behaviors were associated with an average of seven work impairment days within the past month, (Tolin, Frost, Steketee, Gray, & Fitch, 2007). They also found that hoarders were three times as likely to be overweight as were their family members. The study explains that the hoarders reported a "broad range of chronic and severe medical concerns and had a five-fold higher rate of mental health service utilization" (Tolin, Frost, Steketee, Gray, & Fitch, 2007, p. 200). Another important finding within this study was that eight to twelve percent of the participants had been evicted or threatened with eviction notices by their landlords due to their extreme behaviors. Up to three percent also disclosed that they had a child or elder removed from the

home at some point due to poor and unsanitary living conditions (Tolin, Frost, Steketee, Gray, & Fitch, 2007). This information indicates that hoarding behaviors can cause problems on many levels.

The information obtained from this particular study supports the argument that hoarding can be an economic and social burden to the individual and those around them. The impairment caused by hoarding symptoms prevents the individual from attending work on a consistent basis. This can eventually lead to financial burdens within the home and create added stress for the entire family. Another thing to consider is that hoarders tend to live in confined spaces and usually isolate themselves from the outside world. This makes it difficult for them to leave their home to seek proper medical attention or participate in physical activities. Their isolation places them at high risk of being overweight and developing medical problems.

As previously stated in Chapter One, hoarding syndrome can become a problem on a personal and community level. The symptoms of the illness create obstacles for the individual and the extent of the behaviors can eventually create concerns within the community. Hoarding

has become more of a societal problem and social service providers, mental health professionals and various health departments are becoming involved.

## Summary

The review of the literature above suggest that clinicians who continue to treat hoarding syndrome as another symptom of obsessive-compulsive disorder will be ineffective in addressing this mental illness. Clinicians should look outside the realm of OCD, and work with the behaviors of the population to better educate and treat these individuals. The extent of the problem makes this study relevant and necessary in order to understand what treatment methods work best to assist hoarders in changing their behaviors. The information obtained from this study provides important information as to which mental health interventions are most effective in treating this illness.

# CHAPTER THREE

# METHODS

## Introduction

This chapter will discuss the study sample and the sampling process. It will also explain the data collection process, the instrument used to conduct the study, as well as the procedures that took place within the study. The protection of human rights will also be discussed to explain how the confidentiality of the participants will be ensured. Finally, the data analysis will be explained to describe what procedures were utilized to answer the research questions on the effectiveness of mental health services among those with hoarding syndrome.

## Study Design

The purpose of this study was to define what interventions are necessary to treat hoarding syndrome effectively as a mental illness. In order to do this it is important to look at hoarding syndrome as its own entity, which is outside the realm of obsessive-compulsive disorder (OCD). As stated in previous chapters, hoarding syndrome has particular

characteristics and behaviors that are different from usual OCD symptoms. The study examined these behaviors and classified them as outside the realm of OCD in order to predict the most effective type of intervention to use with the hoarding population.

The study gathered information about effective interventions by asking the hoarders themselves. The study consisted of a population of 35 hoarders. A survey questionnaire containing a few open-ended questions was used to collect the data for this study. Therefore the study contained a mix of both quantitative and qualitative data. This method of research represents a step by step procedure that guided the research through obtaining data to reveal what type of mental health interventions are most effective in treating individuals with hoarding syndrome. This study sought to determine whether an expansion of current cognitive behavioral therapy, which keeps in mind the specific characteristics and behaviors of hoarders, will be more effective than general treatments of obsessive-compulsive disorder. In considering this hypothesis, a sample of hoarders were surveyed to reveal what types of mental health services are needed to assist those with hoarding syndrome.

## Sampling

The sample from which the data was collected consisted of 35 participants. The sample that was used to collect the data is a purposive sample. This type of sample allowed for the study of a specific hoarding group, which consisted of individuals that have gone through the clean-up process of their homes. The participants are previous clients of a clean-up company called Steri-Clean. Steri-Clean has assisted many hoarders who either voluntarily agreed to the clean up of their homes or were forced to clean them by the city's code enforcement. Steri-Clean has come into contact with these individuals through family members of the hoarder, the hoarder themselves, or by professionals such as code enforcement personnel or Adult Protective Services workers. This agency agreed to provide client contact information so that a survey could be conducted to provided valuable information about the life of a hoarder.

The agency was interested in this study because they hoped to gain information on whether their clients are receiving adequate follow-up after the clean up process. They were also interested in gaining knowledge about

their clients' mental health services. Through this study, the effectiveness of mental health services among the hoarding population was examined. Information on current or past mental health services was obtained from the individual to determine how effective they have been in controlling the symptoms of hoarding and preventing regression. The study sample that was chosen has gone through the difficult process of having their valuable possessions cleared out of their home. This allowed the study of only those who have already undergone the clean out ordeal and those who are currently seeking mental health services to prevent regression of their symptoms.

## Data Collection and Instruments

The survey instrument used was created for this specific study, (Refer to survey in Appendix A.) The researchers, along with the management at Steri-Clean, compiled a group of questions that ask the hoarders what they found to be effective in terms of clean-up and mental health services. The instrument asked for general demographics, history of the hoarder (personal as well as family), mental health history, past/present mental health services to treat their hoarding, and past/present

clean up of clutter attempted by the hoarder. These topics were then compiled at the end of the questionnaire and the participant was asked about their current state; whether he/she is hoarding again and what he/she found effective in the services they received from mental health and clean-up. The mental health portion of the survey acts as the main focus of this study, as the clean-up portion is an agency request. What makes this instrument strong is the collaborative effort of its creation.

The use of a survey questionnaire in this qualitative and quantitative study helped research the relationship between the independent variables of mental health services such as effectiveness of type of therapy (individual therapy, homework, and medication) and the dependent variables such as improvement of hoarding. Others variables measured included demographic information such as age, gender, marital status etc. It was hoped that the use of nominal and ordinal levels of measurement not only would prevent the exhaustion of the individual being surveyed, but also help in data analysis as the questions can easily be given mathematical values.

This survey brought about issues of validity and reliability in terms of when the survey would be conducted and how the hoarder would feel when the survey is filled out. Unfortunately, there is no way to fully be in control of how the questionnaire is answered. The hoarder's mood at the time of questioning may have affected the reliability of the survey. The validity may have been affected if the hoarder was not the one who was completing the survey. These issues were addressed and considered while the data were collected and analyzed. Adjustments to the questionnaire itself were also made to make it more culturally sensitive. For example, a translator was available in distributing the instrument for the participant if needed. It was also important to keep in mind the wording of the questionnaire, as statistics suggested that hoarders are elderly. Although this survey was simple and easy to understand, the clarification of questions was provided for the participants during the surveying process.

## Procedures

Due to the private behaviors of hoarders and their tendency to isolate, the best way to contact the hoarders

would be through telephone calls. With the help of Steri-Clean, access to the sample population was provided through the contact list of the agency. The phone numbers on this list were those of the hoarder's home. This list was used to personally call the hoarders and read the survey questionnaire to them. The phone calls were made at the Steri-Clean office, as they have multiple phone lines within that space. To ensure proper distribution of the survey the phone calls were conducted by the researchers themselves. Data were collected within a span of five weeks, as the phone calls were made at least five days a week from the hours of 8am to 2pm, and again from 5pm to 8pm. We hoped this range in time would help contact as many people as possible.

## Protection of Human Subjects

In order to ensure the confidentiality and anonymity of the participants of this study, data collection was completed within the agency that provided the client information. Data were collected and the findings were placed in a locked-box that remained in the researchers possession at all times. Within the survey, the name or contact information of the participants was not included.

The informed consent (Appendix B) was read to the participants over the phone when the study was conducted. The informed consent explained to the individual that the main purpose of the study was to determine whether they were receiving effective mental health services to help them deal with their hoarding. It also informed them that the information gathered from the study would contribute to the identification of more adequate interventions overall. The participants were also provided with a debriefing statement (Appendix C) via mail explaining where they could obtain the results of this study.

## Data Analysis

For the purpose of this study, quantitative procedures were used to answer the research question of the effectiveness of mental health services among individuals with hoarding syndrome. The concept that was used within this study was hoarding syndrome. This concept is defined as an illness which causes an individual to collect large amounts of items to such an extreme that it causes safety hazards within their living environment. The variables within the study consisted of a primary independent variable, which is mental health

services, and a dependant variable, which is the symptoms of the illness. As we prepared to conduct our study, we hypothesized that there is a correlation between the variables of mental health services and the symptoms of hoarding syndrome. The correlation likely exists based on the fact that the value of one variable is associated in a systematic way with the value of the other variable. We also determined that the statistical tests include T-test and Chi-square test since the hypothesis indicated an assertion between the effectiveness of mental health services and the symptoms of hoarding.

## Summary

Having direct access to hoarders made this study of determining the effectiveness of mental health services among those with hoarding syndrome possible. With the help of Steri-Clean, this study provided insight into what is needed in mental health services to better treat hoarders. We took the steps in quantitative and qualitative research to reveal that an expansion of cognitive behavioral theory used to treat general obsessive compulsive disorder will be more effective in treating individuals with hoarding syndrome. The study

also brings about a new way of viewing the mental illness of hoarding. The questionnaire was administered by phone to survey the hoarders themselves and ensured the safety of this population through confidentially and the culturally sensitive and noninvasive language of the questionnaire.

# CHAPTER FOUR

# RESULTS

## Introduction

This chapter will summarize the results obtained from the research sample utilizing both qualitative and quantitative design methods. Univariate findings consisted of frequencies regarding general demographics and mental health treatment variables such as gender, marital status, experience of death or trauma, whether or not the individual has received therapy and if individuals hoarding has improved. Many of these variables were also included in a Pearson correlation coefficient in order to determine if there were significant correlations between two variables. Some bivariate findings consisted of calculated T-tests of whether or not the individual is still hoarding and age as well as duration of hoarding and if the individual has lived in a home with a hoarder. Some of the variables mentioned above were also examined in a Chi-squared test with therapy related variables. Therapy related variables include if the individual received therapy, if their therapist understood hoarding and whether or not

different therapeutic interventions (individual therapy, homework and medication) were effective. Additional information obtained from our qualitative method of study is also presented.

## Presentation of the Findings

Thirty-five hoarders participated in our study and completed a questionnaire that consisted of both open-ended and closed questions. No participants were excluded from this research project. Age was an open-ended question that consisted of ages ranging from 37 to 90 with a mean age of 66.54, (SD = 14.03). The sample consisted of 24 females (68.6%), and 11 males (31.4%).

In addition, 60% of the participants reported being married at the time of the interview, while 40% reported never being married or divorced. Significant variables also included whether the participant experienced a death or trauma in their life. The survey revealed that 27 participants had experienced a death or trauma (77.1%), while only eight participants (22.9%) have not.

History of depression in the family was also considered. Out of the 35 participants, 16 (45.7%) stated

that there was a history of depression in their family while 19 (54.30%) reported that there was not. Relationships between family and friends were also examined. The data shows that 65.7% of the participants reported that their hoarding behaviors resulted in issues with family or friends, and 34.3% reported no issues.

In addition, 65.7% of the participants reported not allowing others in their home, and only 34.3% reported that they do. Another variable measured was whether the participants received mental health services. Only 22.9% of the participants reported ever receiving therapy or counseling for their hoarding symptoms and 77.1% never had.

Out of the eight participants that did receive mental health services, five stated that their hoarding symptoms had gotten better and three stated that it had not. In considering these variables, the participants were also asked if they continue to hoard regardless of whether or not they received mental health services. Of the 35 participants, 17 (48.6%) reported that they are still hoarding and 18 (51.4%) no longer do.

The T-test which involved the variables labeled still hoarding and age, found that the average age of

individuals who reported that they are still hoarding was 61.3 and the average age of those who are no longer hoarding was 71.5 ($t = -2.28$, $df = 33$, $p = .029$).

The T-test involving the variables years hoarding and lived in a home with a hoarder found that the average years that individuals who lived in a home with a hoarder was 38.4 years. Those who did not live in a home with a hoarder hoarded for an average of 17.2 years ($t = 3.45$, $df = 23$, $p = .002$).

The Chi-square for the variables living in a home with a hoarder and having a family history of hoarding shows the following. Of those who reported having lived with a hoarder, 11 stated that they had a family history of hoarding while three did not. Out of those that did not live in a home with a hoarder, two stated having a family history of hoarding while 19 stated they had no family hoarding history ($\chi^2$ (1) = 17.153, $p < .05$).

Table 1. Home with Hoarder and Family Hoarding History

| Home with Hoarder & Family Hoarding History | | Family Hoarding History | | |
|---|---|---|---|---|
| Home with Hoarder | | Yes | No | Total |
| | Yes | 11 | 3 | 14 |
| | No | 2 | 19 | 21 |
| | Total | 13 | 22 | 35 |

For the variables of gender and marital status, 15 of the female participants reported being married and nine of them reported that they were not. In regards to the male participants, six reported being married and five were not ($\chi^2$ (1) = .199, $p < .05$).

Table 2. Gender and Marital Status

| Gender & Marital Status | | Married | | |
|---|---|---|---|---|
| Gender | | Yes | No | Total |
| | Female | 15 | 9 | 24 |
| | Male | 6 | 5 | 11 |
| | Total | 21 | 14 | 35 |

The variables for gender and allowing someone in their home, of the total number of female participants, 12 stated they allowed people in their homes while 12 did

not. Of the 11 male participants none allowed people in their homes ($\chi^2$ (1) = 8.370, $p < .05$).

Table 3. Gender and Allow in Home

| Gender & Allow in Home | | Allow in Home | | |
|---|---|---|---|---|
| Gender | | Yes | No | Total |
| | Female | 12 | 12 | 24 |
| | Male | 0 | 11 | 11 |
| | Total | 12 | 23 | 35 |

Some analysis could not be tested statistically due to small numbers, but are worth noting. In regards to the therapy variables of the survey and whether or not the therapist had an understanding of hoarding syndrome, of the eight that received therapy, four stated that their therapist had a good understanding of their hoarding while four did not.

For the variables regarding if the hoarder participated in therapy and if the were satisfied with their therapy, of the eight that did receive therapy, four stated that they were satisfied and four are not.

As stated earlier, only eight of the 35 participants have undergone mental health services. From those eight,

a cross tabulation of three different types of therapy interventions and whether or not their hoarding had gotten better was run. Of those who stated that their hoarding had not gotten better, two reported that individual therapy was somewhat effective, while one stated is was not. Of those who reported that their hoarding had gotten better, four stated that individual therapy was effective, while only one reported it to be very effective.

Of those who stated that their hoarding had not gotten better, two stated that homework interventions were not effective, while one stated it did not apply. Those who stated that their hoarding had gotten better, two reported homework interventions to be effective, one stated it was somewhat effective, and two stated it did not apply.

The findings also show that of the participants who reported that their hoarding had not gotten better, three reported that they were taking psychotropic medications while none said they were not. Of those that stated their hoarding had improved, four reported that they are taking psychotropic medications and one stated that they are not.

Qualitative

After looking at the quantitative data, we then examined the qualitative variables in the study. The following data is relevant to understanding hoarding behaviors. Such variables include experience of death or trauma, type of treatment services received, most helpful treatment services, and whether the participants were still hoarding or not.

Death/Trauma

Of the 35 participants surveyed, 27 reported having experienced a death or trauma in their life. Of those who reported a death, 11 reported a death of a loved one such as the loss of a child, sibling, fiancé, wife, husband, or parent. In regards to trauma, seven participants reported that being in an abusive relationship, divorce, witnessing warfare, and being involved in a car accident were traumatic experiences in their lives. Three of the participants reported health issues such as a stroke, physical injury, and low functioning after an injury as a traumatic event. Two of the participants reported job loss as a traumatic event in their lives. The remaining participants simply stated that they had experienced

death or trauma in their lives, but did not provide further information regarding their response.

Type of Therapy

Those that reported receiving therapy for their hoarding symptoms stated that the type of therapy which they received consisted of counseling sessions, a life coach, homework, medication, and individual therapy. Medications reported by participants included anti-depressants and anti-anxiety medications such as, Wellbutrin, Zoloft, Prozac, Paxil, and Lexapro. Within the individual therapy, treatments for obsessive-compulsive disorder were used. According to the participants, this type of treatment was not very effective. Cognitive behavioral therapy was also used in treating hoarding behaviors.

Most Helpful Treatment Services

Those that reported receiving treatment services stated that having a therapist that understood their hoarding behaviors was beneficial to their treatment. This allowed them to feel comfortable in discussing their need of acquiring items with their therapist. Participants reported specific interventions such as purchasing a paper shredder and discarding of five items

per day to be effective. The participants also reported that the most helpful treatment services for their hoarding symptoms were individual therapy, homework and the use of medication. In some cases it was a combination of two or three of these services that were the most effective.

Still Hoarding

The participants were also asked if they continue to hoard regardless if they received therapy or not. Eight-teen of the participants stated that they are still hoarding and 17 stated that they no longer hoard. Among those that continue to hoard, some reported that their hoarding behaviors have decreased, but things continue to pile up in their home. Others stated that cleaning more frequently prevents them from collecting as much as they did in the past. Others reported that they no longer hoard items in their home and instead, collect items in their car. Another way in which they reported that their hoarding behaviors have decreased is by controlling the items that come into the home. According to the participants, when something new goes into the home, another is thrown out.

The participants who stated that they no longer hoard explained that a change in their living situation prevents them from collecting items. Some have downsized from a larger home and space is now limited. Others reported that they have less money to purchase items which has put a stop to their hoarding. A few others disclosed that they receive assistance with cleaning their home from their family members or from a maid service. Only one participant stated that they are now able to throw things out without a problem.

## Summary

This chapter focused on the analysis of quantitative data and discussed qualitative findings. Quantitative analysis consisted of univariate and bivariate findings. Frequencies were run for demographics, behaviors and therapy related variables. A Pearson correlation coefficient was run in order to view significant correlations between variables. T-tests and Chi-squared tests were calculated between variables that signified strong correlations as statistics were revealed and significance was acknowledged. The qualitative data were reported by the researchers in order to express specifics

in variables such as experience of death or trauma, type of treatment services received, most helpful treatment services, and whether the participants were still hoarding or not.

# CHAPTER FIVE

# DISCUSSION

## Introduction

This chapter will explore the significant findings from the results and whether the results answered or supported the research hypothesis. It will also identify unanticipated results of the findings and any limitations of the study. Suggestions for future research as well as implications for social work practice will also be explained.

## Discussion

The purpose of this study was to determine whether those with hoarding symptom obtained mental health services and if the services they received were effective in treating their symptoms. The data collected through quantitative and qualitative methods provided a variety of information to describe hoarding behaviors and the use of mental health services. The data obtained from the study sample of 35 hoarders demonstrated many demographic features that support the findings of studies presented in the literature review. In Chapter two, it was reported that hoarding behaviors can affect both men and women and

are also common among those that are well educated and make a decent living. One particular study reported that 49% of their participants were college graduates, 29% had attended some college, and 42% were employed as higher executives, business managers, or administrative personnel (Samuels, Bienvenu, et al. 2008). Within this study, it was found that the majority of the participants had a high level of education based on their occupation. The occupations reported ranged from active and retired teachers and engineers to psychologists and administrative personnel. Only a few reported entry-level jobs or not having a job at all.

In regards to age and gender, this study reported that hoarding is more common among older adults and females. The results demonstrate that those who participated in this study ranged in age from 37 to 90 years old and the mean age of the participants was 66.54. This supports the suggestions made by Steketee, Frost, and Kim (2001) that hoarding individuals tend to be significantly older. The sample also consisted of 24 females (68.6%), and 11 males (31.4%) which supports the literature stating that hoarding in more common among females.

Marital status was also a demographic feature presented in Chapter two. In the literature review, one study by Samuels, Bienvenu, et al. stated that the men were 53% less likely to have ever been married than the women, 70% of whom had been married (2008). The findings for the variables of gender and marital status support this study due to the fact that 15 of the female participants reported being married and only six of the male participants were married.

The general demographics of hoarding presented within the literature review, as well as the results from this survey, suggest that hoarding symptoms can affect anyone regardless of age, gender, education and socioeconomic status.

As suggested in Chapter two, traumatic life events are common among individuals who hoard. Cromer, Schmidt, and Murphy reported that "traumatic experiences have been posited as one potential catalyst for the abrupt onset of compulsive hoarding" (2007, p. 2581). They also suggest that those who had experienced a traumatic life event also had greater hoarding symptom severity than hoarders who had not been exposed to any type of trauma (Cromer, Schmidt, & Murphy, 2007). The results from this study

revealed that 27 (77.1%) of the 35 participants had experienced a death or trauma during their lifetime. The existing data and the current findings show that there is a strong association between trauma and hoarding behaviors.

The research within the literature review stated that characteristics associated with compulsive hoarding suggest that a person suffering from a social phobia and depression may develop hoarding symptoms. This study does not support or reject these findings considering that 16 (45.7%) of the participants stated that there was a history of depression in their family while 19 (54.30%) reported that there was not.

Findings also support existing studies regarding the effects of hoarding on relationships with family and friends. As stated in the literature, hoarding behaviors affect the individual and also cause a strain on those living in the home. A study by Tolin, Frost, Steketee and Fitch (2008) reported high levels of frustration and hostility among family members of hoarders (p. 334). The data collected in this study show that 65.7% of the participants reported that their hoarding behaviors resulted in issues with family or friends. Findings also

support the fact that hoarding behaviors cause the individuals to be isolated and to seclude themselves within their home, away from family, friends, and their community. When asked whether they allow others in their home, the participants reported as follows. Out of the 12 female participants, 12 stated that they allow people in their homes while 12 did not. Of the 11 male participants, none allowed others in their home.

Although there were only eight out of 35 participants who reported ever receiving mental health services, this low percentage of participants reflects upon a characteristic of individuals with hoarding syndrome, which is lack of insight. As stated earlier in this report, hoarders tend to lack awareness of their illness. This characteristic is reveled through the fact that only eight out of 35 participants received mental health services. This information coincides with Luchian, McNally, and Hooley's (2006) study as they suggested that hoarders tend to lack insight about their behaviors and rarely seek treatment by mental health professionals unless insisted on by friends or family. The high number of participants reporting issues with friends and family, as discussed above, may suggest that a weak support

network can also hinder an individual in seeking mental health services. Overall, the small number of participants who reported having mental health treatment for hoarding coincides with existing studies which reveal that a low number of individuals seek out mental health services for their illness.

This study also outlines therapeutic interventions that were discussed in Chapter two. Interventions mentioned included individual therapy, family therapy, group therapy, homework, home visits and medication. Although the survey used in this study included questions regarding the effectiveness of interventions mentioned above, there were no responses for family therapy, group therapy or home visits. Therefore, the therapeutic interventions included in these results only consisted of individual therapy, homework and medication.

The fact that there were no individuals who reported that they received family therapy, group therapy and home visits suggest some limitations on the current interventions that this population has received. Current studies such as the three manifestations of hoarding by Tolin, Frost and Steketee (2007) suggest that models of intervention for the hoarder should include "both office

and in-home visits" as it helps the hoarder cognitively assess the importance of their items through direct exposure (p. 1463). Unfortunately, due to the fact that no individuals stated that they have received home visit interventions in therapy, we were unable to specifically test if hoarders feel that home visits are effective. On the other hand, a point should be made that the qualitative data reveal reasons why some individuals have stopped hoarding. Some of these reasons consist of family members or a maid coming into their home and helping them dispose of items. This information suggests that assisting the hoarder with the discarding of items can effectively limit or eliminate hoarding behaviors.

The data in this study states that out of the eight participants who received therapy, five of them reported that their hoarding had improved, while three reported that it had not. As revealed in the cross tabulations of regarding individual therapy, homework and medication, only one person stated individual therapy to be ineffective, and two stated homework to be ineffective. On the other hand, seven reported individual therapy to be very effective, effective and somewhat effective, as three reported homework to be effective and somewhat

effective. Three reported not to have received individual therapy without homework interventions.

In terms of medication, of the seven that stated taking medication, four reported that their hoarding had gotten better while three stated that it had not. Only one individual reported not taking any medications. The data suggest that of three different types of therapy interventions, individual therapy and homework had stronger relationships with improvement in hoarding than did medication. It is important to note that four of the eight hoarders who received therapy and are taking medication do report that their hoarding has gotten better, but the data suggest that this is coinciding with some form of other therapeutic interventions such as individual therapy and/or homework. Saxena and Maidment (2004) state that "hoarders and saving compulsions have been strongly associated with poor response to SRIs" (p. 1146). Therefore, of the hoarders who stated their hoarding has improved, individual therapy appeared to be the most effective in helping them do so, while medication alone was not. The results in this study challenge the current interventions of using medication

as the sole treatment for individuals with hoarding syndrome.

This study suggests that professionals who understand hoarding syndrome tend to provide interventions that are more tailored to hoarding characteristics and therefore may be more effective. Of those who received mental health treatment, valuable information was gathered that supported the importance of having a clinician who is aware of hoarding behaviors and characteristics in order to provide effective mental health treatment. As reported in the previous chapter, when asked if their hoarding has improved after receiving mental health services, four out of the eight (50%) stated that their therapist or counselor understood hoarding syndrome. The percentage of individuals who stated their hoarding had gotten better and were satisfied with their services was 50%. Although there is relevance in this data, one cannot assume that those who reported to be satisfied with mental health services were also those who had a therapist who understood hoarding syndrome.

## Limitations

In assessing the results of this research project, certain limitations should be considered. One limitation was the small sample size. In spite of the many phone calls that were made, the researchers found it difficult to contact actual hoarders who were still able to participate in the study. The list provided by Steri-clean consisted of all their past hoarding consumers. Due to the fact that most hoarders are of the elderly population, those who received the services years ago, many are deceased or are currently in nursing or assisted living facilities where they could not be reached. Therefore, many of the individuals that were reached were descendents of the hoarder, and therefore could not participate in this study. There were also a few individuals who did not agree to participate in this research project. The duration of the survey was also longer than anticipated, as many of the participants elaborated on questions asked by the researchers. Although this may have caused limitations in terms of sample size, information was valuable and taken into consideration.

Another important limitation to consider is the population of hoarders that we had access to. Those that participated in this study were all previous consumers of Steri-Clean, which is a home clean-out service that works directly with individuals who are hoarders. The cost of a home clean-out is usually very expensive, therefore limiting access to hoarders who cannot afford such a service. It can then be assumed that the population surveyed was mostly those with a higher social economic status.

Another limitation as well as unanticipated findings came about through the analysis of the data as we found most of the participants to be Caucasian. Out of the 35 hoarders surveyed, 29 were Caucasian (83%). The small number of representation of minority populations did not provide substantial data for research purposes. Therefore, there were no variables representing ethnicity in the analysis.

## Recommendations for Social Work Practice, Policy and Research

There are several recommendations for social work practice and policy that come from the outcomes of this study. In regards to social work practice, clinicians

need to be aware of the distinction between hoarding behaviors and Obsessive-Compulsive Disorder (OCD). By doing so, the use of OCD treatments can be eliminated and better cognitive behavioral interventions can be developed. In working with a hoarder, clinicians need to realize that they are dealing with an issue of control rather than an issue of obsession. Interventions such as individual therapy, homework, medications, and follow-up methods should be used when working with this population. A combination of various mental health services are needed in order to be effective and prevent relapse of symptoms. Social workers and mental health professionals are ethically bound to research unfamiliar areas of practice, and so, further examination of the symptoms and issues hoarding syndrome entails should be conducted.

In regards to policy, outcomes of this project should be considered by the American Psychiatric Association in future revisions of the Diagnostic and Statistical Manual of Mental Disorders. We propose that hoarding be seen as a stand alone diagnosis and be eliminated from the criteria for OCD. Also, trainings for mental health professionals, APS workers, and anyone working with older adults should be required so that

professionals can become familiar with hoarding behaviors in order to understand the hardships caused by this illness.

Most importantly, further studies on hoarding should be done with a larger study sample in order to expand on the existing and developing literature on the topic. Due to the fact that most literature on this illness suggests more home visits and homework as forms of interventions, study should occur regarding what type of home visits and homework is more effective in treating this population. An awareness of such would bring about better results in surveys such as the one used in this study.

Research on effective interventions need to be examined in responding to the needs of hoarders as well as more detailed standardized measurements of insight. Further qualitative research would be essential in identifying the needs of hoarders and what they feel would help them decrease their hoarding behaviors and prevent relapse. Examining the proper use of medications in treating this illness needs to be reviewed to prevent the misuse of unnecessary medications.

## Conclusions

The purpose of this research project was to look further into the lives of hoarders and determine whether mental health services were being utilized and whether current methods were effective. Unfortunately, the survey sample of 35 participants only consisted of eight individuals who actually received services in treating their behaviors. The information obtained, however, provided valuable outcomes that can be used in future studies. We hope that our results will be considered in the implementation of new treatment methods and bring forth the severity and prevalence of this illness to the social work profession and the community.

# APPENDIX A

# QUESTIONNAIRE

## QUESTIONNAIRE

Gender: ____F ____M

Age: ____

Ethnicity: ____ Hispanic
____ Asian/Pacific Islander
____ African-American
____ Caucasian
____ Other

What is your occupation? _____

How long have you been collecting? _____
Do you have a family history of hoarding? ____Y ____N
Did you grow up in a home with a hoarder? ____Y ____N
What is your earliest hoarding memory?

_____
_____
_____
_____

When did you first notice that hoarding was a problem for you?

_____
_____
_____
_____

Is there a history of depression in your family? ____Y ____N
Did you experience a death or trauma before the hoarding began? ___Y ___N
Are you currently on any psychiatric medication(s)? ____Y ____N
If so, what medication(s)? _____
Have you ever been on any psychiatric medication(s)? ____Y ____N
If so, what medication(s)? _____
Do you use drugs or alcohol? ____Y ____N
If so, how often? _____

Are your married? ____Y ____N
Do you have children? ____Y ____N
Do you have a close relationship with your family? ____Y ____N
Do you have any close relationships with friends? ____Y ____N
Has hoarding caused any issues between you and your family members or friends?
____Y ____N
Do you allow family members or friends into your home? ____Y ____N
If not, when was the last time a family member or friend was allowed in your home?

_____

Has a family member or friend offered to clean your home? ____Y ____N
Has a family member or friend attempted to clean your home when you were not present?
____Y ____N

Have you every been in therapy or counseling for your hoarding? ___Y ___N

- If so, did the therapist or counselor understand hoarding? ___Y ___N
- If so, how effective did you find the interventions to be in reference to your hoarding?

1=very effective 2=effective 3=somewhat effective 4=not effective 5=doesn't apply

____individual therapy/counseling
____group therapy/counseling
____family therapy/counseling
____homework
____home visits
____medication

- If so, are you still receiving therapy or counseling for hoarding? ____Y ____N
- If so, was there a follow-up made by the therapist or counselor after completion of services? ____Y ____N, if yes what type? _____
- If so, has your hoarding gotten better? ____Y ____N
- If so, are you satisfied by the therapy or counseling you have received? ____Y ____N
- If so, what did you find most helpful with the therapy or counseling services you received?

_____
_____
_____
_____

If so, are you still hoarding? ____Y ____N

Have you ever received help to clean up your home? ____Y ____N

- If so, how helpful were those who helped with the clean up?

1=very helpful 2=helpful 3=somewhat helpful 4=not helpful 5=doesn't apply

____family
____friends
____clean up company workers
____clean up county workers

- If so, was the clutter completely cleaned out? ____Y ____N
- If so, was there a follow-up made by those who assisted with the clean up? ____Y ____N, if yes, what type? _____
- If so, what did you find most helpful with the clean up process?

_____
_____
_____
_____

- If so, after the clean up did you start hoarding again? ____Y ____N
  If so, how long did you keep your home clutter free? _____
- If so, prior to clean up did you feel:
  Anxious? ____Y ____N
  Depressed? ____Y ____N
  Suicidal? ____Y ____N

- If so, during the clean up did you feel:
    Anxious? ____Y ____N
    Depressed? ____Y ____N
    Suicidal? ____Y ____N
- If so, were you receiving therapy or counseling during clean up process? ____Y ____N

As of today:
    Are you still hoarding? ____Y ____N
        If not, are you currently receiving therapy or counseling? ___Y ___N
        If not, do you have a relationship with your family/friends? ___Y ___N
        If not, do you have family/friends over to your home? ___Y ___N
        If not, do you feel you are getting the ongoing support you need? ___Y ___N

How do you think you could have been better assisted through the entire process?

Thank you for sharing your heart with us! Above all else we respect your privacy as all information will remain confidential and be considered anonymous.

# APPENDIX B

## INFORMED CONSENT

## INFORMED CONSENT

The study in which you are being asked to participate in is designed to explore how helpful mental health services are to people who hoard. This study is being conducted by Yadira Cardenas and Girlyanne Lacson under the supervision of Dr. McCaslin, Professor of Social Work. This study has been approved by the Department of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

In this study, you will be asked to answer several questions regarding how helpful mental health services are among individuals who hoard. The survey should take about 5 to 15 minutes to complete. All of your responses will be anonymous. Your name will not be reported with your responses. All data will be reported in group form only. You may receive the group results of this study upon completion after September, 2009 through contacting Steri-Clean at 1-888-577-7206.

Your participation in this study is totally voluntary. You are free not to answer any questions and withdraw at any time during this study without penalty. When you have completed the survey questions, you will receive a debriefing statement describing the study in more detail.

If you have any questions or concerns about this study, please feel free to contact Dr. McCaslin at 909-537-5501.

By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

☐ Today's Date: _____

# APPENDIX C

## DEBRIEFING STATEMENT

## DEBRIEFING STATEMENT

This study you have just completed was designed to investigate how helpful mental health services are among people who hoard. Thank you for your participation. If you have any questions about this study, please contact Dr. McCaslin at 909-537-5501. If you would like to obtain a copy of the group results of this study, please contact Steri-Clean at 1-888-577-7206 after September 2009.

Thank you for your participation.

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## ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:

   Assigned Leader: Yadira Cardenas

   Assisted By: Girlyanne Lacson

2. Data Entry and Analysis:

   Team Effort: Yadira Cardenas & Girlyanne Lacson

3. Writing Report and Presentation of Findings:

   a. Introduction and Literature

      Team Effort: Yadira Cardenas & Girlyanne Lacson

   b. Methods

      Team Effort: Yadira Cardenas & Girlyanne Lacson

   c. Results

      Team Effort: Yadira Cardenas & Girlyanne Lacson

   d. Discussion

      Team Effort: Yadira Cardenas & Girlyanne Lacson