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ATTITUDES AND BELIEFS TOWARD HOARDING AMONG
ADULT PROTECTIVE SERVICES WORKERS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Jade Yuko Lambert

June 2009


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ADULT PROTECTIVE SERVICES WORKERS

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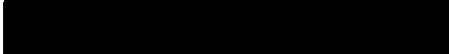
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ABSTRACT

This study examined the attitudes and beliefs toward hoarding among Adult Protective Services workers. The interview participants were 12 APS workers in the Department of Aging and Adult Services in San Bernardino County. These participants were asked to provide their perceptions of hoarding behavior and experiences with hoarders. Following the interviews, qualitative analysis, "grounded theory" was conducted. The findings demonstrated the characteristics of hoarding behavior, APS workers' interventions in hoarding behavior and their challenges, cooperation and communication of hoarders perceived by the workers, and outcomes. Social work implications and study limitations were also discussed.

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CHAPTER ONE

INTRODUCTION

This chapter will discuss the issue of hoarding. The study of hoarding is relatively new. Frost and Steketee (2004) mentioned that before the early 1990's, there was no research conducted on compulsive hoarding. Hoarders have been commonly misunderstood as packrats and slobs, and their behavior labeled as lazy; however, recent research indicates this is not the case. The characteristics of hoarding behavior, a possible link between hoarding and mental disorders, and a brief background of Adult Protective Services (APS) will be discussed.

Problem Statement

Hoarding is a problematic behavior; however, it has never been considered as a serious problem. The seriousness of hoarding is not clearly understood, and it is generally viewed as an individual's laziness or simple clutter. However, this general view needs to be corrected. Hoarding is a form of self-neglect, and this phenomenon has been increasingly seen in people, especially among the elderly population. Hoarding is

defined as, "the acquisition of, and failure to discard, a large number of possessions that appear to be useless or of limited value...living space sufficiently clutters so as to preclude activities for which those spaces were designed" (Frost & Hartl, 1996, p. 341).

To visualize and comprehend hoarding behavior, one needs to describe the homes of hoarders; living spaces are literally filled with garbage. Soiled clothing is piled up on the floor, and unwashed pots and pans and unwashed cups and plates are left in the kitchen. Other things such as garbage, animal feces, human feces, and dead bugs are also frequently seen in living spaces. Infestation with pests is also common. There is very limited space to walk in, thus, making it very difficult to move around. It is also hard to breathe inside the house because of a strong foul odor that usually comes from rotten food or feces.

People who live in this condition also do not seem to practice personal hygiene, especially the elderly population who do not have their own family or social support. Their clothes are torn, stained, and oftentimes soiled. Their hair is also unwashed and filthy. Strong body odor is usually smelled from them. Only 36 percent

of hoarders are described as well-kept and clean with the help of caregivers, but the rest of them have difficulty making themselves clean (Steketee, Frost, & Kim, 2001).

Moreover, Steketee et al. (2001) note that elderly women seem to be the most prone to hoarding. The profile of elderly female hoarders is unmarried and living alone; their "never-married" status is strongly associated with more severe hoarding and impairments (Steketee et al., 2001). The reason elderly women have a stronger tendency to hoard than elderly men is unknown. One possibility is that women may be more cooperative for research studies and readily disclose to others so that elderly female hoarders are more noticed by society than male hoarders (2001).

Although hoarders appear to be careless about their living condition, most of them strongly hesitate when people ask to see inside their house. They are often embarrassed by their living condition and refuse to invite people over (Saxena & Maidment, 2004). They limit their contact with the outside world due to embarrassment about their living environment. For instance, hoarders speak to their visitors without opening the door, or communicate with others through a tiny crack in the

window. Their unclean appearance also does not help them to have social interaction. Hoarders are unable to groom themselves due to the clutter covering their bath tub or kitchen which prevents the use of the shower and access to water in the kitchen (Steketee et al., 2001). Their living condition impedes their personal maintenance and their lifestyle, creates social isolation and keeps their problem hidden.

Some of the recent research suggests that hoarding behavior is associated with mental disorders. One study states that hoarding behavior has been observed in "several neuropsychiatric disorders, including schizophrenia, dementia, and mental retardation" (Saxena & Maidment, 2004, p. 1143). Studies also reveal that hoarding is "in the context of Diogenes' syndrome, which is characterized by gross self-neglect" (Steketee, Frost, & Kim, 2001, p. 177).

Despite suggestions that there is a strong link between hoarding behavior and mental disorder, there is currently no definition or formal diagnostic criteria for hoarding in the Diagnostic and Statistical manual of Mental Disorders, Forth edition (DSM-IV). One suggests that there is a correlation with obsessive compulsive

disorder since hoarding is mostly found in patients who have OCD (2004). Saxena and Maidment (2004) suggest that hoarding also has comorbidity other than OCD symptom factors such as social phobia, personality disorder, and pathological grooming disorders.

Although an intervention for hoarding behavior is necessary, many factors make it very difficult. For one, hoarders often refuse the intervention or social services because they just do not see their hoarding behavior as a problem. They are also uncooperative towards social service workers because they are often paranoid and embarrassed (Franks et al., 2004).

Moreover, hoarders also seem to have a strong trait of excessive anxiety. Oftentimes, hoarders have inappropriate attachment to their possessions and erroneous beliefs about possessions (Steketee, Frost, & Kyrios, 2003). Due to these distorted beliefs, hoarders, especially elderly hoarders get paranoid that social workers or care providers will steal or throw away their possessions. One organization called COH (Children of Hoarders) in an example of an inappropriate attachment introduces a striking quote from a husband of a hoarder: "I buried my wife yesterday. She was a hoarder. ... After

fifty years of marriage, her dying words to me were not 'I love you.' They were 'Don't touch my stuff'" (eSMMART, 2008, p. 5). The priority in life of hoarders changes because of distorted attachment.

Furthermore, elderly female hoarders who have a never-married possibly could display the strongest refusal of an intervention because they tend to have a greater attachment to objects since they have never had a partner (Steketee et al., 2001).

Whether hoarders have a desire to live a normal life or not is unknown; however, their lifestyle is easily being judged. The characteristics of hoarders such as uncleanness, uncooperativeness, and stubbornness are not understood well, and viewed as a burden to the community. What needs to be understood is that these characteristics of hoarders are not necessarily tied to their unwillingness to change their living environment.

Hoarders may have the desire to change their living condition. However, hoarders, especially elderly hoarders have been in the same condition for many years with very little or no family or social support, which leaves them no choice but to accept their situation. As Erickson's developmental stage theory "Integrity vs. Despair"

indicates, they may perceive themselves as a failure due to the fact that they have to live in a deplorable condition for a long time. They may have lost all the motivation for a quality life.

One organization that has the closest contact with hoarders is the government agency, Adult Protective Services (APS). APS serves adults who are over 65 years old or any mentally and physically disabled adults. They respond to a variety of forms of adult abuse and neglect. Currently, hoarding is considered as self-neglect, and APS workers help hoarders and provide services for them for a better life.

Purpose of the Study

Some past quantitative studies provide useful data on outcomes of APS services; however, hoarding behavior is not normally found as a separate category. In statistical research, it is uncertain in which category hoarding behavior should be classified, either under 'neglect' or 'abandonment' or others.

Moreover, although statistics are very useful, the voices of hoarders or workers are not reflected on the results of these quantitative studies. In order to

understand hoarding better, it is necessary to go beyond the numbers and to know certain factors such as experiences of APS workers during intervention, their attitude towards hoarding behavior, and indirect voices of hoarders which are rarely heard.

APS workers' caseloads are normally very heavy due to the imbalanced ratio between the number of workers and cases. However, they still spend hours to investigate each case and revisit clients repeatedly. APS workers are trained to handle many types of cases, including hoarding. This is an exploratory study of APS workers' experiences as experts and their attitude towards hoarding behavior.

The study consists of interviews of 12 APS workers in the Department of Aging and Adult Services, in San Bernardino County. APS workers' experiences with hoarders, experts' opinions about the behavior, and perception of hoarding were examined with 16 open-ended questions. Each worker's professional expertise in hoarding was explored.

Significance of the Project for Social Work

As mentioned, hoarding behavior is a hidden social problem. Although several studies about hoarding behavior have been conducted in the past, comprehension of the behavior is rare in the community. The data about hoarding is still limited because hoarders isolate themselves from society and stay behind closed doors, and they make their life almost untouchable. It is difficult to find out what goes on behind the door and determine exactly what type of services and resources they need. APS workers have direct contact with hoarders and many interactions with them. Their knowledge and hands-on experiences are extremely valuable to understand hoarding, and these will contribute to finding a better way to intervene in the behavior. The purpose of this study is to acquire more in-depth understanding about hoarding behavior through APS workers' professional perception.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The first section of this chapter will cover relevant literature on hoarding behavior. Theories of hoarding, a historical overview, and correlations between hoarding and mental health disorders will be covered. Also, the characteristics of hoarders and the risk of hoarding among elderly population will be addressed.

In the second part of this chapter, specific research studies and literature on Adult Protective Services (APS) will be covered. The history of APS, the role and competency of APS workers, and a brief discussion of interactions between hoarders and APS workers are also addressed.

Theories Guiding Conceptualization

Psychologists in the past have studied hoarding behavior as a concept. The behavior was not clearly defined at first; however, psychologist Sigmund Freud laid the foundation to characterize the behavior. In 1908, Freud stated in his study "Anal Erotism" that three characteristics of human beings, orderliness, parsimony,

and obstinacy, are closely associated and tend to occur together (as cited in Greenberg, 1987). Four years later, a Freudian psychoanalyst, Ernest Jones, defined one of the characteristics, parsimony, as "the refusal to give but the desire to gather, collect, and hoard" (Greenberg, 1987, p. 409). Years later, another psychologist, Karl Abraham, observed and articulated the behavior that,

the difficulty our [clients] have in separating themselves from objects of all kinds when these have neither practical use nor monetary value, [and] such people often collect all sorts of broken objects in their attics under the pretext that they may need them later; the same persons cannot get rid of these possessions. (as cited in Greenberg, 1987, p. 409)

Hoarding behavior has been an untouchable issue due to a variety of hidden factors and has not gotten much attention as a problem; however, it is clear that the problematic behavior was already identified and analyzed by psychologists a century ago.

Recently, a concrete and formal definition of hoarding was established as "the acquisition of, and failure to discard, a large number of possessions that appear to be useless or of limited value; living space

sufficiently clutters so as to preclude activities for which those spaces were designed" (Frost & Hartl, 1996, p. 341). Until recent years, hoarding behavior has not been addressed properly because of several reasons, some of which are the following. 1) It is what happens in the private living space so that it is easy to conceal; 2) many hoarders are embarrassed about their behavior and isolate themselves from others; and 3) some view this behavior as completely normal and as a lifestyle choice (Franks, Lund, Poulton, & Caserta, 2004).

The cause of hoarding behavior has been discussed by many researchers; however, their research is still ongoing to determine the reason why the behavior happens, and conclusive results are not yet in. Currently, hoarding is not categorized as a disorder and has no diagnostic criteria in the DSM-IV. However, many researchers believe that hoarding should be viewed as a discrete entity and categorized as a disorder. One study states that hoarding behavior comes from several neuropsychiatric disorders, including schizophrenia, dementia, and mental retardation (Saxena & Maidment. 2004). On the other hand, Steketee, Frost, and Kim (2001)

discuss hoarding behavior as in the context of Diogenes syndrome, which is typified by gross self-neglect.

Although there still is no formal diagnostic criterion of hoarding, many researchers seem to come to one common understanding that hoarding behavior is frequently associated with obsessive compulsive disorder (OCD). One study shows that hoarding behavior represents a primary or secondary symptom in 16-31% of patients with OCD (Steketee, Frost, & Kyrios, 2003).

However, the National Alliance on Mental Illness (NAMI) in San Diego (2008) suggests that not all hoarding is compulsive, and the symptoms need to be clarified and carefully examined. Saxena et al. (2004) assert that compulsive hoarding should not be a part of OCD, but should be categorized as a different type of OCD. This was based on their empirical findings that hoarders have much lower glucose metabolism in their brain, compared to OCD sufferers, with the implication that hoarders will not respond necessarily to medication for OCD (Saxena et al., 2004).

In addition, there is also another implication that hoarding could possibly be a genetic disorder. Saxena (2007) suggests, based on the result of the lab

experiment, that hoarding could be a genetic disorder, and should be established as a genetically and neurobiologically affected syndrome. Saxena (2007) is convinced that there is enough evidence to justify that hoarding is a separate mental disorder and should be placed in the future DSM-V as a discrete entity separate from OCD. Although many researchers agree with his finding, the research still needs to be replicated before coming to the conclusion that "there is a special susceptibility locus for hoarding" (Grootheest & Cath, 2007).

Danger of Hoarding among Elderly

People with hoarding behavior have been perceived by society as being lazy or slob. However, as many studies already indicated, hoarding behavior happens not because of laziness, but most likely because of mental disorder. Hoarding behavior is seen in all ages, but the problem among elderly is significantly increasing and seriously threatens the quality of their lives (Franks et al., 2004).

Historically, hoarding behavior in the elderly population was at first considered as part of the

Diogenes syndrome. The symptoms of this syndrome are extreme self-neglect, social withdrawal and domestic squalor (Jefferys & Moore, 2008). However, the validity of this study has been disputed because of the overlap of its symptoms with obsessive compulsive disorder, dementia, and other psychiatric illnesses (Steketee et al., 2001). Due to the significant increase in hoarding behavior among the elderly population, the prevalence of the behavior in dementia patients was examined and it was found that hoarding was one of the common symptoms of dementia (Steketee et al., 2001). The Department of Psychiatry at Taipei Veterans General hospital also found that over 22% of hospitalized dementia patients engaged in significant hoarding (Brown, 2007).

Hoarding is a complicated, multifaceted problem (Franks et al., 2004). It is difficult to intervene in the behavior among elderly because they are either incapable of being aware of the problem or are embarrassed and thus, isolate themselves from society. Many elderly hoarders do not interact with family members or friends, and most of them live alone (Steketee et al., 2001). This is a great concern. Hoarding behavior is problematic enough, but second-hand negative effects such

as health hazards are also a great concern. The social isolation that elderly hoarders create for themselves does not help to prevent unnecessary health deterioration. One study indicates that hoarding behavior constitutes a physical health threats to 81% of them (Saxena & Maidment, 2004). Similarly, another study indicates that hoarders' health can be threatened from contamination of perishable food, dust pollen, and bacteria in the air (Frost, Steketee, & Williams, 2000). These factors can cause numerous illnesses such as a respiratory problems, dermatological problems, and bacterial infections.

Hoarding behavior can also pose risks to the community. The most detrimental one is if it causes fire hazards. If flammable materials, for example, such as newspapers and magazines are piled up near a stove, controlling fire would be harder, especially when other possessions block the way out (Frost et al., 2000). Communities also complain about infestation of rodents and unpleasant odor, which are some of the negative effects of hoarding.

Elderly hoarders not only live in squalor, but fail to maintain self-care standards, which is becoming a

serious public health issue and also considered to be an independent risk factor for death (Pickens et al., 2007). The Federal Interagency Forum on Aging Related Statistics (2008) predicts that the elderly population will be over 20.3% of the whole U.S. population by the year 2050. Understanding hoarding behavior correctly is critical, and intervention and prevention will be necessary.

Role of Adult Protective Services

The Adult Protective Services (APS) agency is the first responder to elderly abuse and self-neglect, including hoarding behavior. APS workers directly contact hoarders, interact with them, and investigate what goes on. The mission of APS is to ensure the safety of the elderly and disabled adult population.

The establishment of the APS is relatively new. The history of adult protective services in the United States is ambiguous due to lack of records and some are gleaned from oral history (Otto, 2000). According to a study by Hall and Mathiasen, the earliest formal record of the need for adult protective services was a conference of the National Council on the Aging in 1963 (as cited in Otto, 2000). The first official adult protective services

program was established in the State of Texas in the mid-seventies after the passage of the Title XX amendment to the Social Security Act in 1974 (Otto, 2000). The title XX is the funding source for the State's human services to protect children, elders, and disabled adults from abuse, neglect, and exploitation. This act gave social workers expanded mobility for their work (Staudt, 1985).

In the state of California, Child Protective Services agencies were initially handling adult abuse cases; however, the Adult Protective Services programs were standardized and branched out in 1999.

APS provides services for elders aged over 65 years or mentally or physically developmental-delayed adults who are over 18 years of age. The mission of APS is to provide a safe environment for its clients. They investigate reported abuse cases and provide solutions; however, in order for APS to perform its duties, they always require a client's consent. A client's wishes and right to decline intervention or help are always respected.

Service of APS is sometimes declined by a client, depending on the characteristics and environment of

abuse. Once a client refuses, APS cannot do their work even if APS workers recognize a serious problem. Due to this policy, oftentimes APS workers express frustration at not being able to resolve the situation and of 'failing the client' (Lauder, Anderson, & Barclay, 2005).

Competency of Adult Protective Services Workers

APS workers are required to follow multidisciplinary but appropriate procedures in order to establish working relationships with clients. APS workers' caseloads are very high; especially self-neglecting cases as well as hoarding make up the high caseloads. These cases are complicated and will take a great amount of staff time, and other agencies either refuse to get involved or do so briefly, eventually turning to APS workers for help (Otto, 2000).

Moreover, building and establishing a trusting relationship with "a fearful client" takes time and skill (Otto, 2000). APS workers are also required to establish relationships with healthcare providers and law enforcement in order to provide better services and respond jointly to elder mistreatment occurrences (Heath, Kobylarz, Brown, & Castano, 2005). Overall, APS workers

can be defined as "network service providers - social, medical, legal, and others" (Staudt, 1985, p. 205).

In order to improve competency of APS and maintain service quality, many training opportunities are given to the workers. National Adult Protective Services (2008) often have conferences and workshops for APS workers to participate in, and provide resources and information for them to use for their services. There are also monthly meetings and trainings provided by the government (NAPS, 2008).

The role of APS workers has been defined; the purpose of adult protective services is "to protect those individuals who are unable to protect themselves and APS workers must use supportive services and intervention" (Staudt, 1985, p. 207). The competency of APS workers is adequate and it only improves under these training and daily interaction with clients.

Interaction between Hoarders and Adult Protective Services Workers

Actual interactions between APS workers and hoarders are difficult to track due to confidentiality and workers' heavy caseloads. Yet Franks et al. (2004) utilized a case study approach for a hoarding case. The

case study introduced a brief interaction between an APS worker and a hoarder, and procedure of intervention for the client's hoarding behavior. APS workers' numerous attempts to visit the elderly hoarder and collaboration with other agencies to intervene in the hoarding behavior were addressed in the study. The case study stated that "while APS worker continues to work with her, the hoarding behavior seems to have abated" (Franks et al., 2004, p. 87). APS workers' competency is verified, and it is necessary to know their perception about hoarding, in order to have better understanding of hoarding behavior.

This study was also addressed from a theoretical approach, the theory of reasoned action (TRA). The TRA is a study of people's attitudes developed by Martin Fishbein and Icek Azjen (Lezin, 2007). There is a correlation among attitude, behavioral intent, and subjective norms. Behavioral intent is the main determinant of behavior. The TRA focuses on a population's attitudes towards that behavior as well as subjective norms of influential people and groups that could influence those attitudes (Lezin, 2007). According to the TRA, attitudes and subjective norms are the greatest influences on behavioral intent, and these

factors seem to be the main motivators of behavior (2007). Applying the TRA to a relationship between hoarders and APS workers, the attitude was the hoarders' attitude (whether it was positive or negative), the subjective norm was APS workers' attitudes and beliefs, and the behavioral intent was intervened hoarding behavior.

Summary

There are not very many studies that show interaction between APS workers and hoarders; actual dialogues are never found. However, the characteristics and theoretical background of hoarding are presented. The literature suggests that hoarding is not a personal choice, but more likely a mental disorder. Many research studies show that hoarding behavior is not only dangerous to hoarders alone, but a threat to their communities as well. This section introduces and describes the mission and tasks of Adult Protective Services, and it shows the competency of APS workers. The research studies are essential to draw correct attention to hoarding behavior, and the competency of APS workers provides the best reliability of their testimony about hoarders.

CHAPTER THREE

METHODS

Introduction

This chapter introduces the methods used in conducting this research. It discusses study design, the method of data collection, the instruments used for gathering the data, and the procedure of analysis. It also addresses the protection of human subjects as well as promises to protect anonymity.

Study Design

The purpose of the study was to explore APS workers' professional attitudes, beliefs, and perceptions about hoarding, in order to acquire in-depth understanding of hoarding behavior. This study employed a qualitative exploratory method. This method was chosen because it was the most suitable method for obtaining detailed data, including APS workers' expertise, their views, the interactions between APS workers and hoarders, and their dialogues. The focal points of this exploratory study were: the behavior and social environment of hoarders, APS workers' attitudes and beliefs about hoarding

behavior, and the needs for professional assessment and interventions.

Sampling

The sample for this study was twelve APS workers from the Department of Aging and Adult Services in San Bernardino County. The main office is located in the city of San Bernardino, and five other APS offices are spread throughout San Bernardino County. This study was being discussed with a supervisor in the APS office in San Bernardino County, and permission for interviews for this research study was granted.

Data Collection and Instruments

Data for this study were collected from twelve APS workers in San Bernardino County, and sixteen questions were answered. This instrument was developed by this researcher and addressed attitudes and beliefs of hoarders and APS workers, social environments of hoarders, and interventions for hoarding. The dialogues between hoarders and APS workers were collected.

The survey (Appendix .A) was consist of sixteen open-ended questions designed to help understand the characteristics of hoarding behavior perceived by APS

workers. Sample questions asked to APS workers were: How are hoarders cooperative or uncooperative when you go into their living space? What is their attitude like? What is the most beneficial service for the elderly hoarders? How do hoarders' family members perceive their living situation?

As this study was conducted with a qualitative-exploratory method, there was no independent or dependent variable. Also, as for dialogues between APS workers and hoarders, statements made by hoarders were indirectly collected from APS workers.

Procedures

Interviews with APS workers were conducted individually in the APS office in San Bernardino County. Initially, APS workers were contacted by the researcher over the telephone, and appointments for the interview were scheduled at each worker's convenience. Each interview took approximately 30 to 45 minutes to complete. Audio from ten interviews were recorded in order to keep accurate records of the data. Notes of two interviews were also taken thoroughly by the researcher.

Protection of Human Subjects

All the names of APS workers were kept anonymous. An informed consent form (Appendix B) was given to each APS worker. Also, all information such as case numbers, names, and addresses regarding their elderly clients was kept anonymous as well. This researcher kept all the collected data and destroyed it after analysis was completed. Confidentiality was strictly protected in this study. A debriefing form was also given to each APS worker after completion of each interview.

Data Analysis

This study used open-ended questions to explore the seriousness of compulsive hoarding behavior. The correlations between the questions and the reasons for elderly hoarding behavior were examined. The collected data, audio-recorded interviews and notes taken by the researcher, were transcribed. The transcribed narratives from the interviews were coded utilizing open-coding technique from Grounded Theory.

Summary

The purpose of the study was to understand hoarding behavior, and the method was qualitative in-depth

interviews. Data were coded for analysis and utilized to see the characteristics of hoarders. Confidentiality of the subjects in this study was strictly maintained.

CHAPTER FOUR

RESULTS

Introduction

This chapter is a presentation of the results of this study. Qualitative data analysis was performed, code words that represented Adult Protective Services workers' responses were extracted and grouped into categories, and categories were developed based on the characteristics of hoarding. Gender ratio is also discussed as well as ethnic background. The chapter concludes with a summary.

Presentation of the Findings

For obtaining results, audio recordings were transcribed verbatim. This produced approximately three to four pages of narrative per participant and 29 pages of combined narrative. Notes that were taken during the interviews with participants who did not wish to be audio recorded were also reviewed and transcribed to approximately nine pages of combined narrative. Transcribed data were reviewed and analyzed using qualitative data analysis, and open-coding techniques were used. These codes best reflected what the

participants meant by their statements. Gender and ethnic background were also evaluated.

Codes were extracted from the transcribed interviews with the application of open-coding techniques. The following is an example of the statements that the participants made.

Hoarding is so complex. People hold on to and collect things that have personal value to them. Mail, advertisements, boxes, cans, and food; most of these things are potentially counterproductive, basically trash.

But I believe that hoarding is kind of a diary of life in a sense. You go through your life, and you have all of the objects a wife and husband may have accumulated over a lifetime that have a lot of meaning. Many of them have very strong emotional attachment to whatever the objects are.

One client was a retired physician, very bright, living in a very tiny place, and her hygiene was bad, and she was isolated, but she had tons of medical journals all over. She was

keeping her past; this was a big part of her life.

From these statements, the code of emotional attachment was extracted. In these statements, the APS workers explained one of the reasons that hoarders may collect items and hold onto them. Hoarders' strong attachment to collected items was mentioned by most of the participants, and classified into the category of characteristics of hoarders. Following this initial coding process, all of the extracted codes were classified into five main categories: Characteristics of hoarders, Interventions, Communications, APS workers' challenge, and Outcome, as shown in Table 1.

Table 1. Main Categories

Categories	Codes
Characteristics of Hoarders	Isolation Great Depression Rationalization Nice People Animal Infestation Emotional Attachment Accumulation of property Property value Life Threatening
Intervention	Assisted Living Eviction Long-term psychotherapy Temporary Remedy Forced Intervention Code Enforcement
Communications	Embarrassed Upset Ashamed Uncooperative Defensive
APS Workers' Challenge	Establishing Rapport Trust Refusal of Services
Outcome	No Change

These categories were determined based on the researcher's interpretation of the meaning of the codes.

For example, the category "Characteristics of hoarders" was chosen because this represented aspects of hoarding behavior. It explained its complexity and emphasized that this phenomenon was not just laziness, that there were much deeper underlying factors. Some of the response statements that led to the development of the category included:

It's also about feeling worthless. If you feel worthless, having possessions, even if it's only mail, gives some sort of recognition that you are worth something. (Isolation).

Many elderly people who lived through the 1929 Great Depression became hoarders as part of the way of surviving. (Great Depression).

You know, hoarders collect things that have memories and attachment. My wife used to love this, my husband used to love this, you know, this is an emotional bank account. But you go in and tell them that these things are all trash and throw them away. Then people come in and do the cleaning pretty fast. This is like wiping a bank account. It is devastating to them. (Emotional Attachment)

One client had many things collected in her house and could not get up from the couch. She probably didn't want to get up. The couch was made of vinyl. After a year or two of being soaked in urine, her skin melded with the plastic. When the paramedic lifted her off the couch, the vinyl had grown into her skin and filled with maggots. But after the intervention, she died. That was the only environment she was familiar with, and after she was taken out of her house, she did not survive. (Life Threatening)

In addressing the category "Intervention," several options that APS workers had were reported. Several participants made their mission statement very clear, saying that APS would respect a client's wish if they declined their services, unless there was something harmful to themselves or others that was recognized. Some of participants also stated that mental health services could be useful; however, it would be difficult for them to receive the services due to the nature of the behavior. Several participants stated that hoarders needed to be closely monitored and that daily long-term

psychotherapy would be desirable. Most APS workers also reported that the most effective intervention for hoarding behavior was a forced intervention, which would be done by law enforcement or code enforcement personnel. Suggesting moving into an assisted living facility was also somewhat effective. However, these forced interventions were only effective for physical change. It did not change them emotionally and mentally.

We encourage hoarders to go to assisted living where they can be assisted with nutritious food, doctor's care, medication, transportation, and socializing with people; however, they don't want to go because that is the first serious step towards losing their independence.

They are very resistant. Everything is attached to some significance. One lady kept a dead bird in her fridge and she did not want to throw it away. It took the fire department and code enforcement coming in and condemning the house to get her to agree.

Short-term therapy won't work. They are in their 60s, 70s, and 80s. Personality dynamics

won't change overnight. In terms of counseling and trying to change them, I think you are pretty much barking up the wrong tree there.

The "Communication" category consisted of hoarders' attitudes and how they communicate with others. Some participants said that hoarders were friendly and nice people and most of the time pleasant to talk to until they brought up the hoarders' living situations and health risks. At this point, they became upset and angry. In addition, some of the participants reported that hoarders did not perceive their living conditions as a problem; it was just their lifestyle and choice. However, some participants reported that hoarders knew that their living situation was not normal. They refused to open the door because they were embarrassed and ashamed.

They are embarrassed. They know that they have four, five feet of clutter in their homes. They don't want to open the door for us. They don't want to hear about the safety risks. Once you suggest cleaning up their homes, they rationalize and try to convince us why they need to keep it the way it is.

Their attitudes were basically "get out of my house," and they often refuse our services. Their trash is their treasure. They don't want us to touch it at all.

Most of them are ashamed. Some are embarrassed and tell us that their body hurts or they are tired; they make excuses not to open the door for us.

Another category is "APS workers' challenge," which involves their daily interactions with hoarders, how they approach hoarders, how they break through the thick wall hoarders put up, and their limits and frustration. Although APS workers deal with hoarders' reluctance, resistance, and uncooperativeness, they try to built trust and establish a good relationship with them in a non-threatening manner. All of the participants reported that building a strong rapport with them was crucial. However, it is not an easy process and most of the participants reported that a hoarder's defense level is very high.

Even though we think that we are nice puppies from the government and here to help them, well, in a sense we are, but I think at times

we overlook the public's perception. You know, here we are with this badge knocking on the door, and I think they attribute a lot more authority to us.

Hoarders are understandably very defensive and guarded. Even though we are not the social Nazis, and we are not there to act in a punitive manner, we are being paid by the County or State to be coercive and put all kinds of intellectual terminology on them. Basically we are perceived as authority.

They don't want us. They don't want our services. We go out with our middle class values and say you should clean. We really impose the middle class values on them. If they want to live in trash, it is their constitutional right.

You have to be civil with them. Spend five minutes to talk about the weather. You don't want to say that you need to clean the place as soon as you open the door. Some of them are paranoid about seeing us. Elderly who

experienced the Great Depression, they are proud and don't want any assistance.

The last category was "Outcome." There was one code in this category. All of the participants reported that there was one realistic outcome. Some APS workers stated that there were few exceptions; the situation became better only when hoarders obtained their family's support or constant monitoring from private agencies, which rarely happened. All of the participants stated that in almost all cases that had had an intervention, things went back to the way they were.

This one client; there was a cleaning company that came out to empty her house. Seven dumpsters were filled with her possessions, but as soon as they left, she went back to the dumpsters and emptied all seven of them and brought everything back to the house.

It's not cured. Heavy cleaning can be done, but in two weeks, it will go back, and then we get a call for the same person.

Within one to six months, the situation returns to the way it was. It seems to be a deep-seated part of the personality structure.

Cleaning and intervention can be done, but realistically, we expect them to go back to the situation that we encounter initially. They go back and make another collection of newspapers, advertisements, and other stuff.

Finally, the gender ratio and ethnic background of hoarders were also reported by the participants. Eight out of 12 participants reported that hoarders tended to be Caucasian females. Other reports indicated that there were Asian females, Pakistani males, Caucasian males, and African American males.

Summary

Chapter Four presented and reviewed the results extracted from the interviews. Data were transcribed by the researcher, and extracted into codes, which were classified into five different categories based on their commonality and meanings. In order to produce a theoretical statement about the connections between the categories, an "open-coding" technique from grounded theory was used. The characteristics of hoarding behavior and APS workers' deep insight about this behavior were investigated.

CHAPTER FIVE

DISCUSSION

Introduction

This study explored Adult Protective Services workers' professional perceptions of hoarding behavior. It includes a presentation of the conclusion resulting from this study. The limitations of the study and the recommendations for social work practice and policy drawn from the study are also presented. Lastly, the chapter concludes with a summary.

Discussion

The purpose of this exploratory study was to acquire better knowledge and understanding of hoarding behavior through APS workers' professional perceptions. This study found that hoarding behavior is not simple neglect, rather there seemed to be a deeper rationale behind this behavior. What appears on the surface may be an intolerable sight; however, there may be personal emotions and stories hiding in an affected person's extremely cluttered home. What can be visibly seen in hoarders' living space are non-valued, unnecessary items that could be almost counter productive to daily life.

However, this study shows that APS workers do not seem to perceive hoarding in that way. Instead, they respect the different standards and values that hoarders have, and acknowledge personal valuables that are probably trash to others' eyes.

Not all hoarding cases are necessarily emotionally driven. Some cases happen due to the loss of executive functioning; however, the statement Steketee et al. (2001) made that single elderly women who live alone are prone to severe hoarding does make sense. They seek emotional replacement and compensate for their loneliness by collecting items and holding onto them. It becomes a problem only when it gets out of hand. In this section, what was found and what was not found in this study will be discussed.

This study identified the characteristics of hoarding behavior. It was interesting that most participants focused more on what is not seen on the surface. They focused more on emotions and feelings underlying the hoarding behavior. They certainly explained what is seen on the outside; however, their focal point was on internal and emotional content.

It was quite interesting that OCD was never brought up during the interviews. According to the DSM-IV, hoarding is a feature of obsessive compulsive disorder; however, this was never identified in this study. The participants considered hoarding behavior as a loss of executive function, inability to organize, or emotional dependency. Hoarders are an isolated, untouchable population; however, APS workers' ability to identify hoarders' inner thoughts and emotions may create a better interaction between hoarders and APS workers possible.

Despite the compassionate approach of APS workers and their efforts to communicate, they still find that it is difficult to have hoarders open the door for them. APS workers understand that hoarders perceive them as authority figures and feel intimidated, and this oftentimes acts as barrier between them.

Since an emotional context is deeply involved in hoarding behavior, interventions are not always easy. This study found that APS workers perceived that a forced intervention was the most effective way to physically intervene in the situation. APS workers were also aware that it would not be effective to intervene emotionally.

This would be more likely to counteract negatively and harm hoarders emotionally.

A forced intervention conducted by code enforcement is oftentimes devastating to hoarders. APS workers informed that they were prohibited from calling code enforcement since the nature of code enforcement's intervention and the APS's mission statement conflict with each other. Code enforcement is called through law enforcement, not APS workers, and they condemn the house and a hoarder is more likely become a homeless. Although this is not the best way for APS workers to intervene, it is sometimes the only way to prevent further harm to the hoarder from himself or others, and unfortunately, this is the most effective way to stop hoarding since affected people are forced into resolving the situation.

In addition, it was striking to find that only one solid outcome was expected despite several interventions. APS workers and other agencies intervene in hoarding behavior to achieve only a temporary, short-term change. All APS workers responded consistently that the hoarding behavior would relapse.

Limitations

This study was intended to obtain an in-depth understanding about hoarding behavior through the professional view of APS workers. However, the study had several limitations, including a very small sample size (n=12), and that the findings on the characteristics, interventions, and outcome of hoarding behavior only applies to the elderly population.

Recommendations for Social Work Practice, Policy and Research

The findings of this study show that monitoring hoarding behavior may contribute to achieving a better outcome. APS workers have limited time for providing monitoring services; however, volunteers would be able to provide this service to hoarders. Several APS workers mentioned a youth volunteer group for San Bernardino County. However, this group no longer exists and APS workers were unsure of the reason why.

Making regular visits to hoarders' home will contribute to diminished loneliness, and help them to take a baby step to throw items away when it is found as health hazard.

It is also recommended to that further qualitative research be conducted on hoarding behavior and its correlation with mental health status.

Conclusions

This looks to be consistent with previous findings as discussed throughout Chapter Two. Just as APS workers do not identify hoarding behavior as OCD, some psychologists and a mental health organization such as the NAMI suggested that hoarding behavior may not be categorized as OCD. Further research is needed to find out the correlation between hoarding behavior and OCD.

As a finding of this study, through APS workers' humane approaches towards hoarders, the true face of hoarding behavior was revealed. What is behind the hoarding behavior, especially when it is part of hoarders' long life history, is overwhelming. It is an extension of them. Hoarders do not socialize with others, and not very many people pay attention to them. They are comfortable surrounded by treasure that they have collected over years. As long as a physical hazard is not present, hoarding behavior may be considered as a choice of the way they live.

APPENDIX A
GUIDE LINE QUESTIONS FOR ADULT
PROTECTIVE SERVICES WORKERS

Guide Line questions for APS workers

1. What is hoarding? Define.
2. What is the ratio between male and female hoarders?
3. Are hoarders cooperative or uncooperative when you go into their living space? What is their attitude like?
4. When you speak to the hoarder, is s/he willing to speak about their environment s/he lives in?
5. How do hoarders' family members perceive their living situation?
6. Do you think that hoarders need some type of professional attention? If so, what is it?
7. Do you think that the hoarders are willing to take an assessment? If so why?
8. What is the difference between hoarding and neglect?
9. Do you see any influence and affect that hoarding behavior brings to the community?
10. Do you see some improvements in the hoarders' living condition when you visit them for the second time? If so, in what way?
11. In your opinion, what is the most effective service or tool to intervene in the hoarding behavior? And how effective is it?
12. What is the most beneficial service for the elderly hoarders?
13. Is there any possibility that elderly individual's life being endangered because hoarding behavior? Can it be life threatening? If so why? If not why?
14. What is your challenge that you have to face while providing you services for hoarders?
15. What outcome do you realistically expect after the intervention?
16. What is the most effective way to interact with hoarders?

APPENDIX B
INFORMED CONSENT

Informed Consent

The study in which you are being asked to participate is designed to explore the characteristics of hoarding behavior from APS workers' perspective. This study is being conducted by Jade Yuko Lambert, MSW Candidate, California State University San Bernardino, School of Social Work. The study is being supervised by Dr. Rosemary McCaslin, Professor of Social Work. This study has been approved by the School of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

In this study you will be interviewed face-to-face and asked to respond to several questions regarding hoarding behavior and your perspective as an APS worker. The questionnaire should take about 30 to 45 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. You may receive the results of this study upon completion after September, 2009, at DAAS administrative office.

Audio recordings will be made upon your permission during the interview as a back up for clarification and accuracy of responses and will be destroyed immediately after review. You will receive a five dollar gift certificate for Starbucks Coffee as a sign of appreciation. Any foreseeable risks to participate in this study are not anticipated.

Please be reassured that your name will not be used in this study at any time. 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 interview, 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. Rosemary McCaslin, Professor of School of Social Work, California State University San Bernardino at (909)537-5507.

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.

- ☐ I have read, understood, and agreed to participate in this study.
- ☐ I agree to be audio-recorded.

Today's Date: _____

APPENDIX C
DEBRIEFING STATEMENT

Debriefing Statement

“Attitudes and Beliefs toward Hoarding among APS Workers”

The study you have just completed was designed to investigate the characteristics of hoarding perceived by APS Workers. The researcher is particularly interested in studying in-depth understanding of hoarding behavior from professional perspective.

Thank you for your participation and for not discussing the contents of the survey with other participants. If you would like to obtain a copy of the group results of this study, a copy will be available at DAAS administrative office. Also, if you have any questions about the study, please feel free to contact Dr. Rosemary McCaslin at (909)537-5507.

Again, thank you for your participation.

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