The study of being an adult daughter of a hoarding mother: A qualitative description

Hope P. James

Thesis submitted to the faculty of the Virginia Polytechnic Institute and State University

In Partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

In

Human Development

Angela J. Huebner, Committee Chair

Sandra M. Stith Committee Member Eric E. McCollum Committee Member

May, 2007 Falls Church, Virginia

Keywords: Compulsive hoarding, adult children

Copyright 2007, Hope P. James

The study of being an adult daughter of a hoarding mother: A qualitative description

Hope. James

ABSTRACT

Research into the phenomenon of compulsive hoarding has only been conducted during the last twenty years. To date, no studies have been done that examine the impacts of compulsive hoarding on young and grown children. The purpose of this qualitative study was to explore what the positive and negative impacts on children or adult children are. Twelve women, each identifying themselves as an adult child of a compulsive hoarder completed a qualitative questionnaire via email. Participants were recruited through membership in the internet support group, "children of hoarders". All participants identified their mother as the compulsive hoarder. Three distinct themes emerged over three distinct time periods. The first time period begins with early childhood and continues through adolescence. The second begins with the time they first moved away from home. The third starts with the end of the second and continues through to whatever age they are today. The first theme's focus was the participants' feelings as associated with their mother's hoarding. The second theme dealt with a need to understand what "normal" is. The third theme was the means they use/used to cope with the situation. Clinical implications include support for using systems theory, ambiguous loss and attachment frameworks. This study also provides valuable information relevant to participants need to normalize their experiences.

Table of Contents

Chapter 1: Introduction	5
The problem and it's setting. Significance	8
Rationale	
Theoretical frameworkPurpose	
1 urpose	12
Chapter 2: Literature Review.	13
How having a parent with a mental illness affects other family members	13
What we know about compulsive hoarders	
Reasons people save	
Treatment	17
Neurological characteristics	19
Summary	19
Chapter 3: Methods	20
Participants and recruitment	20
Design and analyses.	
Design and analyses	21
Chapter 4: Results	22
Introduction	22
Participants	
Life Cycle Time Periods	25
Stage One	26
Feelings: How do I feel about this mess	
"Normal": Am I normal?	
Coping: Or escaping?	
Stage Two	
Feelings: About new potential.	
Normal: What should be	
Coping: Organization is key	
Stage Three	
Feelings: "Stuff" vs people	
Normal: The continued struggle	
Coping: Making sense and finding meaning	35
Chapter 5: Discussion	
Consistency with the literature	38

42
43
45
46
50
50

CHAPTER ONE: INTRODUCTION

The problem and its setting

"Woman suffocates under piles of clutter in her home" is the headline for a news story dated January 2006. The woman, reported missing by her husband, was eventually found by authorities upon their second search of her home. What made searching the house so difficult were the numerous and enormous piles of debris that filled the entire structure. The husband, who now believes his wife must have fallen and been suffocated by one of the piles while searching for their phone, was completely unaware that his wife had died and that her remains were in the house. So huge were the piles that police officers reported hitting their heads on the ceiling of the home while climbing amongst the clutter.

Another recent headline reads "Clutter blamed in fatal home fire", this one from a Houston paper in August 2006. A 64 year old Houston woman reportedly refused offers of help for years from friends and family members to get her house full of books, magazines and papers in order. That refusal may have cost her her life. It is believed that, once the fire began, the stacks of books and magazines ignited so quickly that flames raced through her house. Firefighters initially tried to gain entry through the front door but encountered excessive clutter and had to go to the back door where they discovered her. The piles burned fast and made an enormous amount of smoke. It appeared that she had tried to escape but was overcome by the thick smoke. The firefighters had to crawl over the piles in their efforts to extinguish the fire. The woman's daughter was devastated. Because she had been trying to respect her mother and preserve a relationship with her, she had adopted a philosophy of non-interference.

She is now left to wonder as to whether or not interceding might have preserved her mother's life.

Finally, another recent headline reads "Hoarder's conviction in aiding son's suicide overturned" (August, 2006). That her conviction was overturned is not as remarkable as her being convicted in the first place. This is the case of a woman being convicted of aiding in her son's suicide because of the excessively cluttered living conditions she provided. Her twelve year-old son hung himself with a necktie in his closet in 2003. It is believed that his suicide was (at least in part) due to the shame and humiliation he felt from living the way he did. The mother's explanation of her sons suicide suggests that he was distraught at the severity and frequency with which he was being bullied at school. In court in 2003, authorities testified that the medical examiner had to climb over heaps of "debris" just to get to the boy's body. The mother's conviction was eventually overturned because "the law used to convict [her] was unconstitutionally vague". The court was ordered to acquit her.

All three of the preceding headlines are examples of the deleterious effects of compulsive hoarding. The acquiring and collecting of possessions, in humans, can be seen as a useful tool to ensure survival of the species in times when commodities are sparse (Grisham & Barlow, 2005). When this is taken to the extreme, as in the case of compulsive hoarding, acquisition and collection are no longer helpful survival tools, but become the physical manifestation of a serious mental illness. Compulsive hoarding can be defined as "the acquisition of, and failure to discard, possessions which appear to be useless or of limited value" (Frost & Gross, 1993), and having living spaces that are so cluttered, the activity for which the space was originally designed is no longer possible

(Frost & Hartl, 1996) (for example not being able to use the bedroom for sleeping, the kitchen for cooking and so on). Compulsive hoarders have such an excessive accumulation of goods, that their living conditions create serious fire, health and safety hazards (Frost, Steketee & Williams, 2000). These hazards affect not only the individual(s) living amongst the clutter, but also family, neighbors, and fire and rescue personnel who may have reason to try to enter the dwelling. Finally, many basic home maintenance tasks go undone because repairmen either cannot physically access the item or because they are denied entry to the home due to the embarrassment felt by the hoarder.

Additionally, one of the most common problems in the elderly is falling.

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

It is believed that 1 to 2 million Americans exhibit behavior that could be described as compulsive hoarding (Feusner & Saxena, 2005). We can only speculate as to how many children are affected by this but based on the above numbers, a likely guess would seem to be at least in the millions. This study hopes to provide preliminary insight into understanding the impact that compulsive hoarding has on the adult child or children of the hoarder. I will use the terms hoarding and compulsive hoarding interchangeably. Compulsive hoarding of animals is also a significant problem in its own right (Frost et al., 2000) but one which I will not be discussing during this study. Finally, although

inquiry into how compulsive hoarding affects the elderly is also worthy of study, it will not be a focus of this project.

Significance

Significance to the family

Children who have parents with a mental illness tend to become parentified at a young age, minimize their own needs, and struggle to make sense of their experiences with their mentally ill parent or parents (Marsh, 1998). Although research on the topic is controversial, compulsive hoarding could also be considered on par with other mental illnesses. Additionally alarming is the fact that the majority of hoarders lack insight into their illness and, in many cases, deny it altogether. Because they do not acknowledge how damaging their behavior is to themselves, they are equally incapable of acknowledging the negative impacts their behavior has had or is having on their children. Significance to the community

Compulsive hoarding can have "dramatic effects on the individual and the community at large" (Frost & Steketee,1999). The excessive accumulation of possessions can pose fire, health and safety hazards. The most commonly hoarded items are newspapers, magazines, lists, receipts, old clothes, letters, mail, bags and books (Frost et al., 1993, Kaplan & Hollander, 2004, Saxena et al., 2002, Winsberg & Koran, 1999). All of these are extremely flammable and are frequently piled near heat sources such as stoves or furnaces, making ignition possible. The means of egress from a dwelling that is congested with debris can be significantly restricted or, in extreme cases, blocked altogether making exiting in the case of an emergency difficult or impossible. In addition, excessive debris can also result in substantial hazards to anyone seeking access

in order to address an emergency situation. The sheer volume of material can make a fire harder to control (Frost et al., 2000). The excessive volume can also overstress joists and beams causing structural overload. When this overload occurs, floor systems crack, sag, or even collapse. When hoarding extends to the kitchen, the excessive grease, food and trash add to the potential for a fire and can create a severe insect and/or rodent infestation; similarly, when staircases are filled with piles, the risk of falling increases significantly. Finally, constant exposure to dust pollen, bacteria and the unhygienic conditions created by the accumulation of excessive debris can pose significant health problems.

Hoarding also poses a variety of dangers to members of the community. If the hoarder lives in close proximity to other dwellings, the excessive amount of flammable materials makes the spread of fire to other inhabited residences much more likely. If vermin are attracted to the hoarder's dwelling, the spread of vermin to other areas of the community is practically assured.

Monetary significance

The monetary ramifications can be practically endless. From squandering inheritances, to creating situations where children must financially support parents who have spent their savings compulsively shopping, to the money it takes to clean out a hoarder's house. Finally, complaints about a hoarder usually involve multiple community agencies, resulting in significant monetary cost to the community (Frost et al., 2000).

Rationale

Recognition of hoarding as an illness has increased in the last decade. During the 1990's Frost and colleagues did much to further research into the phenomenon. In the

last year or so, there has been a noteworthy trend in online support groups developing for hoarders, spouses of hoarders, children of hoarders, friends of hoarders and so on.

Examples of these websites are: www.childrenofhoarders.com,

www.squalorsurvivors.com, www.messies.com and www.ocfoundation.com.

Hoarding is most often associated with Obsessive Compulsive Disorder (OCD) but there are ongoing clinical and empirical debates as to whether hoarding belongs in a diagnostic category of its own. This study seeks to examine how an individual's compulsive hoarding behavior affects their adult children. While gathering material for this proposal, I was struck by the complete absence of any research concerning the impact of hoarding on the hoarder's children and family. What perhaps confirms such a familial link is the fact that many hoarders report having one or more first degree relatives with hoarding tendencies (Frost et al., 1993). Gaining an understanding of the experiences of a child whose parent exhibits hoarding tendencies, will serve as a first step in exploring more about this link and how families might better address and deal with it. Since there is no other data available, I believe that exploratory, qualitative interviews are an appropriate place to start in examining the experience of having a parent who hoards.

Theoretical Framework

Systems theory and phenomenology will be the guiding theoretical frameworks throughout this study. Systems theory is appropriate because it seeks to discover why a family operates the way it does. It asks the questions: How do families perpetuate their own problems? Why do families sometimes resist taking obvious steps toward improved relations? (Nichols & Schwartz, 2001). It is precisely this kind of information that this study hopes to elicit.

Phenomenology will also guide this research. It makes the assumptions that: knowledge is socially constructed; researchers are not separate from the phenomena they study; knowledge can be gained from art as well as science; bias is inherent in all research regardless of method used; common everyday knowledge about family worlds is epistemologically important; language and meaning of everyday life are significant; objects, events or situations can mean a variety of things to a variety of people in the family (Boss, Dahl and Kaplan, 1996).

Phenomenology uses the "method of reduction" (Boss et al., 1996). The phenomenon continues to be uncovered as the researcher keeps letting go of what the phenomenon **is not** in order to get at what it actually **is**. Boss and Colleagues (1996) use the metaphor of peeling an onion to describe this process. That is a perfect visual to describe how this investigation unfolded. As each layer of a response was uncovered, I gained a unique and in depth understanding of what the experience of being the child of a compulsive hoarder is and/or has been.

Phenomenology is concerned with accurately capturing a given individual or family's experience. It is more concerned with portraying experiences than being able to make sweeping generalizations (Boss et al., 1996). This again fits with the purpose of my research as I do not intend to make generalizations.

Another basic assumption of phenomenology is that bias is inherent in research regardless of method used. By using qualitative methods, I hope to embrace my own biases and make them a part of my research. My specific bias with regard to this research effort is that I have two first degree relatives whom I suspect are compulsive hoarders. I have undoubtedly been impacted by their hoarding (in primarily negative ways) as has

my entire family system. Most commonly, their hoarding behavior is something that is not discussed nor even alluded to, making interactions difficult at best. Their homes are avoided due to the excessive clutter. This avoidance results in misunderstandings and limited interaction. It is these and other first hand experiences that contribute to my suspicions with regard to familial impacts. Additionally, I must admit to having noticed hoarding tendencies within myself.

I have attempted to keep my biases in check throughout the process by cross coding the data with my thesis chair. I am hopeful that this methodology coupled with frequent communication has enabled me to see if and where my biases might be affecting the data and/or analyses.

Purpose

Among patients with OCD it is estimated that 18% to 42% have hoarding and saving compulsions (Feusner et al., 2005). Because "approximately 2.3% of the population between ages 18-54 suffers from OCD, which out ranks mental disorders such as: schizophrenia, bipolar disorder, or panic disorder" ("Understanding Obsessive Compulsive Disorder", 2006), the need to find out more about this disorder is evident.

Because we know how damaging it can be to a child to have a parent with a mental illness (Marsh, 1998), it is surprising that there has been no effort to explore how compulsive hoarding might affect offspring. It should also be noted that many feel having a parent with a mental illness, despite being challenging, has also made them stronger (Marsh, 1998). This study hopes to uncover what the positive and negative experiences are of being an adult child of a compulsive hoarder.

CHAPTER TWO: LITERATURE REVIEW

How having a parent with a mental illness effects other family members

It has been well documented that having a family member who suffers from a

mental illness puts additional stress and unique burdens on relatives living with them

(Stengler-Wenske et al., 2006). Children tend to become parentified and take on
responsibilities that are far beyond their developmental level. When not only children but
other relatives take on the responsibilities of the loved one suffering with a mental illness,
they do so at some detriment to their own physical and/or mental health (Geffken et al.,
2006).

The impacts on family members of those affected by obsessive compulsive disorder (OCD) seem to take these eventualities a step further. What seems to differentiate a family coping with OCD from one coping with a different type of mental illness is the inextricable way in which they become ensnared by the illness. In one study, close to 75% of relatives (of patients with OCD) reported participating (at least minimally) in rituals, avoidance and/or modifying their behavior to accommodate their loved ones symptoms (Stengler-Wenske et al., 2006). Frequently, prolonged exposure to and eventual participation in a loved ones struggle with OCD can have both external and internal ramifications. Externally, there can be, amongst other things, loss of income, loss of privacy, loss of pleasure and freedom and disruption of normal family activities (Cooper, 1996). Internally, exposure and participation can result in losses of self-esteem, control, hope, security, pleasure in a child's success and a positive sense about the life of the family (Cooper, 1996).

Traditional treatment for OCD has been medication (selective seratonin reuptake inhibitors) combined with cognitive behavior therapy (CBT). The addition of exposure and response prevention (ERP) has lead to higher rates of treatment response (Renshaw, 2005). Despite a recognized treatment protocol and occasionally encouraging results, up to 25% of OCD patients do not respond to treatment, and large numbers relapse after initial treatment response, particularly after stopping medication (Renshaw, 2005). Because family members play such a large part in the maintenance of this illness, researchers are now looking into how to use the family system to influence treatment and maintain positive treatment results (Renshaw, 2005).

What we know about compulsive hoarders

In recent years, the issue of compulsive hoarding has gained increased attention due largely to media coverage of seemingly extraordinary cases like the ones discussed in the beginning of this thesis. Of particular interest to me was the discovery that up until the 1990's there had been virtually no research done on the subject whatsoever. Randy Frost and colleagues have since led the effort in investigating compulsive hoarding. They have discovered specific character traits common to hoarders (Frost et al., 1996), developed a measure for hoarding behavior (Frost, Steketee & Grisham, 2003), made a link with compulsive hoarding and compulsive buying (Frost, Steketee & Williams, 2002) and illustrated how compulsive hoarding extends into the community (Frost et al., 2000). Saxena and colleagues are leading the current effort in the investigation of whether hoarding behavior might be related to specific neurological characteristics (2004) by identifying what a hoarder's brain activity looks like. Finally, compulsive hoarding is most frequently considered to be a component of OCD, although it is actually

listed in the DSM-IV-TR as a component of obsessive compulsive personality disorder (OCPD) and absent in OCD (American Psychiatric Association, 2000).

Compulsive hoarding is not typically presented for therapy by itself. It is more frequently associated with Obsessive Compulsive Disorder (OCD) (Frost et al.,1993) and Obsessive Compulsive Personality Disorder (OCPD) (American Psychiatric Association, 2000), as well as Anorexia, Schizophrenia, Dementia, Autism, Schizotypal Disorder (Kaplan et al., 2004), PTSD, Major Depression (Frost et al., 1996) and Attention Deficit/Hyperactivity Disorder (Hartl, Duffany, Allen, Steketee & Frost, 2005). The importance of inquiring about potential hoarding tendencies when seeing clients with these co-morbid diagnoses should be evident.

Reasons people save

Frost and colleagues have discovered several character traits common to individuals exhibiting hoarding behavior. They appear to suffer from large deficits in the ability to process information, this trait manifesting itself as a lack of organizational skills and a chronic indecisiveness (Frost et al., 1996). They exhibit a great deal of behavioral avoidance usually in the form of avoiding any acknowledgment of a problem altogether. They have difficulties in forming emotional attachments (to people) and faulty beliefs about the nature of their possessions (Frost et al., 1996). They become so emotionally attached to their possessions that they appear to have no room in their lives for emotional attachments to people. They appear to take great comfort from and experience an unaccountable degree of safety with regard to their possessions, feelings that are normally derived from relationships with other people. They also report problems with

memory and great difficulty organizing and/or categorizing things and information (Frost et al., 1996).

Perfectionism

Deficits in information processing are a distinguishing feature of compulsive hoarding. Hoarders go to great lengths to avoid making decisions for fear of making a mistake (Frost et al., 1996). Hoarders attempt to limit if not eliminate the potential for making mistakes by saving practically everything. By doing so, they avoid potential regret for having discarded something they later discover a need for. Akin to aspects of OCPD, hoarders tend to be overly concerned with perfectionism (Frost et al., 2002). They can become so consumed by it that they fail to complete important tasks and can even lose touch with the initial point of pertinent activities. When faced with the task of sorting through possessions and making decisions as to what to save and what to discard, compulsive hoarders can become so preoccupied with ensuring that piles line up, they forget all about the initial task of saving and discarding. The consequence of years and years of avoidance leads to an entirely new obstacle. The immense effort required to sort through decades of collecting is enough to make even a well adjusted person want to avoid it. This in particular is where I see familial involvement as critical. The effort involved in cleaning out a compulsive hoarder's home requires more people be involved than just the hoarder and his or her therapist.

Emotional attachment

Compulsive hoarders have a tendency to become extremely emotionally attached to their possessions (Frost et al., 1996). They frequently feel their possessions to be an extension of themselves (Frost et al., 1996). When other people touch, move or use their

possessions without permission, compulsive hoarders report feelings of excessive anxiety, loss of control and a sense of having been violated (Frost et al., 1993). Compulsive hoarders have reported inexplicable feelings of safety and security simply by being in the presence of their possessions. (Frost et al., 1996). When faced with the challenge of discarding items, hoarders have compared the resulting sensation to that of losing a close friend or loved one. These emotional attachments are what well adjusted people strive to achieve in their relationships with other *people*. It has been noted that most hoarders are single (Feusner et al., 2005) which would seem to substantiate the preceding data.

Compulsive shopping

Frost and colleagues (2002) have also discovered an interesting link between compulsive hoarding and compulsive shopping. Compulsive hoarders and compulsive shoppers share excessive emotional attachment to possessions as well as a sensation of excitement experienced during the acquisition of things, particularly the acquisition of free things. Compulsive shoppers exhibit great difficulty in resisting a bargain. The result being that they acquire an inordinate amount of things for which they have no need simply because said things were "too good to pass up" (Frost et al., 2002). For hoarders, this is just one more way to increase the amount of their possessions.

Treatment

Compulsive hoarding is notoriously resistant to treatment and family members' attempts to intervene have a tendency to worsen relationships and further the hoarder's social withdrawal (Feusner et al., 2005). This fact results in a difficult Catch-22 situation for the adult child of a compulsive hoarder. If they do not attempt to positively affect the

potentially dangerous situation that their parent is in, the guilt and angst can be substantial. But, if they do take action or, in the eyes of the hoarder parent, appear unwilling to accept the situation without comment or action, the relationship with the hoarder parent can become strained or dissolve altogether resulting in it's own occurrence of pain and negative emotions.

There have been very few large, well-organized studies that examine the efficacy of treatment of people with compulsive hoarding. Of the few that I could locate, none addressed how to treat an adult child affected by it. Despite the lack of empirical information, "experts", on talk shows such as Oprah, Dr. Phil and Dr. Keith Ablow, and in one of the few books available to the lay person "Overcoming Compulsive Hoarding", advise family members that trying to throw the hoarder's possessions away without their knowledge is not recommended. It may even worsen their condition due to their increased paranoia and heightened anxiety resulting from the violation of disposing of their belongings without permission (Neziroglu, 2004). Frost and Steketee in their recent guide for therapists also advise against it and note that "forced cleanouts" are not an effective treatment alternative due to the strong angry and hurt reactions experienced by the hoarder and a continuing and sometimes worsening struggle with hoarding (Steketee et al., 2007).

The preferred method used in treating compulsive hoarding is medication combined with Cognitive Behavioral Therapy (CBT) (Feusner et al., 2005). The medications most frequently used are those used commonly to treat OCD. Usually it is with the selective seratonin reuptake inhibitors (SSRI's), which are tried at high doses for twelve week trial periods (Feusner et al., 2005). If these prove ineffective (which they

frequently do) stimulants, mood stabilizers and/or atypical antipsychotics are added as adjunctive medications. Randy Frost and Gail Steketee have recently published a therapist guide to treat compulsive hoarding along with a companion workbook intended for the hoarder to utilize (Steketee et al., 2007) because these tools have only recently become available, it is too earlier to gauge their effectiveness.

Neurological characteristics

Saxena and colleagues have uncovered neurobiologic data that confirms that hoarding is a distinct variant of OCD (2005). Using a positron emission tomography (PET) scan, they compared the brains of OCD patients with hoarding tendencies, OCD patients without hoarding issues and a control group. The hoarders had unique brain activity and significantly lower cerebral metabolism (Feusner et al., 2005). Finally, "the hoarding phenotype has been significantly associated with genetic markers on chromosomes 4,5 and 17" (Feusner et al., 2005).

Summary

Throughout this chapter, I have discussed how having a parent with any mental illness can greatly impact children and family. I have also described the research on the subject of compulsive hoarding itself. Unfortunately, no prior research into the relationship between adult children and compulsive hoarding has been done.

Consequently no literature in this specific area could be reviewed.

CHAPTER THREE: METHODS

Participants and Recruitment

This study used semi-structured, qualitative interviews. Since this is an exploratory study, I recruited twelve individuals. In order to recruit participants, I posted an email request to the internet based support group "Children of Hoarders". Once people replied and met the qualifications of being over the age of 18 and have a hoarding parent (that is not elderly nor a hoarder of animals), I emailed them a consent form. Once they "signed" it, I emailed them the questions listed in appendix A. As themes started to emerge, I met with my thesis chair to cross code and do the final coding.

The questions hoped to elicit as much meaning as possible. The interview attempted to explore how having a hoarding parent has impacted each individual (both positively and negatively). For example, it is my speculation that many hoarders eventually sever ties with their families of origin and are therefore not a part of family celebrations such as weddings, births or holidays. Assuming this is true, I wondered what the resultant impact is on the adult children because the absence of communication and physical interaction does not end the emotional process, just the opposite occurs, it becomes intensified (Carter & McGoldrick, 1999). Alternately one must consider the possibility that having a parent who hoards might have enabled the child to develop unique character and emotional strengths they might otherwise never have attained.

Because participation in these interviews might have resulted in unexpected emotion on the part of the interviewee, I referred participants back to the website www.childrenofhoarders.com which has informational tools and an exhaustive list of potentially useful websites.

Design and Analyses

The analyses were conducted via open coding as described by Strauss and Corbin (1990). It was done on an ongoing basis from the moment the data was collected. One of the core assumptions of phenomenology is that researchers are not separate from the phenomena they study. Because this is the case, my notes, memos and journals written about the experience were included in the analyses.

This process looked for themes that emerged among individuals as well as between participants. I examined the importance of these themes and how they related or did not relate to the issue of compulsive hoarding. Once themes emerged that were relevant to the data, I began to analyze and interpret them.

CHAPTER FOUR: RESULTS

Introduction

The goal of this study was to explore the impact of compulsive hoarding on adult children whose parent(s) exhibit that behavior. In order to gain individual perspectives, twelve self-identified adult children of hoarders were interviewed via email. Participant replies were rewarding. None were brief and several were quite lengthy and detailed. Combined, the participant responses provided 59 pages of text. This was not entirely unexpected. All participants, because of their membership in on-line support organizations, were accustomed to expressing themselves via e-mail. The responses were then coded and analyzed for themes using the coding method described by Strauss and Corbin (1990).

This chapter begins with an introduction to each of the participants followed by a discussion of the themes that emerged from their responses. As will be evidenced, three consistent themes emerged across three distinct periods of life. The first period is early and middle childhood through adolescence. The second period is when they first left home and extends into that time when they establish their own home. The third period begins with the establishment of their own home and extends into where they are in life today.

Participants

What follows are brief biographical sketches of each participant. All participants are female and each considers her mother to be the primary exhibitor of hoarding behavior. Some respondents discussed their fathers as "secondary" hoarders, meaning they developed these behaviors later and their hoarding did not impact living conditions the

same way as their mother's hoarding did. Fictitious names have been employed to ensure participant confidentiality. Additionally, although unsolicited, several participants included information about their geographic location. These are reported as available.

Amy

Amy is thirty-three, married and is pregnant with her first child. She has two significantly older sisters and describes growing up as "essentially an only child". Amy's parents are each in their seventies and live approximately one hour away from her. Amy also considers her father to be a compulsive hoarder, reporting that his behavior became apparent approximately 15 years ago. She lives in Wisconsin.

Brenda

Brenda is twenty-one, single and has no children. She has a younger sister. Her parents are in their fifties. Brenda is currently studying abroad in Ecuador and therefore lives a considerable distance from her parents. Brenda believes that her father acts as an enabler of her mother's hoarding behavior.

Carolyn

Carolyn is thirty-seven years old, married and has no children. She is fifth amongst six siblings. Her mother is sixty-nine, her father is deceased. She lives over three thousand miles away from her mother, in Mexico

Denise

Denise is in her thirties, married and has two children. She has a younger sister. Her parents divorced when she was thirteen. Her mother is fifty-five years old and lives twenty minutes away.

Eleanor

Eleanor is thirty-two, married and has two children. She is the youngest of four, having two older brothers and one older sister. Her parents are both seventy-three. She lives two hundred miles away from them, in Michigan.

Felicia

Felicia is thirty-seven years old, single and has no children. She has a younger sister and an older half sister. Her parents are both in their seventies. She lives seven hundred miles away from them.

Gretchen

Gretchen is thirty-three years old, married and currently pregnant with her first child. Gretchen is an only child. Her mother is sixty and lives twenty five hundred miles away. Gretchen lives in California. She did not mention her father in her response.

Helen

Helen is thirty-six years old, married and has no children. She is an only child. Her mother is sixty-six. Her mother lives forty-five minutes away. She did not mention her father in her response.

Isahel

Isabel is fifty-one, married and has two adult sons. She has a younger sister. Her mother is seventy-four, her father is deceased. She has guardianship of her mother and lives twenty-five minutes away.

Julia

Julia is thirty-three, single and has no children. She is the oldest of four children, having two younger sisters and a younger brother. Her mother is fifty-two. Half of the

year her mother lives in another part of the country and the other half she lives right down the street. In her response, she mentioned growing up with an abusive step-father and did not mention her biological father at all.

Karen

Karen is forty-two years old, married and has three children. She has two younger sisters. Her parents are both in their seventies. They live ten hours away. Lauren

Lauren is fifty-three years old, married and has two children. She has an older sister and brother. Her mother is seventy-nine, her father died in 2001. Her mother lives one hour away.

Life Cycle Time Periods

In exploring the transcripts, it became apparent that each participant reflected on hoarding across three distinct life periods. I use the term life period somewhat loosely and have defined my own timeframes for each stage. The first period is the time from early childhood through adolescence. This is the time in life when children are virtually completely dependent on their parents and typically live under the same roof. The second time period is very brief. It consists of the first few years when the young adult first moves away from home and has her first experiences as an independent young woman. The third time period is quite long. It ranges from the end of the second stage all the way to mid-life.

Across the three stages, three consistent patterns of discussion emerged. The first dealt with the feelings respondents associated with their parents hoarding behavior such as how they felt about themselves, the situation and/or their mothers. The second was a

process of noticing what "normal" is and/or should be. They wanted to know what is was/is and had decided they definitely were not "it" but were on a path to discover what "it" is. Finally there was the utilization of differing coping mechanisms employed to manage the distress they felt as a result of the powerlessness of the situation.

Stage One

The first time period began with participant's memories of their early childhood and continued through their adolescence. A key element of this time period was the child's dependence on their parents. The child had no choice but to rely on them for everything and usually lived under the same roof.

Feelings: How do I feel about this mess?

In the first stage, the theme of feelings became apparent. The feelings participants described during this life stage consisted mostly of how they felt about living amongst such cluttered conditions. Interestingly, responses seemed polarized. They were typically either negative of the shame, low self-esteem and anger type or very positive as in an adult looking back fondly on a loving parent. There were few neutral or "middle" responses given. Isabel remembers how she felt about the clutter as full of shame and exclusively negative:

"I lived most of my childhood in shame and guilt...My childhood was spent being sad, scared, shamed and angry."

Lauren felt similarly to Isabel and described her experience as:

"I grew up thinking I could not achieve enough nor excel enough to get her to want me, like me or be interested in me."

Denise remembers things quite differently. She remembers things fondly as is indicated by this comment:

"I remember my mother spending time with me, reading with me, teaching me to cook and garden, giving me love and affection."

"Normal": Am I normal?

The notion of "normal" emerged as an important theme during stage one. At some point during this first stage, all participants described becoming aware that their family was "different". Specifically, they described this as the time when they first noticed and started to pay attention to and/or care about what their perception of "normal" was compared to others' families. This experience revealed itself to be pivotal in that most described their parents' hoarding behavior as not having impacted them prior to this awareness. Their descriptions included the common themes of not having friends over, noticing the lack of housekeeping, recognizing co-morbidity of other mental health illnesses in the parent, and realizing the importance of maintaining outside appearances. Denise describes her experience of recognizing the need to maintain the façade of "normal"

"When I was around 8yo, I watched a documentary with my dad's family about a two brothers who were dairy farmers, called, "My Brother's Keeper". They were watching it for some other purpose but all I saw was that these farmers, had the same piles of things as my mom had in her spare rooms. That would probably be my first awareness that I wasn't alone that other people out there had piles too.

But from the comments made by my dad's family, I also knew that it was a good idea to keep those realizations to myself."

Beth describes her struggle with the "normal" experience of playing with friends as a child and how the hoarding impacted it.

"It was frustrating having to make up stories about why I could stay at my friend's house, but why they couldn't come over to mine."

Coping: Or escaping?

The third sub-theme to emerge in stage one were the coping mechanisms respondents utilized in response to their mothers' hoarding behavior. What is meant by coping is how the participants dealt with the distress they felt as a result of living amongst such difficult conditions. This is illustrated as some participants became parentified, others talked about how the distress aided in the development of sibling issues, and many discussed how they developed ways to mentally "tune out" as a way to hide from the behavior. Parentification refers to a child switching roles and acting as the parent long before such a role reversal would be expected (such as caring for an aging parent). The sibling issues revolved around one child being identified as the "good" or "bad" child, thus ostracizing the others. The use of mental escapes refers to participants description of developing the ability to "escape" mentally despite their lack of ability to actually "escape" physically. Amy describes her experience of parentification:

"My mom always treated me as a peer rather than a daughter, and I've been her emotional caretaker for as long as I can remember. From the age of about 11 on, she routinely confided adult things to me, including the relationship and sexual problems between her and my dad. We had an extremely unhealthy triangle

between Mom, Dad, and me. As a teen, I felt responsible for my mom's emotions, and for keeping her relationship with my dad on an even keel. Even though I knew it was destructive, I gave in to her demands for me to fill that role because I craved her approval and unconditional love—"

Karen describes how escaping mentally helped her to cope with the situation:

"I remember wishing I could wiggle my nose like Sabrina or wave my magic wand like Mickey Mouse or Merlin so that all the stuff could be gone in a flash...

I would take a book outside after that and go read in a great big tree out behind our house in the neighbor's field. I loved to read. I could escape reality with books."

Beth describes this process of mentally escaping as well:

"I spent a lot of my childhood escaping from my environment through the use of computer games, books and the Internet. I notice that I tend to do the same nowadays when I am depressed or avoiding something."

Stage Two

The second stage is relatively short. It encompasses the first few years after the young women first move away from home. Some respondents left for college and some just left. This period is defined as their first experiences as independent young adults.

Feelings: About new potential.

The feelings theme emerged not as much in the sense of how participants felt in response to the hoarding but more in a sense of how they felt once they left it. Many

discussed how this led to having a fierce sense of independence. Amy remembers this experience as losing her home:

"I moved out permanently after college, and my room was soon completely taken over by my mom's hoarding. I couldn't visit overnight because there was no place for me to sleep."

Eleanor, Gretchen and Lauren discuss how excited they were establishing their independence.

Eleanor: "I was eager to establish my independence and never look back."

Gretchen: "I was fearless in pursuing my dreams. I had nothing to lose and nothing to go back to when I left home."

Lauren: "I was driven to succeed."

Julia remembers this time with much angst:

"I didn't feel that I belonged anywhere, that I had a right to have anything and pretty much thought that any person that you randomly pointed to was far more deserving than I was of anything you cared to mention."

Normal: What should be.

The theme of being aware of the notion of "normal" was noteworthy during this time frame in much the same sense as the first but with the recognition now that things *should* have been different. Some respondents described this time period as their first recognition of how a home might actually look with some routine housekeeping. This is also described as a time when they began to realize the seriousness of their mother's problem. Amy describes her experience of noticing how housekeeping can make a

difference as well as the realization that her mother has more of a problem than she realized.

"I'll never forget the feeling of having my first apartment: the space, cleanliness, and freedom of having my friends over whenever I wanted was fantastic!...It wasn't until I had a new lifestyle to compare with the old that I realized my parents had a serious problem."

Here, Carolyn describes her experience of the realization of the lack of housekeeping she had grown up with.

"When I moved out I didn't know other people actually washed their sheets once a WEEK."

Coping: Organization is key.

Respondents also reported an inability to feel comfortable in a cluttered environment. They described severe reactions to being faced with clutter and spoke of the aura of determination they often feel to live in a manner completely different from how they grew up. Following is Beth's description of how this experience is for her:

"I very much like to keep my space neat and organized, and I love cleaning. I get very stressed out by being in a cluttered environment."

Stage Three

The third and final time frame that emerged begins with the end of stage two. It generally begins once participants have established lives of their own independent of their parents. They might have finished college and no longer had thoughts and/or hopes

of returning to live with their parents. This period extends to where in the life cycle each is today, which ranged from young adulthood to middle age (twenty-one to fifty-three).

Feelings: "Stuff" versus people.

The feelings participants associated with this time in their lives were quite similar to those described in stage one. They were polarized again with shame, guilt and anger at one end and love and warmth at the other. This life stage added the discussion of worry, guilt, responsibility and powerlessness. Many also discussed the feeling that their mothers value their hoarded things more than they value their daughter. Eleanor describes the worry she feels now:

"Being an adult child of a hoarder, to me, means a constant worry about the welfare of my parents."

Lauren describes the feeling that her mother values things more than her.

"I believe I am less valued by my mother than are things. The most vile things, too. A bathtub full of used adult bladder pads is more treasured."

Gretchen describes how this feeling that her mother values things more than her extends into other areas of her life:

"I have a hard time trusting or depending on people I think it's because my mom's hoarding taught me that I'm not a top priority, things are. When the space filled up the things stayed and I had to go, so I was always ready for a loved one to tell me there's not enough room for me in their life."

Karen describes her experience as not so much an interpreted emotion about where she stands in relation to the things in her mother's life but a reality that her mother has verbally expressed to her.

"Mom has said that if I touch her treasures, she will haunt me for the rest of my life."

Carolyn describes how she feels about her mother despite having many similar feelings as described above.

"I love my mom and want her to be around as long as possible....My mother has so many wonderful qualities- I love her thoughtfulness, her creativity."

Denise also talks about her love for her mother:

"In general, I would say that I have a good relationship with my mom. I probably talk to her at least once a week. And see her every other month at the least. I have no doubt of her undying love for me and feel that she is proud of me. And I would hope she knows how much I appreciate every sacrifice she has made for me and just how much I love her... I love my mom and would change this for her if I could."

Finally, the theme of how powerless respondents felt with regard to their inability to influence their mother's situation was reflected in virtually every response. A few examples follow:

Carolyn: "She was able to beat alcoholism, not hoarding."

Isabel: "She is a virtual recluse, obese with limited mobility, yet she would buy clothes and jewelry til her dying day if she could."

Normal: The continued struggle.

The appearance of the important concept of being "normal" emerged during this life stage again, this time more in the context of relationships. Participants discussed

their feelings of how their relationships were impacted as a result of their mother's compulsive hoarding. They talked about longing for a "normal" mother/daughter relationship. They also lamented the absence of "normal" grandparent relationships for their children. This was discussed from an emotional as well as a logistical perspective. They felt that their mother's behavior made/makes having an emotional attachment difficult if not impossible. The sheer lack of space makes visits to their mother's home undesirable. The discussion of how their mother's hoarding has impacted their ability to experience or maintain "normal" housekeeping routines is also revisited during this time. Carolyn best illustrates the feeling, shared by all, that hoarding has impacted her relationship with her mother.

"Hoarding and the paranoia has gotten in the way of having a "normal" relationship with my mom. I moved away from home almost 20 years ago-my mother has never visited me anywhere I've lived because she won't leave "her stuff" for fear of someone "stealing it" or maybe she just doesn't want to. I still am not sure of the real answer to that, in all honesty."

Amy and Lauren reveal how the hoarding has affected their children's relationships with their mothers.

Amy: "It still affects me now in that my husband can't visit my parents, and especially because our soon-to-be-born child won't be able to either, and thus won't have a normal grandparent relationship with them."

Lauren: "My children have never spent time at their grandparents' alone. Their relationships are limited and I believe less rich because of the lack of 'normal' experience. The only running water currently is at the kitchen sink. The toilet

has not worked since At least Dec, 2006; the shower/bath not working since before."

Eleanor and Julia best express how they struggle with "normal" in all aspects of their lives, not just in the context of relationships.

Eleanor: "I spend a great deal of time wondering what 'normal' is, and trying to BE 'normal' because I don't feel that I know what it is... The relationships we have with our parents are not 'normal' and the experience of our childhoods was not 'normal'. Yet we find ourselves wanting so desperately to fit into the 'normal' role of a 'good child. We all fear that if/when our parents are discovered in crisis, everyone will look to us and wonder why WE, the perfectly capable adult children, didn't step in to help them. Any 'normal' child would offer help to a parent who needs it, right?"

Julia: "The hoarding kept me from being normal as a child and having a normal childhood, and because of how it twisted my brain, it keeps me from being normal now."

The assertion that hoarding has impacted a sense of "normal housekeeping" was again discussed. Gretchen, Helen and Julia describe how they feel about things, objects and clutter in general now that they are adults.

Gretchen: "I will develop a sense of depression and anxiety if my own home becomes cluttered. I panic that I'm becoming my mother and toss a bunch of whatever out on the curb."

Helen: "I can't see clutter or dirt in my own house. And when I do see it, it can overwhelm me terribly...My mom had poor cleaning habits, which I've

unfortunately picked up. Since I can't seem to shake the bad habits and the shame that goes along with them, I'm hiring a cleaning service to help me out."

Julia: "I don't really see messes unless they are literal PILES of junk."

Coping: Making sense and finding meaning.

The theme of how participants coped with their mother's hoarding was apparent again during this life period. Most often discussed during this life stage, was the need to make sense of the hoarding. Despite a desire to make sense of it, many discussed the difficulty in doing so because so little is known about compulsive hoarding and so little information is available. Many respondents lamented the lack of support available to people close to hoarders who are affected by it. Eleanor describes how educating herself on the subject has helped in this regard.

"Now that I have educated myself about hoarding disorder, I feel genuine pity for my mother."

Gretchen best illustrates the isolation experienced as a result of a lack of understanding about hoarding.

"It is also quite hard because hoarding is a relatively new topic in the public forum. Most cities have AA or NA. There's lots of literature about personality disorders and how to cope with people's behavior. I have yet to physically meet up with someone who has a hoarding parent or partner. There is a lot of vertigo wit(h)out a support network."

As a final point, Eleanor, Helen and Lauren all describe how the powerlessness of the situation negatively contributes to their ability to make sense of it:

Eleanor: "Trying to keep a hoarder's home safe (if that's even possible) is like bailing water out of a leaky boat where the leak keeps getting bigger. And for people who aren't even able to 'bail' (e.g. the hoarder won't let them in, they live too far away, etc.), the stress of KNOWING that a parent lives in such hazards is unbearable."

Helen: "Short of having our hoarders bound in duct tape, there really isn't much we can do."

Lauren: "I value what little we have. The only thing that has kept me from reporting the conditions to APS (adult protective services), is that she told me she would be done with me. I would no longer be her daughter. I feel good about neither, wanting to report her and not reporting her."

Summary

In summary, three distinct times in these adult daughter's lives emerged as did three distinct sub-themes of each time. The first stage in life was from early childhood through adolescence. The second stage was the first few years after the women first moved away from home. The third and final stage was the end of the second extending through to whatever life stage each is in today (ranging from young adulthood to middle-life).

The first sub-theme that emerged was participants feelings, which varied between stages from how they felt about themselves, the situation and/or their mothers. The second sub-theme of "normal" arose in the sense that all realized they were not "it" and seemed to have a heightened sense of wanting to be "it". The final sub-theme of coping

emerged in the sense of learning the ability to manage their distress they felt as a result of the powerlessness of the situation.

CHAPTER FIVE: DISCUSSION

This study was conducted for the primary purpose of discerning what current and/or retrospective impacts compulsive hoarding by a parent has on their adult children. A secondary purpose was to add literature to an area of study that, to date, has enjoyed little if any professional attention. This chapter discusses how the findings in this study are consistent with the available literature, the limitations of the study and the perceived clinical implications for therapists working with adult children of compulsive hoarders.

Consistency with the literature

Because there is essentially no literature available that deals with the effects of compulsive hoarding on adult children, I will discuss this section in terms of how my findings are consistent with the literature in other areas of study. I will begin by describing experiences related by respondents in my study that paralleled those of children of parents with other mental health disorders. Additionally, I will discuss how my study fits with systems theory. Both of these areas were discussed in the earlier literature review

While conducting this research I also became aware of two additional areas, not included in the literature review, that meet the criteria of the parallelism phenomenon mentioned above. The first is how the experience of being the adult child of a compulsive hoarder mimics the experience of someone struggling with ambiguous loss. The second is how their experience fits with attachment theory.

How parental mental illness affects children

As stated previously, it has been well documented that having a family member who suffers from a mental illness puts additional stress and unique burdens on relatives living with them (Stengler-Wenske et al., 2006). Children tend to become parentified and take on responsibilities that are far beyond their developmental level. When not only children but other relatives take on the responsibilities of the loved one suffering with a mental illness, they do so at some detriment to their own physical and/or mental health (Geffken et al., 2006). All of these views were confirmed through this study. *Systems theory*

Systems theory seeks to discover why a family operates the way it does (Nichols et al., 2001). It proposes that individuals cannot be understood in isolation from one another. Rather they must be looked at as a part of their family, as the family is an emotional unit. Families are systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system. A result of this interconnectivity and interdependence is that family members intensely affect each other's thoughts, feelings, and actions. People seek each other's attention, approval, and support and react to each other's needs, expectations, and distress. A change in one person's functioning is predictably followed by reciprocal changes in the functioning of others (Carter et al., 1999).

Many participants reported having children. Because these children are now part of the system, they cannot avoid being affected. Parents who have not been able to resolve their own family of origin issues, can have a large negative impact on their own children (Siegel & Hartzell, 2004). Siegel and Hartzell (2004) explain that even if you

have had a difficult childhood, if you can find a way to make sense of it, you are not bound to re-create the same negative cycle. On the flip side, without such an occurrence, history will be likely to repeat itself since negative patterns of family interaction are passed down through the generations (Siegel et al., 2004). Findings in this study suggest this to be an important part of treatment.

Ambiguous loss

Ambiguous loss is loss without closure (Boss, 2000). Losses considered to be ambiguous are experiences such as having a loved one with alzheimer's disease, soldiers missing in action or immigrants separated from their family. This list is by no means exhaustive rather illustrative to give examples of what such losses tend to look like. Ambiguous losses can also be thought of as when children go off to college each fall, or even when loved ones are away for significant periods of time. According to Merriam-Webster online dictionary, the second part of the definition of the word ambiguous is "capable of being understood in two or more possible senses or ways (www.mw.com, 2007). In a permanent loss such as death, the loss is concrete and not open to interpretation. Conversely, ambiguous losses can be understood in a myriad of ways. For example, the immigrant who is happy with the new life they have created for themselves yet still mourns the loss of the family connections they left behind. Do they feel happy since they like the new situation or should they feel sad because of all they left behind? These conflicting thoughts and emotions put the person in such a bind that high levels of stress can result.

In her book titled "Ambiguous Loss", Pauline Boss (2002) asserts that "Psychological absence can be as devastating as physical absence". While never

mentioned exactly in these terms, this notion of ambiguous loss came up frequently throughout the responses in this research. Participants' mothers are still physically here but seemingly psychologically absent. How can they not see the impact their inappropriate attachment to things is having on their life? How is a child supposed to cope with allowing their mother to live in constant avoidable danger? Virtually every respondent discussed the difficulty they have in dealing with their conflicting emotions about their mother. On the one hand, they love their mother and want nothing more than for her to be happy in life. On the other hand, they dread the reality of what will be waiting for them when their mother dies, quite possibility as a result of her hoarded living conditions, and feel anger towards her for keeping them in limbo. Add to this the guilt they feel for feeling this way and the tension that results from such conflicting emotions can be paralyzing (Boss, 2000). Consistent with Boss' findings, participants reported that they are unable to make decisions, take action and most importantly cannot let go (Boss, 2000). Due to this ambiguity, they cannot make sense of the situation. They are pulled in opposing directions, love and hate for the same person.

Attachment Theory

Attachment theory is a well-researched explanation of infant and toddler behavior and mental health. Attachment theory is the psychological theory that contends that human beings have an *innate* tendency to maintain a connection to their attachment figure (Johnson, 2004). Attachment is the "lasting psychological connectedness between human beings" (Bowlby, 1969). This need for connection is not something exclusive to children, nor is it something that gets outgrown (Johnson, 2004). This attachment connection can be considered as is the tie that binds parent and child together and endures

over time. When this connection is not established, attachment injuries can occur. An attachment injury is a betrayal of trust from a significant other at a time of deep need (Johnson, 2004). In attachment theory it is believed that these injuries are what cause people to act out in an effort to minimize stress. Findings from this study suggest this type of injury is common for an adult child of a compulsive hoarder.

An additional component to this connection is the need for this attachment figure to serve as a secure base. His description is that of the parent being the "home base" from which children can venture out and explore the world (Bowlby, 1988). What makes it secure is knowing that they can return and be nourished physically and emotionally, reassured if frightened and comforted if distressed (Bowlby, 1988). Most respondents made mention of their lack of any "home base", both when they were children as well as currently. Findings in this study suggest this is significant to the experience of being an adult child of a compulsive hoarder.

Limitations

The largest limitation to this study was the unavailability of a measure to determine consistency among the population interviewed. It is unknown if they all grew up in similar cluttered environments of if some of their mother's developed this behavior later in life. In other words, in this study there was no way to compare the extent of the hoarding in which each participant grew up. Additionally, there is no measure currently available to determine who fits the category of an adult child of a compulsive hoarder.

Additionally, due to the difficulty in otherwise finding the adult children of hoarders population, participants were chosen via their membership to the internet support group "children of hoarders". Because this is a support group, all were

assumably already on a trajectory to be thinking about and potentially discussing the questions I asked. One would also assume the group was unique in that they were actively seeking support and beginning to make meaning of their experience.

Finally, all respondents were female and discussed their mother as the parent who compulsively hoards. The inclusion of male participants and the discussion of having a father as the primary hoarder may have resulted in different results (some fathers were discussed as "secondary" hoarders).

Clinical Implications

Systems theory, ambiguous loss and attachment theory all provide a useful framework for working with adult children of compulsive hoarders. The findings of this study alone will be a useful part of treatment in their already expressed need to normalize their experience. An additional part of treatment that is common to all three frameworks is the need to help adult children make sense of their childhoods.

Systems Theory

In applying systems theory to work with adult children of hoarders, it is important to look for emotional cut offs. In the family system, when anxiety goes up, the emotional connectedness of family members becomes more stressful than comforting. Eventually, one or more members feel overwhelmed, isolated, or out of control. An effort commonly used to attempt to alleviate this stress, is to emotionally cut off from the relationship. This cutoff might be in the form of moving far away and visiting home infrequently or staying in physical contact but avoiding "sensitive" issues. Because we know this cutoff does not actually end the emotional process--the opposite actually occurs and it

intensifies (Carter et al., 1999)--findings from this study suggest this to be an appropriate part of treatment.

Ambiguous Loss

Using the framework of ambiguous loss, the loss remains unresolved. The goal is to find some way to change despite the ambiguity remaining (Boss, 2000). Having a parent that has a mental illness can be considered to be an ambiguous loss experience. Therapeutic work involves resolving issues, and helping clients first understand, then work on learning how to meet their own needs (Marsh, 1998). Clients often may have gotten so focused on the responsibilities they likely took on at a young age in response to the parent's illness, they not only do not know how to meet their own needs, they likely do not even know what they are (Marsh, 1998). Respondents in this study shared this experience. Many reported being their mother's emotional caretaker from a young age and even some being her physical caretaker now. Findings from this study suggest it is likely they would not know of nor how to meet their own needs.

Attachment

Attachment theory is appropriate because the findings suggest that participants did not develop a secure attachment to their mother. Resulting from the lack of a secure attachment, the findings suggest attachment injuries did and continue to occur.

As children, participants had *inappropriate* attachment modeled for them. Many participants reported the feeling that things are more valuable to their mother than they. Their mothers chose to attach to things rather than to their child(ren). Because an attachment injury is a betrayal of trust at a time of deep need (Johnson, 2004) and many

participants reported great difficulty in trusting others, a focus of treatment should be helping clients learn how to form secure connections.

The positives

Although much of the discussion about this experience has focused on the negative parts of it, it should be noted that some participants also discussed how their experience resulted in positives. These were usually discussed in the sense of what strengths they had developed as a result. They varied from the independence discussed in stage three to increased creativity, increased tolerance for distress and even a heightened sense of empathy. This discussion of positives would be an important part of the therapeutic process.

Future Directions

The final question of the questionnaire asked what participants wanted other to know about this experience. The overwhelming responses were a desire to be able to talk about it openly and be taken seriously. Many compared the experience to that of having a parent with an addiction. Finally, they talked about the need to understand how difficult it can be for a child to grow up in these kind of conditions.

Conclusion

This study strongly suggests the need for additional study. Because we think the number is somewhere in the millions for people who hoard compulsively, the need to develop a treatment protocol for the children who have been negatively impacted (even if only half that population has children) was confirmed. Without having a greater understanding of the problem, therapists who come into contact with this population are

likely to find it difficult knowing how to help. Having a further awareness of this experience will open doors that were previously locked for adult children of compulsive hoarders and their therapists.

REFERENCES

- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*. Washington, DC: American Psychiatric Association.
- Boss, P. (2000) *Ambiguous Loss*. Cambridge, Massachusetts: First Harvard University

 Press
- Boss, P., Dahl, C., & Kaplan, L. (1996). The use of phenomenology for family therapy research: The search for meaning. In D. H. Sprenkle & S. M. Moon (Eds.), *Research Methods in Family Therapy*. New York: Guilford Press.
- Bowlby, j. (1969). *Attachment(Volume 1 of Attachment and Loss)*. New York: Basic books.
- Bolby, J. (1988). A secure base. London: Routledge
- Carter, B., & McGoldrick, M. (1999). Coaching at various stages of the life cycle. In B. Carter & M. McGoldrick (Eds.), *The Expanded Family Life Cycle: individual, family and social perspectives* (Third ed.). Boston: Allyn and Bacon.
- CDC. www.cdc.com, 2007
- Cooper, M. (1996). Obsessive-compulsive disorder: effects on family members. *American Journal of Orthopsychiatry, 66*(2), 296-304.
- Feusner, J., & Saxena, S. (2005). Unclutter lives and homes by breaking anxiety's grip.

 *Current Psychiatry, 4, 13-26.
- Frost, R. O., & Gross, R. C. (1993). The hoarding of possessions. *Behaviour Research and Therapy*, 31(4), 367-381.

- Frost, R. O., & Hartl, T. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research and Therapy, 34*, 341-350.
- Frost, R. O., & Steketee, G. (1999). Issues in the treatment of compulsive hoarding.

 Cognitive and Behavioral Practice, 6, 397-407.
- Frost, R. O., Steketee, G., & Grisham, J. (2003). Measurement of compulsive hoarding: saving inventory-revised. *Behaviour Research and Therapy*, *42*, 1163-1182.
- Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: A community health problem. *Health and Social Care in the Community*, 8(4), 229-234.
- Frost, R. O., Steketee, G., & Williams, L. (2002). Compulsive Buying, Compulsive Hoarding, and Obsessive-Compulsive Disorder. *Behavior Therapy*, *33*(2), 201-214.
- Geffken, G. R., Storch, Eric. A, Duke, Danny C., Monaco, Linda, Lewin, Adam B., Goodman, Wayne K. (2006). Hope and coping in family members of patients with obsessive-compulsive disorder. *Anxiety Disorders*, *20*, 614-629.
- Grisham, J. R., & Barlow, D. H. (2005). Compulsive Hoarding: Current Research and Theory. *Journal of Psychopathology and Behavioral Assessment*, 27(1), 45-52.
- Hartl, T. L., Duffany, S. R., Allen, G. J., Steketee, G., & Frost, R. O. (2005).
 Relationships among compulsive hoarding, trauma, and attention-deficit/hyperactivity disorder. *Behaviour Research and Therapy*, 43, 269-276.
- Johnson, S.M. (2004). *The practice of emotionally focused couple therapy* (Second ed.). New York: Brunner-Routledge
- Kaplan, A., & Hollander, E. (2004). Comorbidity in Compulsive Hoarding: A Case Report. *CNS Spectrums*, *9*(1), 71-73.

- Marsh, D. T. a. D., Rex. (1998). *How to cope with mental illness in your family*. New York: Tarcher/Putnam.
- Neziroglu, F., Bubrick, Jerome, Yaryura-Tobias, Jose A. (2004). *Overcoming compulsive hoarding*. Oakland: New Harbinger.
- Nichols, M. P., & Schwartz, R. C. (2001). The fundamental concepts of family therapy.

 In *Family Therapy: Concepts and Methods* (Fifth ed.). Boston: Allyn and Bacon.
- Renshaw, K. D., Steketee, Gail, Chambless, Dianne L. (2005). Involving family members in the treatment of OCD. *Cognitive behavior therapy*, *34*(3), 164-175.
- Saxena, S., Brody, A. L., Maidment, K. M., Smith, E. C., Zohrabi, N., Katz, E., et al.. (2004). Cerebral Glucose Metabolism in Obsessive-Compulsive Hoarding. *American Journal of Psychiatry*, *161*, 1038-1048.
- Saxena, S., Maidment, K. M., Vapnik, T., Golden, G., Rishwain, T., Rosen, R. M., et al. (2002). Obsessive-compulsive hoarding: symptom severity and response to multimodal treatment. *Journal of Clinical Psychiatry*, *63*(1), 21-27.
- Steketee, G., & Frost, Randy O. . (2007). *Compulsive Hoarding and Acquiring (therapist guide)*. Oxford: Oxford University Press.
- Steketee, G., and Frost, Randy O. (2007). *Compulsive Hoarding and Acquiring* (workbook). Oxford: Oxford University Press.
- Steketee, G., Frost, R. O., & Kim, H.-J. (2001). Hoarding by Elderly People. *Health and Social Work*, 26(3), 176-184.
- Stengler-Wenske, K., Kroll, M., Matschinger, H., Angermeyer, M. C. (2006). Quality of life of relatives of patients with obsessive-compulsive disorder. *Comprehensive Psychiatry*, 47, 523=527.

- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA: Sage.
- Understanding Obsessive Compulsive Disorder [Electronic (2006). Version] from http://understanding_ocd.tripod.com/ocd_facts_statistics.html.
- Winsberg, M. E., S., C. K., & Koran, L. M. (1999). Hoarding in Obsessive-Compulsive

 Disorder: A report of 20 cases. *Journal of Clinical Psychiatry*, 60(9), 591-597.

 Merriam- Webster online dictionary. www.m-w.com, 2007.

APPENDIX A

Adult Children of Hoarders Questionnaire

- 1. Tell me in depth about your experience of being an adult child of a compulsive hoarder.
- 2. How would you describe your relationship with your hoarding parent(s)?
- 3. How do you feel their hoarding has impacted your life (both positively and/or negatively)?
- 4. What would you like for others to understand about being an adult child of a hoarder?