Title

The Influence of Aging on the Process of Accumulation: A Qualitative Study of Older Adults with Hoarding and Cluttering Behaviors

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The Influence of Aging on the Process of Accumulation: A Qualitative Study of Older Adults with Hoarding and Cluttering Behaviors

by

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DISSERTATION

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Acknowledgements

In 1996, Hillary Clinton published a children's book titled, *It Takes a Village to Raise a Child*, introducing most Americans to this African proverb. This also happened to be the year I started my nursing career as student in a masters-entry nursing program. Now after spending seven years as a doctoral student, I can say with some authority that it also takes a village to nurture and support a doctoral candidate in nursing.

Indeed, it took a virtual metropolis to get me where I am today. Many individuals have encouraged and supported me over the past seven years that I would like to thank. First and foremost, I thank the members of my faculty committee: Dr. Margaret Wallhagen, Dr. Carol Mathews, Dr. Michael Tompkins and Dr. Beth Phoenix. Without their unique and vital contributions to my growth and development, I would not have reached this goal. Dr. Wallhagen is my dissertation adviser and has encouraged my enthusiasm for conducting research on older adults with hoarding behaviors since the start. She has given me invaluable advice on conducting research, teaching courses, and developing my career. She has set high standards and expectations for me, ones that at times I thought were out of reach, and I have benefitted from her confidence that I could achieve them. Dr. Mathews has challenged me to examine my research topic from various psychological and biological viewpoints. She has helped me to expand my network of research partners to include scientists from psychiatry and neuropsychology. Dr. Tompkins has inspired me to translate research into practical applications that individuals, families, and communities can use. His advice as a clinician, scholar, and educator has helped to keep me grounded in the real-world issues faced by individuals with hoarding behaviors and their families. Dr. Phoenix has reinforced my conviction that

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The Influence of Aging on the Process of Accumulation:

A Qualitative Study of Older Adults with Hoarding and Cluttering Behaviors

Monika B. Eckfield

ABSTRACT

Individuals with hoarding and cluttering behaviors have difficulty discarding items, acquiring such a large number of items that their home environments become severely cluttered. Severe clutter interferes with activities of daily living and often causes distress to those living in the environment. Once viewed as personal lifestyle preferences, these behaviors are currently recognized as a mental health disorder associated with anxiety disorders and cognitive dysfunction. While hoarding and cluttering behaviors affect individuals of all ages, older adults are at increased risk of isolation, injury and other poor outcomes as a result of these behaviors. However, very little is currently known about the influence of age-related factors on hoarding and cluttering behaviors.

To address this gap in our understanding, a qualitative study using Grounded Theory Methodology was conducted. Twenty-two adults age 65-91 with hoarding and cluttering behaviors were interviewed in their homes. Interviews were transcribed verbatim and analyzed using Atlas Ti software. All participants noted long-standing problems with hoarding and cluttering but narratives suggested how aging contributed to their current situation. Participants described a three-part process of accumulation that included acquiring, maintaining and discarding items. Patterns of behaviors emerged from data, describing two distinct "types" of individuals with hoarding behaviors. These two types, called *Impulsive Acquirers* and *Anxious Keepers*, differed in the ways in which

they acquired, maintained, and discarded their belongings. In addition, participants described a dynamic interaction between the process of accumulation and aging. Changes in health status, social context, and home environment associated with aging generally contributed to worsening of the behaviors or outcomes, although some participants indicated that growing older increased their motivation to make changes in their home environments.

By identifying these age-related factors and distinguishing the "type" of behaviors exhibited by older adults, clinicians will be able to develop more targeted interventions to reduce the risk of harm to older adults living in severely cluttered homes.

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CHAPTER I: INTRODUCTION

Overview of the Topic

Hoarding and cluttering behaviors have been defined as the acquisition of and inability to discard items that appear to others to be useless or of limited value (Frost & Gross, 1993; Frost & Hartl, 1996). These behaviors become problematic when they result in the accumulation of so many belongings that the ability to conduct normal activities of daily living is impaired or they cause distress to the individual or to others living in the home (Steketee & Frost, 2007). While it is likely that these behaviors have existed for centuries, the pace of research on these behaviors has accelerated greatly over the past 25 years.

Currently, we understand that these behaviors affect individuals across the life span, not just older adults, and that the onset of behaviors is often in childhood or early adulthood (Ayers, Saxena, Golshan, & Wetherell, 2010; Grisham, Frost, Steketee, Kim, & Hood, 2006; Storch et al., 2011). It is estimated that about 5% of the United States population have hoarding and cluttering behaviors, which translates into 15-16 million Americans (Samuels et al., 2008). We also know that these behaviors are not specific to American culture. They are seen not only in affluent, developed, Western societies, but in Asian cultures, and less-developed countries in South and Central America as well (Chavira et al., 2008; Fontenelle, Mendlowicz, Soares, & Versiani, 2004; Matsunaga, Hayashida, Kiriike, Nagata, & Stein, 2010; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009). The term "hoarding disorder" has been proposed as the new name for these behaviors, and diagnostic criteria are being developed which will be included in the

fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual, to be published in 2013(American Psychiatric Association, 2010).

While research on hoarding and cluttering behaviors continues to grow annually, only a small fraction of this research has focused on understanding the impact of these behaviors on older adults. Yet, many of the most severe instances of this behavior have involved older adults (Franks, Lund, Poulton, & Caserta, 2004; Patronek, 1999) and a recent study suggest that the severity of hoarding and cluttering behaviors increases with age (Ayers et al., 2010). Prevalence studies indicate that older adults are the most likely age group to have problematic hoarding and cluttering behaviors in the community (Samuels et al., 2008). Additionally, older adults seem to be at greater risk for poor outcomes due to these behaviors compared to younger adults. This may be because they are coping with age-related changes in health and social supports which complicate the effects of hoarding and cluttering behaviors (Franks et al., 2004; Kim, Steketee, & Frost, 2001; University of Kansas School of Social Welfare, 2007). However, the influence of aging on hoarding and cluttering behaviors and the impact these behaviors have on the lives of older adults, have been greatly understudied.

Introduction to the Dissertation Study

The purpose of this dissertation study was to explore the experiences of older adults with hoarding disorder who are living independently in the community. The specific aims of this study were to:

1. Describe the contextual factors and processes that influence the onset of hoarding behaviors and contribute to the worsening or improvement of the behaviors over time.
2. Describe how hoarding behaviors currently affect an individual's life, including their ability to engage in relationships and access social support, the effects on their physical and mental health, and their ability to conduct normal daily activities.

Pilot Study

A pilot study was conducted from 2005-2006 in which 9 interviews were conducted with 8 women age 65 and older in their homes. Three main results from this pilot study guided the design of the main dissertation study:

1) Feasibility: accessing older adults living in the community and interviewing them about their hoarding and cluttering behaviors was not a problem. While clearly there would be some individuals who would not volunteer to participate in such research, there were plenty of individuals with problematic levels of hoarding and cluttering behaviors who would allow a nurse to come into their home to discuss their behaviors and the impact of these behaviors on their daily lives;
2) Influence of aging: growing older influenced how hoarding and cluttering behaviors affected participants. Age-related factors such as declining health and having less energy made the tasks of sorting, organizing decision making and discarding items more difficult. Becoming widowed and losing social supports also complicated their ability to manage in their homes.

3) Impact of living with clutter: severely cluttered home environments posed hazards to older adults' physical and mental wellbeing. Pilot participants described injuries they sustained from bumping into, slipping or tripping on items. They also described how living in these environments exacerbated pre-existing problems with anxiety and depression. For a variety of reasons, participants restricted others' access to their homes, contributing to increased isolation.

With these preliminary findings in mind, the recruitment strategy was expanded and the interview guide used for the dissertation study was revised in order to gather more information on these and related themes.

Dissertation Study

From May 1, 2009 to March 1, 2010, twenty-four interviews were conducted with 22 participants. Study participants were age 65 to 91 with an average age of 74. The sample included 6 men, 3 African American women, 2 Asian American women, 1 man from India and 1 Hispanic man. The eight participants of the pilot study were invited to participate in the dissertation study and four women responded and were interviewed again using the updated interview guide. Their interviews from the pilot study were included in the data analysis, bringing the total of interviews transcribed and analyzed for the dissertation study to 29.

Organization and Preview of this Dissertation Report

This dissertation is the culmination of the research conducted by this nurse on the topic of older adults with hoarding and cluttering behaviors from 2005-2010. It is divided into six chapters, Introduction, Literature Review, Methodology, Results, Discussion, and Summary. The Literature Review, focuses on summarizing the research to date on older

adults with hoarding disorder, the gaps in our knowledge, and identifying areas for future research. The Methodology chapter briefly reviews the philosophical underpinnings of grounded theory before discussing the setting and recruitment strategy, study sample, data collection and analysis procedures, and methods for establishing rigor in this study. The results chapter is organized around "the process of accumulation", a three phased process described by participants that includes acquiring, maintaining and discarding belongings. Within each phase, there are distinct factors and motivations that are more salient to some participants than others. Within this framework, two main findings are presented: the influence of age-related factors; and the identification of two "types" of individuals with hoarding behaviors. These findings emerged as the two most important "storylines" from the participants' transcripts and most directly address the specific aims of this study.

Age-related factors that influence the process of accumulation fall into three core categories: changes in health status; changes in social context; and changes in home environment. These categories describe the dynamic between hoarding and cluttering behaviors and the aging process. Generally, age-related factors contributed to worsening of the behaviors or outcomes, although some participants indicated that aging had a positive impact, particularly on their motivation to discard items. In addition, patterns of behaviors emerged from participants' stories that may help researchers and clinicians to distinguish "types" of hoarding and cluttering behaviors. Two groups were identified in this study: the *Impulsive Acquirers* and *Anxious Keepers*. These groups differed in their modes of acquisition, the reasons why they kept items and were reluctant to discard

items, and the degree to which their accumulated belongings interfered with their day-to-day lives.

A particularly novel perspective presented in the Results chapter is the information participants shared about "maintaining" their homes and collections of belongings. Most research on hoarding and cluttering behaviors to date has focused on the acquisition of items or the difficulties individuals have discarding items. The period in which individuals live with their belongings has generally been thought of as an inert period where nothing much is happening. In this study, participants reveal that nothing could be further from the truth. Maintaining their home environments takes considerable effort, involves much energy expenditure, and results in much mental anguish. In fact, describing what is involved in maintaining their environment was the main topic of most of the interviews. Data in this Results section gives us an unprecedented look at the day-to-day experiences of older adults with hoarding and cluttering behaviors.

In the Discussion chapter, results from this study and the ways in which they fit with and expand upon other current research on hoarding behaviors is presented. Limitations of the study are discussed, as well as the clinical implications of the two main findings will be discussed. The chapter concludes with a summary of the outstanding questions and areas for future research.

The final chapter in this dissertation is a brief summary that pulls all the pieces of this research project together. Ultimately, the result of this research is a more comprehensive understanding of the experience of older adults with hoarding behaviors. In addition to increasing our empathy for those living in severely cluttered environments, it suggests new ways in which we may be able to provide more sensitive and effective

interventions to those who want to decrease the accumulation of belongings in their homes. It is this author's goal to develop manuscripts based on this dissertation report and submit them to a range of health and social science journals as a resource for others and to guide future research efforts.

CHAPTER II: LITERATURE REVIEW

Introduction

In 1947, two elderly brothers in New York City made news headlines when both were found dead in their Harlem brownstone townhouse, buried under towers of stuff. It took over two weeks for police and workmen to clear out 130 tons of belongings, debris, and garbage which had accumulated in their home over the decades. Two decades later, in 1966, two geropsychiatrists from Nottingham, England, published a paper in the British Medical Journal describing a condition they termed "senile breakdown" in which older adults in the community were living in a state of squalor with lapses in both personal hygiene and accepted standards of household cleanliness (Macmillan & Shaw, 1966). Ten years later, in an article in The Lancet in 1975, another team of British physicians described similar squalid living conditions in a series of 30 elderly hospital patients, many of whom were also said to have syllogomania, or the compulsive hoarding of rubbish (Clark, Mankikar, & Gray, 1975). Dr. Clark and his team termed the behaviors that lead to these cluttered and squalid home environments "Diogenes Syndrome". These three events are often cited as the very beginning of research on hoarding and cluttering behaviors. Over the past 40 years, a small but growing body of research on these behaviors has emerged. Several case studies describe individuals who have poor personal hygiene and are living in severely cluttered and squalid conditions, including those which involve the hoarding of animals (Franks et al., 2004; Greenberg, Witztum, & Levy, 1990; Patronek, 1999). However there are other individuals who live in crowded, cluttered homes but do not hoard rubbish or animals and who do not live in squalor. Within the past 25 years, a growing number of researchers have focused their attention on these

individuals who generally maintain clean personal appearances, but have accumulated large volumes of belongings in their homes that limits their ability to move around.

Hoarding and cluttering behaviors are currently defined as the acquisition of and inability to discard items that appear to others to be useless or of limited value (Frost & Gross, 1993; Frost & Hartl, 1996). These behaviors become problematic when the accumulation of belongings leads to impaired ability to conduct normal activities of daily living or causes distress to the individual or to others living in the home (Steketee & Frost, 2003). Until recently, hoarding and cluttering behaviors have commonly been thought of as a subtype of Obsessive-Compulsive Disorder (OCD, see Abramowitz, Wheaton, & Storch, 2008 for discussion). However, recent research has lead clinicians to view hoarding behaviors as a separate disorder (Mataix-Cols et al., 2010). In fact, the diagnosis of "Hoarding Disorder" has been proposed for the fifth version of the American Psychological Association's Diagnostic and Statistical Manual (DSM), to be published in 2013. The proposed diagnostic criteria for hoarding disorder are: a) persistent difficulty discarding or parting with objects; b) difficulty discarding due to strong urges to save or distress from discarding items ; c) symptoms result in accumulation of possessions that clutter living or working areas to the extent that it is not possible to use them as intended; d) symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning; and e) symptoms not better accounted for by medical conditions or other mental health conditions (American Psychiatric Association, 2010). Inclusion of hoarding disorder in the DSM-V would provide a consistent definition which would aid in both the identification and study of this disorder.

Studies have given us insight into the factors that lead to the behaviors and the impact these behaviors have on individuals and the communities in which they live. We now know that these behaviors are not only seen in older adults, as was theorized by the Macmillan (1966), Clark (1975), and their colleagues, but affect individuals of all ages including children (Grisham et al., 2006; Storch et al., 2011). However, there is research to support the idea that older adults are at greater risk of negative outcomes as a result of these behaviors compared to their younger counterparts (Ayers et al., 2010; Chapin et al., 2010; Kim et al., 2001). While research on hoarding and cluttering behaviors in general has increased dramatically over the past twenty-five years, very little of it has focused on older adults. This is a significant oversight that needs to be remedied since the Baby Boomer generation in the United States is aging and over the next 20 years, the number of adults over the age of 65 is expected to grow from 35 million to 71 million by 2030 (CDC, 2003). Thus, it is reasonable to expect there to be an increasing number of older adults with hoarding disorder living in the community in the coming decades.

The purpose of this paper is to systematically review and critically evaluate the current research on older adults with hoarding and cluttering behaviors. For the purpose of this paper, the terms hoarding behavior and hoarding disorder will be used to identify these behaviors. By reviewing the state of the research on older adults with these behaviors, we will have a better idea where the gaps in our knowledge lie and will help us focus research efforts in the most effective manner.

This paper was a part of a larger literature review that evaluated the current state of the research on hoarding disorder in general. Following the introduction, the search methodology for the entire literature review is described, and a brief background of the

behaviors in general, including their prevalence and significance, is presented. A critical review of the literature on older adults is presented next, followed by a discussion outlining the gaps in our current knowledge about older adults with hoarding disorder.

Search Methodology

A comprehensive review of the research literature was conducted to examine the current evidence on adults with hoarding and cluttering behaviors and gather information about older adults in particular. PubMed, CINAHL, and PsychInfo databases were searched using the search term "hoarding" and limited to articles published in English. This identified a total of 463 articles. This group of articles was then sorted by age of participants, identifying 117 that included adults age 65 and older. Through this initial search, three additional terms, "Diogenes Syndrome", "squalor" and "self-neglect", were discovered and subsequently searched. These searches were limited to English language and involving adults age 65 and older. This search added 164 additional articles to the analysis. From this total number of 627 articles, 228 were selected for closer review based on key words, abstract, and availability. Additional articles were selected for review from the reference lists of pertinent articles. A total of 29 articles were found to address older adults with hoarding behaviors.

Background on Hoarding Behaviors in All Ages

It is estimated that as many as 5% of the population in the United States have problematic hoarding behaviors (Samuels et al., 2008). There is documentation that individuals across the lifespan, from late childhood to older adulthood, exhibit hoarding behaviors (Grisham et al., 2006; Kim et al., 2001; Mathews et al., 2007; Pertusa et al., 2008). While there is some evidence to suggest that the onset of hoarding behaviors is in

late childhood, most individuals do not seek treatment for these behaviors until they reach 40-50 years of age (Muroff, Steketee, Himle, & Frost, 2010; Tolin, Frost, & Steketee, 2007).

The three key characteristics of hoarding and cluttering behaviors include a cluttered home environment, excessive acquisition of items, and difficulty discarding items (Frost & Hartl, 1996; Steketee & Frost, 2003). Family studies indicate there may be a genetic component to hoarding and cluttering behaviors. Individuals with a first degree relative with hoarding behaviors are 25-35% more likely than others to develop the behaviors, suggesting that some individuals may have a genetic predisposition to hoard (Katerberg et al., 2010). In addition, evidence indicates both physiological and psychological factors contribute to the behaviors.

Studies utilizing brain imaging techniques and neuropsychiatric evaluations have reported a variety of cognitive impairments and dysfunction in those with hoarding behaviors (Mataix-Cols, Pertusa, & Snowdon, 2011). While consensus has not yet been reached, several studies suggest that there is impairment in parts of the brain responsible for executive functioning (Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Mackin, Arean, Delucchi, & Mathews, 2011). "Executive functioning" describes cognitive abilities needed to accomplish goal-oriented tasks such as categorization, problem-solving, and decision making. In addition, individuals with these behaviors report symptoms such as impulsivity (Frost, Meagher, & Riskind, 2001; O'Sullivan et al., 2010), attention disregulation (Sheppard et al., 2010; Tolin & Villavicencio, 2011), and actual or perceived alterations in memory (Hartl et al., 2004), which has lead researchers to investigate the overlap between hoarding disorder and attention deficit hyperactivity

disorder, a cognitive disorder involving executive functioning.

In addition to cognitive symptoms, those with hoarding disorder frequently report co-morbid psychological disorders. Anxiety disorders including generalized anxiety disorder, social phobia, and obsessive-compulsive disorder, as well as depression are the most commonly observed co-morbid mental health diagnoses in individuals with hoarding and cluttering behaviors (Tolin, 2011). Personality characteristics such as emotional attachment issues, perfectionism, and procrastination or behavioral avoidance have also emerged as common issues for individuals with hoarding behaviors (see Steketee & Frost, 2007).

Research on Older Adults with Hoarding and Cluttering Behaviors

Although hoarding behaviors were originally conceptualized as a problem affecting older adults, only a small fraction of the research over the past 40 years has focused on understanding these behaviors in older adults. Sadly, when these articles are critically evaluated, some of the research has limited utility in informing us on older adults with hoarding disorder because of differences in how hoarding behaviors are defined. In case studies published prior to 1996, when Frost and Hartl published their definition of compulsive hoarding, several of the individuals described do not reflect our current understanding and definition of hoarding behaviors, but rather describe situations in which squalor, self-neglect, and hoarding are a result of other mental health issues such as schizophrenia or undiagnosed dementia (Greenberg et al., 1990; Hogstel, 1993; Thomas, 1998). In other articles, the term "hoarding" is used to describe behaviors that also do not fit the Frost and Hartl definition, but are described as infrequent, repetitive, or

agitated behaviors seen in older adults with Alzheimer's disease and other types of dementia (Baker, Raetz, & Hilton, 2011; Hwang, Tsai, Yang, Liu, & Lirng, 1998; Marx & Cohen-Mansfield, 2003). While these agitated behaviors can be problematic, particularly for caregivers, they do not result in the same degree of accumulation as seen in hoarding disorder. Thus, what we currently know about hoarding disorder in older adults comes mainly from twelve articles published between 2001 and 2011 (Table 1). These findings can be categorized into three topics: 1) similarities and differences between older and younger adults with hoarding disorder; 2) the course and outcomes of hoarding disorder as individuals age; 3) treatments or interventions for older adults with hoarding disorder.

Similarities and Differences between Older and Younger Adults

Older adults with hoarding disorder seem to share the same basic demographic characteristics as younger adults with these behaviors. While several study samples have included educated Caucasian women who live alone, many of whom are retired from professional careers (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2008; Cermele, Melendez-Pallitto, & Pandina, 2001; Franks et al., 2004; Kim et al., 2001), other studies have included participants with more varied and diverse demographic characteristics. In all but one study of older adults with hoarding disorder (Cermele et al., 2001), men are represented in the samples and in two studies (Ayers et al., 2010; O'Sullivan et al., 2010) more men are represented than women. Additionally, African-Americans were disproportionally represented in one study of hoarding behaviors (Chapin et al., 2010). Like younger adults with hoarding disorder, older adults seem to come from a range of

socioeconomic backgrounds (Chapin et al., 2010; Franks et al., 2004; Turner, Steketee, & Nauth, 2010).

The daily lives of older adults with hoarding behaviors are affected in many of the same ways as younger adults. Mobility within the home is restricted due to the accumulation of belongings and the ability to conduct activities of daily living, such as bathing, preparing meals, and sleeping in a bed can be impaired (Andersen et al., 2008; Franks et al., 2004; Kim et al., 2001). Younger and older adults with these behaviors live in homes where basic utilities such as heat or water have been shut off, where safety hazards have resulted from deferred home maintenance, and where public authorities such as the health department or fire department have become involved because of the state of their homes (Chapin et al., 2010; Frost, Steketee, & Williams, 2000; San Francisco Task Force on Compulsive Hoarding, 2009). Older adults, like their younger counterparts, often refuse interventions aimed at decreasing the volume of belongings that are offered by family members or from health or social service agencies (Chapin et al., 2010; San Francisco Task Force on Compulsive Hoarding, 2009).

There are several important differences between older and younger adults with hoarding disorder that are emerging from recent research. Older adults with hoarding disorder are more likely to have co-morbid health issues, such as chronic health conditions that are often accompanied by physical disabilities or limitations (Andersen et al., 2008; Chapin et al., 2010; Kim et al., 2001; San Francisco Task Force on Compulsive Hoarding, 2009). In addition, there is evidence to suggest that older adults with hoarding disorder are more likely to live alone and are more socially isolated than one would expect from a healthy community sample (Ayers et al., 2010; Chapin et al., 2010; Kim et

al., 2001; San Francisco Task Force on Compulsive Hoarding, 2009). Social isolation, coupled with the presence of health conditions, is likely to contribute to a greater risk for poor health outcomes in older versus younger adults. While it has been found that younger adults with hoarding disorder may have a wide range of co-morbid mental health disorders, including schizophrenia and anxiety disorders, older adults with hoarding disorder may be at greater risk for developing depression (Ayers et al., 2010; Mackin et al., 2011) compared to younger adults. The impact of poor health, social isolation and depression on hoarding behaviors has not been studied, but clearly these factors describe a more complex situation in which older adults may live.

The research examining the link between dementia and hoarding behaviors raises more questions than it provides answers. As mentioned previously, studies on dementia, particularly Alzheimer's Disease, define hoarding as a covert, low-severity behavior that is similar to hiding objects and poses more of an inconvenience to caregivers when items go missing than a limit on one's ability to function in the home (Baker et al., 2011; Marx & Cohen-Mansfield, 2003). In fact, in most studies of older adults with hoarding disorder, researchers have remarked on the somewhat surprising absence of cognitive impairment or dementia (Ayers et al., 2010; Kim et al., 2001). One study of older adults with depression found that study participants with hoarding disorder showed greater impairment in cognitive function on measures of categorization ability, information processing and verbal memory than non-hoarding older adults with depression (Mackin et al., 2011). These particular cognitive tasks are part of a group of abilities called executive functions and are thought to be mediated by the frontal lobes of the brain. The finding by Mackin et al. (2010) is similar to results found in studies of executive

functioning in younger adults (Grisham et al., 2010; see Tolin, 2011). At this point, there is no evidence to suggest that older adults with hoarding disorder show greater cognitive impairment in the frontal lobes than younger adults; although one might hypothesize that incremental decline in cognition commonly observed with advancing age may further erode executive functioning. On the other hand, the development of hoarding behaviors does not seem to be common among those with frontotemporal dementia (FTD). Those with FTD who are said to "hoard" tend to have the type of repetitive, perseverative behavior described in the literature on hoarding in Alzheimer's disease, rather than behaviors that would be considered a hoarding disorder (Boxer & Miller, 2005; Mendez & Shapira, 2008; Nakaaki et al., 2007). Thus, currently available data suggests that dementia is not likely to be a cause or a major contributing factor to hoarding disorder.

Course and Outcome of Hoarding Behaviors as Individuals Age

Research into the age of onset of hoarding behaviors indicates that most individuals start exhibiting hoarding and cluttering behaviors before age 20 (Ayers et al., 2010; Grisham et al., 2006). However, there is also evidence that hoarding behaviors are more prevalent in older adults than younger adults living in the community (Samuels et al., 2008) and that as individuals age, the severity of the symptoms of their hoarding behaviors increases (Ayers et al., 2010).

The reasons for these increases in prevalence and symptom severity with age are not understood. It is not clear whether the behaviors themselves become worse with age, whether the home environment becomes more cluttered and difficult to navigate over time, or whether as an individual's physical abilities decline their ability to function in the home becomes problematic. It may also be that other age-related changes, such as

becoming widowed or losing in social supports impact the mental and social wellbeing of older adults and in turn contribute to a worsening of hoarding symptoms. For instance, one study examined the effect of family on hoarding behaviors and found that those who were married or living with others had significantly lower scores on a hoarding assessment tool than those who were single, divorced or widowed (Tolin, Frost, Steketee, & Fitch, 2008). Research into the impact of age-related changes, including changes in health and social supports may shed light on the reasons older adults may experience different outcomes than younger ones as a result of having a hoarding disorder.

Treatment for Older Adults with Hoarding Disorder

Only three studies have been published on treatments for hoarding disorder in this age group. One case study describes a 72 year old divorced Caucasian woman and a therapeutic intervention conducted by a team of psychologists based on the Frost and Hartl (1996) theoretical model of compulsive hoarding (Cermele et al., 2001). The intervention consisted of a three part strategy, each step of which actively included the individual with hoarding behaviors. The strategy included pre-intervention planning, collaborative "dehoarding" of the home, and on-going follow-up over 6 months. By engaging the woman in cognitive restructuring, building decision-making skills, and emphasizing her control over the situation, the therapy team assisted her in clearing her home of years of accumulated belongings. The intervention successfully met its goal and within six-months the woman was able to make repairs and sell her home so she could move closer to her adult daughter and grandchildren.

More recently, two teams of researchers have piloted interventions based on the *Compulsive Hoarding and Acquiring Therapist Guide* published by Steketee and Frost

(2007). This multi-modal intervention combines elements of motivational interviewing and cognitive behavioral therapy to promote new behaviors in individuals with hoarding disorder. Turner and colleagues (2010) reported on the outcomes of an intervention trial involving six older adults (5 women, age 56-87 with an average age of 72.5) with hoarding disorder. The intervention consisted of 28 to 41 weekly meetings with a social worker who had been trained by the research team which included Dr. Steketee. Meetings mostly took place in the older adult's home and lasted 1.5 to 2 hours. The intervention was conducted over a period of 11 to 13 months. Study participants were referred to the intervention mainly by a community mental health agency or administrators at an elder housing site.

During the course of the intervention, the treatment protocol was modified by the research team in important ways to adapt to the needs of older adults. These included: a) allocating more time in the beginning of the intervention to develop a trusting relationship between the social worker and the study participant; b) accommodating for the diminished health status and energy level of some participants by providing additional time to complete specific tasks; c) paying greater attention to minimizing or eliminating health and safety risks than outlined in the original treatment protocol since the researchers determined that study participants had more limited physical capacity than younger adults and therefore were at greater risk for injury as a result of the health and safety hazards in the home. In addition to these modifications, if the participant brought up declining health or end of life issues, the social worker was encouraged by the research team to cultivate these discussions. These topics proved to be useful in helping the older adult reframe their priorities about keeping and discarding items and reassess

the value of items they had collected. For example, during the intervention period one participant was hospitalized for an acute exacerbation of a chronic health condition. After returning home and as a result of discussions about her declining health, the study participant accepted help from a home health aide in order to speed up the process of sorting through clutter and discarding items from her home.

Improvement was measured on four scales: 1) the overall amount of clutter was rated on the Clutter Image Rating (CIR, Frost, 2008), a series of 9 photographs depicting progressively increasing amounts of clutter; 2) the amount of interference in daily life was rated on an Activities of Daily Living (ADL) scale; 3) the types of safety hazards present in the home as a result of hoarding behaviors was rated on an ADL- safety scale; and 4) a hoarding interview outlined in the treatment protocol facilitated the assessment of four domains of hoarding behaviors, difficulty using rooms due to clutter, difficulty discarding, excessive acquiring, and organizational problems. At the conclusion of the intervention, all participants had measurable improvements in the overall amount of clutter in their homes and ability to conduct ADLs, as well as reductions in the number of safety hazards. Improvements were also noted on three of the four hoarding behavior domains: ability to use rooms as they were intended, ability to discard items, and limiting acquisition of items. However, no improvements were made in participants' ability to organize their belongings. Unfortunately, the researchers did not discuss why they thought older adults in this study did not improve on this last domain.

This study provided evidence that an intervention model developed for younger adults could successfully be adapted for use with older adults with hoarding disorder. However, the researchers did not provide any information about the ongoing ability of

study participants to maintain the gains they had achieved or continue to make improvements on their own after completion of the intervention. These shortcomings were addressed by the intervention study reported by Bratiotis et al. (2010).

Bratiotis and colleagues adapted the same multi-modal treatment protocol (Steketee & Frost, 2007) for use with 26 older adults referred to the study through Adult Protective Services. Eleven participants in this study lived in subsidized housing and were at risk for eviction due to the state of their homes while 15 participants lived in their own homes and were referred to the program by local boards of health, fire personnel or elder service agencies. Participants ranged in age from 60-90 and 12 were male. The clinicians who provided the intervention visited the older adult weekly for approximately 2 hours. Improvements were measured using the CIR, the Hoarding Rating Scale (Tolin, Frost, & Steketee, 2010), the Saving Inventory-Revised (Frost, Steketee, & Grisham, 2004), and the hoarding interview outlined in the treatment manual. Echoing the experience of Turner and colleagues (2010), modifications to the treatment protocol were made to allow more time to build a trusting relationship between clinician and participant and additional time was also allowed for the completion of individual tasks to accommodate for the health constraints and energy limits of the older adults.

Within four to six months, 12 of the participants had developed new skills enabling them to organize and discard items even without the clinician present. For these individuals, weekly sessions ended and the clinician followed up with the participant on a monthly basis. For the remaining 14 participants, they continued to sort, organize and discard items only in the presence of and with coaching from the clinician. Weekly sessions for these participants continued indefinitely. After one year, the pilot study had

achieved its goals of improving participants' home environments and preventing evictions, however specific improvements on the outcome measurements were not reported by the researchers. The characteristics that distinguished those who learned and applied new organizational skills to their belongings from those who required ongoing weekly support were not discussed. Identifying these factors will be important to determine so that interventions such as this can be recommended to individuals who are most likely to benefit from them. In addition, the researchers mention that 52% of the participants in this study lived in squalid conditions, including the presence of trash or rotting food, in addition to having hoarding behaviors (Bratiotis & Flowers, 2010). No further information was provided indicating whether those with squalor had different responses to the intervention. Thus, determining for whom such an intervention is most appropriate is still an area for further research.

As evident in these two intervention studies, complex situations can arise as a result of hoarding behaviors in older adults. These problematic situations often involve a range of health, social service, and public safety agencies (Chapin et al., 2010; Kim et al., 2001). Furthermore, it appears that older adults with hoarding disorder are more likely than younger adults to be referred to Adult Protective Services because their behaviors are seen as self-neglect, a form of elder abuse (Bratiotis & Flowers, 2010; Chapin et al., 2010). Cases involving older adults tend to be more complex than those involving younger adults due to the additional health issues and absence of social supports that affect elders (Andersen et al., 2008; Franks et al., 2004; Turner et al., 2010).

Because of this complexity, there has been a call for multi-disciplinary teams (MDTs) to work together to coordinate services efficiently and effectively, particularly in

cases involving older adults (Chapin et al., 2010; Lee, 2010; San Francisco Task Force on Compulsive Hoarding, 2009). However, few guidelines on how these MDTs should work and few reports on their efficacy exist in the literature (Chapin et al., 2010; Koenig, Chapin, & Spano, 2010). One study of MDTs in a Midwestern state found that the teams were only effective in reducing the accumulation of belongings in an older adult's home and helping them to remain in their home 14% of the time while nearly 56% of the time the older adult remained in their home with no change to the environment (Chapin et al., 2010). Others have pointed out the ethical challenges that arise when a variety of public and private service agencies try to work together to intervene and resolve issues arising from a problematic hoarding situation (Koenig et al., 2010). These include protecting the individual's rights to privacy and managing the different, sometimes competing, priorities of the service agencies involved. While the premise of MDTs collaborating to develop the best course of action to support older adults with hoarding disorder is laudable, more research is needed to develop practical guidelines for communities to follow.

Gaps in Our Knowledge about Hoarding Disorder in Older Adults

Over the last few decades, our understanding of hoarding disorder has developed considerably. However, when considering older adults in particular, pronounced gaps in the current knowledge appear. These may be summarized by the following three questions: 1) Can data on younger adults with hoarding disorder be applied to older adults with the behaviors? 2) Do certain physical, mental, and social changes that affect older adults in particular influence the course and outcomes of hoarding disorder in this older population? 3) When, and in what ways, do hoarding behaviors overlap with squalor and self-neglect? To summarize the findings from this literature review and

highlight the gaps that require further study, these three questions must be explored in more detail.

Can data on younger adults with hoarding behaviors be applied to older adults with these behaviors?

Hoarding behaviors typically involve difficulties with organizing and making decisions which can be traced to alterations in cognitive function that involve executive function. Hoarding behaviors frequently co-occur with other mental health issues such as mood and anxiety disorders or may exist on their own in the absence of other mental health issues. However, the majority of these findings have been based on studies of individuals who are younger than 65 years old.

It cannot be assumed that older adults are the same as younger adults. Physical, mental, and social changes affect how older adults experience the world compared to younger counterparts (see Estes, Biggs, & Phillipson, 2003). Recent studies have begun to outline potential differences between older and younger adults with hoarding behaviors, such as co-morbidity with depression and degree of isolation (Ayers et al., 2010; Mackin et al., 2011).However, more research is needed to confirm these findings and to illuminate other ways in which age may influence hoarding behaviors. Replications of existing studies of younger adults with hoarding behaviors that focus on older study participants is one avenue of inquiry that would provide data on the similarities and differences in hoarding behaviors between different age groups.

Do certain physical, mental, and social changes that affect older adults in particular influence the course and outcomes of hoarding disorder in this older population?

Evidence that hoarding behaviors begin in childhood or early adulthood and worsen in severity as individuals reach middle- and late-adulthood is mounting (Ayers et al., 2010; Grisham et al., 2006). Indeed, as mentioned previously, most individuals who seek treatment for hoarding behaviors are between the ages of 30 and 50. Several possible scenarios could lead to worsening of hoarding behaviors in later life. If individuals have a predisposition for hoarding behaviors due to genetic factors, one hypothesis is that it could be triggered later in life in response to traumatic events, such as a move, loss of a loved one, or the onset of chronic health conditions (Koenig et al., 2010; Tolin, Meunier, Frost, & Steketee, 2010). Alternatively, it could be that subclinical hoarding behaviors are present for years before the clutter reaches a level that impairs functioning or causes distress to the individual or others in the home (Chapin et al., 2010; Koenig et al., 2010).

It is also possible that the presence of others in the home, such as spouses and children, provide social reasons for keeping hoarding behaviors in check. Changes in the household composition, such as adult children leaving home, divorces, or becoming widowed could significantly worsen hoarding behaviors because the social impetus to limit these behaviors is removed. There are minimal data indicating whether life events such as these contribute to the worsening of hoarding symptoms or exacerbate existing behaviors (Ayers et al., 2010; Tolin, Meunier et al., 2010).

Evidence suggests that adults with hoarding disorder are also coping with multiple physical and medical concerns (Tolin, Frost, Steketee, Gray, & Fitch, 2008). In older adults, physical factors such as the onset of illness or increased frailty may change the way individuals experience their hoarding disorder (Andersen et al., 2008; Turner et

al., 2010). There may be aspects of hoarding behaviors become more problematic and cause greater impairment as people age. There is minimal data on how hoarding behaviors complicates the management of chronic health conditions and impacts an older adult's ability to remain functionally independent (Andersen et al., 2008; Kim et al., 2001). It is also not yet clear what role cognitive impairment and cognitive decline may have on the expression of hoarding behaviors.

Individuals who have hoarding behaviors are reported to be socially isolated, yet we do not yet have a full understand of the ways in which hoarding behaviors affect an older adult's social interactions (Ayers et al., 2010; Bratiotis & Flowers, 2010). Generally speaking, older adults who are socially isolated and lonely are at risk of poor health outcomes, whereas social integration predicts independence and general health (Pillemer, et al. 2000). What we don't know yet is how social isolation and loneliness may affect older adults with hoarding behaviors and whether the isolation that has been observed in this population is a cause or effect of living in a cluttered home environment.

Thus, an important direction for future research is to explore how age-related factors that are known to affect physical and social functioning in older adults impact older adults with hoarding behaviors. Currently, the impact of these factors is largely unknown, yet may indicate new areas to address and ways to offer age-specific interventions or support. It is likely that some outcomes of hoarding behaviors are different for older adults than for younger adults, as evidenced by a greater emphasis on the involvement of Adult Protective Services, aging services agencies, fire departments, and departments of public health found in the literature on older adults with these behaviors than is seen in the research focused on younger adults. If older adults are at

greater risk for more dire outcomes as a result of hoarding behaviors, what factors contribute most to this increased risk and what can be done to prevent these outcomes? Further research is needed in these areas.

When and in what ways do hoarding behaviors overlap with squalor and self neglect?

Squalid home environments and neglect of personal hygiene is frequently mentioned in reports of older adults with hoarding behaviors (Bratiotis & Flowers, 2010; Franks et al., 2004; Kim et al., 2001), and yet squalor is not a key characteristic of hoarding disorder. Therefore, other factors must be present that are contributing to squalor in these cases. Diogenes syndrome includes both squalor and hoarding behaviors, however research on this syndrome has not shed light on the factors that contribute to its development. In fact, recent questions have been raised as to whether "Diogenes syndrome" is still appropriate or useful given the development of our understanding of hoarding disorder (Marcos & Gomez-Pellin Mde, 2008). Even so, the question remains as to why hoarding behaviors are accompanied by squalor in some cases and not others.

Hoarding behaviors and squalor are also often seen in reports of self-neglect. Self-neglect is a form of elder abuse and is defined as a refusal or failure to provide adequate food, water, clothing, shelter, personal hygiene, medication, and safety precautions for oneself (National Center on Elder Abuse). Individuals who are self-neglectful frequently live in severely cluttered and squalid conditions with poor nutrition and personal hygiene (Pavlou & Lachs, 2008; Poythress, Burnett, Naik, Pickens, & Dyer, 2006). As in the research on hoarding disorder, several studies have documented functional impairment, social isolation, and challenges managing chronic illnesses among self-neglecting older adults (see Pavlou & Lachs, 2006). In addition, poor executive functioning in self-

neglecting older adults has been reported by several researchers (Dong et al., 2010; Schillerstrom, Salazar, Regwan, Bonugli, & Royall, 2009).

Certainly, not all self-neglect cases involve hoarding behaviors and not all cases of hoarding result in self-neglect. However, it is possible that one acts as a risk factor for the other. In the United States, cities and counties have increasingly viewed hoarding as a "subtype" of elder self-neglect in order to mobilize public agency resources to address emerging problems (Chapin et al., 2010; Koenig et al., 2010). Whether hoarding disorder on its own constitutes self-neglect or whether it is considered self-neglect only when combined with other issues such as dementia or squalor, is a question that needs to be addressed. As a form of elder abuse, this broad use of the term self-neglect brings with it serious legal and civil rights ramifications for older adults (Connolly, 2008; Heisler & Bolton, 2006). Identifying a situation involving self-neglect requires mandated reporters of elder abuse and various human service agencies to take certain actions to protect the older adult. Some researchers have advocated for criteria that distinguish different types of self-neglecting behaviors (McDermott, 2008) so that interventions are not overreaching.

Self-neglect is the most common reason older adults are referred to Adult Protective Services (Lachs, Williams, O'Brien, Hurst, & Horwitz, 1996; National Center on Elder Abuse), and in one urban community, an official from Adult Protective Services reported that approximately 50% of the self-neglect cases involving hoarding that are referred to them are adults over age 65 (San Francisco Task Force on Compulsive Hoarding, 2009). Thus, sorting out the overlap between hoarding behaviors, squalor, and self-neglect would benefit public agencies as they train staff on these issues and allocate

resources to effectively intervene in such cases. It is important to remember, too, that these reports likely underestimate the actual prevalence of self-neglect in the community, since not all cases are reported. Surely, as the population of older adults grows over the next several decades, the number of reported cases of self-neglect, squalor and hoarding among older adults will rise. Developing a better understanding of the relationship between hoarding disorder and self-neglect is urgently needed.

Conclusion

Much more research is needed to better understand how growing older influences hoarding behaviors. Research focused on this age group is critically important because older adults are potentially at greater risk for poor outcomes due to hoarding behaviors. Health and social service providers are likely to encounter a growing number of older adults with these behaviors over the next decades. Both qualitative and quantitative research studies are needed in order to develop a complete picture of this phenomenon, develop sensitive assessment tools, and guide interventions for individuals in this age group.

Table 1: Key research articles on older adults with hoarding disorder

First Author, Year	Title	N	Sample Description	Design/ Methodology	Data sources/ Measurements Used	Major Findings/ Comments
Anderson, 2008	Reasons to Accumulate to Excess: Older Adults Who Hoard Possessions	8	3 men, 5 women, receiving home health care in urban area; age 71-90, mean 82	Interpretive Ethnography	participant observation, interviews, photographs, field notes	Older adults accumulate for 5 main reasons: 1) Freedom from anxiety; 2) Feeling connected and socially engaged; 3) Needed by others; 4) Proud and productive; 5) in control
Ayers, 2009	Age of onset and clinical features of late life compulsive hoarding	18	11 men, 7 women, in urban San Diego area; age 60-87, mean 67.5; recruited thru UCSD psy clinics and VA; 4 married, 7 divorced, 1 widowed, 6 single; co-morbid mental health and physical health conditions	Quantitative investigation; structured interviews; chart review	Structured psychological interview, UCLA Hoarding Scale, Savings Inventory-Revised, Sheehan Disability Scale, Beck Anxiety and Depression scales, SCID and MINI psych assmt tools, "Grisham procedure" for recalling decades of life and reporting on hoarding symptom severity.	Anxiety disorders and depression or dysthymia were the most prevalent comorbid mental health issues reported. Age of first onset of hoarding behaviors was under age 20 for 15 participants. "Severity of hoarding behaviors" increases with each decade of life and generally moves from "mild" to "moderate" in their 40's. "life-events" and "age-associated factors" may affect the course of hoarding over time.

First Author, Year	Title	N	Sample Description	Design/ Methodology	Data sources/ Measurements Used	Major Findings/ Comments
Bratiotis, 2010	Home-Based Intervention for Elderly Hoarders: What really works?	26	14 female, 12 male, age range 60-90. 14 never married. 11 in subsidized housing, 15 living in privately owned homes.	Pilot of home-based intervention; modification of Steketee &Frost (2007) combined with harm reduction approach	CIR, Hoarding Rating Scale, Saving inventory- Revised (SI-R), "hoarding interview" conducted by clinician following guidelines in Steketee & Frost treatment manual (2007).	12 of 26 participants learned discarding and organizational skills within 4-6 months and did not require ongoing tx, but received monthly check ins for 4 add'l months. 14 prts required ongoing intervention, could discard only with clinician. 14 of cases involved squalor in add'n to hoarding.
Cermele, 2001	Intervention in Compulsive Hoarding	1	72 year old divorced Caucasian woman, with depression and anxiety, employed part time, lived independently in community	Intervention based on Frost & Hartl (1996) model of compulsive hoarding.	Clinician report	Successful intervention involving 5 clinicians. Discusses key components that made the intervention successful.
Chapin, 2010	Hoarding cases involving older adults: The transition from a private matter to the public sector	52	52 cases (file reviews) of adults 60+ from rural and urban areas in Kansas	Mixed-method, "environmental" study	File reviews of open hoarding cases from public sector health and social service agencies; telephone interviews with members of Multi-agency hoarding teams (MAHT) across 7 counties in 6 states.	MAHTs interventions unsuccessful in most cases. Only 6 in 43 cases accepted services to clean up or repaired homes. Approx 25% are moved from home: 1/2 go to nursing homes and 1/2 relocate in the community. Women and African Americans disproportionally represented. 40% of cases had medical conditions or disabilities

First Author, Year	Title	N	Sample Description	Design/ Methodology	Data sources/ Measurements Used	Major Findings/ Comments
Franks, 2004	Understanding hoarding behavior among older adults: a case study approach.	5	2 single women (80, 67) one single man (77) and one couple (61,63) living in suburban area; all had significant mental heath issues and squalor in add'n to hoarding	case reports	Written records and interviews with personnel from APS, Office of the Public Guardian and city Police Department.	Hoarding was secondary to mental illness in all cases. Significant squalor and self-neglect, most individuals not able to continue to live in their homes.
Kim, 2001	Hoarding by elderly people	36/ 62	data collected from 36 community-based service providers and board of health officials; data collected reflects 62 older adults, age 77 years (65-92), 73% female, 90% white; 55% never married; 29% divorced or widowed, 82% living alone,	questionnaires-descriptive, non-experimental	Telephone interviews following semi-structured interview protocol.	Hoarding interfered with service delivery in 63% of cases; never-married individuals had worse impairment from hoarding; interference from hoarding incl. inhibition of movmt, restricted access to food prep, health and safety hazards, ADLs. Interventions by service agency proved ineffective in most cases and in some cases contributed to worsening symptoms.

First Author, Year	Title	N	Sample Description	Design/ Methodology	Data sources/ Measurements Used	Major Findings/ Comments
Mackin, 2010	Cognitive functioning in individuals with severe compulsive hoarding behaviors and late life depression	52	34 females, 18 males, mean age 70.6, 73% Caucasian, 10% African American, 10% Asian, 5% Amer Indian, 2% Pac islander, participating in a larger study of cognitive function in LLD at an urban university psychiatric hospital	quantitative study; psychological testing	Thorough battery of well validated assessment tools for anxiety, depression, cognitive functioning	LLD + hoarding participants showed greater impairment on cognitive measures of categorization ability, information processing, and verbal memory than LLD participants. Also, 10% of LLD sample reported SCH, a much higher incidence than would be expected in the general population, indicating that SCH may be more prevalent in older adults with LLD. No differences between groups on levels of depression or anxiety.
Mueller, 2009	The prevalence of compulsive hoarding and its association with compulsive buying in a German population-based sample	2307	A random sample of German addresses, participants aged 18-93, 55% female, 31% age 18-39, 38% 40-59, 31% 60+, 55.6% married, 29.3% living alone	quantitative, questionnaires administered in person by interviewer	German Compulsive Hoarding Inventory (GCHI), a modified version of the SI-R; German Compulsive Buying Scale (CBS-G), based on American Compulsive Buying Scale.	Estimates 4.6% of the German population has comp. hoarding behaviors. No difference across age groups or by gender. Compulsive buying correlates with the acquisition and clutter subscales on the GCHI but not the difficulty discarding subscale.

First Author, Year	Title	N	Sample Description	Design/ Methodology	Data sources/ Measurements Used	Major Findings/ Comments
O'Sullivan, 2010	Excessive Hoarding in Parkinson's Disease	99	75 men, 24 women with Parkinson's disease (PD), mean age 64; 10.7 years average length of time with PD; all were outpatients at a PD clinic in the UK. No further demographic info given.	quantitative questionnaires	SI-R, OCI-R, Hospital anxiety and depression scale (HADS), brief self-control scale (BSCS), impulse buying tendency scale (IBT)	12% of PD sample had hoarding based on >40on SI-R. These individuals also showed greater proportion of other impulse control behaviors and less self control compared to non-hoarding PD group and controls.
Samuels, 2008	Prevalence and correlates of hoarding behavior in a community-based sample	741	Adults age 34-94 in an east coast urban area; 63% women; 60% white (40% "other"); 50% married/cohabitating, 13% never married, 24% divorced, 11% widowed; 80% lived alone	Analysis of data from an epidemiological study of personality disorders	Interviewer asked questions based on the hoarding criterion from DSM-IV for OCD: "unable to discard worn-out or worthless objects eve when they have no sentimental value"	Estimates 5% of general population have hoarding behaviors. Those in the aged 55-94 were 2x and 3x more likely to report hoarding behaviors than those in the 45-54 and 34-44 age groups, respectively.
Turner, 2010	Treating elders with compulsive hoarding: A pilot program	6	1 man, 5 women, age range 56-87, avg 72. 5 in subsidized rental units, 1 lived with roommates. No ethnicity given. Referred by community mental health, elder housing site and private therapist.	Pilot intervention: modified CBT intervention based on S&F (2007) with Motivational interviewing	CIR, ADL scale, Safety scale (Grisham, 2006) with reliability/validity under study	Significant improvement in amt of clutter on CIR, significant improvements in ability to conduct ADLs, significant improvements in safety. No improvement in organizing skills. Of 11 who enrolled, only 6 completed intervention. Some discussion of early vs. late life "onset" of behaviors.

CHAPTER III: METHODOLOGY

Introduction

A qualitative study using Grounded Theory Methodology was conducted to address the dynamic between aging and hoarding and cluttering behaviors. Grounded theory is a method of qualitative research which aims to develop a theoretical understanding about basic social processes through a systematic process of data collection and analysis (Speziale & Carpenter, 2003; Strauss & Corbin, 1994). The philosophical roots of grounded theory are in Symbolic Interactionism, which proposes that individuals make sense of the world around them through the meanings they ascribe to their interactions with others and with the objects and symbols with which they come into contact (Blumer, 1969). Since meanings are socially constructed, the only way to understand them is to perceive the interactions, processes and changes from the actors' viewpoints (Strauss, 1987). In this research study, the "actors" are the older adults with hoarding and cluttering behaviors who participated in the interviews.

In this chapter, the methodology used to conduct and analyze the study is explained. The chapter is divided into the following parts: a) the setting and recruitment strategy, b) study sample and protection of participants, c) data collection procedures, d) data analysis procedures, e) methods for establishing rigor, and f) focus of the analysis for the dissertation report.

Setting and Recruitment Strategy

A range of participants including men and women from various ethnic and racial groups and from varying socio-economic backgrounds was sought for this study. The

study took place in the San Francisco Bay Area region of Northern California. Participants lived in both urban and suburban communities. Data collection procedures took place in study participants' homes which included houses, apartments, and units in senior-only housing facility. Homes were either owned or rented by the participants. One participant was interviewed in a private psychotherapy office, determined by the researcher and the participant to be a neutral location, prior to being interviewed a second time in her rented apartment in a senior-only apartment building.

A recruitment flyer was developed (Appendix A) which posed the following questions: "Do you have a large number of things in your home? Do you have difficulty organizing them or deciding what to throw away? Does the volume of things in your home make it difficult to do everyday activities or affect your quality of life?" The flyer instructed individuals who were age 65 or older and answered "yes" to two of the three questions to contact the researcher by telephone if they were interested in participating in a study on hoarding and cluttering behaviors. The researcher confirmed by telephone that the potential participant met the age requirement and believed he or she met the definition for having hoarding and cluttering behaviors before describing the study procedure and scheduling an interview.

Recruitment flyers were distributed in two ways: 1) a digital copy of the flyer was posted on the Mental Health Association of San Francisco (www.mha-sf.org) and the San Francisco Bay Area Internet Guide for Extreme Hoarding Behavior (www.hoarders.org) websites; and 2) flyers were distributed to local health and social service agencies by the researcher, usually along with a 15-30 minute presentation about the research study to the nurses, social workers, and case managers affiliated with these agencies. Professionals

working in these agencies were asked to distribute copies of the flyer to any client they worked with who they believed qualified for the study and might potentially be interested in participating. The decision remained up to the client as to whether or not they wished to contact the researcher. In at least three cases, participants learned of the study because a recruitment flyer had been downloaded from the internet and posted in senior centers by staff that had no other contact with the researcher. Additionally, four participants who had participated in an earlier pilot study on the same topic responded to a letter sent by the researcher to all pilot study participants inviting them to participate in this dissertation phase of the research.

Study Sample and Protection of Participants

Participants were English speaking older adults age 65 or greater, and lived in an apartment or house in the community in the San Francisco Bay Area. All participants had hoarding behaviors, defined as "the accumulation of and inability to discard items to a degree that it interferes with activities of daily living and/or negatively impacts the quality of life of those in or around the home" (Eckfield, 2008). This definition was used rather than the Frost & Hartl (1996) definition for compulsive hoarding in order to avoid the two problems encountered by researchers associated with that definition: 1) the challenge of assessing the value of someone else's possessions and 2) requiring that the individual experience distress or impairment from their hoarding behaviors when in fact, these may be experienced by others, such as family members (Tolin, Frost, Steketee, & Fitch, 2008; Wilbram, Kellett, & Beail, 2008).

Potential participants who contacted the researcher or who gave permission to be contacted by the researcher was given an informed consent form (Appendix B). The researcher reviewed the informed consent form with the potential participant in person prior to collecting data. Some potential participants wanted to review the informed consent form prior to meeting with the researcher, and in those cases the consent form was sent to them in advance by mail or e-mail.

Prior to beginning the interview, I verified whether participants had the mental capacity to consent to take part in this study by asking them to review the informed consent with me and asking the individual a few questions to confirm their comprehension of the material. If I had any doubt about their cognitive capacity, I had with me a brief "Capacity to Consent" questionnaire (Appendix C). Participants had an opportunity to ask any questions they had about the study prior to the start of the interview. None of the participants gave me reason to believe they did not have capacity to consent to participation in the study. Individuals who were under age 65, did not live within the greater San Francisco Bay Area, did not speak English, or did not have the cognitive capacity to consent to participate in the study were excluded from the study.

Additional steps were taken to ensure the protection of participants in this study, including: a) explicitly explaining any situations that would require the researcher to report the participant to the authorities prior to participants enrolling in the study, b) interviewing the participant at a time and location that is convenient, private and felt safe for him or her, c) interviewing the participant in a nonjudgmental manner, and d) reminding the participant that he or she may end the interview at any time. No health or safety situations were uncovered by the researcher which posed an immediate and

dangerous risk to the participant or others. Potentially reportable situations included, but were not limited to, any form of elder abuse including self-neglect, which is defined as "the behavior of an elderly person that threatens his/her own health or safety; generally seen as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions" by the California Welfare and Institutions Code.

In order to protect data collected from participants, only the researcher, the researcher's faculty adviser, and a trained research transcriptionist had access to the audio recorded interviews. No identifying information was retained on the written or audio records after the audio recordings have been transcribed. The audio recorded interviews were erased at the conclusion of the study. Any identifying information in the transcripts was replaced with codes. The key to the codes have been kept in a separate, locked location away from the transcripts and other study files. No other private information such as medical records or interviews with health services providers were sought for the study.

In this report of the study's main findings, the information has been presented in aggregate so that no individual participant can be identified. Case examples have used participant numbers and any potentially identifying details will be sufficiently disguised so that the participant or someone who knows the participant will not be able to identify the person.

There were no direct benefits to the study participants who took part in this research study. However, at the conclusion of several interviews the study participants told me they enjoyed participating in the study, that it was helpful to think about the

reasons why they have collected so many things, and that they hoped the information would help health care professionals better understand the needs of others like them. Study participants did not incur any costs by participating in this study, and they received $20.00 at the end of each interview they completed as a token compensation for the time they spend talking with the interviewer. The maximum that any participant received was $40.00 for completion of two interviews. A second follow-up interview was only requested in two cases: in one case we did not get through the interview guide in the amount of time allotted for the interview and the participant was eager to share more information; in the second case the participant wanted to meet me in a neutral location first and then invited me to her apartment for a second, follow up interview.

Data Collection Procedures

From May 1, 2009 to March 1, 2010, twenty-four interviews were conducted with 22 participants. Transcripts from five additional interviews (from four study participants) that were a part of the pilot study phase of this research effort were added, bringing the total number of interviews included in this study to 29.

Data was collected through participant interviews, participant observations and field notes, photographs (when permitted by the participant) and through administration of the Clutter Image Rating scale (CIR, Frost, 2008). The interviews were based on a semi-structured, open-ended interview guide (Appendix D). The interview took between 1.5 and 2.5 hours to complete. The interviews were audio recorded and transcribed verbatim and the researcher's observations were recorded, either manually or recorded verbally, as field notes at the conclusion of each interview. The digital audio files, digital

photographs and transcriptions of the interviews have been kept on a secure computer and password protected.

The interviews conducted by this researcher were designed to elicit stories from the participants that would provide information to address the two aims of the study. The interview guide began by collecting basic demographic information from the participant. This included their age, gender, marital status and current living situation (alone or with others, in a home or apartment, rented or owned), education, race or ethnicity, and amount of time living in their current location. This information allowed me to compare and contrast individuals to each other as well as the sample of participants with others who have been described in the research literature. The second part of the interview guide asked about the participant's lifetime experience with hoarding behaviors. Participants were asked to describe events or periods in their lives that lead to the worsening or improvement of their hoarding behaviors, or any other events that have relevance to their experience of hoarding behaviors. Follow-up questions encouraged the participant to describe the particular context, circumstances, and factors associated with each important period of time identified by the participant. The third part of the interview guide asked about the impact of hoarding behaviors on various aspects of their life at present. Questions probed the themes of social contact and support, physical and mental health, and ability to conduct normal daily activities. Open ended questions allowed the participant to discuss other ways hoarding behaviors impact their lives.

Because the severity of clutter can vary widely and the level of impairment may not be strictly tied to the quantity of items in the home, the study utilized the Clutter Image Rating scale to document the amount of clutter in each participant's home. While

the severity of clutter is just one aspect of hoarding behaviors, in the absence of other clear diagnostic criteria, it can be a helpful measure for comparing and contrasting cases and understanding individual experiences. The participants were asked to rate their bedroom, kitchen and living room using the visual analog scale of nine photographs each depicting an incremental accumulation of clutter. The researcher also made an independent assessment using the CIR. By applying this scale to each participant's environment, three things are accomplished: 1) it helps consumers of this research compare the experiences of these participants to other study participants where the CIR has been used; 2) it provides an opportunity to compare the participant's perception of the clutter to the researcher's perception; and 3) it provides information about how the amount of belongings affects the individual's experience of hoarding behaviors.

In addition to the CIR, the researcher sought permission to photograph areas that exemplify the result of hoarding behaviors within the participant's home. The purpose of the photographs was to capture a visual representation of the environment in which individuals live and to provide a visual context for the stories told by the participants. Photographs were only taken with the consent of the participant, did not include the participant or information that identified the participant.

Data Analysis Procedures

The process of data analysis in Grounded Theory is methodical and systematic and includes a careful reading and rereading of verbatim transcripts, making margin notes and developing a system of codes to identify common themes and categories; engaging in open coding, axial coding and selective coding in order to distill salient properties and

themes from data; and developing core concepts and a conceptual framework of the relationship between these concepts (Strauss & Corbin, 1994).

Data analysis in this Grounded Theory study began immediately after the first interview and continued concurrently as new interviews are conducted. Audio recordings of the interviews were transcribed verbatim by a research transcriptionist. This researcher then listened to each interview while following along with the transcript. This served to proof-read the transcript and identify important main concepts. Following the initial read-through, transcripts were entered into the Atlas.ti qualitative research management software program (version 5.6), where coding of phrases and passages in the transcripts took place. Open coding of the 29 transcripts resulted in the development of 355 codes. Upon further analysis, many of these codes expressed similar or redundant ideas and codes were combined and defined. Relationships between codes were identified through the process of axial coding as recurring themes began to emerge from the data. As analysis of the transcripts continued, broader categories and concepts were identified as well as the codes and themes that fit within them. Constant comparison analysis across participant data took place to clarify emerging codes, themes and concepts, and to indicate new lines of questioning (Strauss & Corbin, 1994). Coding continued in this manner as an iterative process whereby the researcher returned to earlier transcripts as new concepts emerged to ensure all transcripts had been thoroughly coded and all salient issues had been identified. Participants were recruited until no new significant themes or categories were found in the data set. This was considered the point of "saturation", at which time the researcher can feel confident that sufficient data has been collected to address the study questions (Strauss & Corbin, 1990).

Throughout this process of data analysis, the researcher actively engaged in memo writing, which served to capture thoughts, ideas, and questions the researcher had during the analytical process, and provided an analytic trail that documented the development of themes and categories (Corbin, 1986; Schreiber, 2001; Strauss & Corbin, 1990).

Methods for Ensuring Rigor

Specific steps were taken to establish the rigor of this qualitative study. These steps address the credibility, fittingness and auditability of the research findings (Beck, 1993; Chiovitti & Piran, 2003). To establish the credibility of the research, a solid foundation of data was gathered that includes rich illustrations of the key findings. Field notes that described the research process, the environments where each interview took place, as well as any feelings or biases that the researcher experienced during the study were recorded. The researcher analyzed any "negative" or contrasting cases and any conflicting information that emerged in the study in order to further support the credibility of the findings (Beck, 1993; Chiovitti & Piran, 2003). Excerpts of transcripts and the researcher's initial interpretations were discussed with a peer group of qualitative researchers as well as with the researcher's dissertation adviser. These discussions and debriefings helped the researcher to identify new information or other ways of interpreting data in order to ensure the completeness of the data analysis.

Fittingness is defined as how well the hypotheses and propositions that emerge from a study apply to other contexts, samples, and settings besides the one originally studied (Beck, 1993; Chiovitti & Piran, 2003). This is established by providing a detailed description of the study participants and the setting of the interviews, as well as by

sampling from a range of participant backgrounds and experiences. A clear description of the study goals, specific aims, and limitations also help readers to evaluate the study's fittingness, as well as the discussion of how this study's findings fit with other research on this topic (Beck, 1993; Chiovitti & Piran, 2003).

The auditability of the research is established through detailed and transparent recording of each step of the research process (Beck, 1993; Chiovitti & Piran, 2003). Data from the study has been reviewed by research colleagues familiar with Grounded Theory methodology to ensure that interpretations and decisions about the data made by the researcher have been clear and consistent (Corbin, 1986). The use of audio recording devices to capture raw data, writing field notes promptly after the completion of interviews, and analyzing verbatim transcripts of the interviews were methods used to strengthen the accuracy of the data set. By keeping the research questions clearly in mind when analyzing data, the researcher was better able to stay on track during the analysis process (Beck, 1993; Chiovitti & Piran, 2003).

Focus of Analysis for the Dissertation Report

In qualitative research, it is hard to overestimate the volume of data that is collected through interviews and field notes. The hundreds of transcribed pages that resulted from this study are filled with more information than can reasonably fit within a dissertation report. Multiple "storylines" have emerged that are worthy of being told, each of them contributing something new and valuable to the overall body of literature on this subject. For the purpose of this dissertation three main themes were selected as the most important ones to develop and report: the process of accumulation described by participants, the influence of age-related factors on this process of accumulation, and the

identification of two distinct "types" of individuals with hoarding behaviors who participated in this study. The decision to focus my analysis on these topics was made in consultation with my dissertation adviser and is in keeping with the overall goals of this research project as discussed by the dissertation committee at the time the study was proposed. Results discussed in the following chapter focus on the qualitative component of these topics (i.e. the interviews and field notes) and do not include analysis of the CIR or discussion of photographs taken within participants' homes. While preliminary analysis of these visual components has taken place and will yield useful information, additional analysis and development of these results are needed. It is my intent to continue analyzing data from this study and to include those results in research reports generated from this dissertation study for publication in health and social science journals.

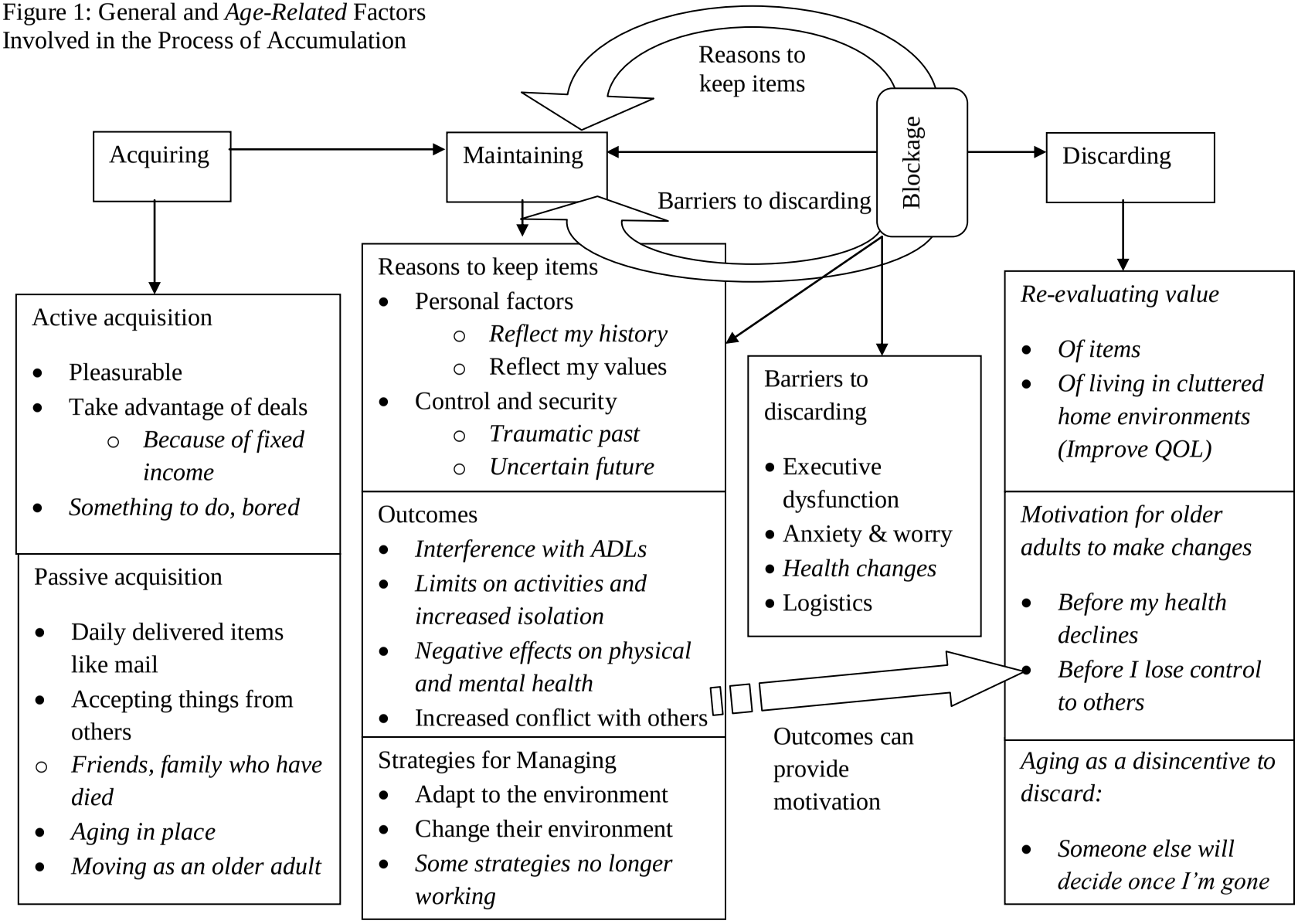
CHAPTER IV: RESULTS

Overview of Findings

All of the twenty-two individuals in this study met the definition of having hoarding and cluttering behaviors and described long-standing problems with hoarding and cluttering. In most cases the behaviors have been present for several decades, but narratives suggested how their behaviors and their ability to manage in their homes changed over time. From these interviews, two main findings have emerged which help us to understand the experiences of older adults with hoarding behaviors.

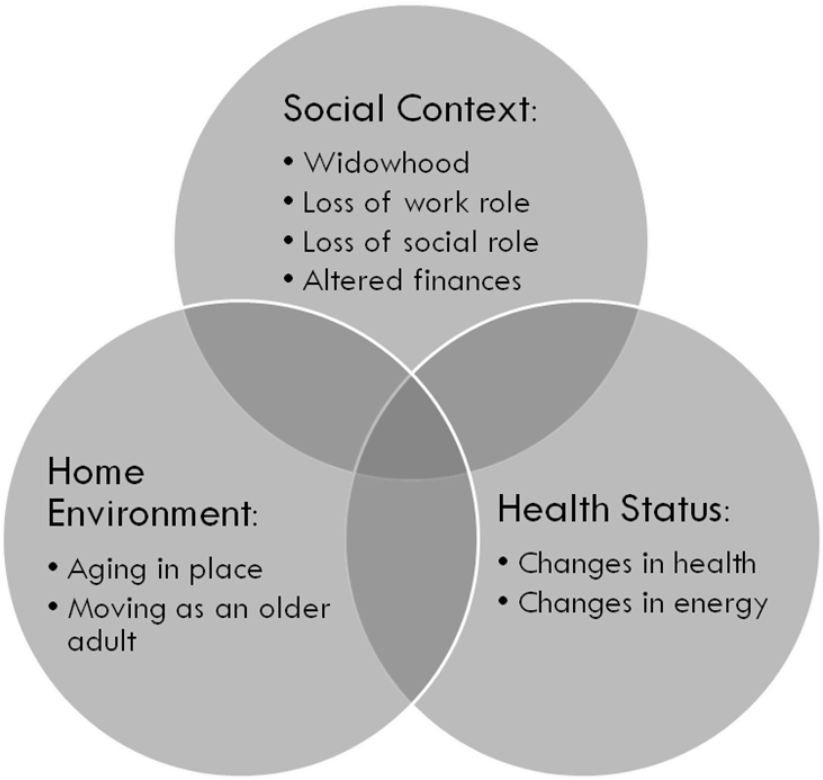
The first finding is that at the heart of hoarding and cluttering behaviors there is a core process of accumulation that occurs in three phases: acquiring, maintaining, and discarding items (Figure 1). While these phases are generally linear and sequential, they are not completely unidirectional. Participants acquire items and spend considerable time and energy in the "maintenance" phase of this process. Typically, they spend the least amount of time in the discarding phase. Within the maintenance phase, there is a cyclical pattern that emerges whereby participants' actions do not result in forward motion into the discarding phase. Instead, participants encounter a blockage that causes them to circle back to into the maintenance phase. Within each phase, participants describe specific factors that influence their behavior. Some of these are similar to those reported in research studies on the experiences of younger adults but their saliency is enhanced due to circumstances particular to older adults. In addition, new age-related factors that affected study participants' behaviors in each of these phases emerged, as discussed below.

Figure 1: General and *Age-Related* Factors Involved in the Process of Accumulation



The second finding is that factors associated with the normal aging process influence hoarding and cluttering behaviors. These can be grouped into three core categories: changes in health status, changes in social context, and changes in home environment (Figure 2). These categories highlight a dynamic interaction that occurs between hoarding and cluttering behaviors and aging processes. Generally, age-related factors contributed to worsening of the behaviors or outcomes. However, 13 participants indicated that aging had a positive impact by helping them to reevaluate the value of their belonging or motivating them to address problems associated with hoarding and cluttering behaviors before their health declined or they lost control of the process to others.

Figure 2: Age-related factors that impact hoarding and cluttering behaviors



In addition to the influence of aging on the process of accumulation, there are important variations and distinctions in the way participants engage in these three phases. When these variations are compared and contrasted across study participants, two distinct "types" of hoarding and cluttering behaviors, an impulsive type and an anxious type, begin to emerge.

The purpose of this chapter is to present data that support these two key findings, *influences of aging on hoarding and cluttering behaviors* and *variations on the process of accumulation*. Following a description of the study participants, the chapter is divided into four sections: Acquiring; Maintaining; Discarding; and Conclusions. The first three sections describe the process of accumulation and are illustrated with quotes from the study participants. Within each phase of this process, important age-related factors that emerged from the transcripts are emphasized, as are unique variations in how participants engaged in the process of accumulation. Analysis of these variations has led to the identification of two potentially distinct "types" of individuals with hoarding disorder (Table 2).

When read together, data presented in these first three sections provide an insider's view of the day-to-day experiences of older adults with hoarding and cluttering behaviors. In the Conclusions section, a synthesis of the material is presented and conclusions drawn from this sample of older adults. A detailed discussion of how these conclusions contribute to our understanding of hoarding and cluttering behaviors in general and in older adults in particular is the topic of *Chapter V: Discussion*.

Demographic Information

Twenty-two adults age 65 to 91 (average 74) participated in the study. Six of the participants were men and 16 women. Participants primarily lived in San Francisco County (16) but individuals from Alameda County (5), and Santa Clara County (1) also participated. The study participants represented a highly educated group. Six participants had Master's degrees, 6 had Bachelor's degrees, and 7 had attended some college. Only two participants ended their formal education after receiving their high school diplomas and one stopped attending high school after completing 10th grade. Socioeconomic status was not directly ascertained through questions about income level, however, questions related to participants'' home environment, work history and current daily activities provided data on participants' socioeconomic status. Eight participants were considered to be in a low-income category because they either lived in subsidized low-income housing, qualified for In-Home Support Services (a program providing personal assistance services to low-income adults), were enrolled in Medi-Cal, or received Social Security Disability Insurance (indicating they are unable to work due to a long-term disability and are unable to earn at least $1000 per month). Eleven participants were considered to be in a moderate-income category because they mentioned retirement savings and/or pensions in addition to social security income. Three participants were currently employed full time, and one worked part-time. Two-thirds of the participants (n=15) had retired from their careers and 3 described themselves as homemakers who had not primarily work outside of the home.

With regard to marital status and living situations, 5 were married at the time of the interview, 9 were divorced, 3 were widowed, and 5 were never married. Ten owned

the home where they lived, and of these, nine owned single family homes while one owned a condominium. Twelve rented their homes and of these 4 rented apartments and 8 rented units in either subsidized or senior-only apartment buildings or facilities. None of the participants lived in assisted living facilities or skilled nursing facilities. Nine had lived in their current home for less than 10 years and twelve had lived in their home for over 20 years.

Thirteen participants described themselves as being in good health while six described themselves to be in fair health and three reported their health as poor. Twenty of the participants were active, able bodied and able to ambulate in their homes without assistance, but two participants needed a significant amount of help. One participant was able to move about her home with a cane but needed assistance leaving the home and one participant had severe mobility restrictions and was only able to transfer from her bed to a bedside commode or wheelchair independently. Both of these participants had in-home caregivers who came daily to assist them with personal and household tasks.

As a part of the interview, participants were asked about their mental health as well, both currently and in the past. All 22 participants reported either having been diagnosed with an anxiety disorder or described being anxious. Thirteen participants reported depression or depressive symptoms. Eleven participants reported symptoms of attention deficit/hyperactivity disorder (ADHD), nine of whom also reported difficulty with impulse control. Two participants reported a history of alcohol abuse and one had been diagnosed with schizophrenia.

Process of Accumulation

Hoarding disorder is defined as the persistent difficulty discarding items due to urges to save or distress from discarding that results in living areas that are not able to be used as intended or clinically significant distress or impairment in social, occupational or other important areas of functioning (2010). The process of accumulation refers to the specific ways in which individuals came to amassing so many material possessions in their homes. This process highlights the actions taken by individuals with hoarding disorder and the factors they identify as contributing to their behaviors.

First Phase in the Process of Accumulation: Acquiring

Participants described both active and passive modes of acquisition. Active modes included buying items, bringing home free items or items that others had discarded, accepting items that others offer to them, and, in some cases, downloading and printing out information from the internet. Passive acquisition primarily involved the daily delivery of items to the house such as mail, newspapers, magazines and catalogs. It also included items like paper or plastic bags, receipts, or other items that might be brought into the home as a result of buying day-to-day necessities such as groceries. Eleven participants primarily acquired items in an active way while 7 participants primarily described passive modes of acquisition. Three participants described acquiring items as a result of both active and passive means, suggesting that there is a continuum between active and passive styles of acquisition.

Active Acquisition

Those who actively acquired items described the pleasure they found in seeking items to bring home. Nine participants recognized that they were driven by impulsive

behaviors rather than a true need for the item. Some of these participants also shared the thrill they felt when they outwitted others or were able to exploit or manipulate rules to their advantage. For example, one participant acquired excessive amounts of non-perishable food items from various food pantries that he qualifies for because of his age and income level. He describes the thrill of acquiring items for free or at a great discount in this story:

> [Participant #8, male, 70's]
> When I retired I found out about [food] pantries, yeah. But even in - even in the old days, we had the bargains. Sheesh, did I get the bargains! I used to go in there and get eleven bottles of [salad] dressing for free. Back when they had those dollar coupons, the damn thing was selling for $2, you bring a dollar coupon, it was double at the Cala. And then they finally had a rule that you can't do that with so many coupons, you know, because people were cleaning up on the coupons. We all were cleaning up. I was piling up from that. That's when it all started, with the coupon days, yeah.

However, older adults who actively acquire items often gave a variety of reasons for their behaviors, many of which are the same as those cited in research on younger adults. These include: not being able to turn down a sale; acquiring broken items with the idea that they can be repaired or repurposed; buying items as future gifts for others; or acquiring items in case they or someone else might need it someday.

> [Participant #2, female, age 73]
> You know, if I see something cheap or easy, plentiful that I may use, I'd rather - I'd rather have it on hand, than to feel like I'm going to be totally out.

> [Participant #1, female, age 87]
> See, all those are new. But they're things I got on sale, 5 bucks, 7 bucks. I buy two of everything so I can give one to somebody.

For some older adults, these reasons have additional saliency due to their current station in life. For example, five study participants mentioned that because their retirement income is fixed and limited, they feel an additional urge to purchase items when they are on sale, since this will save them from having to buy the item in the future at a higher price, as in the following example:

> [Participant #21, female, 81]
> P: [M]y income is something like, $902 a month. So I go to great pains to stretch a dollar. For example I'll buy things on sale at the grocery store, when they're on sale.
> I: [D]o you find that you use everything that you buy or do you end up buying…
> P: I'm using it but I'm not using it fast enough.

In addition, some participants describe factors that influence their acquisition of items that are unique to older adults, for example, feeling bored because of retirement or feeling they lack goals or a purpose. Going shopping is a way to fill time and provides an easily accessible, socially acceptable, opportunity to interact with others, as illustrated by the following participant:

> [Participant # 2, female, 73]
> P: [I would like] to find a position and a place to make you feel that you are doing something worthwhile and that's real important to older people. Older people - you know, with older people, they feel like they lost their usefulness and that affects a lot of things that goes on with them. Younger people you might say they get restless and start doing drugs, start doing - you know - you know, you switch it around but it's the same thing. That you have lost that, um - that place…having some kind of goal.
> I: Yeah. Do you feel like that's where some of your shopping excursions come in? Do you feel like that sort of gives you a role?
> P: Yeah, it does really. What it does is - Well, I just like to go - Yeah, I like to hunt for those little unique things and it's just looking, you know, it's just a job looking, you know, and I can just kind of - like I want - I don't want to go home and I don't know anyplace else I can spend some time. And there - there's a couple people in there and I asked them - you know, there's a couple people that work in there and they really give me compliments and, um - or good - good communication, I'll put it that way. You know, so it's nice to say, "Hello, hey, how you doing?" and that kind of thing.

In the quote above, Participant #2 shares how going to her local thrift store fills a gap left now that she is no longer working or raising children. Shopping becomes a "job" and helps ease the boredom and loneliness she now experiences. She implies that shopping is a healthier way to cope with this boredom than turning to drugs in the way teenagers or young adults sometimes do to cope with their boredom. Because of the changes in social roles that older adults experience, they are more likely than middle-aged adults to feel this lack of usefulness or "place" in society. Six other participants in this study expressed the same or similar sentiment, as noted in the following quote where a participant explains that going shopping gives her a pleasurable outing, something to do other than going to the doctor, that helps her feel she is a part of the fabric of society:

> [Participant #6, female, 73]
> P: [T]hat's my therapy, going to the Goodwill. So I buy things that I really don't need, you know, that I'm not desperate for.
> I: Now you said that's your therapy. What do you mean by that?
> P: I mean I feel that's the only time I got out - get out of the house really on the whole, yeah. Except for some of my appointments I go to.

Passive Acquisition

Seven participants described the passive accumulation of items that came into their home as a part of everyday life: mail, magazines, groceries, and clothing, many of which have accumulated over time, sometimes decades.

> [Participant #20, female, age 69]
> I occasionally would print out some articles and then take them home to read on the bus or whatever and wouldn't necessarily get to them so then they would start accumulate. Mail comes in, [and] I don't get rid of as much of it as I should. And there is so much junk mail, most of it is that. So some magazines, some newsletters, I try not to subscribe to much and I tend to get more newsletters than I do magazines so they take up less space. But I also tend not to read them all that well nor organize them. So everything's very miscellaneous and scattered through the house.

For three participants, being given things by other people contributed to their passive accumulation, such as in this example:

> [Participant #11, female, age 78]
> Someone's always giving me clothes. I don't go and shop for clothes. I know people that have said "what you can't use, pass it on". I don't get it passed on soon enough sometimes … and then that accumulates. People know that I was a sharer so things would be given to me in maybe big, humungous amounts. "Okay, I'll get to this. I'll get to this tomorrow. Tomorrow, tomorrow, tomorrow." And I just didn't get rid of some things quick enough and then more came. I'm not Mother Wright - I know you've heard of Mother Wright that used to give the clothes and the food and things down in West Oakland. I'm not her so I can't work on a scale like she does.

In some of these cases, participants describe acquiring furniture that they do not need and sometimes do not want from friends or relatives who have died. They accept these items in part because of their relationship to the individual who has died. However, they then find it difficult to discard the item, both because of the sentimental attachment to the item and the logistics of arranging for someone come and pick up the furniture and take it elsewhere.

Aging in place and not having to move also clearly contributes to the accumulation of belongings over time. Nine participants described how living in the same home for decades contributed to the accumulation of items. The following quote typifies these experiences:

> [Participant #20, female, 70's]
> I: And how long have you - you and your husband bought this house together?
> P: Right. And we paid off our thirty-year mortgage a year ago. So we've been in here since 1978.
> I: Have you noticed changes in your home over those years?

> P: Well, there's more crap than there had been before. [chuckle] There's just more of everything, more stuff. I can't - there are times when I can't find things as easily as I used to and part of it is just because there's more of it.

One participant had recently cleared part of his apartment so that plumbing repairs could be made. He compared his experience packing up things to make room for the plumber to when he would cull through and pack belongings in preparation for moves when he was younger in this way:

> [Participant #4, male, age 66]
> I've been keeping stuff my whole life. It's just kind of what I've done. Except when we had to move, then I got down to where I could only have one thing of my stuff so I had to cull through it and get it to fit. But now I had to go through all this stuff that had been accumulating really for like thirty years.

As illustrated by the quote above, moving often has the effect of forcing individuals to sort through belongings, discard some and decide what should be moved to the new location. However, for older adults, this process of culling belongings does not always take place prior to moving. In fact, seven participants described how moving actually contributed significantly to the accumulation of items, which was an unexpected finding. Four of these individuals moved from a larger to smaller home and, instead of pairing down their belongings prior to the move, packed everything. As a result, stacks of boxes and furniture cluttered their new and smaller abode. For several of the individuals whose home did not change in size, the processes of packing and unpacking were largely directed by others, effectively prevented any culling of items from taking place.

In the following example, a woman describes the day of her move, over a year ago, from one unit to a similar sized one in a senior apartment building. Her narrative highlights how rushed and disorganized she felt as helpers moved quickly to pack her apartment and move things into the new unit:

> [Participant # 14, female, age 74]
> I: What was it like when you packed everything up -
> P: [T]he staff decided to move me free. They were not going to charge, they just grabbed everything, just put it in a big - one heap. They moved some of the furniture where I had - I had in mind, I didn't really have it fixed like this. I didn't know where to put it, I had no idea how it was going to fit and everything so - the piano's still there and the hutch is still in the original place but everything else has been - I've been moving it around to make more functional space.
> I: And do you remember how you went about deciding what you were going to keep and what you were going to get rid of at that point?
> P: No, because I just had to hurry up and show them where this was, grab this bag, grab that. I was more or less feeding them while they were packing.
> I: It went pretty fast?
> P: Well, it had to. I didn't even fix the hutch yet, not everything's in there. There's two boxes still that are not unpacked.

For others, the process of unpacking and organizing their belongings, which were often packed by hired helpers, was too difficult to accomplish on their own. In the following example, a woman with multiple medical conditions and limited mobility describes the challenges she has had unpacking from her last move over seven years ago. She has a caregiver from in-home supportive services who helps her, but even with someone to help, there are towers of boxes that have not been unpacked.

> [Participant #9, female, age 77]
> I: So tell me a bit about - I see you've got a lot of boxes. And you mentioned that you've lived in this unit for how long?
> P: Seven and a half years.
> I: Seven and a half. Okay. Are the boxes still from when you moved in here? Have they -- been unpacked or --
> P: They've been - I would say all but about four of them have been unpacked from when I moved in but here we have - how can I put it, [my previous in-home caregiver] - unpacked boxes and put stuff back in but not the way they were.

> [T]hen it got to the point that I never knew what was going into anything and we'll find a box that's obviously been opened and packed, uh - we'll open it, we'll look through it, we find everything from, uh - uh - a piece of my good jewelry just in all by itself in the box and a piece of knick-knack, bric-a-brac type stuff and a kitchen pan and maybe a couple of dishes and maybe two or three pieces of silverware and a stack of papers, stuff like that.

In most of these cases, the outcome was similar. Stacks of unpacked boxes and furniture remained in the new home for months and years after the older adult moved in. Their homes became storage units rather than functional living spaces. Since so many belongings were inaccessible to the individual, new items were often purchased to replace them, adding to the overall volume of items in the home.

A variation on the accumulation of items as a result of moving is described by one participant who saw the volume of items in his home escalate following a series of major family transitions. Life events such as coping with the illness and death of a spouse and becoming a caregiver to both a spouse and to an elderly family member are more likely to affect older rather than younger adults. Years later, this gentleman is still struggling to manage the accumulation of belongings that occurred during the time period he describes below:

> [Participant #13, male, age 65]
> P: [T]he peak [of accumulating items] happened with my late wife. Then when she was sick I was her caretaker and - and kind of life got - just went on hold there. [A]round the same time, actually exactly at the same time, my mother moved up here from [out of town] because she was aging. And so my late wife and I helped her to move into an assisted care living facility and I was kind of looking after her too. And some of her things ended up in our storage and some of my wife's things ended up in our storage. And then - that all came together and increased the storage and then after my wife died more stuff went into storage and then after [my current wife] moved here more stuff went into storage and then we had electrical work done in the basement and more stuff went into storage. It's

> sort of like - maybe those are normal life events, you know, and disposing of things at those times I think is normal too, and I didn't do that.

As illustrated by the quotes above, older adults engage in both active and passive modes of acquisition. Some of the reasons given for the acquisition of items seem to be common to adults of all ages with hoarding and cluttering behaviors. However, these common factors often take on new dimensions or greater saliency as a result of factors related to growing older, and additional, new factors that more commonly affect older adults emerged from the narratives. In comparing participants to each other, those who actively acquired as a result of impulsive behaviors or for the thrill of outwitting others have distinct differences from other participants who actively acquired for other reasons, or who passively acquired items. These variations in acquisition style are important distinctions to consider when looking at overall patterns of behaviors across the process of accumulation. As will be discussed in the conclusion of this chapter, those with particular patterns of acquisition tend to have similarities in the subsequent phases of maintaining and discarding. Furthermore, whether the accumulation of items in someone's home has resulted from active versus passive modes will also be important to identify in order to guide efforts to curb the acquisition of additional items.

Second Phase in the Process of Accumulation: Maintaining

Once items were in their homes, participants described what it is like to maintain their collections of items and to live in cluttered, crowded home environments. In this "maintaining" phase, they describe the personal factors that lead them to save items, the outcomes of living in their home environments, and the various strategies they employ, or attempt to employ, to manage in their environments. Participants invariably discuss

factors that lead to a blockage of action in this stage. The blockage prevents them from discarding items. One participant aptly compared this blockage to a biological one, calling her home a "constipated house", emphasizing the fact that items come into the home but do not get out.

As seen in the acquisition phase, some factors described by participants are similar to those reported by younger adults in other research studies, some take on new meanings under the influence of aging, and others appear to be unique to older adults. Variations across participants, particularly in the factors that contribute to the "blockage" of items, are important for discerning the two types of hoarding behaviors.

Personal Factors that Lead to Saving Items

Participants discussed the various meanings ascribed to items that contributed to their desire to save them. These reasons fall into three main categories: items represent important parts of their personal history; items reflect aspects of their personality that they value; or items represent a degree of control over their lives, including security over an uncertain future. Age-related factors contributed to the desire to save items in some examples. For instance, six participants expressed concerns about a failing memory and saving things was one way to guard against forgetting. Four others described how having a limited retirement income affects their feelings about saving items and their ability to acquire what they might need in the future. While participants often named various reasons for saving specific items, they usually identified one of the main categories described above when discussing their belongings in general. As they discussed their

reasons for keeping things, it was interesting to find that several participants also pointed out drawbacks of living in cluttered homes.

Items represent parts of my personal history. Participants described how items represent important times of their life such as their career identity or travels they've taken. While it may not look like much to other people, their "stuff" represents a lifetime of experiences, as expressed in this example:

> [Participant #4, male, age 66]
> My daughter calls it "garbage." I go, "Don't call it garbage. It's my stuff. It's my - you know, I mean archeologists are going to come through, "Look at how much stuff this guy had. What is all this stuff?" … So everybody's got those little things that are like high points in their history - *their* history. Anybody looking at it wouldn't have a clue what it [is].

Memories triggered by certain items reflect these "high points" in their personal histories, as narrated by this participant who reminisced about traveling the globe while showing me a small, damaged suitcase:

> [Participant #10, female, age 69]
> P: Now this suitcase is perfectly useless, but when I left [airline] this was my farewell present. I used to travel - oh, I traveled with this suitcase!
> I: And do you do much traveling these days?
> P: I used to but not anymore because I'm retired. I can't afford it, you know, I'm - I'm on Social Security so -- and also travel isn't - it's not pleasant, you know. I traveled when nobody traveled. I traveled before everybody traveled in the Sixties and Seventies and at that time the planes were empty, and staff traveled "space available". And if there was a first-class seat available you got a first-class seat. It doesn't happen anymore. That's gone.

Others describe pastimes and hobbies that they love, but are no longer able to enjoy in because the sheer volume of items gets in the way of engaging in them, as in this example:

> [Participant #12, female, age 83]
> I: Tell me what are the types of things that you collect or that you hang onto?
> P: Any - *anything* musical. I make goofy instruments myself and, [for instance] - I play musical saws. I have this guitar I built on a washboard and I make my backup tapes and I specialize in the music from the 1920s, maybe early 1930s. I have things in boxes, different tools, useful instruments. I have a lot of stuff that's not junk. I do my own recording…I need to get in there and do some more recording and - stuff is - is in my way. I have an organ in the front room, I would like to move it out but you can't move it out 'til you move the stuff out of the bedroom that's in the way to get it through there to get it in the big room. It's like a Chinese puzzle where you have these little pieces; you have to move this to move that. And that is beginning to annoy me a lot and if I get annoyed enough, um - who's fault is that? That's mine. I have to do something about it.

Five participants described how concerns about their memories prompt them to save items that remind them of activities or experiences they have enjoyed. However, more often than not, these items are not kept in a way so that the individual can easily retrieve the information, as explained by this participant:

> [Participant #20, female, age 69]
> Some of the things - my memory is so bad that I like to hold onto things. Like, I hold onto programs. When we go to a concert or a symphony or a play, whatever, I like to keep the programs. But then they're not in one spot so I can't get to them. Because I forget. Well, did I see such-and-such an opera and if I did, who was in it? But it's all scattered so it's not really helping me. It's just taking up space, getting dusty.

Items reflect an aspect of my personality that I value. For others, items represent an aspect of their personality that they value, such as a connoisseur who recognizes and collects “fine” things, a generous and helpful person who has on hand items that others

might need, or a resourceful person who finds ways to reuse items and lives by the adage "waste not, want not". However, there are times when these values come into conflict with the way they would like their home to be. In the following example, one participant shared how collecting things enables her to give generously to others, a quality in herself that she values. However, because collecting items has lead to an unmanageable situation in her own home, she has considered whether she wants to continue to have this role. As expressed in this quote, she struggles with the thought that by making changes to improve her living situation she might be acting selfishly, rather than being generous:

> [Participant #11, female, age 78]
> My daughters will say, "Mother, somebody needs a -" what do they call it, emergency bag or something like that. Then I have canned goods and all - whatever I have I'll make up a bag. Or if they just moved or [are] young, they're getting started, I have pots and pans and towels and soap and toothpaste and stuff and I make up and give. [B]ecause if somebody needs something [my daughters] say, "Well, let me make a call. My mother has it. I'm sure she has it." [laughter] That should be flattering but it's not. That means you have so much stuff. I give away a pretty good bit, but maybe I need to not get anything other than what I need. And sometimes when I think like that, [it] seems selfish to me that I - if I can give, give, but then if you don't collect you can't give, so maybe I just need not to collect.

Items represent a degree of control and security. For fourteen participants, maintaining their collection of items gives them a sense of control over their life and their environments. Participants expressed how important it is to be the one to decide what is kept and what is discarded, as well as how angry and resentful they feel when someone tries to wrestle control away from them. Two participants in their 80's discussed their feelings about control in these ways:

> [Participant #12, female, age 83]
> If you're stuff gets ruined because it got rained on, the roof leaks or something, you can accept that. But if somebody comes along and says, "Why don't you

> throw that out? What do you want that for, you never use that." Then the clutterbug gets uptight because they're being attacked and they don't want to hear it. "It's mine. Mind your business. Let it alone." In a way I - I love my junk. Other people might not like it, they don't have to come. It's control. It's control. You want something that you can control yourself.
>
> [Participant #21, female, age 81]
> There's nothing that I've parted with, that I can think of, that I've had a problem parting with. But several years ago when the children were still at home and kind of young, they decided to get rid of a bunch of stuff when I wasn't there and I had a, I don't know if you're familiar with, there's an Electrolux vacuum from a very long time ago, the brand was very expensive and I had one and they got rid of the attachments and such. Things like that bother me a lot, and so it really destroys trust. I don't trust anybody and I realize it's a control issue for me and my things, but it's not so much the attachment as "let me decide, let me make the choice," you know.

Twelve participants described periods of scarcity, financial insecurity, and traumatic losses in their lives, which contribute to current feelings of insecurity. For these individuals, keeping items represented security over an uncertain future. Items are kept as a safeguard "just in case" items are needed in the future and the individual is unable to acquire it at that future date, as expressed in this quote:

> [Participant #21, female, age 81]
> I think it's just the fear that if I get rid of everything I am definitely going to need something and I am definitely going to have no way to get it, to replace it.

One participant identified the death of her husband as a pivotal event that lead her to cling to items even more than before, as she describes here:

> [Participant #22, female, age 84]
> [My struggle with too much stuff] came when my husband died. That's why the garage was such a mess. I couldn't throw anything away. I might need it. And for me it's a matter of, [I] kind of think of it as a widow's having her future destroyed and not really knowing will there be enough money, will I really be able to take care of myself. [I]t was easier to put it in the garage than to throw it away.

Having many belongings is sometimes seen as a reminder that they are self-reliant and no longer vulnerable to the sorts of traumatic events they experienced in the past, as in this example:

> [Participant #18, male, age 65]
> I used to buy clothes because when I was a kid I didn't - I really didn't have enough clothes. I mean it was a real deprivation kind of thing. And then I worked for [a clothing store] from '94 to 2000, so that was six years so - and so I got clothes at a discount, you know. And then I'd go down to those sales and if you hang around enough, man, you can - you can get a lot of clothes.

Seven participants discuss the financial investment they already made by acquiring items and told me they resisted giving belongings away because they were "worth something". One participant shared how, as an 81 year old woman, her ability to earn extra money is greatly limited. Selling items on Craigslist or through friends' garage sales is one of the few opportunities open to her. Her belongings are viewed as resources that could be sold or bartered for something else, as she states below:

> [Participant #21, female, age 81]
> The problem with my just giving everything away is then - what if I need this money? They are my only assets and they're not, as you can see, of great value. [chuckle] But nevertheless it's like - well, now and then I try to sell something for twenty dollars, for ten dollars and that's my attachment to my things, it's a financial attachment. Not that that's a good excuse but that is mine.

In summary, older adults in this study described a variety of factors that lead them to save items once they have been acquired. There are several main reasons given for maintaining their collection of items. Participants expressed that some items represented an aspect of their personal history or reflected a personal value or quality. Other participants discussed how important it was to maintain a sense of control over their

belongings. By extension, owning items gave them a sense of control over their life. Their belongings reassured them that they will not endure times of scarcity as they may have in the past and provided a safeguard against future needs. While participants often endorsed several of these reasons, some clearly identified particular reasons as the main factors that lead them to maintain their collections. It is interesting to note that in the process of articulating the reasons why they kept items, individuals also commented on the negative outcomes of keeping so many items. These outcomes of living in crowded, cluttered environments are the focus of the next section. The reasons for keeping items also contribute to the barriers participants identify to discarding items, as will be discussed later in this paper.

Outcomes of Living in Cluttered Home Environments

Throughout the interviews, participants described the day-to-day impact of living in cluttered home environments and the outcomes on their lives. While for some, the act of acquiring items may have initially given them a positive feeling and keeping items may remind them of important and pleasant times in their past, the outcomes of living in these environments discussed by participants were nearly always negative. Exceptions to this include one participant who mentioned that her 10 year old grandson liked coming to visit her; he told her that coming to her home was like going on a scavenger hunt. Another participant mused that having hoarding and cluttering behaviors perhaps imparted an evolutionary advantage, albeit with limitations:

> [Participant #18, male, age 65]
>
> P: I mean I think there's got to - my guess is that there's got to be a genetic factor. I mean because, you can see that there's a value to this gene, right? I mean if we're

back a hundred thousand years ago and I see, "God, this rock could really be useful as a - you know, we could make a hand axe out of this." And somebody else says, "Ay, there'll be other rocks," you know, I've got an advantage - until the cave gets so full of rocks that -
I: Of rocks. [chuckle] That haven't been put to use.
P: That we have to sleep outside with the tigers.
I: Right. [both laugh]
P: [chuckle] So, you know, there's got to be a balance there but obviously acquisitiveness has a value.

Identifying advantages to living in cluttered, crowded homes such as these was an uncommon finding. More frequently, participants discussed the ways in which their homes negatively impacted their quality of life. These outcomes can be grouped into four categories: interference with activities of daily living; limitations on their ability to engage in pleasurable activities and increased isolation; negative affects on their physical and mental health; and increased conflict with others.

Interference with activities of daily living. All of the participants described ways in which their crowded home environments made it more difficult for them to perform normal activities of daily living such as sleeping in their beds, eating meals at a table, moving about within the home, or maintaining their hygiene. For example, for most people preparing to go to sleep in one's bed typically requires few steps other than pulling down the bedsheets. In contrast, one study participant described the following process she goes through daily:

[Participant #20, female, age 69]
I: You mentioned when we sat down that you find that the things get in the way of your daily life.
P: Right.
I: Can you tell me a little bit more about that? How does it get in your way?
P: Well, it literally gets in my way. To go to bed I have to move some of the piles from there into the kitchen area so that there's room enough for me to lie

> down. And then during the day I have to take those same piles [and put them] back onto the bed. It's an obstacle course, if I want to move quickly through the house I can't really do that. I have to be careful not to trip or fall. And when I do clear part of the bed I don't clear that much of it, there really isn't a place to clear it to, so I kind of sleep with my arms down at my side. I can't really stretch out a whole lot. And it's harder to - well, the place isn't clean because it's impossible to clean it. I can't get the bedspread off of the bed to wash that. I can't get the bottom sheet off because it's underneath all the stuff. The top sheet I take off to wash and what I do with that, I fold that in two so I'm sleeping on a clean sheet.
> I: Ah, on the top and bottom -
> P: Yeah, and I'm sandwiched in between.

Others described narrowing walkways in their homes and the challenges that creates when furniture or appliances need to be moved in or out. In the following quote, one participant described such an event and also voiced concerns about her own ability to get through her home if she were to ever need a wheelchair:

> [Participant #12, female, age 83]
> I: Well, one thing I was wondering about is if you could share with me or explain to me other ways that you've noticed the clutter impacting your day-to-day life.
> P: Yeah, the paths were getting narrower and more and more narrow. And I'm getting older and older and I'm thinking now if I were in a wheelchair you couldn't get through here.
> I: Uh-huh. [yes]
> P: And one day the washing machine, died and we had to get it out and I had to clear a bigger path to get it out. So I had to use the backyard and move the washing machine out and then new washing machine in and then bring things in from the backyard. Now that's not functional.

A plumbing leak "sometime ago" prompted one participant to turn off the water to his house. He has not arranged for a plumber to make the necessary repairs because it would mean clearing out large quantities of belongings in order to access the pipes. As a result, he shared with me the extra efforts he has to take to maintain his hygiene:

> [Participant #18, male, age 65]
> I: Does the accumulation of stuff interfere with any of your sort of daily activities, having access to the sink, to the shower, to areas in the kitchen?

> P: Well, actually, I'll - This is - this is a little appalling. [nervous, embarrassed chuckle] Here's another layer of it--so sometime ago the pipes that connected to the city water supply started leaking so I called the city and they said, "It's on your side. You need to get - have that done." And I haven't had it done and I've turned off the water. So, basically I don't have running water at home. Which is another reason I've worked out [at the gym] very regularly, because it's where I take a shower. [chuckle] So I can turn it on but - but, uh, you know, when I have to shower at home or if I have to wash myself at home I've got, um, gallon jugs of water and I'll, you know, pour water on myself and soap up and rinse off. And I'll - I pee in a - in a container and put it on our compost heap. So - or if I'm at home for the weekend I'll go to the library and use the restroom there or go to the supermarket, which is right down the street, and, you know, do that. So, yeah, that's - probably aren't very many people that work here that don't have running water at home.

As seen in these examples, not only do their home environments cause impairment in their ability to carry out day-to-day activities, it also contributes to as sense of "otherness". They recognize that they are not functioning the way others do, and things are not the way they would like them to be. All of the participants in this study described ways in which normal daily activities were affected by living in cluttered environments. For two participants, interference in these basic, daily activities was minimal, requiring them to take an extra step or two, but did not cause major disruptions to their ability to function. However, for most participants the accumulation of items resulted in significant interference in performing normal activities of daily living, as represented by the participants quoted above. Given that older adults are at greater risk for disability and functional decline than younger adults, living in cluttered environments such as these may have a more pronounced impact on older adults and result in significant functional impairment.

Limitations on pleasurable activities and increased isolation. Not only did participants' home environments interfere with basic activities of daily living, but they

also limited participants' ability to engage in pleasurable activities and to do the things they would prefer to do. For four participants, activities such as sewing or making crafts or artwork were limited due to the physical lack of space in the home for the activities to take place. In addition, thirteen participants also described a loss of spontaneity due to self-imposed limitations on how they "should" spend their time. These participants expressed how they feel they should work on organizational projects at home before they spend time in other ways. Many participants described how they limit others' access to their homes and how this presents a challenge to maintaining friendships. Other participants described how coping with their home environments has altered or called into question long-term plans for their retirement years. In many cases, these limitations curtail participants' ability to interact with others and contribute to feelings of loneliness and isolation.

In the following example, a participant describes the guilt she feels when she engages in pleasurable activities outside the home rather than working on the unpleasant task of decreasing clutter, an experience I heard repeatedly from participants:

> [Participant #21, female, age 81]
> For one thing, the minute I go out the door to enjoy the sunshine or have a commitment I feel guilty about not being here and going through things. So the guilt kills me. And I thought, this is stupid. I need to just stay here and stick with it, and so I do. And I'll sit and I'll spend hours going through papers and shredding a lot of old records and things that I think "this really doesn't matter any more" and "I don't need it".

However, staying at home and "just sticking with it" contributed to increased feelings of loneliness and isolation, as seen in these examples:

> [Participant #5, female, age 69]
> It's very lonely work, it's isolating work, it's depressing work. Sometimes it's boring. And sometimes it feels like I'm being punished.

[Participant #17, female, age 72]
I'm very lonely and I love to be with people. But if I go out (a) I spend money and (b) I should be here doing my stuff. So I feel blocked.

Not only do participants feel like they should spend time on tasks in their home rather than enjoying activities or the company of others, many participants find that living in cluttered environments restricts their ability to invite others into their home. As a result, there are very few types of social interactions they are able engage in and their ability to maintain social connections is compromised, as described by these participants:

[Participant #17, female, age 72]
There's no room for me to have my friends [over] and I think I have lost a lot of friends because I have not been able to return their invitations for what they do.

[Participant #12, female, age 83]
I: Well, is there anything else about your experiences with these behaviors or your home that we didn't cover that you wanted to tell me?
P: Well, it limits the - the - people that I can - have a good, warm, close relationship with. It limits the people that are not judgmental. There are people that I have a good relationship that I have to kind of keep on the outside.
I: And how does that feel to you?
P: Well, it is, uh - inconvenient. Somebody says, "Oh, can I come in?" and I say, "No." [chuckle] And yet I go in their house. I mean they would let me in if I asked "Can I come in."

Limiting others' access to their home was a way to protect themselves from the negative comments of others, or from the shame and embarrassment participants felt about their homes, as expressed in these examples:

[Participant #12, female, age 83]
I have found that there is an intolerance about it in general in society. So [sigh] you have to not let certain people come in your house. They say, "Oh, how can you live like this? Oh, my god."

[Participant #11, female, age 78]
I don't entertain, I don't have company. It was so bad I didn't want anybody to come here and see that.

Repeatedly, participants told me that I was the first person, other than family members, who they had allowed into their homes for a very long time. While limiting others' access to the home minimized negative feelings associated with others seeing your living situation, it also reinforced feelings of isolation for many of these individuals.

In addition to limiting pleasurable activities and social interactions, living in cluttered homes had a negative effect on long-term plans for some participants. For many older adults, their retirement years are envisioned as a time to travel, perhaps move to smaller communities with lively arts or recreation cultures, or simply to be unencumbered from the constraints of work-life. However, four participants who had accumulated a tremendous amount of items in their homes over time described ways in which their plans for retirement have been altered or called into question because of the state of their homes. One participant explained that she and her husband would like to retire to an artists' community out of state, but the task of clearing their house, making repairs, and selling their house seemed insurmountable. Another told me she feels her stuff owns her, rather than the other way around, and that taking care of her house prevents her from traveling, as described below:

[Participant #12, female, age 83]
I: And when you mentioned the stuff owning you- can you explain that a little bit more?
P: Oh, sure. Maybe you want to go on a trip or something and you've got to have somebody watching your house. I don't want anybody in there when I'm not

there. I wasn't able to afford to go on trips until just a few years ago and, uh, I inherited a little money to be able to do that, but it's too late.

One man told me he was concerned that he may be prevented from joining his wife on an opportunity of a lifetime because of the tasks he needs to complete at home first:

> [Participant #13, male, age 65]
> I: And when do you plan to retire?
> P: I could retire by the end of this year. [My wife] has been approved to become a minister and she would like to minister in New York or even in Europe. She's kind of adventurous. And, [pause] she would like me to go with her and, uh - I kind of like the idea of living in Europe. When I separate myself from all of this it seems kind of attractive in some ways. It's like, how many people get an opportunity for that? But I have thought maybe I need to retire in order to deal with this [cluttered and crowded home] just full-time.

Thus, as described above, participants indicated that their personal activities were limited as an outcome of living in cluttered homes. This restriction takes place both inside and outside the home. Participants feel guilty when they are out of the house and not working on tasks at home, but inviting others into their home makes them vulnerable to a host of negative experiences. As a result of these limitations, participants felt lonely and isolated. Beyond these restrictions on day-to-day activities, cluttered and crowded home environments can become a burden which limits older adults' ability to make long-term plans to enjoy their retirement years.

Negative effects on physical and mental health. Another outcome of living in cluttered homes is the negative effects on their physical and mental health. Participants gave many examples of these outcomes. Physical hazards described by participants

included narrowed pathways and obstacles to ambulating in the home, health risks from dust and mold, and safety issues that arose from homes in disrepair. Participants also described how their living situation affects their mental health, increasing feelings of stress and anxiety, compounding problems with depression, and contributing to a general sense of unease and dissatisfaction with their lives.

A variety of health and safety hazards were reported by participants as a result of the accumulation of belongings. Twelve participants told me about how they were at elevated risks of physical injury from falls or bumping into things, as in this example:

> [Participant #5, female, age 69]
> I have tripped over piles, like this one (steps over pile of laundry on the floor), so it is… and it's a fire, a fire hazard as well.
> I: You just mentioned that you have tripped over things. Have you ever injured yourself?
> P: I haven't broken any bones, no, but I have gotten bruised.

As one participant described her home situation, it became clear that if she was to experience any physical limitations such as changes in gait or balance, or her health declined, her home situation would quickly become much more hazardous to her:

> [Participant #20, female, age 69]
> I: You mentioned that [your husband] has fallen before, has tripped on things in the home.
> P: In the house, yeah.
> I: Has he ever injured himself?
> P: Probably he's hurt his back a little bit, yeah.
> I: Yeah. And what about you? Have you tripped over things or -
> P: I have a little bit. I've gotten more black-and-blue marks than anything else. [chuckle] Banging - banging my knee. So I try to be really careful. I've slipped. I've - but - I guess I might have fallen a little bit but not as much as [my husband]. So I'm - I'm more agile than [my husband] is. So this is one room here [her bedroom]. Don't even try to come in here, you'll fall.
> I: Okay.

P: But, you know, I can actually - I can show you how I can balance. There are places where I can put my feet. I'm not sure --
I: Uh-huh. [yes] I see a little spot of blue [rug] by that one bag. [chuckle]
P: I'm not sure that [my husband] actually could get back here without tripping or knocking things over. I can somehow do that.

Four participants described health hazards from mold, dust, or pests, and safety hazards from homes that have fallen into disrepair, as in these examples:

[Participant #13, male, age 65]
We had a neighbor who's a contractor look at them and he said, yes, that the foundation on that side needs to be replaced too because it has some water damage. And I guess that whole side of the house in that area has water damage and there may be work on the foundation that needs to be done at the back side of that room. And because of the water damage there's some mold in that room. [My wife's daughter] has cleaned it up and it comes back, and she's worried about her health.

[Participant #12, female, age 83]
And - watch out. [opening a closet door revealing boxes that are stacked to the ceiling inside the closet] That's the kind of stuff I have at the house, stuff in boxes and, look out, rats like to nest in things like that.

Living in cluttered homes not only impacts older adults physically, it also impacts their mental health and sense of wellbeing. Twelve of the participants in this study shared that they had long standing problems with anxiety or depression and discussed how they feel their mental health impacts their hoarding and cluttering behaviors and vice versa. For example, one participant describes how feeling depressed was intermeshed with her hoarding behaviors. To her, the two factors were inseparable and had an additive, negative effect making the clutter that much more difficult to cope with:

[Participant #11, female, age 78]

> I: And with feeling depressed, were you depressed and that - made the accumulation of things worse? Or was it the accumulation of things that--
> P: That intermeshed. That was like together. I was depressed because of the accumulation. I was depressed because I didn't want to tackle it. I was depressed because I was tired of being depressed looking at it and doing nothing about it. Just - just depressed. Just annoyed. Annoyed with me. Depression, feeling depressed is one thing but I was depressed because I kept myself in that condition.

In the following example, I asked a participant to tell me about the sorts of items she has kept in her kitchen where we were sitting. From this passage it is clear that the disorganization in her home makes her feel anxious and agitated:

> [Participant #1, female, age 87]
> Yeah, well, I'll tell you, I can't find anything. I'm going crazy with my things. I had this; I'm trying to find this. Like this where I kept all the paper. All this is paper. [mumbling and shuffling papers]. It drives me crazy. And I can't find anything now because [the caregiver] took, uh - what did she take out the other day? She took all my letters out but - but they're not filed. I don't know what I - I just can't get it together and that drives me crazy. I'm in a state of anxiety, you wouldn't believe.

Similar to the example above, other participants described their living condition as a source of constant stress preventing them from feeling at ease when they are at home, as in this example:

> [Participant #6, female, age 73]
> [I]t just keeps- you never - you can't ever relax. I mean really go in your room and says, "Ahhh," and you turn the TV on and - you - I never feel that way. I just - I start looking around and it looks like it's closing in and then I try to not - you know, I just concentrate on the movie or whatever. And then when [the movie] goes off it's back again. So it's just like all - all the time occurring, it never goes away and it's nothing I can do about it.

These examples illustrate the second outcome of living in crowded, cluttered home environments, namely the increased risks to the physical and mental health of the study participants. While individuals at any age would experience these elevated risks,

older adults may be at greater risk for poor outcomes due to age-related factors such as increased physical frailty or decreased physical reserve. Mental health issues such as depression and anxiety tend to be under-identified in older populations in general. Given this, these older adults may be less likely than their younger counterparts to receive mental health support for the depression, anxiety and stress that accompanies and compounds their hoarding behaviors.

Increased conflict with others. A fourth outcome of living in crowded and cluttered homes mentioned by participants is an increase in conflicts with others. Participants shared examples of conflicts with family members living in the home, with apartment managers, and with supervisors at work when workspaces become cluttered with too many items. These conflicts added to the amount of stress and worry felt by these individuals.

All five study participants who were living with spouses at the time of the interviews described how the accumulation of belongings in the home was a source of conflict for them. Typically, participants' spouses expressed frustration and anger with the perceived lack of action on the part of the participant on issues that clearly have been discussed before, as in this example:

> [Participant #13, male, age 65]
> Wife: I think [my husband] is truly distressed about it but he's just not able - [to husband] Am I correct that you're distressed about this? You just haven't been able to deal with downstairs to get [the contractor] in to look?
> Participant: I would say that's true. I'm going to get new energy to it and - try again.
> Wife: But that is what has been the issue, right?
> Participant: I would say so.
> Wife: Right. And in the winter when it rained, the rats came in. So it really needs to be done. It's urgent.

Participant: So I moved things out yesterday and I will continue to move things out so [the contractor] can get to them and we'll just have to - uh - go through it. Don't paint me as a bad boy.
Wife: I know this is really hard for you, honey, and I appreciate it.
Participant: Okay.
Wife: So, I'm not going to accompany you to the basement, my blood pressure goes up.

Six participants who lived alone described ways in which they were in conflict with apartment managers or other authorities over the state of their homes. Participants who were living in apartments designated for low-income or older adults were subject to annual inspections by the property manager. One participant, who had previously been threatened with eviction for not having adequate clearance for a fire escape, described the stress induced by the annual inspection in this way:

[Participant #21, female, age 83]
P: Every year they have to come and make sure you're taking care of the apartment and stuff because you're in Section 8. I don't know what to do. I wish I had a place to put these, a lot of these, boxes, temporarily for a few days or something. I know I have too many and I know it would be considered a fire hazard. That's the problem. So that's why I have to…
I: Do you know what the process is, if they come before you're ready and they say "gosh, there are…" you know.
P: Well, the process is, "We'll be back in a week and it better all be gone." Or three days or, I don't know what it is. It's very short. And, I really feel, that's where I really need some physical help. I need, I mean, I don't know if, again, I can't rent a storage place and um, just have… [to try] to deal with all this without transportation on the bus and trying to get rid of…
I: One bag at a time.
P: Yeah, well, two bags at a time. I usually can make two bags, one for each hand. And it doesn't help to have physical problems as well. So, I don't know. I don't know what I'm going to do.

One participant who was employed at a large corporate office told me about a conflict he had with his supervisor over the state of his cubicle. He points out that, unlike his home to which he can restrict others' access, his hoarding behaviors are exposed at

work. Anyone passing by could see his cubicle, compare it to others' cubicles, and could complain about its status to supervisors, as he narrates here:

> [Participant #18, male, age 65]
> [A] couple of months ago some visiting manager made some complaint to some boss, you know, three levels up from me that my place - my cubicle was a disaster. So I had to come in on a Sunday and I - and I did - you know, first I did a little bit here and a little bit there and then they said, "No, it's - you need to really get it together." So I really did do a dramatic clean up and you can take a look at other cubes as we walk by. [T]here are some people who are ready for *Architectural Digest* to come in and photograph it, you know, but there are others who are not. But now my cube has degenerated - and, of course, this is what I present to the world, right, this is not my house, this is - people get to come here.

Participants discussed how conflicts at home or at work added stress to their lives. As described above, participants felt pressure from others to clear their environments in order to meet certain requirements or expectations. At the same time, they often expressed that others do not understand how difficult it is for them to make these changes. The strategies employed by participants to meet these requirements are often temporary, such as moving boxes elsewhere for a short period of time, or cleaning an area only to see it "degenerate" to its previous state again. Experiences such as these add to the frustration and sense of hopelessness many participants expressed over their ability to make lasting changes to their environments.

In this section, four categories of outcomes of living in cluttered environments were discussed: interference with activities of daily living; limitations on their ability to engage in pleasurable activities and increased isolation; negative affects on their physical and mental health; and increased conflict with others. In the next section, the strategies employed by participants to minimize these outcomes are presented.

Strategies for Managing in Their Environments

Participants described coping or management strategies they employed in order to minimize negative outcomes and to maximize their ability to function in their home environments. Two main categories of strategies were described by participants, either they attempted to adapt to the environment or they attempted to change their environment. In the first category, participants describe strategies such as maintaining relationships outside of the home, developing ways to work around the clutter within the home, and developing a knack for "knowing" where items are kept among the clutter. These strategies enabled them to carry out daily activities without directly addressing the volume of belongings in their homes. In the second category, participants described strategies to limit the acquisition of new items and to organize belongings in the home. While some of these strategies were successful, others were not. When strategies were unsuccessful, participants described how this negatively affected their morale. Participants became discouraged, frustrated, and in many cases gave up on trying to effect change. Avoidance became a strategy employed by many after several unsuccessful attempts to reduce the clutter in their homes. In addition, some participants described how as they have aged, strategies that previously worked for them are no longer working.

Strategies to adapt to the environment. One of the outcomes of living in crowded, cluttered homes was increased difficulty maintaining social relationships because individuals severely restricted who they allowed into their homes, as discussed previously. Meeting people away from home was a strategy mentioned by nine

participants to bypass this problem. These participants were active and physically able to come and go easily from their home, as seen in this example:

> [Participant #10, female, age 69]
> I: You mentioned when I first came in that it's been a while since you've had anyone over. Why is that do you think?
> P: Well, actually, I have one good friend who is working who is really busy so we go out – and I really don't entertain. I mean it's like, you know, she has a really busy schedule so there's no reason for her to park the car and come up two flights of stairs to sit here before we go out. Or we meet at the place. So, okay, that's one friend. I don't have that many friends. When you're not working you kind of lose friends. I have another friend and we go to the ballet and to the opera and it's the same thing. I mean we really don't, um - [pause] we don't socialize at home.

Not surprisingly, this strategy was not mentioned by study participants who had greater physical limitations. Those unable to meet friends easily outside of the home did not have this strategy available to them and as a result tended to describe greater isolation and feelings of loneliness.

Several study participants told me about strategies they had developed to work around clutter and accumulation of items at home. For example, seven participants showed me clothing racks, clothing hooks they installed on doors, or rods stretched across doorways to hang clothing on. In these cases, their closets were inaccessible either because they were blocked with boxes or furniture or they were so full that they were unusable. Other participants described alternate ways of preparing food because the stovetop and oven had become storage for items. One participant used her stovetop as a desk and it is covered with various piles of papers. In the following quote, she shares her thoughts on keeping herself safe as well as her strategy for preparing food:

[Participant #17, female, age 72]
P: This is where I do all my paperwork. [indicating the top of the range]. I never use the stove, obviously - but I'm very careful - it could be very dangerous.
I: Uh-hm.[yes]
P: But I'm not so old that I have to lean on things. I'm very aware of it because apparently my great-grandmother leaned on a gas stove and that was probably when she was walking across the room and she was very old and that probably was when you had to light it with a match.
I: Yeah. So the gas came on?
P: So she was asphyxiated.
I: Oh, boy.
P: So I'm very careful with this. I definitely watch it to be sure that they're always off. It's an electric stove. And I cook everything in the microwave. And I've learned to cook actually normal food in the microwave.

Multiple participants described how they developed an adaptive skill that enabled them to find specific things among the clutter as a result of living in their environments. These participants told me, "I know where everything is", as if they had a sixth sense about their belongings' whereabouts. However, some participants reported that as they have aged, this strategy is starting to fail them, as related in this story:

[Participant #18, male, age 65]
P: I used to have the ability to deal with all of that stuff. Like, for instance, one story that I really liked was two jobs ago, I guess, I was - I shared an office with a guy and my side was all of these piles of stuff. So I was out for lunch and …my officemate said, "Watch this. We'll take this package of microfiche, and I'll put it in here in the middle of the pile and I'll bet you it's six months before he even notices." And, I came back from lunch, you know, I said, "What's this?"[chuckle] And so it wasn't six months, it was six seconds. So that got me a little bit of credibility, like - it might look like a mess but he knows where everything is. And at one time it sort of was like that and people would say, "Hey, you know, where's this paper?" and I'd say, "Oh, you know, it's in this pile about two-thirds of the day down." And I'd get it out. But, you know, I can't do that anymore.

Another participant described the effect of aging on her ability to know where everything was, and expressed concern that these age-related changes might make it more difficult for her to improve "her situation" in this way:

[Participant #11, female, age 78]
I used to know where everything was, everything. I don't care if it was cluttered. But as I'm getting older I find that I forget some of the things I have. When I'm going through stuff I'll say, "I didn't realize I had this. How long have I had this?" So that's why I need to make this a lifelong - and I'm sorry I've waited so long in my life - to really get serious about my situation here.

Strategies to change their environments. In order to minimize most of the negative outcomes of living in crowded, cluttered environments, a number of participants recognized they needed to reduce the number of items in their homes and organize those which they intended to keep. Seven of these participants developed strategies to minimize the ways in which new items entered their homes. For example, a few study participants recognized that active acquisition of items led to their crowed home environment and have attempted to minimize their collecting behaviors, as in this example:

[Participant #12, female, age 83]
I: Are there certain places where you go and shop, or do you find things, how do things come into the home?
P: I have cut down on my visits to the Salvation Army and thrift shops. I know now what that is. You come home from - you're returning from doing something unpleasant like you've been to the doctor or had to go somewhere and you want to reward yourself. So you go in a place like that to give yourself a present. Well, I've stopped doing that. I might do that once a month or something.

Other individuals recognized they had difficulty discarding items that passively came into their home. One participant described her strategy to minimize the inflow of paper materials in this way:

[Participant #5, female, age 69]
It just complicates everything [when you have cluttering issues] because your heart - you know, you want to get involved in this stuff [referring to charity/church projects] but that it adds to all of the clutter and the stuff. So now I

> have a rule that if someone asks me to do something I think to myself, "Would this mean bringing much more paper into my apartment? So I decided I will never be the secretary of any organization or board or, you know, whatever. And I shy away from chairing anything. And so I figured out what- like with the Coffee Hour all I have to do is like five times a year just show up. And I say, "Okay, I can slice and dice and that's not stuff." So that's how my mind has started to work is, you know, "Is this going to be bringing in -" And, again, like with magazines. I get a *TV Guide* and that's it.

While only a few participants attempted to curtail the inflow of items, most of the participants described strategies for sorting and organizing belongings. "Going through everything" was an essential step for these participants in order to decide what to keep, what to discard, and how to organize the items that were kept. Seven participants clearly stated this initial sorting step was something that "only they could do". This approach maximized the amount of control individuals felt over the disposition of items, but often proved to be painstakingly slow as described by this participant:

> [Participant #12, female, age 83]
> P: I want to go through a lot of this old history that I'm uncovering right now. I'm in the process of doing that with these shelves so that I can go through some of these boxes. And it's working but it's slow. It might take a very long time but there's nobody else can do it but me. And I keep my fingers crossed that nothing happens to me like an accident or something because nobody else can do it for me.
> I: And what would it feel like if, under your direction, if someone were to come and just assist you -
> P: They'd have to be a mind reader. They'd have to be a mind reader.

Six participants had accepted the help of others in this initial sorting step. Some of these participants considered the involvement of others a part of their overall strategy to decrease their isolation and improve their living situation. One participant described how working with her two daughters helped to bring humor and perspective to the process of

sorting items, which had been overwhelming and “a drudge” when she had tried to do it on her own:

> [Participant #11, female, age 78]
> I: It sounds like you're able to do the big projects with your daughters' help.
> P: I could do it on my own if I took the time but when we're together and we're working there's laughing and joking and talking about old times or talking about anything and the time goes faster and it's not such a drudge or as boring as it is - or overwhelming. Because how some of this got so bad - I would start maybe in there pulling out stuff and then I get so overwhelmed I said, "Oh, I can't stand this anymore," and I'd leave it like it was. Then I'd come out here and start pulling out - well, I'm sick of that. Then I go over there. So then I had - the whole place was just chaos and then I didn’t want to deal with it at all. So when I was dealing with it to try to get things a little better it took longer because I just made a mountain out of a molehill.
> I: Yeah, and if your daughters are here working with you on it, you're able to get through it?
> P: Yeah, we get - we get - we get through. We have - the three of us and we get along. They respect me as their mother but we're also friends and we've always gotten along great. So there's - there's no problem, we just - pitch in and get it done.

When strategies proved successful, participants proudly shared with me their accomplishments. Breaking tasks into smaller steps was one way some participants were able to make progress, as in this example:

> [Participant #5, female, age 69]
> So what I have to do is I have to break things down into very small, do-able, I call them baby steps and stepping stones. And I’ll say, OK, what’s involved? [L]ike that (pointing to a pile of papers) is all something that I’m going to shred. So now I can look at and say “Oh God, I don’t have the energy” but if I, well, what I’m going to start doing is to say, just try 10-15 minutes a day, set the timer or whatever and just try that. Because I thought, everything we accomplish in our day to day lives is a step, is a series of baby steps, I mean pretty much everything.

Projects that were small enough to be accomplished in a short period of time and for which the participant had a clear, defined goal in mind tended to have successful outcomes, such as the project described by this participant:

[Participant #10, female, age 69]
P: Oh. I'm so proud of this. This is the "under-bed" or "bed-under" that they advertise on TV but you can buy it at Walgreen's. I keep losing my silk underwear. So this [canvas container with dividers and a plastic zip-top] is for shoes. I have all of my silk underwear [in it] and, you know, I don't wear slips anymore but I love this slip so everything is organized. It makes me very happy. [chuckle]
I: Uh-huh. [yes] And what makes you happy about it?
P: I know where it is and everything is right here in this - all sort of totally organized. And I think I have it organized so, um - uh - the bottoms are here. So I think I have the long-johns here. [opening package] Yeah.
I: And you can see everything because of the clear top.
P: Exactly. Right. Now if I were thinner I could wear these [camisoles] underneath a long tunic, but I think these are - [examining article] a medium. So - -but everything is right here.
I: And is this something that you've recently -
P: I just did it like a month ago. Because there was a cold spell and I couldn't find any of my silk underwear. I mean I could find certain things but I couldn't find what I really wanted.

However, when participants' strategies were poorly defined the tasks often proved to be time consuming and resulted in minimal improvement. For example, several participants described a strategy that could be called "Work, work, work. It never ends." to paraphrase this participant's experience:

[Participant #8, male, age 66]

I've got to work on that room because there's stuff I don't remember anymore, you know. They got stuff in the - box - I got boxes that are empty so I got to do something with the boxes that are empty. I need to put something in it. [chuckle] I got one box that's broken, I got to take that out. There's a lot of work - there's always work in that room, always work, work, work. It never ends.

Another participant described the frustration she felt after attempting to "straighten" things in her bedroom without having developed a plan for where things should go:

[Participant #6, female, age 73]

> And then I- it's so hard - I'm doing a little bit of straightening up a little bit in a way but then I put things in so many bags and suitcases and things 'til I don't know what I done put away. Then I got to open them again to see if I put that in there. And it's - it's - you can just go out of your mind like that.

Unsuccessful strategies such as these generally resulted in frustration and discouragement. After a series of unsuccessful attempts, participants reported avoiding these tasks all together. The following participant explains the reasons why she has given up trying to sort through her many stacks of papers:

> [Participant #20, female, age 69]
> I: What is it like when you sit down with a pile and - well, you've talked about the newspapers.
> P: I've tried to do that and it's - Because there's so many pieces of paper in any given pile and it just takes forever to go through the stuff and I feel like I'm not making much headway and I have to - Some of these bags have gotten so dusty I have to vacuum them so I don't have to have a sneezing fit before I even get to anything.
> I: Yeah. So it's quite a process.
> P: It is. And I can always think of better things to do.

For this particular participant, avoidance became the primary strategy used to manage in her environment, to the degree that she reported no longer even noticing the clutter around her. As we walked through her dining room, I asked her about the various piles that were on the table, chairs, floor, and other pieces of furniture. She replied, "I haven't looked at this. I just walk by it. It's like I don't see it anymore."

Blockage

Invariably, participants described barriers that prevented them from discarding items. The resulting blockage kept items that entered the home from effectively leaving the home. While it is true that participants kept items because of reasons discussed earlier

in this chapter on "maintaining", these additional barriers prevented participants from discarding items, even in circumstances where they had identified items they were willing to discard and clearly stated that they desired a change in their home environment.

Barriers discussed by study participants fell into four categories: difficulties related to executive functioning tasks; difficulty with anxiety and worry; difficulties related to health changes; and difficulties related to logistics.

Difficulties related to executive functioning tasks. From a cognitive standpoint, the work of sorting through and organizing belongings requires processes collectively known as "executive functioning". These executive functions include decision making, sorting and categorizing items, initiating activities and focusing attention, and problem solving, among other cognitive tasks. Recent studies utilizing brain-imaging technology have suggested that in adults with hoarding and cluttering behaviors, regions of the brain's frontal lobe are not working effectively, which may lead to impairment in executive functioning. When study participants described their attempts to sort through items, make decisions about their disposition, problem solve and generate solutions, and focus sufficient attention on a project to see it through to its completion, all of their stories reflected possible impairment in executive functioning. These difficulties compromised their ability to make changes in their homes and contributed to the blockage they experienced. The following quotes illustrate the difficulties participants expressed initiating projects, making decisions, sorting items, problem solving and completing projects.

Initiating projects was a barrier discussed by eight participants. As Participant #12 put it, “it’s easier not to even be bothered by it, but then it collects”. Motivating oneself to engage in difficult sorting activities and to keep that momentum going takes a lot of effort, as described by this participant:

> [Participant #11, female, age 78]
> P: [I tell myself]… if I got a mind and it's working, I know what has to be done. Do it. Don't keep saying, "I got to do this." You really don't want to. You don't want to tackle that job. It's just bad. It's easier to say, "Yeah, I got to do this. I'm going to do something about this." You don't convince yourself sometimes. [If] you convince yourself then you're - you're getting started. But if you just say it, "Oh, I'll start tomorrow." It was always tomorrow, like mañana never comes. But just keep putting it off, putting it off. And then once I did a little bit and maybe that little tiny area was better, I felt better. I said, "See. Yeah. Now I'm going to do some more." Okay, maybe I didn’t get to it for a week or two …but it's not easy to get on it and keep on it, I mean with a passion, to just keep on it. But I'm going to. It's not easy, I will - I will do it.

Nine participants discuss how difficult it is for them to make decisions about their belongings. In the following quote, one participant described the difficulty she has making decisions about what to do with items as well as how to begin the process:

> [Participant #17, female, age 72]
> P: There's a lot of stuff, I know. There are things that will be hard to make decisions about and maybe I'll save a bunch of it and maybe I won't, I don't know. In spite of how badly I want to get it done, I just can't pick myself up and do it.
> I: And is it sort of a feeling of being overwhelmed by the task?
> P: I think so, yeah. Yeah. And I know that I could do each task, you know, individually. But it's making a decision about where to start.

As described previously in the section on strategies, nearly all of the participants discussed what it is like for them to sort through their belongings. Most participants used adjectives like “boring”, “time consuming”, “overwhelming” and “depressing” to

describe this process. In the following quote, one participant also describes how mentally taxing these projects are for her; they "short circuit" her brain, limiting her progress:

> [Participant #12, female, age 83]
> I: Tell me about that. What is that like to - do you decide on a certain area of a room and start working?
> P: Well, it's a treasure hunt in a way because you find things that "I wish I knew that was there." Um, and then at some point your brain short circuits and you have to stop and do something else. Because you find if you keep doing it for too long you stop and - and want to stop and read things that you've saved and all that and then you're - you're - you have to quit at that point.

If problems arose while individuals were engaged in organizational projects, participants may have needed to problem solve or generate alternate solutions in order to complete the task. One participant described what the process of sorting is like for him, illustrating the difficulty he has problem solving and completing tasks:

> [Participant #13, male, age 65]
> I: Tell me a little bit more - you were saying in terms of getting rid of things, that you are concerned that your habits are sort of fighting against that goal?
> P: Well, habits like - I think I tend toward being perfectionistic. And I don't know what it is, there's a quality in me that is either despairing or distracted and I won't finish projects. I have to really make myself work to finish a project.
> I: And is that because it gets sort of overwhelming once you're halfway through it or -
> P: It might get overwhelming. I might get overwhelmed by something, I might reach an impasse that I can't figure out how to get around. Or I can't do it correctly.
> I: And what - in those situations what helps you to push through and finish a project?
> P: What helps me is if I have a clear vision of what I want to do. If I don't have a clear vision or I feel an impasse in some way, um, I can feel sort of defeated and - and want to just go away from it. I have, I guess, a strong sense of avoidance on some things.

Study participants shared numerous examples of the ways in which they struggled with organizational tasks that require executive functioning abilities. The above quotes have been selected to highlight the various experiences of the participants. Because the

process of sorting through belongings and making decisions about their disposition is so challenging for participants, they approach these tasks reluctantly, if at all. Clearly, difficulties with these types of cognitive functions contribute to the blockage reported by participants in this study.

Difficulties related to anxiety and worry. Even when participants were able to make decisions about what to keep and what to discard, several participants struggled with pathological doubt, or the nagging worry that decisions they have made are the wrong ones or may lead to negative consequences. For two participants, this led to a cycle whereby they made a decision to discard an item but then worry about having made a mistake and re-check whether they intended to discard the item. This sometimes led to a reconsideration and retrieval of the item, resulting in a paralysis of the decision-making process. The following participant gives an example of this experience:

> [Participant #20, female, age 69]
> I don't throw anything away. And sometimes what I do is I do throw things out - although I haven't done that much of that recently - for the few things I do throw out just to go through it again and make sure I'm throwing - not including something that I don't want to throw out.

Another participant describes her fear that something bad may happen if she makes the wrong decision, which leads her to save things that intellectually she recognizes she could discard:

> [Participant #5, female, age 69]
> I went through a period where I couldn’t throw out empty envelopes, even windowed envelopes. I mean, a part of me can look at it and say there’s nothing there but there’s that other part of me that says, “but you might have missed something”. So I had, I think I still have a few boxes stuffed away in one of the

> closets, of empty envelops. Fear plays a part, that somehow I'm going to screw up and bad things will happen.

Anxiety over making the wrong decision is different from having difficulty making decisions as a result of executive dysfunction. For these individuals, it seems that were it not for the anxiety and worry that arose after a decision about the disposition of an item had been made, they would be able to follow through with their plan of action. However, because they do not trust their decisions, their anxiety increases when decisions are made. Only by reversing their decision or avoiding making decisions all together can they alleviate their anxiety.

Difficulties related to health changes. The participants in this study were asked to describe their physical health currently and to reflect on whether or not, and in what ways, their health impacted their hoarding and cluttering behaviors or their ability to manage in their home environments. While thirteen participants were quite healthy and active, others were not and health issues were identified as a barrier to maintaining their homes in an organized fashion. Participants described how changes in their health, changes in their level of energy, and physical and mobility limitations negatively impacted their ability to function in their home environments.

Eleven participants described how their health had declined as they aged and the impact this had on their physical ability to sort through their belongings and maintain their household in an organized way. In the following example, a participant shares how her health complaints makes it difficult to work on sorting tasks, and how one strategy meant to assist her with such projects resulted in more accumulation and clutter in her home:

[Participant #9, female, age 77]
I: And are you able to sit with a bunch of papers and do that type of sorting?
P: Uh - sometimes. Yeah. Sometimes. When I can feel [she has numbness in her hands]- which I don't always. When I can feel and when my eyes are not bothering me and - and when - you know, when I have some - But if I'm in bed, which I am a lot, I need someplace to put the stuff as I'm sorting it out. And that's why - that lovely card table. That is a recent addition from downstairs. I needed a card table but not to do that to it. [it's now covered with piles of things] I needed the card table so that I could like layer out the papers when I'm trying - or whoever was helping me with the papers could have the stacks.

Eleven participants told me that as they have aged, their energy levels have declined. This lack of energy has impacted their ability to work on organizational projects at home, as narrated by this participant:

[Participant #21, female, age 81]
I've never felt there were enough hours in a day. And the older I get the shorter the day gets. And I do get tired. I mean, I get up in the morning between 5 and 5:30 and I'm fine until noon or so. And then it starts going downhill in the afternoon.

The combination of health problems and waning energy acted as a barrier to this participant as well, who had recently been moved into a new unit in her senior apartment building:

[Participant #3, female, age 91]
I: Being a part of this study is completely voluntary and completely your choice. So do you have any questions for me about this?
P: No. Not really. Excepting that I don't like my apartment to be seen the way it is. Because I'm not accustomed to this but it's circumstantial that I'm living like this. And then not only that, I'm old, you know. I do some work and then I'm tired, I got to sit down or lay down because my back hurts, you know, and I can't - and not only that, I can't do much because of my neck. I can't raise it, you know, so it's tiresome, you know what I mean?
I: Yeah. Do you have arthritis?
P: Osteoarthritis and rheumatoid.

Through the stories told to me by these participants, it was clear that they had hoarding and cluttering behaviors prior to their health decline. However, it was also clear that their physical ability to sort, organize, and discard items was significantly hampered by their health status. In these ways, declining health in older adulthood contributed to the blockage of items in participants' homes, and a barrier to their ability to discard items.

Difficulties related to logistics. Thirteen participants explained to me that their problems stemmed from a difficulty discarding items, rather than "hoarding" or the desire to keep items. These participants described their struggle with the logistics of discarding items, which tended to fall into two categories: finding the "right way" to discard items or finding the time to discard items. These participants told me they were willing to discard items, but they had specific ideas about where they should go, wanted to be sure they went to people who would appreciate the items, or wanted to recoup some money by selling items. Particularly for those participants who had amassed "collections" of items, it was important for them to dispose of items properly rather than throwing them away or donating them in bulk to a charity organization, as described by this participant:

> [Participant #13, male, age 65]
> P: I guess the hardest thing for me to do is to figure out how to dispose of things without throwing them away. How to find ways to sell things, how to find ways to donate things. It's actually just kind of the work of it. Resources. Where do I donate art supplies, where do I donate clothes, where do I donate good clothes, where do I, um - you know. Are there people who will sell estates? I think there are. Are there people who will sell for you? When you were talking I was thinking of a joke, "I don't have hoarding issues, I have disposal issues." I don't think that's true if I thought about it because I want to keep things, too. So that's the hoarding side of it. But, I have - I have problems getting rid of stuff and part of it is just the mechanics of it. At this stage I can't just give away things one at a time to people who like them. [laughter]
> I: That's a very long process, isn't it?

For other participants, the logistical dilemma they struggled with was the sheer amount of time involved in sorting through and clearing items from their home. When talking about this, participants often reflected on their current age and how much longer they could reasonably expect to live. The incongruence between the time they had "left" and the time it would take to discard things led participants to question the logistics of clearing the home. For example, one participant had told me how frustrated he felt after spending hours sorting through and discarding items and not seeing much of a difference as a result of his efforts. His wife was so put off by the state of the home that she refused to stay there and lived in a home she owned a few hours away. In the following quote, he discusses the relief he would feel if somehow, magically, older magazines and newspapers were removed from his home and how this could jump start additional improvements in his quality of life:

> [Participant #18, male, age 65]
> P: I don't really think of it as hoarding, you know, I think of it as - not being able to throw things out and - and also not being able to get organized. Those two things. Because - because when I look at those 1994 magazines, you know, I - I kind of think - it's not like - Well, I guess it is hoarding.
> I: What does hoarding mean to you?
> P: Well, I guess hoarding means, "Wow, this is - here's something - here's something great. Here's something that I want to keep." And - to me it's not exactly that I want to keep it, it's just that I can't bring myself to get rid of it, you know. I mean if - if you told me right now that magically you had caused every magazine more than two years old to disappear from my house, you know, um - I mean I would have to stop and think about that because there might be some old issues that I was really looking forward to. [But] I look at this stuff and I say, "You know what? I'm 65. I mean I could last thirty more years but I'm not going to last fifty more years and you know, let's try to see what the carpet looks like in here." [chuckle] I mean what if everything - all the old magazines and newspapers disappeared? You know, it wouldn't be bad. As a matter of fact, it might be good, maybe I'll do that. I mean I hadn't actually crystallized this thought before I said it to you but - but it's true. If all - if all my old magazines

> disappeared, you know, I think my life would be better because I would miss out on reading a few interesting insights like that thing about Hillary's health plan from '94 but, you know, there are definitely a lot of interesting articles that I'm going to die without having read. And it would mean that my place would be more manageable, you know, and it would bring - and maybe that could snowball and my wife could spend the night, you know.

There are many reasons why participants decide to keep items, and equally important to uncover are the barriers participants describe when trying to discard items. Together, the desire to keep items and the barriers to discarding them, some of which are related to aging, lead to the overcrowded home environments characteristic of individuals with hoarding and cluttering behaviors. As Participant #12 described it, "[A]t some point it becomes impacted. You have a constipated house." Some participants are no longer acquiring new items, but nevertheless are experiencing this blockage. They do not see themselves as having hoarding issues, as described by the two men quoted above, but rather have "disposal issues".

Third Phase in the Process of Accumulation: Discarding

As outlined in the second phase of "maintaining", there are many reasons participants give for keeping items and additional factors that prevent them from discarding items. However, all of the participants in this study gave me examples of items they had discarded. For example, none of the participants in this study lived in squalor and several participants made a point of telling me that they regularly threw away trash and spoiled food. Thus, it was not that individuals were completely unable to discard items, but they were not able to maintain a balance of items coming into and leaving their homes. As one participant put it,

> [Participant #12, female, age 83]
> I thought, what if I had a scale at the bottom of the stairs and measured everything that comes in and everything that goes out. And if so many pounds go in, so many pounds should have to be made to go out. But - it doesn't really work.

In this final phase of "discarding", participants often discussed how growing older affected their thoughts about their belongings and their home environment. For thirteen individuals, growing older was a call to action. Some described how growing older gave them new perspectives and caused them to re-evaluate the value of things they have kept. Others sought to improve their quality of life and determined that reducing the clutter in their homes would help them reach this goal. Participants also told me that remaining in control of the disposition of their belongings was a motivating factor to discard items. As they aged, they recognized two factors that threatened their ability to remain in control: becoming physically unable to manage their belongings; and losing control of decisions to others, such as adult children or social services. However, not all participants interpreted aging as a call to action. Nine were not particularly motivated to discard belongings and of these, two participants expressed a contrasting perspective on aging: they were relieved to know they had chosen someone else who would clear out the belongings after they have died, absolving them from the task of doing it ahead of time.

Re-evaluating their Belongings and Home Environments

Seven participants reflected that as they have aged, they have re-evaluated the reasons they kept items and whether items still retained their value. While they might remember why they originally decided to keep the items, over the years these reasons lost their importance. In the following quote, one participant summarizes this experience:

[Participant #20, female, age 69]
Well, some of the things are so old now that if I were actually to look at them I probably would throw them away but it's just getting to them. As I age, I wonder at the value of them and I know perhaps why I might have saved them initially but they lose value after a while.

In the following example, one participant had a similar experience when she looked through her closet. She recognized that clothing she had worn when she was employed were no longer useful to her and could now be discarded:

[Participant #21, female, age 81]
I think one of the reasons I've kept a lot of them is I've thought I'd have some use for them. But then I was going through the closet recently and I had a lot of clothing, the kind of clothes that I would wear in an office, which is what I was, I was mostly a white-collar worker most of my life. And I thought, well, I'm never going to work again, I don't need this many clothes. I mean this is how I dress every day. Either at T-shirt at the top [and] I'll wear a sweatshirt over it and I wear jeans, most of the time. The only time I dress up is to go to church. I rarely go out and I, what do I need? Two or three outfits and I still have more than I need.

Other participants discuss how information they had collected in the form of papers and articles over the years have lost their value. One participant took a very modern perspective, noting that discarding these articles would not mean losing the information since updated versions were available to her online, as she states here:

[Participant #5, female, age 69]
There is a point at which you just kind of say, "I can't - you know, this is bigger than me and I can't worry about all of this stuff." Others have talked about in this day and age most information you can get online, in the library. So hanging onto that article about, you know, Tunisia because you might go there someday, you know. I've gotten past a lot of that. Some of that just comes with being alive as long as I've been alive. I turn 70 this year.

Another way participants discussed re-evaluating things as they had grown older was in the way they wanted to live their final decades. As Participant #5 put it, "I could die tomorrow or I could live another fifteen years. Is this how I want to spend the next fifteen, twenty years if I live that long?" Seven participants described how they wanted to take steps to clear out their homes and how doing this would improve their quality of life in general, as in this example:

> [Participant #11, female, age 78]
> This is not the person that I want to be. I would like it to be much more - sparse, if that's a good enough word. Now I'm - it's making me feel better inside to work toward a goal that I will feel great inside. I want to get to the goal where I can come here [to my apartment] when it's just crazy everyplace else. I've had a bad day or whatever and I can come in and it's quiet and I can sit down and I don't have to explain to anybody, I don't have to talk to anybody. I can just sit here, meditate a little bit or whatever - and feel better. I want to get to the place where I just feel good about my residence where I live and I think that'll make a better me. Because I think clutter causes confusion in the mind, in the brain. I think it does. And I will be so much - much more of a peaceful person once I get a lot of this out. I think I'll just feel better about myself and - everything.

In these ways, growing older gave participants a different perspective on their belongings and their home environments. Several participants recognized that the reasons they had originally kept items may no longer be valid for them. Additionally, some found that having fewer belongings and decreasing the clutter in their homes imparted greater value to their quality of life in their later years. These changes in perspective served as motivating factors, encouraging some participants in this study to discard items.

"Doing It Now" While Still in Control

Growing older brought with it potential threats to participants' ability to remain in control of their belongings. Taking steps to discard items while they were still able to was

a factor motivating thirteen participants to make changes in their home environments. It inspired a sense of urgency to sort and clear things out while they are still physically able to do so, or before they lost control over the decisions about their belongings to someone else. Therefore, these participants expressed their intention to clear items from the home sooner than later. Nine individuals recognized that as they aged, it would likely become harder for them to accomplish the tasks related to clearing their homes, as expressed by these two participants:

> [Participant #18, male, age 65]
> Well, there's that intellectual understanding that I'm not going to use it all, you know, that I'm going to die and some - a lot of those books are going to be unread and a lot of those t-shirts are going to be in great shape. [chuckle] [I]n ten years I'm not going to be as spry as I am now and I'm not going to be as able to deal with stuff so I'm - you know - I'd rather prepare a nice, easy to live in house or easy to get out house, easy to sell, now than when I'm 75 or 85.

> [Participant #5, female, age 69]
> I figure I want to deal with it now and not, you know, if I get older and frailer and it's more difficult.

Participants discussed how their motivation to clear items from their homes stemmed not only from concerns about declining health but also losing control of the decisions to others. A few participants shared that they did not want to leave these decisions, and the burdensome task of sorting through belongings, to adult children, as expressed by this participant:

> [Participant #21, female, age 81]
> My greatest fear is dying before I'm rid of everything because I don't want my children to have to go through this. So I really have pressure on myself. Not that I feel like I'm going to die, I've got lots of things wrong with me but none of them are life threatening, I don't think. I mean, that I know of.

Alternatively, a few participants expressed fears of relinquishing control of their belongings to an outsider, such as a social worker. Losing control over their items was viewed by a few participants as a step toward losing control of other decisions in their lives to others, as expressed by this participant:

> [Participant #17, female, age 72]
> P: I want to clear this out because I can do some things. I know I can do some things.
> I: Yeah. And what are your thoughts about your ability to do these things as you get older?
> P: Well, I imagine it will be less - it will be harder and harder, you know. I don't want to be one of those people who [hears] the knock on the door and it turns out to be a social worker, you know. And I don't want my kids to take over.

However, concerns about maintaining control of the final disposition of items was not universally held by participants. In contrast, two participants described the relief and comfort they felt knowing that when they died, they had selected someone who they trusted to sort through and discard their belongings:

> [Participant #12, female, age 83]
> P: I told my friend [who] will get this house, "When you come in this house when I'm gone and you're going through stuff just remember there's trash and treasures all mixed. Look at everything that you're going to throw away, don't just blindly throw something away. My family, I made no provision for them. They would see everything as junk - guitars, accordions, banjos, records, tape machines, all that. Um - so, um -
> I: Do you think she'll do a good job at sorting it?
> P: She's a musician so she will. I can't control that. I'll be gone. How can I care?
>
> [Participant #16, female, age 82, and husband, age 81]
> P: Okay, I want to tell you something. [My friend], the one who came yesterday, she's the one after I die she's going to take care of my junk. She says, "Don't worry." That's the reason -
> Husband: Don't count on her.
> P: - I show it to her. She's - she's my executor. Him and my will, she's the one. Soon after we both die she going to come here, take care of anything that she

wants. So I show my junk and she say, "Oh, don't worry. Don't worry, just leave it. I will take care," she say.
I: Yeah. So you feel - does that make you feel good that -
P: Yeah, I feel, "Oh, somebody going to take care, somebody I love." And I know since she was 4 years old. Just like I'm feeling like my daughter. She can see anything, anything that she wanted she can use to have it and throw everything in the Pacific Ocean outside.
I: [chuckle] So you don't really mind what she does with it, you just trust that she'll take care of things.
P: That's right. I won't mind, just anything.
Husband: She won't be here then. [chuckle]

These quotes illustrate the ways in which aging influences the way participants think about their belongings and their home environments. While it is often difficult for participants to sort through and make decisions about discarding items, for many, growing older has provided them with an opportunity to reevaluate what is valuable to them. This re-assessment includes the value of certain belongings they have kept, as well as evaluating how they have kept their home in general and the way in which it impacts their quality of life. Recognizing that their health may decline and that their time may be limited provides motivation for some participants to work on discarding items. Fears of leaving their belongings for others such as adult children to sort through, or losing control of their belongings to social service workers provided additional push for some individuals to take action. However, for a few participants, it was comforting to know that if they died before they had discarded their belongings, it would be left to someone else and it would be out of their control. These factors that influence their motivation to discard items are unique or more salient to older adults than to younger adults. They highlight one potentially positive way in which aging influences hoarding and cluttering behaviors in older adults.

Conclusions

Participants in this study all discussed their hoarding and cluttering behaviors and the impact of these behaviors on their lives. Through their narratives, they described a process of accumulation, consisting of three phases in which they acquired, maintained and discarded items. Within each phase, participants outlined various factors that influenced their behaviors. Some of these factors, such as acquiring items because it is pleasurable to do so, or keeping items because they reflect a personal value, appear to be common to individuals of any age with hoarding behaviors. However, additional factors mentioned by participants are unique or more salient to older adults. These age-related factors can be summarized into three categories: changes in health status, changes in social context, and changes in home environment.

Summary of Age-Related Factors that Influence the Process of Accumulation

In the acquisition phase, participants told me that being on a fixed retirement income was one reason they bought extra items when they were on sale. To their minds, buying items in advance at a discount was one way to maximize their limited income. Another reason some of these older adults bought items was because they had lost their sense of purpose and place in society and the act of going shopping, usually at a local thrift store, gave them an opportunity to engage in a meaningful activity and social interactions. Participants who passively acquired items described accepting items, often pieces of furniture, from friends or family members who had died. While these items were initially welcomed because of their sentimental value, they were often unneeded and participants felt both guilty about and burdened by disposing the items. Aging in place resulted in the accumulation items over decades, creating layer upon layer of

belongings in some households. However, for others who moved in late life, the act of sorting and discarding things often did not take place before belongings were packed and moved. More often than not, once the participant was in their new home, they did not fully unpack and organize their belongings, but left them in stacked towers of boxes, giving their living rooms and bedrooms the appearance of storage lockers.

In the phase of maintaining items, participants described the meaning items held for them and the reasons they saved items. While individuals of all ages keep items that remind them of their personal history, older adults, by nature of being older and having lived through more experiences, kept items that spanned a longer period of time than younger adults with these behaviors would have. Participants also described traumatic events in their past where resources were scarce, and said how keeping items that they currently own gives them a sense of security over future needs.

Participants described the outcomes they experienced as outcomes from living in crowded, cluttered home environments and the strategies they employed to manage at home. Outcomes included interference with activities of daily living, limitations on pleasurable activities and increased isolation, negative effects on physical and mental health, and increased conflicts with others. While these are possible outcomes for anyone with hoarding behaviors, it is clear from the participants' stories that these outcomes are compounded by age-related issues such as health changes and changes in social roles and support. Likewise, as participants discussed strategies they employed to either adapt to or change their environments, age-related factors, particularly declining health and levels of energy, undermined the effectiveness of these strategies.

In addition to health concerns, participants described cognitive difficulties with tasks involving executive functions, difficulty overcoming anxieties and worries, and challenges with logistics as barriers to discarding items. These barriers, in combination with the reasons to keep items, effectively created a blockage preventing items from being discarded from the home. According to participants' narratives, it is this blockage that leads to the crowded and cluttered home environments characteristic of those with hoarding and cluttering behaviors.

In the final phase of discarding, some participants discussed how growing older has given them new perspectives on their belongings. This has led some to reevaluate the value of keeping certain items and the risks of living in such cluttered environments. For example, several participants discussed how they no longer needed work related clothes and paper files now that they were retired and these items could potentially be discarded. Identifying items that no longer had value to them was only the first step toward discarding items. All of the participants reported struggling to find the motivation to engage in the process of discarding items. However, several participants described how factors related to growing older motivated them to take on these tasks. Nine participants felt they wanted to decrease the volume of items in their homes before their health declined and were no longer physically able to do so. Other participants expressed dismay over the idea of burdening adult children with the task of sorting through and discarding belongings after their death. Similarly, other participants voiced fears that they would lose control of their belongings to family members or others, such as someone from social services, if they did not take care of these matters first. In contrast, two participants described how growing older had been a disincentive to clearing their home.

These participants took comfort in the fact that they had designated someone they trusted to handle their belongings after they had died, absolving them from their responsibility to do so while they were alive. In these ways, participants explained to me the ways in which growing older influenced their hoarding and cluttering behaviors.

Emergence of Two Types of Older Adults with Hoarding Behaviors

In addition to this age-related finding, another important finding has emerged from participants' data. As the various factors related to acquiring, maintaining, and discarding were compared and contrasted across participants, two distinct "types" of individuals with hoarding and cluttering behaviors emerged. I call these two types the "Impulsive Acquirers" and the "Anxious Keepers" (Table 2).

Table 2: Comparison of the predominant factors that distinguish "Impulsive Acquirer" and "Anxious Keeper" Participant Types

	Impulsive Acquirer	**Anxious Keeper**
Number of participants	9 (5 of the 6 men)	13 (1 man)
Stability or change in living situation	Age in place (8 of 9)	Move in late life (10 of 13)
Self-reported mental health issues	Symptoms of ADHD and impulsivity (9 of 9)	Diagnoses of specific anxiety disorders (OCD, Panic, PTSD, Agoraphobia); symptoms or diagnosis of depression (10 of 13)
Primary mode and reasons to acquire	Active, impulsive, thrill of "gaming the system"	Active acquisition related to social connections/something to do, plus passive acquisition
Reasons to keep items	Items reflect personal interests, past experiences	Items represent security, control over future uncertainty, safeguard against worry
Strategy for managing	Adapt to environment	Change the environment
Barriers to discarding	Difficulty with logistics, perfectionism	Difficulty with sorting & decision making tasks; declining health
Motivation to discard	Lower motivation	Higher motivation
Outcomes	Interference with ADLs	Interference with ADLs, limits on pleasurable activities, increased isolation, negative effects on mental health

Nine participants fell into the "Impulsive Acquirers" group, and interestingly, five of the six men in this study are in this group. These individuals primarily engaged in active, impulsive acquisition of items and described the thrill they felt when they had outwitted or manipulated others to acquire items for free or at significant discount. When asked about the meaning of the items they acquire, these individuals described personal factors, such as reflecting their personality or a characteristic they value, items that reflect a part of their personal history, or things that are part of pastimes or hobbies they enjoy currently or have enjoyed in the past. Rarely did these participants report that their belongings were kept primarily as security against future needs or potential times of scarcity. Eight of the nine participants in this group had aged in place and lived in their present home for decades. They tended to describe adaptive strategies for managing in their home environments, rather than strategies to change their living situations. In fact, several seemed rather indifferent about the severely crowded state of their homes. The main outcome of living in crowded, cluttered homes for individuals in this group was interference with ADLs due to the accumulation of belongings. These participants generally were not very motivated to discard items, but those who had tried were likely to describe difficulties related to logistics as a barrier to discarding items.

In contrast to the "Impulsive Acquirers", thirteen participants fell into a group I have called the "Anxious Keepers". Participants in this group reported both active and passive modes of acquisition. Those who actively acquired items discussed this in relation to wanting to have "something to do" or buying items on sale because they were on a fixed income, rather than on impulse or for the thrill of the hunt. The primary outcomes identified by members of this group were negative effects on mental health,

limitations on pleasurable activities and increased isolation, and interference with ADLs. Of the thirteen individuals in this group, ten had moved in late life. These participants were more likely to employ strategies aimed at changing their environment than those in the "Impulsive Acquirers" group. Stories relayed by the "Anxious Keepers" reflected a much greater sense of dismay at living in cluttered homes and greater motivation to make decrease the volume of items compared with the other group. Rather than challenges related to logistics, these individuals identified difficulties with executive functioning tasks, coping with anxiety and worry, and declining health as barriers to discarding items.

These two groups describe distinctly different patterns of behaviors related to their acquisition of belongings and reasons for their crowded, cluttered home environments. These differences may be due to different sets of cognitive processes or deficits among the two groups. When I compared the participants' self-reported mental health co-morbidities, I found evidence of potential differences between the two groups. Those in the "Impulsive Acquirers" group were more likely to describe a number of symptoms, including difficulty with impulse control, that are associated with attention deficit/hyperactivity disorder, compared to those in the "Anxious Keeper" group. In fact, a few had told me they either had been diagnosed with ADHD or suspected they might have the disorder. In contrast, those in the "Anxious Keeper" group frequently told me they had been diagnosed with a specific anxiety disorder such as OCD, panic disorder, post-traumatic stress disorder (PTSD) or agoraphobia. Those in this "anxious" group were also more likely to report suffering from depression, either currently or in the past, compared to those in the "impulsive" group. Theses findings, while based on limited evidence, raises questions of whether there are measurable differences in Neurocognitive

functioning and in psychological co-morbidities among older adults with hoarding behaviors, and perhaps in adults with hoarding behaviors of any age.

These two findings, the influence of aging on hoarding and cluttering behaviors and the emergence of two distinct types of individuals with hoarding and cluttering behaviors have important implications on the ways in which we assess hoarding behaviors and the types of assistance and interventions we offer to older adults. A discussion of these implications, as well as a discussion of how these findings fit with the current body of literature on hoarding and cluttering behaviors, are the topic of Chapter V: Discussion.

CHAPTER V: DISCUSSION

Introduction

The two main findings from this qualitative study of older adults with hoarding and cluttering behaviors were the identification and description of the following: 1) age-related factors that influenced how participants acquired, maintained and discarded items; and 2) two emerging "types" of individuals with hoarding and cluttering behaviors. These findings contribute new information to the current body of literature on older adults with hoarding and cluttering behaviors. The purpose of this chapter is to put the present study's findings in context of existing published research, discussing where they support or differ from those found by others and identifying where they fill gaps in our knowledge. Limitations of the study are discussed, as well as the implications of the findings for clinicians. The chapter concludes with a discussion of the questions generated by this study and areas where additional research is needed.

Study Findings in Context of Existing Research Literature

Research studies have been pointing to an increased prevalence of hoarding disorder in older adults (Samuels et al., 2008) as well as increased symptom severity as individuals grow older (Ayers et al., 2010). However, little information has been available to explain why this is the case. In this study, participants gave us clear examples of the age-related factors that influenced their hoarding and cluttering behaviors and contributed to worse outcomes as a result of their living environment. However, they also described ways in which growing older provided them with an opportunity to reevaluate the value of their belongings and motivated them to work toward discarding items while they were able to do so. Age-related factors fell into three categories: changes in health

status, changes in social context, and changes in their home environment. Participants described ways in which these age-related factors affected all three phases of accumulation; acquiring, maintaining and discarding. In addition, data from study participants has lead to the identification of two "types" of individuals with hoarding and cluttering behaviors, the *Impulsive Acquirers* and the *Anxious Keepers*. In this section, these findings will be put into context with existing research literature.

Age-Related Factors

Changes in Health Status

Many participants in the present study described the ways health changes, including mobility limitations and changes in energy level, decreased their ability to engage in organizational and discarding tasks in their homes. While several other researchers have noted the presence of health impairments in older adults with hoarding behaviors (Andersen et al., 2008; Ayers et al., 2010; Chapin et al., 2010), until now, only one has described the effects of declining health on older adults' ability to organize and discard belongings. Turner et al. (2010) provided case descriptions of the six older adults who participated in their intervention study, noting that health issues contributed to participants becoming tired easily and having difficulty moving and sorting items over extended periods of time. This caused them to modify their treatment protocol to allow therapists and clients more time to complete tasks. Turner and colleagues also described modifying the intervention to encourage participant-initiated discussions of their declining health and thoughts about their end of life. Therapists providing the intervention found these discussions helped some participants to re-evaluate the value of items, reorder priorities, accept more help and discard more items so that they could

better enjoy their lives in the present. Turner's findings are echoed by some participants in the present study who suggested that growing older can provide motivation to decrease the clutter and volume of items in the home and improve their present quality of life while they are still able to do so.

Changes in Social Context

Participants in the present study identified widowhood, loss of work and social roles, and alterations in finances as social factors that influenced their process of accumulation and contributed to negative outcomes as a result of their behaviors. Although very little research attention has been given to the dynamic between hoarding and cluttering behaviors and changes in the social context of older adults, several studies provide support for the current findings. In several studies, older adults reported that their hoarding behaviors became worse in response to life transitions such as moving or the death of a family member or spouse (Andersen et al., 2008; Ayers et al., 2010; Franks et al., 2004; Turner et al., 2010). In a phenomenological study of eight older adults with hoarding behavior, Anderson (2008) described five categories that captured the reasons why older adults kept items. Three of these reflected changes in the older adults' social roles: "Feeling Connected and Socially Engaged", "Feeling Needed by Others", and "Feeling Proud and Productive" (Andersen et al., 2008). Anderson described how isolated most of the participants were and how their belongings filled the void left when social roles are lost. Similar to the findings in the current study, one individual noted how acquiring items and managing her belongings became her "work" and made her feel productive.

In Cermele (2001), a change in social supports was identified as the motivation for the 72 year old woman with hoarding behaviors to participate in the intervention provided by the researchers. By selling her home and moving closer to her daughter, this individual hoped to restore the social support she lost when her daughters' family moved out of the area. Beyond these few examples, there has been limited discussion of how social changes in late-life affects the process of accumulation or influence the outcomes of living in crowded, cluttered homes.

In addition to the social changes mentioned above, participants in the current study identified how being on a fixed and limited retirement income influenced their ideas about acquiring, keeping, and discarding items. This age-related factor has not been discussed prior to this study. Thus, financial worries may be an additional reason why hoarding and cluttering behaviors become more problematic in late life.

Changes in Home Environment

The home environment is discussed by most researchers when describing the overall context of hoarding behaviors, and it is often noted whether the individual lives in an apartment (often subsidized housing for low-income adults or seniors) or privately owned homes (often single-family houses). Those who own their own homes tend to have lived there for decades, while those living in subsidized apartments are more likely to have moved within the past decade (Franks et al., 2004; Turner et al., 2010), a finding that is supported by data from the present study. However, little attention has been paid to specific ways that either aging in place or moving in late life impact hoarding behaviors. Based on data from the present study, these factors are important and contribute unique information about the reasons why homes have become overly crowded.

In the present study, several participants who lived in their homes for decades described how items accumulate over time. Their reports descriptions provide us with a clearer understanding of how aging in place impacts the process of accumulation than those described in previous studies (Andersen et al., 2008; Cermele et al., 2001; Franks et al., 2004). Other participants in the present study discussed how moving in late life resulted in an unexpected consequence of greater accumulation of items. This outcome resulted from not being able to sort through and discard items prior to moving as well as not being able to fully unpack after the move. While there are several examples in the literature of older adults with hoarding behaviors who live in apartments and who might have moved in the recent past (Andersen et al., 2008; Bratiotis & Flowers, 2010; Turner et al., 2010), few have discussed the impact of moving on hoarding behaviors. Two researchers identified moving in late life, often from a larger to a smaller residence, as a factor that impacted the hoarding behaviors of three older adults (Andersen et al., 2008; Turner et al., 2010). In two of these cases (Andersen et al., 2008; Turner et al., 2010), a significant number of belongings were discarded prior to the move, and in one example decisions were made by a family member without the older adult's consent (Andersen et al., 2008). As a result of these moves, the older adults felt even more attached to the belongings that remained. In a third case (Turner et al., 2010), the impact of a move from a 2-bedroom to 1-bedroom apartment was not explicitly described, however it resulted in the apartment management insisting on a reduction of the volume of belongings. Thus, it could be that the move resulted in stacks of unpacked boxes much like those seen in the homes of some of the current study participants' homes. Thus, the impact of moving as

an older adult on hoarding behaviors as described in the current study represents a new finding that has not previously been discussed and warrants further investigation.

Several researchers (Bratiotis & Flowers, 2010; Chapin et al., 2010; Franks et al., 2004) have found that older adults living in crowded, cluttered living environments are often in conflicts with others, such as housing managers and public health authorities, and are at risk for eviction. Other studies indicate that adults with hoarding behaviors have impaired personal relationships as well, often as a result of conflicts over the home environment (Grisham, Steketee, & Frost, 2008; Wilbram et al., 2008). Many participants in the present study reported conflicts with others, including family members, landlords or property managers, work supervisors, and public health officials, however only one participant had been threatened with eviction and none of them had been forced to move due to problems related to their hoarding disorder. Deferred home maintenance and repairs was mentioned by all of the participants in the present study who owned their homes, and additional examples of such disrepair can be found in the literature (Bratiotis & Flowers, 2010; Chapin et al., 2010; Franks et al., 2004; Kim et al., 2001).

The low number of study participants who were at risk of being removed from their homes by authorities is consistent with several studies (Andersen et al., 2008; Ayers et al., 2010) but is in contrast to others in which evictions were a common outcome (Chapin et al., 2010; Franks et al., 2004) or preventing evictions was a significant goal (Bratiotis & Flowers, 2010). This likely reflects differences in the sampling strategies for the various studies; individuals in the present study and in Anderson's study were primarily recruited through elder service agencies providing case management services,

while participants enrolled in studies by Bratiotis, Franks, and Chapin after coming to the attention of agencies such as Adult Protective Services and Police or Fire Code enforcers. Thus, the severity of the living conditions in these later studies may have been worse than those in the present study.

A unique finding in the present study was the description by one older adult of a conflict with supervisors at work. This finding is consistent with reports of significant work impairment related to hoarding behaviors found in the general population (Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009; Tolin, Frost, Steketee, Gray et al., 2008). It is possible that as the work-force grows older and adults remain in their jobs longer than in previous generations, there will be more reports of work-related conflicts associated with hoarding behaviors involving older adults.

Thus, many of the age-related factors identified in the present study support or expand upon factors identified by others studying older adults with hoarding disorder. In addition, new factors emerged from this study group that warrant further study, most notably the effect of moving in late life on the process of accumulation. Data from this study support the notion that age-related factors contribute to changes in hoarding behaviors, often worsening the symptoms and outcomes of the behaviors, rather than acting as a trigger for a true "late onset" of behaviors.

"Types" of Individuals with Hoarding and Cluttering Behaviors

A three phased process of accumulation emerged from the data that included acquiring, maintaining, and discarding. In addition to the age-related factors described above that influence this process, there are also factors unrelated to aging that were

described by participants, such as impulsive acquisition of items and difficulty sorting and organizing, tasks that involve executive functioning cognitive processes. When looking across all of the factors identified by participants as influencing the process of accumulation, two distinct "types" of individuals with hoarding behaviors began to appear and there is evidence in the research literature to support these findings.

Impulsive Acquirers

Participants who acquired items impulsively and who made plans to exploit loop-holes in order to get deals described behaviors that were akin to compulsive shopping and other impulse control disorders. This fits with existing research that has found impulsivity in younger adults with hoarding behaviors (Grisham, Brown, Savage, Steketee, & Barlow, 2007), and hoarding behaviors in those who compulsively gamble (Frost et al., 2001).

Recent studies involving older adults identified impaired impulse control as a factor contributing to hoarding behavior in two very different study populations. In a large population based study in Germany, researchers found correlation between measures of compulsive buying and the acquisition and clutter subscales of the German Compulsive Hoarding Inventory scale, but not on the difficulty discarding subscale (Mueller et al., 2009), indicating that hoarding related acquisition and compulsive buying behaviors may go hand-in-hand. In a novel study of hoarding behaviors in older adults with Parkinson's disease, O'Sullivan et al. (2010) assessed whether these adults, who often developed impulse control impairments as a result of their disease process, also reported hoarding behaviors. Study participants with high scores on the acquiring and clutter subscales of the Savings Inventory-Revised (SI-R, Frost et al., 2004), also scored

high on scales of impulsive buying and other measures of impulsive behaviors, but not with the difficulty discarding subscale of the SI-R. Results from these two studies suggest that for some individuals with hoarding behaviors, acquisition may be related to impulse control, but that impulsive acquisition does not necessarily correlate with difficulty discarding items.

Participants in the *Impulsive Acquirers* group expressed a similar pattern as found by Mueller (2009) and O'Sullivan (2010). Several participants in this group told me they would be willing to part with a large quantity of items in order to make more room in their homes, but the logistics of doing this, including finding someone to help them as well as finding the time to do it, prevented them from taking action. Thus, it was easier for them to adapt to their crowded homes than to take steps to change the situation that had developed.

It is interesting to note that five of the six men in this study fell into the *Impulsive Acquirers* group. Only one other study on hoarding behaviors has identified differences based on gender. Wheaton and colleagues (2007) compared a range of comorbid psychiatric disorders in a sample of adults with OCD with and without hoarding behaviors. They found that male OCD participants with hoarding behaviors had more social phobia than did male OCD participants who did not hoard, while female OCD patients with hoarding behaviors were more likely to have bipolar disorder, alcohol, substance abuse and binge-eating disorders, panic disorder and social phobia compared to female OCD participants who did not hoard. Unfortunately, impulse control disorders were not evaluated as part of this study. Thus, the suggestion that men with hoarding

behaviors may have more difficulty with impulse control, and that this impacts their acquisition of items is new and requires further study.

Those in the *Impulsive Acquirer* group also expressed greater indifference about their living environments in comparison to those in the *Anxious Keepers* group, even though some of these participants' homes had the greatest number of items and the most restricted living space as a result of the accumulation of items. These participants discussed the ways in which their excessive belongings interfered with their ability to conduct activities of daily living, but most found ways to socialize outside of the home and did not express the same degree of embarrassment, shame, or mental anguish from their home environments as did those in the *Anxious Keeper* group.

Anxious Keepers

Participants in this group described both active and passive modes of acquiring items, although they typically did not express the same types of impulsive behavior described by those in the *Impulsive Acquirer* group. What is most significant about this group is the degree of mental anguish and stress they reported as a result of living in crowded, cluttered homes. Individuals in this group described greater isolation and difficulty maintaining social relationships because of their home environments compared to participants in the other group. Examples of older adults who were embarrassed by their home environments and who felt isolated because they did not want others to see the condition of their homes exist in the literature (Ayers et al., 2010; Cermele et al., 2001). In addition, several researchers have found that older adults with hoarding behaviors tend to be socially isolated and limit others' access to their homes (Bratiotis & Flowers, 2010; Chapin et al., 2010; Kim et al., 2001). However, there has been limited discussion about

the reasons why some participants experience shame or embarrassment about their home environment and others do not.

Two other distinguishing features of the *Anxious Keeper* group were the effort they exerted trying to sort and organize their belongings, and the anxiety they expressed about their environment in general as well as in their judgment about the disposition of items. The ways in which individuals in this group described their struggles with organizational tasks were similar to the difficulties with executive functioning tasks reported in a group of older adults with depression and hoarding behaviors (Mackin et al., 2011), and in studies involving younger adults (Grisham et al., 2010; Lawrence et al., 2006). While it is possible that both the *Impulsive Acquirer* and the *Anxious Keeper* groups have impairments in executive functioning, those in the *Anxious Keeper* group were more likely to engage in tasks involving executive functioning and as a result become frustrated and discouraged when their attempts did not produce the intended results.

Two studies provide additional support for the concept that anxious individuals may have a common set of hoarding behaviors. In one study, researchers evaluated personality traits among a sample of young adults (average age 28) with OCD (Fullana et al., 2004). They found that those with hoarding symptoms were more likely to be "sensitive to punishment", leading to fears of making mistakes and causing harm by their actions, as well as scoring lower on "novelty seeking" and impulsivity scales, compared to those with other OCD symptoms. These findings support the idea that those who are more anxious (as in Fullana's sample of patients with OCD) are also less impulsive. Likewise, when an individual who fits the *Anxious Keeper* description decides to seek

help for their behaviors and change their home environment, this decision may result in increased levels of anxiety. In a sample of adults seeking treatment for anxiety, 15% of adults with social phobia, 17% of those with obsessive compulsive disorder, and 28% with generalized anxiety disorder also reported significant problems with hoarding when asked by researchers (Tolin, Meunier, Frost, & Steketee, 2011). Another way of interpreting these findings is that those who experience more anxiety associated with their hoarding behaviors may be more likely to seek treatment to improve their situation compared to those who are more indifferent about their cluttered living environments.

Other researchers have distinguished different types of individuals with hoarding behaviors. In a study of 18 older adults, Ayers et al. (2010) noted in their discussion that two groups emerged: those with one or more co-morbid mood or anxiety disorders and those without. Unfortunately, the researchers did not discuss whether any differences were found in the age of onset, course, or clinical characteristics that were assessed based on group membership. However, their finding on co-morbid mood and anxiety disorders may parallel results from this study, as those in the *Anxious Keeper* group reported greater mental distress and anxiety than did those in the *Impulsive Acquirer* group.

Frost and colleagues (2009) sought to identify two different groups by examining information gathered from 878 self-identified hoarders in a large internet based study to see if there were differences between those who "actively" and "passively" acquired items. Active acquisition was defined as excessively buying or acquiring free items and passive acquisition was defined as "not excessively acquiring" or "no acquiring". The researchers found that active, excessive acquisition of items contributed to homes with greater degrees of clutter and accumulation of items. However, in contrast to the findings

from the present study, Frost et al. found that participants who excessively acquired items had greater distress and interference as a result compared to those who did not actively acquire items. Only 15% of the study participants in Frost (2009) reported not acquiring items actively, and individuals in this group showed much less clutter severity, less interference, distress and stress as a result of their behaviors, as well as fewer symptoms of co-morbid depression and anxiety compared to those who excessively acquired. Since the majority of participants in Frost (2009) reported active acquisition of items and with it, the cluttered living conditions, interference, and impairments typically associated with hoarding behaviors, the researchers concluded that if two types of hoarding behaviors existed based on different modes of acquisition, the passive acquisition type represented a much milder form of the behavior and resulted in less problematic outcomes.

These conclusions drawn about different "types" of hoarding behaviors by Frost and colleagues differs from the findings presented in this study. This may be due to the single dimension of acquisition they used to differentiate their groups. In the present study, it was not simply the mode of acquisition, but variations described by participants in the reasons that drove their acquisition of items, caused them to keep items, and discouraged them from discarding items, that were important to consider when distinguishing one group from the other.

Limitations

There are several important limitations to this study. A study sample of 22 participants is generally considered to be relatively large in qualitative research, where it is not uncommon to report in depth analyses of data from 5 to 10 participants. However,

it is a small sample in the larger scientific context which limits the generalizability of the findings. Furthermore, any gender differences found are based on the participation of six men, and can only be used to indicate areas of interest for further study.

The recruitment strategy required participants to identify themselves as individuals who were "overwhelmed by too much stuff", as described on the recruitment flyer, and were willing to discuss their hoarding and cluttering behaviors with a nurse researcher from a local university. Thus, the individuals who came forward had sufficient insight into their behaviors and were comfortable enough with their home environments to allow the interview to take place. Therefore, study participants do not represent all older adults with hoarding and cluttering behaviors. Participants in the current study may have had less severe cases of hoarding disorder, or be more functional in their home environments than others who did not volunteer for the study.

The recruitment strategy achieved moderate success in recruiting participants from a range of socioeconomic backgrounds and ethnic groups; housing situations varied from low-income, federally subsidized apartments in dense, urban areas to privately owned homes in well-to-do suburbs and five different racial or ethnic groups were represented. However, it is likely that those in the lowest socioeconomic group were underrepresented in this sample. For example, two individuals who lived in small single-room occupancy hotel rooms in downtown San Francisco contacted me and expressed interest in participating in the study, but were not enrolled. One woman changed her mind and refused to allow me into her room on the day of the interview. Through the doorway, which she opened just a crack in order to speak with me, I could see her small room was filled floor to ceiling with belongings. She informed me that as the day of our

appointment grew closer, she became more uncomfortable with me seeing the condition of her living space and she was not interested in conducting the interview elsewhere. A man who had called me and was interested in participating in the study died a few days before the interview was scheduled to take place. I was unable to discover the cause of his death, but I did learn through an employee at the residential hotel that he had been in very poor health. These two examples suggest that the severity of hoarding behaviors and related anxiety, as well as the impact of health factors on individuals who did not agree to participate in the present study may be greater than those represented by the study sample.

All psychological conditions, such as depression and anxiety, and cognitive difficulties such as decision making, focusing attention, sorting and organizing items, were self-reported by the participants. No formal psychological assessments were made during the study. Participants' reports of the psychological distress they experience as a result of living in cluttered homes can only be used as illustrations of how their home environments impact their day to day lives, and not as definitive evidence of the presence of these conditions.

Implications for Clinicians

Even within the constraints imposed by the limitations, the results from this study have important implications for a wide variety of clinicians who are working with older adults with hoarding behaviors. Results from this study support the conceptualization of hoarding disorder as a chronic set of behaviors that are affected by age-related changes. As such, nurses, social workers, psychologists and case managers should assess for age-

related factors identified in this study that may complicate or worsen outcomes for older adults with hoarding disorder. In addition, evaluating whether older adults fit into either the *Impulsive Acquiring* or *Anxious Keeper* type may guide clinicians in selecting interventions appropriate for particular individuals. In the following section, these clinical implications are discussed in more detail.

Age-Related Factors and Their Influence on Accumulation

Identifying New Strategies to Address Age-Related Factors

Clinicians should be advised to assess for the age-related factors identified in this study that affect the acquiring, maintaining, and discarding phases of the process of accumulation. Specific strategies could be developed to address these factors, helping clinicians tailor specific interventions to the individual. For example, some participants in the current study acquired items because going shopping was a convenient way to fill ones' day and engage in social interactions. Encouraging individuals such as these to not acquire items without offering a substitute social activity to replace the positive reinforcement they receive from shopping is unlikely to be successful. Clinicians might discuss various volunteer or part-time work opportunities with older adults who feel the have lost their role in society. Helping the older adult connect with organizations that interest them and supporting them as they transition away from old patterns of behavior and into their new roles will be important tasks for clinicians.

Likewise, by discussing the factors that lead to the blockage of items in the home, clinicians may learn that the logistics of discarding items has become a barrier. Several older adults in this study said they would rather donate items to a specific charity such as a women's shelter, than to a large, general organization such as Goodwill. Others stated

they would sell collectable items if only they could navigate online resale websites like Craigslist or eBay. Helping the older adult identify and connect with appropriate organizations to donate or recycle items, or services such as on-line consignment resellers may resolve some of these logistical barriers and facilitate the removal of items from the home. In addition, some study participants required physical help removing items they had identified for removal; another example of a logistical barrier that clinicians could work with the older adult to remove.

A new intervention that could be developed based on study findings is increased support for older adults with hoarding disorder prior to and following changes in residence. An intervention such as this could help older adults sort through and possibly discard items well in advance of their move as well as help them to unpack and organize belongings after the move. Providing support and assistance to older adults in this way could prevent problems associated with late-life moves described by study participants and improve outcomes in their new residences.

Modifying Existing Interventions to Accommodate for Age-Related Factors

Clinicians working with older adults should consider modifications to address the specific needs of older adults should be considered when adapting interventions developed for younger adults. As described by Turner (2010) and Bratiotis (2010), when working on organizational tasks with older adults, additional time and support may be needed to accommodate for health and energy limitations. Modifications for older adults might also capitalize on the perspective that growing older provides some individuals, allowing them to reevaluate the value of items they have kept and identify the drawbacks of living in crowded, cluttered environments. Evaluating the types of negative outcomes

older adults identify as results of their living environments, such as social isolation, negative physical and mental health effects, and limitations on their ability to engage in pleasurable activities, may help clinicians identify areas that individuals are willing to work to improve.

Certainly, it is unlikely that a single intervention on its own will result in positive changes in quality of life for older adults with hoarding behaviors. However, the new strategies suggested from this study may be useful additions to the tool chest available to clinicians.

Using "Types" to Guide Interventions

In addition to identifying age-related factors that influence hoarding behaviors, clinicians may find it helpful to determine whether the older adults they are working with fit into one of the two "types" described in this study. Such a determination may guide the clinician toward one set of interventions or another. For example, individuals in the *Impulsive Acquisition* group, tend to actively accumulate items and have low motivation to discard items. Focusing on strategies to reduce the number of new acquisitions will be important for members of this group. Additionally, some participants in this group reported they would be willing to discard certain categories of items, such as "newspapers and magazines older than 2 years old" as identified by one study participant, if someone was willing to help them cull these particular items and discard them. Working with the individual to overcome logistical barriers such as this may be an effective strategy.

In contrast, those in the *Anxious Keeper* group might voice greater motivation to decrease their clutter but will need a different set of strategies in order to accomplish their

goals. Since individuals in this group tend to keep items for fear they will need them in the future and report significant problems sorting through, organizing and making decisions about items, they will need strategies that address their worries and help them build decision making skills. Various cognitive behavioral therapies that address these issues may be appropriate for members of this group. It is possible that techniques such as mindfulness meditation that coach individuals to concentrate on the present rather than worrying about the future or reliving mistakes made in the past would also benefit these individuals.

Determining which strategies and interventions give an older adult with hoarding disorder the best chance at success will be a critical step for clinicians. Since many of these individuals have made several unsuccessful efforts to change their home environment, their confidence in their ability to effect change may be very low. A successful outcome will promote confidence in both the clinician and the individual that problems associated with the behaviors can be corrected. Considering the salient factors involved in the process of accumulation for an older adult with whom a clinician is working may indicate which "type" of hoarding behavior the individual has, thus guiding the clinician to select some interventions over others.

There is evidence in the literature that certain strategies work more effectively for some older adults than others. In an intervention study by Bratiotis and colleagues, nearly half of the participants in their study (n= 26) were able to discard items and maintain their progress independently after participating in their intervention for 4-6 months. These participants developed organizational and discarding skills and received logistical support from the therapeutic team who regularly removed the items the participant marked for

discarding from the home. Bratiotis describes the remaining participants as ones who had greater difficulty making decisions without the clinician's approval and who had greater difficulty focusing their attention on sorting and organizing tasks. Members of this later group were not able to maintain progress on their own and required ongoing involvement from the clinicians. Limited discussion was provided by Bratiotis et al. on the characteristics or factors that differentiated those who more readily responded to the intervention and those who did not. However, the older adults in their study may have had different patterns of acquiring, maintaining, and discarding items that are similar to the two groups described in the present study.

Areas for Further Research

In the sections above, findings from this study were discussed in the context of other research on younger and older adults with hoarding behaviors. Some of the present study findings are consistent with and support those found in existing research, and areas where the findings differed from those found by others were discussed. However, this study has highlighted issues that need further research and new questions that need investigation. In addition, there are outstanding questions about hoarding disorder in older adults that this study did not address. In this section, these areas for future research are summarized.

Issues for Further Study that Emerged from this Dissertation

Data from this study raised several questions that require further research. These include potential gender differences, potential differences based on cultural groups,

differences between "types" of hoarding behavior, the outcomes of age-related factors, and the role of traumatic events on hoarding behaviors in older adults.

Potential Gender Differences

It was surprising to find that five out of six of the men in this study showed similarities across various factors leading to the accumulation of their belongings. It raises the question of whether these similarities indicate true gender differences among older adults, or are an artifact of the small sample size in this study. If they do represent gender differences, are they specific to older adults or are they seen in younger populations?

Potential Cultural Differences

Another question requiring further exploration is whether there are differences in the course or outcome of hoarding behaviors based on cultural or ethnic backgrounds. While data from this study has not yet been fully analyzed to address this question, it is interesting to note that the three African-American participants were all part of the *Anxious Keeper* group and described times of financial scarcity in their past that contributed to their present decision to keep items. It is possible that differences exist within the five cultural groups represented in this sample. Many of the research studies on individuals with hoarding behaviors have included predominantly white samples, however, Chapin and colleagues (2010) found a disproportionate number of African Americans with hoarding behaviors in their study. More information on the influence of racial, cultural, and ethnic factors on hoarding disorders is needed. Therefore, even though the number of participants in this study is small, further evaluation of potential

differences between the cultural groups in this study would be valuable and may indicate additional avenues for future research.

"Types" of Hoarding Behaviors

Data from this study suggested two "types" of older adults with hoarding behaviors. Further study and clarification of these potential "types" is needed, as well as investigation into whether there is there a "mixed" type that includes some features from both groups. Thorough psychological evaluations and cognitive testing of older adults are needed to verify and support my findings of "anxiety", "impulsiveness", and "executive dysfunction" among these groups. In addition, the question remains as to whether these "types" are present in larger study samples of older adults as well as in younger adults.

Outcomes from Age-Related Factors

While several age-related factors were identified in this study that influence the process of accumulation, it is unclear to what extent these factors affect the outcome of these behaviors. For example, participants discussed how growing older has motivated them to discard items before they are unable to do so, but it is not clear whether their heightened motivation has resulted in an increased ability to part with belongings. Likewise, changes in health and energy status were described as a barrier to sorting, organizing and discarding items by several participants. However, it is unknown how much more effective they were at these tasks earlier in their lives, and by comparison, how much these health changes have impaired their current ability to complete these tasks. Thus, further study is needed to understand the degree to which age-related factors impact the outcomes for older adults with hoarding disorder, and which factors cause the greatest impairment. Better understanding of these factors will guide the development of

interventions that most effectively minimize negative outcomes related to hoarding behaviors.

Role of Life Transitions and Traumatic Events

Some researchers (Ayers et al., 2010; Turner et al., 2010) have debated whether late life transitions trigger a "late onset" of hoarding behaviors. Participants in the current study indicated that they either noticed hoarding and cluttering behaviors early in life, or recognized they had behavioral tendencies but that these were kept in check by their work routine, living with others, or some other protective mechanism that they no longer had. For participants in this study, changes in their health, social contexts, or living situation in late life often contributed to a worsening of their home environment. Thus, what other researchers hypothesize to be a "late onset" might simply be worsening of the outcomes or the emergence of latent accumulative tendencies as a result of late life changes.

Several participants discussed traumatic events or periods of hardship in their past that were significant to them and played a part in the development and maintenance of their hoarding behaviors. There is evidence from a study of younger adults that stressful life events and transitions, such as "employment or financial problems" and "loss of or change in relationships", are associated with greater hoarding severity and more symptoms of depression and anxiety (Tolin, Meunier et al., 2010). Clearly, this is an area that needs to be examined further with regard to the course of hoarding behaviors across the life span.

Outstanding Questions about Hoarding Disorder in Older Adults

Questions about the nature of hoarding disorder in older adults remain that were unaddressed by the current research study. As outlined in Chapter II: Literature Review,

there are three main gaps in our understanding of older adults with hoarding behaviors: how well data on younger adults apply to older adults; what differences exist in the course and outcomes of hoarding behaviors in older adults compared to younger adults; and what accounts for the overlap between hoarding behaviors and squalor or self-neglect in some older adults? Results from this study have contributed new information to our understanding of the course and outcomes of hoarding behaviors in older adults, but questions still remain. In this section, a brief discussion is presented on two of these outstanding questions; specifically, what effect does cognitive impairment or decline in older adults have on hoarding behaviors and what is the relationship between hoarding disorder, squalor and self-neglect, which are often observed together in older populations?

Effect of Cognitive Impairment or Decline on Hoarding Disorder

The findings from this study support the notion that hoarding behaviors is a chronic condition that can become worse as individuals grow older as a result of age-related factors. However, it is not clear from this study whether or to what degree cognitive decline contributes to these age-related changes in the behaviors. Certainly, hoarding behaviors were not a result of dementia or significant cognitive impairment this study sample, a finding that is supported by several other researchers who have also found that older adults with hoarding behaviors are not experiencing significant cognitive impairment or dementia (Ayers et al., 2010; Bratiotis & Flowers, 2010; Kim et al., 2001; Turner et al., 2010). At the same time, mild cognitive impairment was probable in at least two participants in this study, and certainly evidence is mounting that frontally mediated cognitive processes are affected in individuals with hoarding behaviors. While there is

some, albeit limited, evidence in the research literature that individuals with frontotemporal dementia may develop hoarding behaviors (Mendez & Shapira, 2008; Nakaaki et al., 2007), studies evaluating hoarding behaviors in older adults with Alzheimer's' disease (AD) generally have been methodologically flawed and do not provide evidence of hoarding behaviors in those with AD. Thus, the impact of cognitive impairment and decline on hoarding and cluttering behaviors is still unclear and warrants further research.

Overlap Between Hoarding Disorder, Squalor and Self-Neglect

This study does not provide insight into area of overlap between hoarding behaviors, squalor, and self-neglect. None of the participants who participated in this study had refuse, rotting food, or unsanitary conditions present in their homes. It may be that older adults with these issues chose not to participate in the study out of fear of alerting outsiders to their living conditions. On the informed consent form it clearly stated that the researcher was a mandated reporter of elder abuse, including self-neglect, and while potential participants with squalor issues would not have necessarily seen a copy of the informed consent, they may have surmised that a public health nurse conducting research might report the state of their homes to the proper authorities. Thus, the question remains: in what ways and under what conditions do hoarding behaviors, squalor, and self-neglect overlap? The factors that predict the presence of squalor and self-neglect in older adults with hoarding behaviors, the ways these additional issues affect the outcomes for older adults, and the interventions that are the most helpful and effective when hoarding is accompanied by squalor or self-neglect have yet to be explored. Research into

these overlapping conditions is greatly needed because they represent some of the most challenging scenarios for families and community agencies to address.

While great strides have been made in the past decade to better understand hoarding disorder in older adults, it is evident that there remain several important gaps in our understanding. Several directions for future research have been outlined above that will further develop our knowledge base and will guide new efforts to develop interventions and treatments for older adults with hoarding disorder.

CHAPTER VI: SUMMARY

Older adults with hoarding disorder may represent some of the most vulnerable individuals to the negative outcomes that often result from living in crowded, cluttered environments. Evidence suggests that hoarding disorder is more prevalent among older adults and symptoms of the disorder increase with age (Ayers et al., 2010; Samuels et al., 2008). However, the reasons for these differences between older and younger adults have not been clear. The goal of this dissertation study was to generate new data to begin to fill this gap in our understanding. A qualitative study was conducted that directly engaged older adults with hoarding behaviors, inviting them to share their experiences and the ways that growing older has affected their hoarding behaviors, home environments, and their day-to-day lives.

Twenty-two participants age 65 and over were interviewed in their homes for this study. Interviews and the researcher's field notes were transcribed and analyzed according to grounded theory methodology. What emerged from these data sources were descriptions of a process of accumulation that had three phases: acquiring, maintaining, and discarding. Within each phase, participants described specific factors that influenced their behaviors. Participants described how their desire to keep items combined with certain barriers to discarding items effectively created a blockage that restricted their ability to move from "maintaining" to the "discarding" phase of this process. Some of the factors identified by participants were ones that seem to be common among individuals of all ages. However, a number of these factors took on greater importance or saliency as participants grew older. In addition, new factors emerged that

were directly related to aging. These age-related factors fell into the categories of changes in health status, changes in social context, and changes in home environment. In these ways, participants illustrated why older adults are more negatively affected by hoarding behaviors than their younger counterparts.

In the process of analyzing data from this study, patterns of behaviors emerged that suggested two different types of individuals with hoarding behaviors. These two groups have been called *Impulsive Acquirers* and *Anxious Keepers*. The group names highlight one of the key differences among the two groups and the primary reason items collected in their homes. In the first group participants actively acquired items, often impulsively, but did not express much anxiety over deciding what items should be discarded (although other factors prevented them from discarding much). In contrast, those in the second group were more likely to passively acquire items and expressed far greater anxiety and distress over deciding what to discard, leading them to keep just about everything. These groups differed in other ways as well, such as how long they had lived in their homes and the degree to which hoarding behaviors interfered with their daily lives.

While this study has limitations, including the relatively small sample size, sampling bias whereby only those willing to discuss their hoarding behaviors were enrolled, and reliance on self-report of psychological and cognitive issues, the information gained from this study have important clinical implications and point to new directions for future research. Health and social service professionals can use findings from this study to modify interventions that were designed for younger adults, as well as develop new interventions to specifically address issues raised by older adults in this

study. Identifying whether an older adult falls into one "type" of behavior pattern or the other may help clinicians target the most important factors and select the most appropriate interventions for that individual. Additional research is needed to determine whether addressing age-related factors results in improved outcomes for older adults. In addition, further research on the "types" of hoarding behaviors identified in this study will clarify the similarities and differences between these two groups, as well as establish whether these groups exist in larger samples and in younger adults.

While there remain several gaps in our understanding of older adults with hoarding disorder, results from this study contribute new, meaningful information to the literature on this topic. It is my hope that clinicians and researchers will use these findings to guide the development of interventions and to direct future research studies. With the aging of the population in the United States and in many countries across the globe, research such as this that assists health and social service providers in their efforts to support older adults living independently in the community is of tremendous value.

> Throughout history, people of all cultures have assumed that environment influences behavior. More than two thousand years ago, Hippocrates' observation that our well-being is affected by our setting was established as a cornerstone of Western medicine. Now modern science is confirming that our actions, thoughts, and feelings are indeed shaped not just by our genes and neurochemistry, history and relationships, but also by our surroundings.
>
> --Winifred Gallagher, behavioral science writer and author of "The Power of Place: How our surroundings shape our thoughts, emotions and actions"

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APPENDICIES

Overwhelmed by too much stuff?

Do you have a large number of things in your home?

Do you have difficulty organizing your things or deciding what to throw away?

Does the volume of things in your home make it difficult to do everyday activities or affect your quality of life?

If you answered YES to these questions, you may have hoarding behaviors.

You are not alone.

As many as 4 million people in the U.S. have hoarding behaviors.

Often older adults encounter more difficulties related to their hoarding behaviors because they have other health issues or live alone.

A research study is taking place at the University of California, San Francisco to learn more about hoarding behaviors in older adults.

If you are 65 years old or older and think you may have hoarding behaviors, we invite you to participate in this important study.

By participating you will:

- Take part in a 90-minute private interview with a nurse researcher
- Receive $20 as a thank you for your time
- Help nurses, social workers, therapists and others better understand hoarding behaviors and how they affect older adults

If you would like to learn more about this study, we would like to hear from you!

Please call **Monika Eckfield, RN, PhD(c)** at **(650) 219-0555**.

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE IN A RESEARCH STUDY

Study Title: ***Exploring the Onset, Expression, and Effects of Hoarding and Cluttering Behaviors in Older Adults***

This is a research study to learn more about hoarding and cluttering behaviors in older adults. Monika Eckfield, RN, is a doctoral candidate who is working with Dr. Margaret Wallhagen in the Department of Physiological Nursing to conduct this research. Ms. Eckfield will explain this study to you. She is available to answer any questions you might have about the study.

Research studies only include people who agree to take part in them. You are being asked to consider taking part in the study because you may have a large number of things in your home, have difficulty organizing things or deciding what to throw away, or the amount of things in your home make it difficult for you to do everyday tasks or affects your quality of life in other ways. Please take your time to make your decision about participating in the study. You can talk about your whether or not you want to join the study with your family or friends if you wish.

Why is this study being done?
The purpose of this study is to understand how hoarding and cluttering behaviors affect older adults who live at home. The study is being paid for, in part, by the John A. Hartford Foundation, an organization that promotes research on the health and well-being of older adults, and by Freedom From Fear, a mental health advocacy organization.

How many people will take part in this study?
Between 20 and 30 people will be interviewed for this study.

What will happen if I take part in this research study?
If you agree to be in the study, here is what will happen:

- You will be interviewed by the researcher in a private place, either at your home or somewhere you feel comfortable. The researcher will ask you about the things you have saved, how you decide to keep or discard items, and about your daily activities. The researcher will also ask you about your general health and well being.

- The researcher will make a tape recording of your conversation. After the interview someone will type into a computer a transcription of what is on the tape

and will remove any mention of names. The tape recording will be kept in a secured location and erased when the study has ended.

- As a part of the interview, the researcher will show you a set of photographs of a kitchen, bedroom and living room in a house that ranges from no clutter to a very large amount of clutter. These pictures are called the "Clutter Image Rating" scale. You will be asked to pick out which picture you think looks most like that room in your home. The purpose of this scale is to make a general measurement of the clutter in your home and your answer will be used as one way to compare your experiences with others who are participating in the study.

- The researcher may also ask for your permission to take a photograph(s) of particular areas in your home. Any photographs that are taken would not include information that would identify you, such as your address, and you would not be in any of the photographs. The purpose of these photographs is to give a visual context for your interview responses. The photographs may be used as part of the researcher's scientific presentations about the study and could possibly be included in research articles about the study findings. This part of the study is optional and you may skip this part if you do not want photographs to be taken. If it is okay for the researcher to take a photograph(s) in your home for these purposes, please initial the statement below:

  "I consent to having non-identifying photographs taken of specific areas of my home for use in data analysis and scientific presentations." _____

- The researcher will interview you once, but after reviewing her notes, she might ask if she could talk with you a second time, but that is up to you. The researcher will not ask for more than two interviews. Each interview takes approximately 90 minutes.

How long will I be in the study?
Your participation in the study will take a total of about 90 minutes for each interview.

Can I stop being in the study?
Yes, you can decide to stop at any time. Just tell the study researcher if you wish to stop being in the study.

What side effects or risks can I expect from being in the study?

- The interview is time consuming and may be boring to you.

- Some of the questions in the interview may make you uncomfortable or upset, but it is ok to tell the researcher if you do not want to answer a certain question.

- The researcher is a "mandated reporter" of elder abuse. That means that if she observes elder abuse, gains knowledge of elder abuse, or if you tell her that you have experienced elder abuse, she is required to report it. Also, if she sees a health or safety situation that poses an immediate risk to you or to others, she is required by law to report it to the proper authorities.

Are there benefits to taking part in the study?
There will be no direct benefit to you from participating in the study. However, the information that you provide may help health professionals to better understand hoarding behaviors and how they affect the health and well being of older adults.

What other choices do I have if I do not take part in this study?
You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you.

Will information about me be kept private?
We will do our very best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. As we mentioned earlier, if there is an immediate threat to your health or others, or if there is evidence of elder abuse, by law we must give your personal information to the authorities. This is the *only* reason why your personal information would be shared. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

The only organization that may look at and/or copy your research records for purposes of research, quality assurance, and data analysis is the UCSF Committee on Human Research.

What are the costs of taking part in this study?
There will be no costs to you as a result of taking part in this study.

Will I be paid for taking part in the study?
Yes, you will be paid $20 for each interview you complete.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way.

Who can answer my questions about the study?

You can talk to the researcher about any questions or concerns you have about this study. Contact the researcher, Monika Eckfield, RN, MSN at (650) 219-0555 or Margaret Wallhagen, PhD, RN at (415) 476-4965.

If you have any questions, comments, or concerns about taking part in this study, firsts talk to the researcher, Ms. Eckfield. If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the CHR office at **415-476-1814**, 8:00 a.m. to 5:00 p.m., Monday through Friday. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

****

CONSENT: You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, please sign your name below.

_____	_____
Date	Participant's Signature for Consent
_____	_____
Date	Signature of Person Obtaining Consent

Capacity to Consent Questions

1. Am I offering you your usual medical care, or am I asking you to be in a research study?

2. Do you have to take part in this study or is it all right to say no?

3. What is the purpose of this study?

4. Will this study mainly help you or others?

5. Please tell me one risk of being involved in this study?

6. If you want to drop out of the study, when can you do this?

7. Considering the risks and benefits we have discussed, what have you decided about taking part in this study?

Interview Guide

A. Introduction

Hello Mr. /Mrs. _____, thank you very much for agreeing to talk with me today. As I said on the phone, I am interested in learning more about you and your experience with collecting and saving things over the course of your life. We have gone over the informed consent form and before we begin, do you have any questions for me?

B. Demographics

First there are just a few basic questions I would like to ask you:

Age?
Do you identify yourself as being a part of any particular race or ethnicity?
Gender?
What level of education did you complete?
Do you work, or if retired, what sort of work did you do?
Living situation: alone or with others? If living alone, have you lived with others in the past?
Do you live in a house or apartment? Rented or owned?
How long have you lived here?

C. Getting to know them

1. To begin with, tell how you came to start saving things.
2. Are there particular things that you save or collect? Tell me about that.
    a. What is it about these types of things that make them worth saving?
    b. How did you come to start saving or collecting this type of object in particular?
3. Have you always collected the same things, or has it changed over time?
4. How do you acquire these things? For instance, do you find them in the neighborhood, or buy them, or do they just arrive at your home (like mail or newspapers)?
5. How do you decide whether to save something or to discard it? Can you give me an example?
6. Are there things that make it easier or harder to make a decision about what to keep or to discard? Tell me about that. Can you give me an example?

D. Timeline

1. When do you first remember saving things? What did you collect?
2. What was else was going on in your life around that time?
    a. Prompts: where did you live, who did you live with, can you describe what your life was like at that time?

3. I would like to learn more about how your saving behaviors or habits changed over the years since then. Thinking back from when you first started saving things until now, were there times when you saved more things or discarded things more often? We can use this timeline to help us if you would like.
    a. Prompts: how about when you moved? Living with roommates/others? Married? Divorced? Children left home? Changed jobs? Parents died? An illness in the family or changes in your own health? Any other life events?
4. Tell me more about what life was like for you during these times.
5. How did these periods of time affect your interest in saving or discarding things?

E. Exploring Current Aspects of Hoarding Behaviors and Effects on Social Supports, Health, and Daily Living

6. Tell me a little bit about your social life—who do you socialize with, where do you spend time with them and what sorts of things do you like to do?
7. Does the way you keep your home affect the way, or where, you socialize with friends or family?
8. How do you feel when others are in your home and around your things?
9. How have others responded to your collections? Call you tell me about that?
10. Are there certain people who you talk with about your belongings?
    a. Follow-up: if there aren't people who you talk with about these things, do you wish you had someone to talk with about it? What sort of support do you think would be helpful?
11. How would you describe your physical health?
    a. Have you ever felt like your health affects your decision to keep or discard things? Tell me more about that.
    b. Have you ever felt like the volume of things in your home, or the way they are organized (or not organized) affects your health in any way?
    c. Has your physical health changed over the years, and if so, in what ways do you think it has affected your decision or ability to save or discard things?
12. How would you describe your mental health?
    a. How do you think your mental health affects how you decide to save or discard belongings at home?
    b. Looking at it the other way, how do you think your collection of things affects your mood or your mental health?
    c. Has your mental health changed over the years, and if so, in what ways do you think it has affected your decision or ability to save or discard things?

13. Are there daily activities like preparing meals, making the bed, cleaning house, showering, or getting ready in the morning that you do a certain way because of the number of things in your home? Tell me about that.
14. Has your ability to do these daily activities changed at all as you have gotten older? If so, how? Is there anything that makes these things easier or harder to do?
15. Have you ever felt like your collection of things has become too large or has it ever become problematic? Tell me about that.

    Prompts: How did you come to realize that it had become problematic?

    a. What did you decide to do about it? How did that go?
    b. Was there anyone you asked for help? Why did you ask them? How did that go?
    c. Was there any sort of help you wished was available to you?

F. Wrapping up

16. How would you imagine your life would be like if you saved fewer things or discarded more things?

17. Is there anything else that you would like to tell me?

18. [Ask participant to review CIR and rate the rooms in their home]

19. [Ask for permission to take photograph(s)]

Thank you so much for your time! I really appreciate it.

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