January 2014

An Examination of the Impact of Hoarding Parent-Adult Child Relationships and Family Functioning

Jennifer M. Park
University of South Florida, jmpark@mail.usf.edu

An Examination of the Impact of Hoarding on Parent- Adult Child Relationships and Family Functioning

by

Jennifer M. Park

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Psychology
College of Arts and Sciences
University of South Florida

Co-Major Professor: Eric Storch, Ph.D.
Co-Major Professor: Vicky Phares, Ph.D.
Ellis Gesten, Ph.D.
Jennifer Bosson, Ph.D.
Kevin Thompson, Ph.D.
Alison Salloum, Ph.D.
Debra Dobbs, Ph.D.

Date of Approval:
June 3, 2013

Keywords: Hoarding, Impairment, Parental Psychopathology, Path analysis

Table of Contents

List of Tables

List of Figures

Abstract

Compulsive hoarding is characterized by difficulty discarding unneeded items and the accumulation of items within living spaces and is associated with significant functional impairment and distress. Along with the negative impact on the individual, previous reports have indicated that compulsive hoarding is not only impairing and substantially burdensome for family members, but also linked to disruptions in family functioning. The present study utilized a path model analysis to examine the associations between an array of hoarding variables hypothesized to impact family functioning and parent-adult child relationships in 199 adult children of hoarders. Results revealed that family functioning mediated the relationship between hoarding severity and parent-adult child relationship. Decreased insight into hoarding symptoms was directly associated with decreased quality of parent-adult child relationships, which was mediated by family functioning. Increased family accommodation was significantly associated with increased impairment (work, social, family domains) in adult children of hoarders. Clinical implications and future directions in research are discussed.

Introduction

Compulsive hoarding is characterized by the following: 1) acquisition of a large amount of seemingly useless items; 2) inability or failure to discard the acquired items; 3) cluttered living spaces that prevent their use for intended purposes; and 4) significant distress and/or impairment in functioning due to the hoarding behaviors (Frost & Hartl, 1996). Compulsive hoarding has an estimated prevalence rate of 5.3% and runs a chronic course in the absence of intervention (Grisham, Frost, Steketee, Kim, & Hood, 2006; Pinto, et al., 2007; Samuels, et al., 2008). There are some discrepancies amongst reports regarding gender distribution, with some noting higher occurrences in males (2:1 ratio) and others reporting an equal rate of hoarding between males and females (Fullana, et al., 2010; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Timpano, et al., 2011). Currently, compulsive hoarding is considered a distinct symptom cluster encompassed within obsessive-compulsive disorder (OCD); however, diagnostic criteria specifically pertaining to compulsive hoarding are not outlined in the current *Diagnostic and Statistical Manual for Mental Disorders – 4th edition* (DSM-IV; (APA, 2000). As increasing evidence has shown that compulsive hoarding is markedly different from other OCD symptom clusters in regards to symptom presentation, neurobiological and genetic underpinnings, and treatment response (for review see: (Mataix-Cols, et al., 2010; Pertusa, et al., 2008), compulsive hoarding has been categorized as its own separate diagnostic entity in the upcoming DSM-5 (American Psychiatric Association, 2013).

Clinical Characteristics

Compulsive hoarding is marked by persistent fears and concerns of losing or discarding items due to sentimentality or future need for use. Exaggerated emotional attachment, as well as inflated beliefs regarding the sentimentality of, responsibility towards, and need for these items lead to difficulties in discarding these items (Cermele, Melendez-Pallitto, & Pandina, 2001; Frost & Gross, 1993; Frost, Hartl, Christian, & Williams, 1995). Indeed, compulsive hoarders subjectively report increased anxiety when making decisions whether to keep or discard items (Tolin, Kiehl, Worhunsky, Book, & Maltby, 2009). Excessive acquisition of items either through compulsive buying or collection of free items (e.g., mail, brochures, giveaways) also occurs frequently with up to 95% of family members of hoarders reporting excessive acquisition of items (Samuels et al., 2002). The small subset of hoarders who do not actively seek out and compulsively acquire items do so passively, and items accumulate gradually due to failure to discard items (Samuels et al., 2002). Excessive acquisition is associated with greater hoarding severity, earlier onset of symptoms, greater work impairment, and increased psychopathology (Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009).

Although increased anxiety is reported regarding the discarding of items, compulsive hoarders do not consider their cognitions or thoughts regarding acquisition and saving to be repetitive, anxiety-provoking or unusual and often describe them to be part of their natural thought processes (Frost & Gross, 1993; Frost, et al., 1995; Grisham, et al., 2009; Kyrios, Frost, & Steketee, 2004). Hoarders often lack insight, or awareness, into their symptoms and do not consider their behaviors to be abnormal or excessive (Frost, Steketee, & Williams, 2000; Kim, Steketee, & Frost, 2001; Samuels, Shugart, et

al., 2007; Tolin, Fitch, Frost, & Steketee, 2010). In a survey of 558 family members of hoarders, over 50% reported that the hoarders "lacked insight" or were "delusional" about their symptoms (Tolin, Fitch, et al., 2010). In the same study, compulsive hoarders with decreased insight were described as experiencing less distress regarding their symptoms (Tolin, Fitch et al., 2010). Similarly, in a survey of health department officials, a detailed account of 58 hoarders described the individuals as having poor insight regarding the clutter that was gathered in their home. Less than half of the hoarders acknowledged the extreme lack of cleanliness in their living spaces and only a small proportion of hoarders were willing to cooperate with health department officials to remedy the situation (Frost, Steketee, & Williams, 2000).

Comorbidity

Comorbid psychiatric disorders occur commonly with compulsive hoarding (e.g., (Samuels, et al., 2002; Steketee, Frost, Wincze, Greene, & Douglass, 2000). Studies have demonstrated higher rates of co-occurring major depression (57%), generalized anxiety disorder (28%) and social phobia (29%) amongst compulsive hoarders (Frost, Steketee, Tolin, & Brown, 2006; Lochner, et al., 2005; Meunier, Tolin, Frost, Steketee, & Brady, 2006; Wu & Watson, 2005). Comorbidity rates with OCD are similar, with 15-40% of OCD adults reporting hoarding symptoms (Hanna, Yuwiler, & Coates, 1995; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999; Rasmussen & Eisen, 1992). Still, compulsive hoarding occurs frequently in the absence of non-hoarding OCD symptoms (Frost, Steketee, Williams, & Warren, 2000; Pertusa, et al., 2008; Samuels, et al., 2008). For example, in a community sample of 104 compulsive hoarders, only 17% were diagnosed with non-hoarding OCD symptoms (Frost, et al., 2006). Furthermore, in an

epidemiological study of hoarding in 742 participants, none of those identified with hoarding behaviors were diagnosed with non-hoarding OCD (Samuels, et al., 2008).

Personality disorders have also been strongly linked with compulsive hoarding (Samuels, Bienvenu, et al., 2007; Samuels, Shugart, et al., 2007). In fact, hoarding is listed as a diagnostic symptom of obsessive-compulsive personality disorder (OCPD) with up to 15% of compulsive hoarders also diagnosed of OCPD (Seedat & Stein, 2002; Winsberg, Cassic, & Koran, 1999). However, increased rates of other personality traits have also been reported amongst compulsive hoarders (Mataix-Cols, Baer, Rauch, & Jenike, 2000). In a study of 75 OCD adults, those with hoarding symptoms had increased rates OCPD, avoidant, dependent, and paranoid personality disorders relative to those with non-hoarding OCD (Mataix-Cols, et al., 2000).

Treatment

Compulsive hoarders have been found to experience limited benefit from current methods of treatment for OCD, such as cognitive-behavioral therapy (CBT) with exposure and response prevention (E/RP) and serotonin reuptake inhibitors (SRIs; e.g., (Abramowitz, Franklin, Schwartz, & Furr, 2003; Mataix-Cols, Marks, Greist, Kobak, & Baer, 2002; Mataix-Cols, et al., 1999; Rufer, Fricke, Moritz, Kloss, & Hand, 2006; Saxena, et al., 2002). For example, among adults with OCD, Mataix-Cols et al. (2002) found that increased hoarding symptoms were significantly associated with premature CBT termination and poorer treatment outcome compared to those with no hoarding symptoms. Abramowitz et al. (2003) found similar results with 132 outpatient OCD adults, where after 15 weeks of CBT, hoarders had greater post-treatment OCD severity relative to the other subtypes. In regards to pharmacotherapy, Mataix-Cols et al. (1999)

retrospectively examined treatment outcome in 354 patients with OCD, taken from various randomized, controlled SRI treatment trials (clomipramine, fluvoxamine, fluoxetine, sertraline, and paroxetine), and found that increased hoarding symptoms significantly predicted poorer treatment outcome. Similarly, Saxena et al. (2002) found in a 6-week multimodal treatment approach (intensive CBT, medication and psychosocial counseling) that hoarders demonstrated worse treatment response relative to the other OCD subtypes.

Attenuated treatment response rates have been posited to be associated with diminished insight and motivation amongst individuals in this population (e.g., (Frost, Tolin, & Maltby, 2010). Indeed, case reports describe a pattern of these behaviors in compulsive hoarders where individuals present with poor insight and motivation and refuse to cooperate with therapy (Christensen & Greist, 2001; Damecour & Charron, 1998; Fitzgerald, 1997). Because of this, a treatment manual depicting a modified version of CBT specifically targeting compulsive hoarders has been developed (Steketee & Frost, 2006). The multicomponent CBT for compulsive hoarders consists of psychoeducation and E/RP, motivational interviewing, and skills training, with a heavy emphasis on the behavioral aspects of the therapy. Through psychoeducation, individuals learn to conceptualize hoarding behaviors as problems with anxiety, avoidance, and decision-making processes (Saxena & Maidment, 2004). Exposure and response prevention involves individuals to systematically be exposed to low anxiety-provoking situations to high anxiety-provoking situations, while refraining from any compulsive behaviors. For example, individuals are first instructed to choose items that are easier to expel (e.g., junk mail, scrap paper) and discard these items as quickly as possible while

refraining from careful inspection of each item (Foa & Kozak, 1997). To increase the rate at which the individual discards these items, the therapist may give the individual an allotted amount of time to sort through and discard the items and gradually make this allotted time increasingly shorter as the individual habituates to the discomfort and anxiety caused by discarding these items without perfectionistic inspection. Eventually the items that are sorted through and discarded increase in difficulty (e.g., clothing, old appliances or electronics, items with greater sentimental value), and the process of slowly increasing the rate of discarding items is repeated. In addition to the exposures (i.e., discarding items, refraining from acquiring), motivational interviewing, skills training (e.g., organization, decision-making), and cognitive restructuring are incorporated as needed into the treatment, as well as regular home and/or office visits.

The multicomponent CBT for hoarders, although still in its development phase, has shown promising results in preliminary trials (Steketee, Frost, Tolin, Rasmussen, & Brown, 2010; Tolin, Frost, & Steketee, 2007). Tolin et al. (2007) conducted an open-trial of 26 sessions of modified CBT over 7-12 months with 14 compulsive hoarders. Four participants terminated treatment prematurely and 5 responded to treatment. Lack of homework compliance was identified as a problematic issue for many patients, which may have lead to attenuated treatment response; therefore, the treatment manual was revised to emphasize the motivational interviewing aspect of the treatment (Pertusa, et al., 2008). Utilizing the refined manual, Steketee et al. (2010) conducted a 26-session (weekly) multicomponent CBT, randomized, wait-list controlled trial with 46 compulsive hoarders. At post-treatment, the multicomponent CBT group had significant reductions in hoarding symptoms relative to the wait list group, with 71% of patients considered

responders at post-treatment. Additionally, from the 46 participants, only 6 terminated treatment prematurely.

Impairment

Despite increased attention to compulsive hoarding and risks associated with the disorder, understanding of variables that may affect the relationship between compulsive hoarders and their family members, especially children, is limited. Various factors associated with compulsive hoarding, such as hoarding severity, attenuated insight, and family accommodation may influence familial relationships and the quality of relationship between parents who hoard and their children. Amongst those with increased hoarding symptoms, significant functional impairment is common. Compulsive hoarding is also associated with substantial health risks and burden to the surrounding community. Increased work impairment is present, with hoarders reporting a mean of 7 psychiatric work impairment days (work loss days plus 50% of work cutback days; (Kessler, Mickelson, Barber, & Wang, 2001) per month (Tolin, Frost, Steketee, Gray, & Fitch, 2008), which is equivalent to reports given by individuals with bipolar and psychotic disorders (Kessler, et al., 1994). Additionally, hoarders have increased difficulty finding and keeping work, with 6% of surveyed hoarders being dismissed from their jobs directly due to their hoarding behaviors (Tolin, Frost, Steketee, Gray, et al., 2008). Within the home, dust pollen, rotting foods, and bacteria can accumulate within the clutter, posing as significant health hazards for the hoarder and other individuals living in the same residence (Frost, Steketee, & Williams, 2000; McGuire, Kaercher, Park, Frost, & Storch, 2012). Clutter can obscure living areas and walkways increasing the risk of slipping and having items fall on top of people while they move through the house. In fact, 1% of

hoarders reported having a child or elder forcibly removed from the home due to the deleterious conditions of the cluttered home (Tolin, Frost, Steketee, Gray, et al., 2008). Severe clutter can also become a community health problem, as the clutter may also accumulate outside the home (e.g., front yard, back yard, sidewalks) and can pose as fire hazards for both the individuals in the home as well as the surrounding neighborhood. Hoarding also places a dramatic burden upon the community as city resources are utilized to resolve hoarding complaints. From a recent study of code enforcement officials, each individual hoarding case cost an estimated $3,700 to resolve (e.g., removal and clean up of items), causing additional burden to the community (McGuire, et al., 2012). As families may be forced to confront the legal, social and community fallouts of having a parent who hoard, family members may experience significant stress and burden when attempting to manage the hoarding behaviors. Families as whole may suffer, as well as the individual children that may live within the home. As hoarding symptoms become more severe and unmanageable, tension and conflict may increase within the home and the negative impact of the symptoms on the adult child may also increase, eventually resulting in the break down of parent and adult child relationships.

Family Accommodation

Family accommodation, which refers to the act of family members facilitating, engaging in, or providing assistance for individuals with OCD to carry out their rituals (Calvocoressi, et al., 1995; Calvocoressi, et al., 1999) is another variable that may negatively impact family relationships and increase functional impairment in adult children. Family accommodation occurs frequently within homes with OCD (including those with compulsive hoarding symptoms) with studies showing rates of

accommodation from 62-100% (e.g., (Albert, et al., 2010; Renshaw, Steketee, & Chambless, 2005). In regards to hoarding, indirect accommodation can occur where family members may refrain from discarding items in the home so to avoid conflict with the hoarder. Additionally, family members may modify daily routines and decrease responsibilities (e.g., completing chores, managing finances, overseeing self-care) for the hoarder because symptoms may interfere with the hoarder's ability to meet expectations (Wilbram, Kellett, & Beail, 2008). Mounting evidence has indicated that providing accommodation for patients can be substantially burdensome for family members (Albert, et al., 2010; Amir, Freshman, & Foa, 2000; Wilbram, et al., 2008). For example, Calvocoressi et al. (1995) found amongst 34 family members of individuals with OCD that family accommodation was associated with increased familial stress, poorer family functioning, and increased rejection of the patient. Similarly, amongst 97 family members of OCD patients, 92% reported experiencing distress due to accommodating the patient's obsessive-compulsive symptoms (Albert, et al., 2010). In the same sample, increased family accommodation was also found to be associated with poorer quality of life of the family member. Amir et al. (2000) found amongst 73 relatives of patients with OCD that family members endorsed increased depressive symptoms when they had to modify their routines and when they did not assist the patient and the patient subsequently became upset. Additionally, family members reported increased anxiety and depression when they had increased negative feelings towards the patient, such as feelings of apathy, irritability and rejection of the patient. As family members, particularly adult children, may feel pressure or a responsibility to continue to accommodate parents, feelings of resentment, fatigue, anger towards the parent who

hoards may increase. These negative interactions may increase family dysfunction and functional impairment in the adult child, leading towards a decreased quality of parent adult child relationships.

Insight

Insight is comprised of three components: the patient's awareness and acknowledgment of the presence and problematic nature of his /her symptoms, the patient's ability to recognize unusual mental events (e.g., distorted thoughts) as pathological, and the patient's compliance with treatment (David, 1990). As previously noted, compulsive hoarders often present with diminished insight in regards to their hoarding symptoms and the consequences caused by their hoarding behaviors (Frost, Krause, & Steketee, 1996; Tolin, Fitch, et al., 2010). Amongst individuals with OCD, lack of insight has been linked to increased psychopathology (e.g., greater number of obsessive compulsive symptoms, higher comorbidity rates), longer duration of illness and poorer response to behavioral and pharmacotherapy treatment (Catapano, Sperandeo, Perris, Lanzaro, & Maj, 2001; Foa, 1979; Foa, Abramowitz, Franklin, & Kozak, 1999; Ravi Kishore, Samar, Janardhan Reddy, Chandrasekhar, & Thennarasu, 2004). In regards to familial relationships, decreased insight has been associated with increased feelings of frustration and hostility towards the hoarder by family members (Tolin, Frost, Steketee, & Fitch, 2008). As family members tend to reject hoarders with attenuated levels of insight (Tolin, Frost, Steketee, & Fitch, 2008), these negative feelings may lead towards increased family conflict and dysfunction within the home, as well as increased impairment in the adult child's life as he/she may spend more time having to contain the

hoarding symptoms, thus leading towards a break down in parent-adult child relationships.

Familial Burden and Dysfunction

As previously noted, hoarding severity, insight and family accommodation may have significant negative impact on family functioning. While case studies and anecdotal evidence have suggested a pronounced disruption within families of compulsive hoarders, only one study has systematically investigated familial burden associated with compulsive hoarding (Tolin, Frost, Steketee, & Fitch, 2008; Wilbram, et al., 2008). In an internet survey of 665 family members (i.e., children, significant others, siblings) and friends of hoarders, informants reported increased negative attitudes towards the hoarder (Tolin, Frost, Steketee, & Fitch, 2008), such as frustration, rejection, and hostility. Informants endorsed higher scores on survey items such as "I don't expect much from him/her anymore", "I just don't care what happens to him/her anymore", and "I wish he/she had never been born" (Kreisman, Simmens, & Joy, 1979). Increased familial distress and impairment was also reported with informants noting difficulty having people over to the home and feeling embarrassed about the state of the home. Wilbram et al. (2008) qualitatively examined familial adjustment and distress in 10 caregivers of hoarders, which comprised of siblings, spouses, parents, and children of hoarders. Informants described a sense of loss of "normal" family life due to the inability to use spaces within the home as intended (e.g., standing in the kitchen to eat meals, lack of access rooms within the home). Disruptions in the caregiver's personal life was also endorsed with informants reporting avoidance of friendships outside the home, feelings of embarrassment regarding the clutter in the home, and inability to have others visit the

home. Family relationships were also negatively affected; caregivers expressed frustration and anger towards the hoarder. Conflicts with the hoarder regarding clutter was also frequently reported; in some instances these conflicts subsequently lead to the breakdown of relationships, with caregivers noting feelings of hatred and resentment towards the hoarder. Similarly, Black et al. (1998) found that families with OCD (including participants with compulsive hoarding), relative to healthy control families report increased family dysfunction in regards to unhealthy communication, unhealthy affective involvement, and overall functioning. Caregivers and spouses of individuals with OCD in this sample also reported experiencing disrupted family and social life, anger and frustration towards the hoarder, family conflicts, depression, fatigue and disrupted personal life (Black, Gaffney, Schlosser, & Gabel, 1998). Given the potential for increased family dysfunction in families of hoarders, family functioning may serve as a mediator between factors associated with hoarding (i.e., hoarding severity, family accommodation and insight) and quality of parent-adult child relationships.

Adult Child Impairment

The consequences of hoarding, lack of insight and presence of family accommodation, may be especially profound on the adult children of hoarders. Indeed, Tolin et al. (2008) found that adult children of hoarders retrospectively reported decreased happiness in their childhood, increased difficulty making friends, and increased feelings of embarrassment about the home relative to siblings of hoarders. Adult children of hoarders also reported increased conflict within the home including arguments and strained relationships with parents. Outside of compulsive hoarding, studies have consistently shown that parent psychopathology negatively impacts both the functioning

and psychological health of children (Beardslee, Versage, & Gladstone, 1998). Children of parents with major depression exhibit increased functional impairment, guilt, and difficulties with attachment and interpersonal relationships (Beardslee, et al., 1998). These negative effects continue into adulthood with 40% of adult children of depressed parents reporting symptoms of major depression (Beardslee et al., 1998). In a large-scale 20-year longitudinal study of the offspring of depressed and non-depressed parents, adult children of depressed parents had an increased likelihood of experiencing major depressive disorder or anxiety disorder, relative to children of non-depressed parents (Weissman, et al., 2006). Similarly, a 5-year longitudinal study found that adult children of anxious parents were also more likely to be diagnosed with an anxiety disorder themselves (Schreier, Wittchen, Hofler, & Lieb, 2008). While the long-term impact on parental OCD on adult children have not been yet examined, increased psychopathology and impairment is also found in children of parents with OCD. Black et al. (2003) found that offspring of OCD suffered from increased emotional and behavioral disturbances and were more likely to be withdrawn, fearful, anxious and depressed. Relative to children of healthy controls, children of parents with OCD were also more likely to develop psychological disorders such as separation anxiety, overanxious disorder, OCD and other anxiety disorders (Black, Gaffney, Schlosser, & Gabel, 2003). These impairments may cause adult children to feel angry, resentful, and frustrated towards parents, thereby causing strains on the parent adult child relationship. Therefore, adult child impairment may also be a mediating factor between hoarding variables and parent-adult child relationship.

Parent-Adult Child Relationship

As parental psychopathology, lack of insight, and increased family accommodation are linked with family dysfunction and impairment, it is likely that increased family dysfunction and adult child impairment may impact parent-adult child relationships as well. Quality of parent-adult child relationships is measured through communication, feelings of emotional attachment and closeness, reciprocity (exchange of financial, emotional, and/or instrumental support), and conflict, (e.g., (Lye, 1996; Rossi & Rossi, 1990; Schwarz, Trommsdorff, Albert, & Mayer, 2005). Although no literature exists directly examining the relationship between compulsive hoarding and disrupted parent-adult child relationships, research indicates that family conflict and adult child impairment may have negative effects on parent-adult child relationships. While parents generally provide children (and adult children) more financial support, adult children often provide more emotional support (via communication) and instrumental support such as taking care of parents' household (Kohli & Kunemund, 2001; Lye, 1996; Rossi & Rossi, 1990). Providing support for parents can be burdensome for adult children, however, with a study indicating that 77% of adult children felt alone with the support of their parents and 80% did not receive positive feedback for their support (Perrig-Chiello & Hopflinger, 2001). Indeed a qualitative study of relationships between parents and adult children identified household standards as a main source of conflict. Specifically, adult children expressed concern about their parents' inability or unwillingness to take care and maintain their household properly (Clarke, Preston, Raksin, & Bengston, 1999). Additionally marital discord and inter-parental conflict negatively impact the quality of parent-adult child relationships (Amato & Sobolewski, 2001). A 17-year longitudinal

study indicated that conflict within the home was associated with a decline in closeness between parents and adult children (Amato & Sobolewski, 2001). As hoarding associated variables have been linked with increased family dysfunction and adult child impairment, it may be possible that hoarding severity, level of insight and family accommodation are also associated with disruptions in parent-child relationships. A theoretical model depicting the relationship between parental hoarding, family functioning, adult child impairment, and quality of parent-adult child relationship is presented in Figure 1.

Aims and Hypotheses

While studies regarding familial disturbance and dysfunction caused by parental psychopathology have been informative, no data exist that specifically targets the impact of hoarding on adult children. Given the depth of family impairment, distress, and dysfunction that is present in families of hoarders, it is likely that these hoarding behaviors may cause substantial damage to the parent-adult child relationship. Accordingly, this study examined the impact of parental compulsive hoarding on adult-aged children.

The following hypotheses were examined in this study:

1. Hoarding severity in parents will be inversely associated with quality of parent-adult child relationship. This relationship will be mediated by family functioning.
2. The relationship between hoarding severity in parents and poorer quality of parent-adult child relationship will be mediated by adult child functional impairment (academic/work, social, family).

3. Decreased level of insight in hoarding parents will be associated with poorer quality of parent-adult child relationship. This relationship will be mediated by family functioning.
4. The relationship between insight and quality of parent-adult child relationship will be mediated by adult child functional impairment.
5. Increased family accommodation will be associated with poorer quality of parent-adult child relationship. This relationship will be mediated by family functioning.
6. The relationship between family accommodation and quality of parent-adult child relationship will be mediated by adult child functional impairment

In addition to the above hypotheses, an exploratory aim was set to examine the self-reported clinical characteristics of adult children of hoarders.

Method

Participants

The present sample was recruited through several sources: a) postings on various hoarding support group and informational websites (e.g., www.childrenofhoarders.com, www.hoarders.org, www.hoarderssonblogspot.com); b) the Sona system from the University of South Florida portal; and c) fliers disseminated in the community. See Figure 2 for a flowchart of participants. Of note, information was gathered only from the adult children of hoarders, and not directly from the hoarders themselves. Participants consisted of 199 adult-aged children of hoarders (86.4% female), ages 19-63 years (M = 37.15, SD = 10.74). The inclusion criteria were as follows: (a) The participant must be 18 years of age or older and his/her parent must have met clinical diagnostic criteria for hoarding, as assessed by the Hoarding Rating Scale Self-Report score (endorsed moderate [rating of 4] or greater clutter and difficulty discarding as well as moderate [rating of 4] or greater impairment or distress; Tolin et al., 2008); (b) The parent who hoards is not deceased; and (c) English speaking as we are unable to translate the measure due to resource limitations. Exclusion criteria for the study were as follows (see Figure 2): (a) the participant did not wish to participate; or (b) the participant did not have a parent who hoards (responded to items regarding other caregiver such as grandparent, step parent, in-laws). In regards to gender, 86% of informants were female (n = 172) and 13% were male (n = 25); 1% (n = 2) of this data was missing. The self-reported racial composition of the adult child informants was 88.9% Caucasian (n = 177),

3.5% African American (*n* = 7), 3.5% Asian (*n* = 7), and 2% Other/Mixed (*n* = 4). Two percent (*n* = 4) did not provide information regarding race. Four percent (*n* = 8) self-identified as Hispanic/Latino.

Procedures

This study was comprised of several questionnaires for adult children of hoarders. All study forms were administered on the computer via internet. Consent was assessed on the first page of the survey in which participants were given information regarding the study and provided with the option to participate (See Appendix A and Appendix B). Participants were asked to continue with the survey only if they gave consent to participate. Participants then completed the survey packet online. The survey was entered into two secure online survey programs: 1) Sona at http://usf.sona-systems.com supported through the University of South Florida's portal; 2) Checkbox at http://hsccm2.hsc.usf.edu/checkbox/ (see Figure 2 for details regarding sample). The survey packet took no more than 45 minutes to complete. To protect the participants' confidentiality, participants were not asked to provide identifying information. Data from the surveys were stored in SPSS files located on password-protected drives and were only accessible to the principal investigator. To account for possible repeat responses, key demographic characteristics (e.g., gender, age, ethnicity) and item responses on primary measures from surveys submitted consecutively were compared to identify duplicate or near-duplicate entries (Johnson, 2001). If demographic information and item responses on the primary measures were nearly identical, the remaining measures were compared to determine if the survey was a repeat response. Through this method, no entries were identified as duplicate responses.

Design Considerations

Several methodological issues were considered when determining the design of the present study.

Access to Population: Compulsive hoarders generally do not present for treatment of their hoarding symptoms. Often those who are in treatment are court-mandated or cajoled into treatment by family members or friends. Further complicating the matter, it is not typical for the population of interest to seek treatment for concerns specifically associated with the negative impact of living with a compulsive hoarder; therefore, attempting to collect data from these individuals in a clinic setting would have been a substantial recruitment obstacle.

Recruitment Methods: Multiple methods of recruitment (i.e., websites, local university, community) were utilized to decrease sample bias. Participants recruited from websites may give a biased sample, as it is likely that the majority of individuals who frequent these websites have had negative experiences with hoarders. Recruiting from the University of South Florida and the community provided access to a larger and more generalizable sample. In a similar internet-based study examining familial burden of hoarding, recruitment primarily consisted of sending e-mail invitations to a database of individuals who had previously contacted the researchers for information about compulsive hoarding (Tolin, Frost, Steketee, & Fitch, 2008).

Sample Size: A large sample size is needed to examine the population of interest and fulfill the aims of the present study. Due to the aforementioned concerns, data collection was conducted via internet. As internet data collection has increased within the past decade, several studies have shown that internet-based surveys are as reliable as

traditional data collection methods (e.g., (Gosling, Vazire, Srivastava, & John, 2004; Yang, Levine, Xu, & Lopez Rivas, 2009). Gosling et al. (2004) compared the empirical quality of data collected from 361,703 web-based surveys relative to 510 published manuscripts utilizing traditional paper and pencil measurement methods. Results indicated that not only are web-based surveys are of comparable quality to paper and pencil methods, but also provide greater sample diversity, result in findings consistent with traditional methods, are generalizable across presentation formats, and are not tainted by false data or repeat responders.

Feasibility: Although an examination of the impact of hoarding on children currently living with compulsive hoarders would be ideal, it was not possible for a number of reasons. First, children who are currently living in a household with a compulsive hoarder are likely under the age of 18 years, and would require the consent of the parent to participate in a study. Second, as compulsive hoarders often do not have insight into their symptoms, parents may keep their children from participating in the study. Even when insight is present, parents may not allow their children to report the conditions of their home for fear of possible legal response.

Measures

Demographic Form (Appendix C): A demographic form assessed information regarding the participant's age, gender and ethnicity. Additionally the form assessed the participant's age when parent's hoarding behaviors onset, the years that the participant resided with the hoarding parent while the hoarding occurred, and the degree to which the participant has contact with the hoarding parent.

Hoarding Rating Scale – Self Report (HRS-SR; Appendix D): The HRS-SR (Tolin, Frost, Steketee, & Fitch, 2008) is a 5-item self-report measure that assesses hoarding severity. Items regarding difficulty discarding, clutter, acquisition, distress, and impairment are rated on a 9-point Likert scale that ranges from 0 (none) to 8 (extreme). The mean score of the 5 items determines the overall hoarding severity score. This measure is modified from the Hoarding Rating Scale-Interview (HRS-I; (Tolin, Frost, & Steketee, 2010; Tolin, Frost, Steketee, & Fitch, 2008). The HRS-SR has demonstrated good internal consistency ($\alpha = 0.82$) and high correlations with the HRS-I ($r = 0.74$-0.92; (Tolin, Frost, Steketee, Gray, et al., 2008). In regards to diagnostic status, the HRS-SR has demonstrated 73% agreement between self- and interviewer report (Tolin, Frost, Steketee, & Fitch, 2008). Previous studies that utilized family informants (including adult children) informants to complete the HRS-SR demonstrated acceptable to good internal consistency ($\alpha = 0.67$-0.83; (Tolin, Fitch, et al., 2010; Tolin, Frost, Steketee, & Fitch, 2008). Internal consistency for HRS-SR in the present sample was acceptable ($\alpha = 0.66$).

Clutter Image Rating (CIR; Appendix E): The CIR (Frost, Sketetee, Tolin, & Renaud, 2008) is a self-report pictorial measure that assesses the severity of clutter in a person's home and consists of nine pictures of three main rooms of homes (kitchen, living room, and bedroom). Each room has three pictures depicting varying amounts of clutter. The CIR is revised to have the individual choose the picture that most closely represents the home that their parents currently live. The CIR has demonstrated good to excellent internal consistency ($\alpha = 0.84$) as well as good test retest reliability ($r = 0.82$), inter-observer reliability ($r = 0.78$ - 0.94), and convergent validity (Frost, et al., 2008).

Family informant (including adult children) reports on the CIR demonstrated good to excellent internal consistency (α = 0.85-0.92; (Tolin, Fitch, et al., 2010; Tolin, Frost, Steketee, & Fitch, 2008). Cronbach's alpha for the present sample was good (α = 0.85).

Insight Ratings (Appendix F): Taken from the modified insight rating utilized by Tolin et al. (2008), insight was assessed with a single item rating based off item 11 on the Yale-Brown Obsessive Compulsive Scale (Y-BOCS; (Goodman, et al., 1989). The response is based off of a 5-point Likert scale ranging from 0 (Excellent insight, fully rational. [Name]'s hoarding behaviors may have been bad, but [name] fully recognized that they were a problem) to 4 (Lacks insight, delusional. [Name] was convinced that he/she had no problems with acquisition, clutter, or difficulty discarding. He/she would argue that there is no problem, despite contrary evidence or arguments). Although no psychometric properties have been reported for the self-report insight rating, item 11 of the Y-BOCS interview format has shown adequate inter rater reliability (κ = 0.73; (Matsunaga, et al., 2002) and significant correlations with overvalued ideation (r = 0.32), which is a construct that is comprised of lack of insight as well as resistance to compulsions (O'Connor, et al., 2005). Additionally, item 11 of the Y-BOCS interviews has demonstrated the ability to differentiate between OCD patients with and without insight (De Berardis, et al., 2005)

Inventory of Parenting and Peer Attachment (IPPA; Appendix G): The IPPA (Armsden & Greenberg, 1987) is a 25-item self-report measure that assesses the strength of an individual's attachment to parents and peers. Only items measuring individual's attachment to parents was administered. The IPPA provides three subscale scores: trust, communication and alienation. The composite parent attachment score is computed by

subtracting the alienation raw score from the sum of the trust and communication raw scores. The IPPA has demonstrated sound psychometric properties, including good test-retest reliability (r = 0.93), internal consistency (Mother relationship α = 0.87; Father relationship α = 0.89), and convergent and divergent validity (Armsden & Greenberg, 1987; Greenberg, 1982; Lewis, Woods, & Ellison, 1987). Good internal consistency was demonstrated for the composite parent attachment score for the present sample (α = 0.82).

Family Assessment Device-General Functioning (FAD-GF; Appendix H): The FAD-GF is a subscale derived from the original FAD (Epstein, Baldwin, & Bishop, 1983), which is a self-report questionnaire that assesses family functioning. The FAD-GF subscale assesses overall family health pathology (problem solving, communication, roles, affective responsiveness, and affective involvement). Utilizing the FAD-GF subscale summary score is noted as conservatively the best use of the FAD due to high overlap within the other subscales of the original measure (Ridenour, Daley, & Reich, 1999). The FAD-GF consists of 12 items on a 4-point Likert scale where greater scores indicate higher family dysfunction. The mean cutoff score for the FAD-GF subscale is 2.00, where means below the cutoff is indicative of healthy family functioning (Epstein et al., 1983). The FAD-GF subscale has demonstrated good scale reliability (α = 0.92; Ridenour et al., 1999). In the present sample the FAD-GF subscale demonstrated acceptable internal consistency (α = 0.63).

Family Accommodation Scale (FAS; Appendix I): The FAS (Calvocoressi, et al., 1999) is a 13-item self-report measure related to the degree to which relatives accommodate patients through participating in behaviors related to patient rituals and

through modification of daily routines and distress and impairment that family members experiences as a result of accommodating or not accommodating the individual. Responses are provided on a Likert scale ranging from 0 (never) to 5 (daily/extreme) and yield a total score that ranges from 0 to 48. The present measure has been revised to refer to specifically hoarding behavior. As the first item asks the informant to identify each present obsessive-compulsive symptom the person of interest, this item has been removed from the present measure. The FAS has also been modified from clinician-rated format to informant-report format. The informant-report FAS has demonstrated good psychometric properties, including internal consistency, test-retest reliability, and convergent validity (Geffken, et al., 2006; Merlo, Lehmkuhl, Geffken, & Storch, 2009; Peris, et al., 2008; Stewart, et al., 2008). Internal consistency for the FAS was good for the present sample ($\alpha = 0.85$).

Sheehan Disability Scale (SDS; Appendix J): The SDS (Sheehan, Harnett-Sheehan, & Raj, 1996) is a self-report measure that assesses the degree of impairment experienced by the individual due to his/her parent's hoarding behaviors. Impairment in social, occupational, and family domains are measured. The SDS has demonstrated good psychometric properties including respectable internal consistency for a 3-item measure ($\alpha = 0.56$-0.84) as well as good construct, criterion, and discriminant validity (Leon, Olfson, Portera, Farber, & Sheehan, 1997). The internal consistency of the SDS for the present sample was good ($\alpha = 0.82$)

Saving Inventory-Revised (SI-R; Appendix K): The SI-R (Frost, Steketee, & Grisham, 2004) is a 23-item self-report measure of hoarding severity and is comprised of 3 subscales: difficulty discarding, clutter, and acquisition. When the SI-R was

transcribed onto the online survey, the last four items of the measure were inadvertently omitted. Due to the accidental omission of these items, respondents only completed the first19-items of the measure. While a composite score of the SI-R is provided in the measure, due to this error, the composite score cannot be determined in the present study. The 23-item scale and subscale items have demonstrated good internal consistency and test-retest reliabilities: total score ($\alpha = 0.94$, $r = 0.86$), difficulty discarding ($\alpha = 0.93$, $r = 0.89$), clutter ($\alpha = 0.88$, $r = 0.90$) and acquisition ($\alpha = 0.80$, $r = 0.78$; (Frost, et al., 2004). Additionally, the SI-R has shown good convergent validity and divergent validity (Frost et al., 2004). In the present study, internal consistency scores for the 19-items scale and all subscale items were demonstrated to be good to excellent (total score, $\alpha = 0.94$; difficulty discarding, $\alpha = 0.92$; clutter, $\alpha = 0.91$; acquisition, $\alpha = 0.81$).

Analytic Plan

Path analysis was used to examine hypotheses 1 through 6. Path analysis is preferred over standard multiple regression models as path analysis provides the ability to examine complex relationships simultaneously (Kline, 2011). Total scores on the following variables were used to run the path analysis: hoarding severity, family accommodation, insight, adult child impairment, family functioning, and parent-adult child relationships. Cases were excluded from the final sample if they were missing more than 10% of the items from any of the exogenous variables used to test hypotheses 1-6. Pearson's product moment correlation coefficients were computed to examine associations among study variables. Associations among the indicator variables were examined via a correlation matrix. Correlations .5 and above were defined as "large", correlations of .3 were defined as "medium", and correlations of .1 were defined as "small" (Cohen, 1988). Multivariate normality was evaluated and univariate indices of skewness and kurtosis was examined; all indices had an absolute value of less than 2.0, indicating that non-normality was not problematic (Mardia, 1970, 1985).

The hypothesized path model was constructed using Mplus version 7 (Muthen & Muthen, 2007). Mplus generates standardized estimates of all parameters not constrained to specific values. As the maximum likelihood (ML) estimation produces the highest likelihood of fit and is robust to slight non-normality, this method was used for parameter estimation. The N:q rule concerning the relation between sample size and model complexity (Jackson, 2003) was utilized to determine the recommended sample size for

the present study. This rule is applicable when ML is used as the model estimation method (Jackson, 2003). Sample sizes are determined based off of a ratio of cases (*N*) to the number of model parameters that require statistical estimates (*q*), where an *N*:*q* ratio of 10:1 is considered acceptable. As there are 16 parameter estimates in the present hypothesized path model, the final recommended sample size was 160.

A variety of global fit indices was utilized (Bollen & Long, 1993), including indices of incremental, residual-based, and population-based fit indices (Kline, 2005). The Comparative Fit Index (CFI; (Bentler, 1988), an incremental fit index, that measures the relative fit of the hypothesized model to an independence or null model. Values on the CFI range from 0 to 1 with 0.9 or greater indicating good fit. The standardized root mean square residual (SRMR) is a residual-based index, which measures the mean absolute correlation residual (differences between observed and predicted correlations). Values on the SRMR range from 0 to 1 with 0.09 or less indicating good fit (Hu & Bentler, 1999). The root mean square error of approximation (RMSEA; (Browne & Cudeck, 1993) is a population-based index, based on a non-centrality parameter, where values 0.08 or less are considered acceptable model fit. A combination of one relative fit index and the SRMR or the RMSEA may be utilized to determine fit (Hu & Bentler, 1995). To further determine model fit of the hypothesized path model, standardized residuals and modification indices were examined. Standardized residuals are the ratio of the covariance residual over its standard error, with estimates between ± 2.58 considered acceptable. Modification indices estimates the amount by which the overall model χ^2 would decrease if a previously fixed parameter is freely estimated; a large modification

index denotes that if that parameter were added to the model, the model fit will improve (Kline, 1998).

Hypotheses 1-6 were examined using tests of direct and indirect effects (Sobel, 1982). Specifically, tests determined whether a significant direct effect existed, and whether the influence of the independent variable on the dependent variable was mediated by one or more other variables. The exploratory aim was examined by gathering descriptive information regarding the hoarding behaviors of the adult children of hoarders.

Results

Informant and Parent Description

Mothers were primarily identified as the hoarding parent (n = 150), then both parents (n = 25), and finally fathers (n = 22; see Table 1). Parents ranged in age from 43-98 years (M = 67.81, SD = 10.74). Approximately 45% of hoarding parents were married or cohabiting and 3% were never married, while a sizable minority was either widowed (25%) or divorced/separated (27%). The majority of hoarding parents were retired or unemployed (51.8%) at the time of the survey, while an additional 13% identified their parent as homemakers. Education levels ranged from less than 5th grade to graduate degree; however, most graduated from a four-year college/university (25.6%) and 13% earned a graduate degree. In regards to family income of the hoarding parent, 67.4% reported $50,000 or less, 24.1% reported an income of $51,000-100,000, and 8.5% had an income over $100,000. Approximately 74% of adult-aged children endorsed having contact with the parent who hoards at least once a month. Sixteen percent of adult-aged children reported contact with parents 6 times a year or less, while 10% percent of adult-aged children reported minimal to no contact with the parent who hoards (i.e., contact once a year or less). From the informants, 8% reported residing in the same home as the parent who hoards, while 31% lived within 30 miles. Forty-five percent of adult-aged children reported substantial geographical distance (e.g., over 120 miles, different state, different country) between their residences and the residence of the parent who hoards. The remaining 16% endorsed living within 30-120 miles of the parent who hoards.

While growing up, 92.4% of informants reported living in the home with the parent who hoards full time. The majority of informants (70.9%) reported living in the same home while the parent engaged in hoarding behaviors for 10 years or longer, while 19.5% was in the home for 2-9 years, and 9.6% were in the home for 1 year or less.

Hoarding Severity

Descriptive information regarding parental hoarding behaviors is provided in Table 1. There were significant gender differences in scores for hoarding severity between mothers who hoard (M = 6.50, SD = 1.08) and fathers who hoard (M = 5.97. SD = 1.17); $t(170) = 2.12$, $p < .05$); Cohen's d = 0.47. Parental hoarding behaviors onset generally when informants were school-aged children. All parental hoarding behaviors (i.e., clutter, difficulty discarding, collecting or buying, distress, impairment) had average scores of above 4 (moderate). All CIR scores had average scores of above 5, indicating substantial amounts of clutter in the main rooms in the home (kitchen, bedroom, living room). Average HRS-SR and CIR scores were significantly correlated (r = 0.65, $p <$ .001). Over 60% of informants lived in the home for 10 years or longer while parents engaged in hoarding behaviors. Notably, the majority of parents who hoard had never received treatment for hoarding behaviors (95%).

Descriptive Statistics

In regards to insight, 78 (39.2%) were described as "lacks insight/delusional", 56 (28.1%) had "poor insight", 51 (25.6%) had "fair insight", 12 (6%) had "good insight" and 2 (1%) endorsed "excellent insight" (see Table 2 for range and mean). Adult children of hoarders experienced the most impairment within their family life due to parental hoarding behaviors (M = 5.10, SD = 3.93), with 71 (35.6%) endorsing "a lot" to

"very very much" disruption within the home. Average social impairment score was 4.62 (*SD* = 3.79) and work impairment score was 3.16 (*SD* = 3.38). Family dysfunction was high; only one informant (0.5%) met the cutoff for healthy family functioning (see Table 2 for range and mean). There were significant differences in quality of parent-adult child relationships between mothers who hoard (*M* = 22.75, *SD* = 18.83) and fathers who hoard (*M* = 35.86, *SD* = 24.12); $t(169) = -2.93$, $p = .004$), Cohen's $d = 0.61$. As seen in Table 2, hoarding severity was significantly and positively correlated with family functioning and negatively correlated with quality of parent-child relationships. However, hoarding severity was not significantly correlated with impairment (e.g., work, home, social) in adult children of hoarders. Family accommodation, on the other hand, was significantly and positively associated with work, social and family impairment in adult children of hoarders; the indicator also correlated significantly and positively with quality of parent-child relationship. Insight was moderately and positively related with family functioning and quality of parent-child relationship, while family functioning and quality of parent-child relationships was significantly and negatively correlated.

Model Fit

The minimum fit function chi-square of the hypothesized path model was significant ($\chi^2(4) = 16.46$, $p = .003$), reflecting inadequate fit; however, the chi-square estimation is biased towards sample size, where larger sample sizes and models with more variables are more likely to result in a significant chi-square. The CFI and SRMR reflected good fit, while the RMSEA was indicative of inadequate fit (see Table 3). An examination of the standardized residuals revealed that all, except two, were within ± 2.58; however those two scores were within ± 3.00. However, modification indices

suggested a direct relationship between family accommodation and quality of parent-adult child relationship (MI = 7.43) and insight and quality of parent-adult child relationship (MI = 7.69). Based on theory, the model was re-specified to include a direct path between insight and quality of parent-adult child relationship. The minimum fit function chi-square of the re-specified path model was significant ($\chi^2(3) = 8.55$, $p = .04$); however, the χ^2 value decreased, while the *p*-value increased. The χ^2difference between the two models was significant ($\chi^2(1) = 7.91$, $p < .05$), suggesting that the re-specified model was a better fit than the original model. All fit indices (CFI, SRMR, RMSEA) improved in the new model (see Table 3). Based off the above, the re-specified path model was considered to have acceptable model fit and was utilized for the path analysis.

Path Analysis

See Figure 3 for final path analysis model. See Table 4 for path coefficients for indirect effects. The relationship between hoarding severity and quality of parent-adult child relationship was fully mediated by family functioning. Adult child impairment, however, was not a significant mediator of hoarding severity and quality of parent-adult child relationship and modification indices did not suggest that the addition of a direct path from hoarding severity to quality of parent-adult child relationship. Modification indices suggested an addition of a direct path between insight and parent-adult child relationship. The direct relationship between insight and parent-adult child relationship was significant. The indirect relationship between insight and parent-adult child relationship, through family functioning, was also significant, suggesting partial mediation. Adult child impairment was not a significant mediator of insight and parent-

adult child relationship. The relationship between family accommodation and parent-adult child relationship was not mediated by adult child impairment; however, there was a significant direct effect between family accommodation and adult child impairment. Family functioning was also not a significant mediator between family accommodation and parent-adult child relationship. There was no significant association between family accommodation and family functioning.

Hoarding Symptoms in Adult Children of Hoarders

See Table 5 for frequency of endorsed items on the SI-R that were rated moderate (2) or above. Informants most frequently endorsed moderate difficulties for the following items: To what extent does the clutter in your home cause you distress? (35%); How often do you decide to keep things you do not need and have little space for? (34%); How often do you avoid trying to discard possessions because it is too stressful or time-consuming (28%); To what extent do you have difficulty throwing things away (22%).

Discussion

The present study examined the impact of parental hoarding on parent-adult child relationships through an array of hoarding and family variables. The majority of responses were recruited from websites targeting family members of hoarders, and 86% of informants were female. Informants were an average age of 9 years when parental hoarding behaviors onset (or were first noticed). Most informants (76%) identified their mother as the parent who hoards, which is inconsistent with previous reports that note either a higher prevalence of hoarding in males or equivalent rates of hoarding between males and females (Fullana, et al., 2010; Mueller, et al., 2009; Timpano, et al., 2011). The gender discrepancy amongst informants may be a reflection of those who choose to frequent the hoarding websites. Many of the websites were intended to provide support for family members of hoarders, and as females are more likely than males to seek emotional support (Ashton & Fuehrer, 1993), this may account for the large gender differences found in the present sample. The gender discrepancy amongst parents who hoard may also be a reflection of the largely female informant sample. Amongst adult children, mother and daughter relationships are considered to be closer than father and adult child relationships, where mothers are in more frequent contact with their daughters (Lawton, Silverstein, & Bengtson, 1994; Rossi & Rossi, 1990) and receive more emotional support from their daughters (relative to fathers and sons; (Lawton, Silverstein, & Bengston, 1994; Marks, 1995; Umberson, 1992). Therefore, adult daughters may be more likely to seek support when there is a disruption in this relationship. Based on the

informants, mothers were also rated to have significantly greater hoarding severity and poorer quality of relationship with adult children relative to fathers. However, as previously mentioned, the size of the two groups were very uneven; therefore, these results may not be representative of the hoarding population as a whole.

As hypothesized, family functioning fully mediated the relationship between hoarding severity and parent-adult child relationships. That is, as parental hoarding severity increased, family dysfunction also increased, which then was associated with decreased the quality of parent-adult child relationships. This is consistent with previous findings noting that family members of hoarders harbored negative attitudes towards hoarders, and that spouses and children of hoarders experienced frequent arguments within the home (Tolin et al., 2008). Increased clutter in the home may be a source of significant stress and conflict between family members. And, as hoarders often experience extreme distress when hoarded items are discarded, adult children of hoarders may perceive these actions as the parent "choosing" items over their relationship with family members, thereby increasing negative interactions and emotions between the parent and adult children.

As expected, diminished insight was indirectly associated with poorer quality of parent-adult child relationship; a direct relationship between insight and quality of parent-adult child relationships also emerged. This relationship was partially mediated by family functioning. These results are in line with past research that found that hoarders with decreased insight were more likely to be rejected by family members (Tolin et al., 2008). Hoarders frequently present with attenuated insight (Frost, Steketee & Williams, 2000; Kim, Steketee & Frost, 2001; Samuels, Shugart et al., 2007; Tolin, Fitch, Frost &

Steketee, 2010), and this sample reflected the same, with only 7% of hoarders described as having "excellent" or "good" insight. The inability (or refusal) of a parent who hoards to acknowledge that a problem exists may also increase family conflict, contributing to increased family dysfunction and the subsequent break down of the parent-adult child relationship. Adult children of hoarders may become frustrated and/or angry with the parent's reluctance to change their hoarding behaviors, while parents who hoard may resist intervention. Indeed, in the present sample, only 5% of parents who hoard sought treatment specifically for their hoarding symptoms. This is consistent with previous clinical and research reports, which note that hoarders often do not present for treatment of their own volition (Christensen & Greist, 2001). As insight is a predictor of treatment-seeking behaviors amongst individuals with OCD (including hoarding symptoms; (Beşiroğlua, Çillib, & Aşkı nb, 2004), it is unsurprising that the present sample endorsed low rates of treatment.

Previous studies have linked family accommodation in adults with OCD with poorer family functioning (Albert et al., 2010; Calvocoressi et al., 1995); however, this relationship was not found in the present sample. As adults, children of hoarders with higher levels of family dysfunction and poorer quality of parent-adult children relationships may choose to disengage from their parent who hoards and may avoid the hoarding behaviors altogether. For more extreme cases, adult children of hoarders may terminate all contact with their parent who hoards, limiting accommodation. Family accommodation had a significant direct influence on impairment in adult children, suggesting that those adult children of hoarders who did provide accommodation for their parents experienced increased disruptions in their lives, particularly in the home.

Impairment in adult children due to parental hoarding behaviors did not significantly influence quality of parent-adult child relationships and there was no direct relationship between family accommodation and adult child impairment. This may be because those who continue to provide family accommodation, while acknowledging the disruptive nature of the parent's hoarding, may have more positive perceptions of their relationship with the parent who hoards. This is supported by the significant positive correlation found between family accommodation and quality of parent-adult child relationships. Alternatively, as prior studies examined family accommodation amongst individuals with OCD (as opposed to hoarding, specifically), the discrepant results may be due to differences in the populations that were examined.

The hypothesis that impairment in the daily lives of adult children due to parental hoarding behaviors would mediate the relationship between hoarding severity and parent-adult child relationships was not supported. While Wilbram et al. (2008) noted significant disruptions in family members of hoarders, those sampled were caregivers of hoarders. Thus, as their roles dictated a sense of responsibility for the hoarder, the daily life of the respondents was substantially enmeshed with that of the hoarder. Again, as adults, children of hoarders may create boundaries and refuse to allow hoarding behaviors to disrupt their daily lives. Additionally, the geographical distance between the residences of parents who hoard and adult children of hoarders may also alleviate the level of impairment experienced by adult children. As up to 45% of the present sample reported living at a substantial distance from their parent who hoards (120 miles or more), these adult children may find parental hoarding behaviors to be less impairing in their daily lives. It may be physically impossible for parents who hoard to impinge upon

their adult children (i.e., by requesting assistance within the home, having adult children repeatedly exposed to the hoarded home). Geographical distance may also limit the amount of physical contact the adult children may have with the parent (e.g., fewer family gatherings, limited opportunities to meet).

Overall, parental hoarding severity, family accommodation, and level of insight have significant negative impact on adult children of hoarders. Specifically, increased hoarding severity and poorer insight appear to have a pernicious influence on family functioning and the quality of parent-adult child relationships. Adult children of hoarders may experience frustration due to the parent's inability to recognize problematic hoarding behaviors and refusal to accept aid in resolving the problem (e.g., allowing family members to clean the house, seeking treatment for hoarding). This may contribute to poorer communication and increased conflict and tension between family members and the parent who hoards, as well as decreases in emotional closeness and attachment between the adult child and parent. Adult children of hoarders who have a more positive perception of the parent who hoards, may facilitate and enable the hoarding behaviors through accommodation. However, this in turn may lead to substantial disruptions in the adult child's daily life. Due to the negative impact of parental hoarding on family members and children, clinicians should implement a family-based element when treating individuals who hoard. As previously noted, multicomponent CBT was developed specifically to target compulsive hoarding behaviors through exposure therapy, motivational interviewing, skills training, and cognitive restructuring (Steketee et al., 2010; Tolin et al., 2007). Family-based interventions can enhance individual therapy by providing psychoeducation about compulsive hoarding (e.g., nature of the disorder,

familial components of hoarding), and teaching family members healthy coping skills and ways to effectively manage symptoms (e.g., provide support without accommodation). Additionally, adult children may act as a "coach" between sessions by providing encouragement, reminding parents to utilize skills learned in session (e.g., cognitive restructuring), and guiding parents through exposures (Steketee & Frost, 2006). A family therapy component may also help increase the hoarder's insight and awareness into his or her symptoms by elucidating the negative impact of the hoarding behaviors on the child. Additionally, families may benefit from learning better communication and problem solving skills. As previous research has noted that perceived support from family members have a positive impact on treatment (DiMatteo, 2004), enhancing the relationship between parent and adult child may also improve the treatment prognosis of the parent who hoards.

In regards to hoarding behaviors in adult children of hoarders, there did not appear to be a high level of pathology within this sample. While it is difficult to make firm assumptions regarding the clinical levels of hoarding from the data that was collected, only a few items were endorsed as moderate difficulty or above. These items were related to clutter and difficulty discarding, while the least endorsed items were related to acquisition. While compulsive hoarding has a strong familial component (Samuels, et al., 2002), the low endorsement on hoarding items may be a function of the population sampled. Adult children of hoarders who do not exhibit hoarding symptoms may perceive their parent's hoarding symptoms to be more disturbing or dysfunctional and may have been more willing and motivated to participate in the present study. While

the present study provides some information, the preliminary nature of these results warrants further research into the hoarding behaviors of adult children of hoarders.

This is the first study to comprehensively examine the impact of parental hoarding on adult children of hoarders. This study has several limitations. First, as the majority of the sample was recruited through hoarding websites, this is a self-selecting group of participants who may have visited these websites because they were experiencing increased distress due to their parent's hoarding symptoms. Therefore, individuals who chose to complete the survey may be those who are the most significantly impacted by parental hoarding. While efforts were placed to also recruit from an undergraduate sample, limited data came from this area. Second, other salient variables that may have affected family functioning and parent-adult child relationships were not examined. For example, hoarding is frequently comorbid with other Axis I and Axis II disorders, such as depression, various anxiety disorders, OCPD and dependent personality disorder (Samuels et al., 2007). Depending on the presence and severity of these symptoms, it is possible that increased parental psychopathology (rather than hoarding alone), may have contributed to poorer parent-adult child relationships and family dysfunction. Third, reports from the informants were not confirmed through a self-report survey from parents who hoard. However, as individuals who hoard often have diminished insight into hoarding behaviors, self-report surveys may be less accurate than the reports gathered from the adult children of hoarders. Additionally, gathering the information from the parents who hoard would not have been feasible in the context of this study. Finally, as inter-rater reliability on the HRS-SR was not a possibility, ratings of hoarding severity may have varied between respondents and may not have captured the true severity of the

hoarding. Responses on the CIR, however, highly correlated with the hoarding severity scores on the HRS-SR, suggesting that responses from informants were consistent.

Overall, this study provides important information for the hoarding literature. Little attention has been provided towards the children of hoarders and the present study has elucidated the negative impact of parental hoarding on adult children and the need to provide proper intervention. As emotional closeness to parents is positively associated with psychological adjustment (Formoso, Gonzales, & Aiken, 2000; Rossi & Rossi, 1990; Umberson, 1992), the presence of parental hoarding and disruptions in the parent-adult child relationship may exacerbate the psychological health of the child. Additionally, as evidenced by the current sample, parental hoarding behaviors generally become noticeable while the child is at a young age, leading the child to have long-term exposures to pathological behaviors. Because of this, future research should examine the psychopathology of adult children of hoarders to determine whether parental hoarding may be a risk factor for the development of psychological disorders. Studies should also examine the effect of enhancing currently developed treatment modalities by incorporating family-based interventions. Gathering information regarding the quality of life, impairment, and burden of children of hoarders while the children are currently living in the home would also provide important information on how to focus intervention for children of hoarders. Finally, as children of hoarders do not present for treatment specifically due to the parental hoarding behaviors, effective ways to disseminate information and reach out to children of hoarders should be investigated.

Tables and Figures

Table 1.

Sample description of adult children of hoarders reporting on parents who hoard

	N (%)	
Parent who hoards		
Mothers	150 (76%)	
Fathers	25 (13%)	
Both	22 (11%)	
Adult Child Informant		
Female (%)	172 (86%)	
	Mean	SD
Age of parent when hoarding onset	37.15	10.74
Age of child when hoarding onset	9.16	9.10
HRS-SR		
Clutter	6.75	1.38
Difficulty Discarding	7.15	1.15
Buying or Collecting	6.30	1.85
Distress	5.59	2.29
Impairment	6.45	1.56
CIR	5.82	1.84
Bedroom	6.46	2.15
Kitchen	5.23	2.04
Living Room	5.76	2.10

Note. HRS-SR – Hoarding Rating Scale – Self Report. Items range from 0 (Not at all) to 8 (Extreme). CIR = Clutter Image Rating. Items range from 1 to 9 (pictures increase in clutter).

Table 2.
Correlation coefficients, means, and standard deviations for indicators

Variable	(1)	(2)	(3)	(4)	(5)	(6)
(1) HRS-SR	---					
(2) FAS	.093	---				
(3) SDS	.013	.550**	---			
(4) Insight	.116	.008	.004	---		
(5) FAD-GF	.296**	-.058	-.055	.274**	---	
(6) IPPA	-.224**	.156*	.058	-.322**	-.686**	---
Mean	6.45	16.79	12.88	2.98	2.81	23.45
Standard Deviation	1.09	9.48	9.56	.99	.40	19.63
Range	4-8	0-46	0-30	0-4	1.92-3.75	-10-82

Note. HRS-SR = Hoarding Rating Scale – Self Report; FAS = Family Accommodation Scale; SDS = Sheehan Disability Scale; FAD-GF = Family Assessment Device- General Functioning subscale; IPPA = Inventory of Parent and Peer Attachment
* $p < .05$, ** $p < .01$

Table 3.

Summary of model fit statistics

Model	χ^2	*p*-value	*df*	RMSEA	SRMR	CFI
Hypothesized Model	16.455	.003	4	0.125	0.035	0.947
Re-specified Model	8.553	0.04	3	0.096	0.023	0.976

Note. *n* = 199 adult children of hoarders. RMSEA = root mean square error of approximation; SRMR = standardized root mean square residual; CFI = comparative fit index

Table 4.

Standardized indirect effects for hoarding variables on parent-adult child relationships

	Total Effect	Total Indirect Effect	Adult Child Impairment Indirect Effect	Family Functioning Indirect Effect
Hoarding severity	-0.18**	-0.18**	-0.001	-0.18**
Insight	-0.31**	-0.16**	0.00	-0.16**
Family Accommodation	0.06	0.06	0.012	0.05

Note. * $p < .05$, ** $p < .001$

Table 5.

Frequency of endorsement of ratings moderate (2) or above on the SI-R

Item	%	Item	%
1. Difficulty throwing things away	22%	11. Keep things that are not needed and have little space for	34%
2. Distressing to throw away items	17%	12. Extent clutter prevents use of parts of home	10%
3. Rooms cluttered	17%	13. Clutter in home causes distress	35%
4. Avoid discarding possessions	28%	14. Clutter prevents inviting people to visit	22%
5. Distressed/uncomfortable if unable to acquire items	19%	15. Actually buy things for which there is no immediate use or need	20%
6. Area of living room cluttered with possessions	11%	16. Urge to save something that will never be used	18%
7. Clutter interferes with social, work or everyday functioning	14%	17. Control over urges to save possessions	16%
8. Compelled to acquire something	10%	18. Home difficult to walk through because of clutter	6%
9. Urge to buy or acquire free things for which there is no immediate use or need	15%	19. Upset or distressed about acquiring habits	17%
10. Control over urges to acquire	11%		

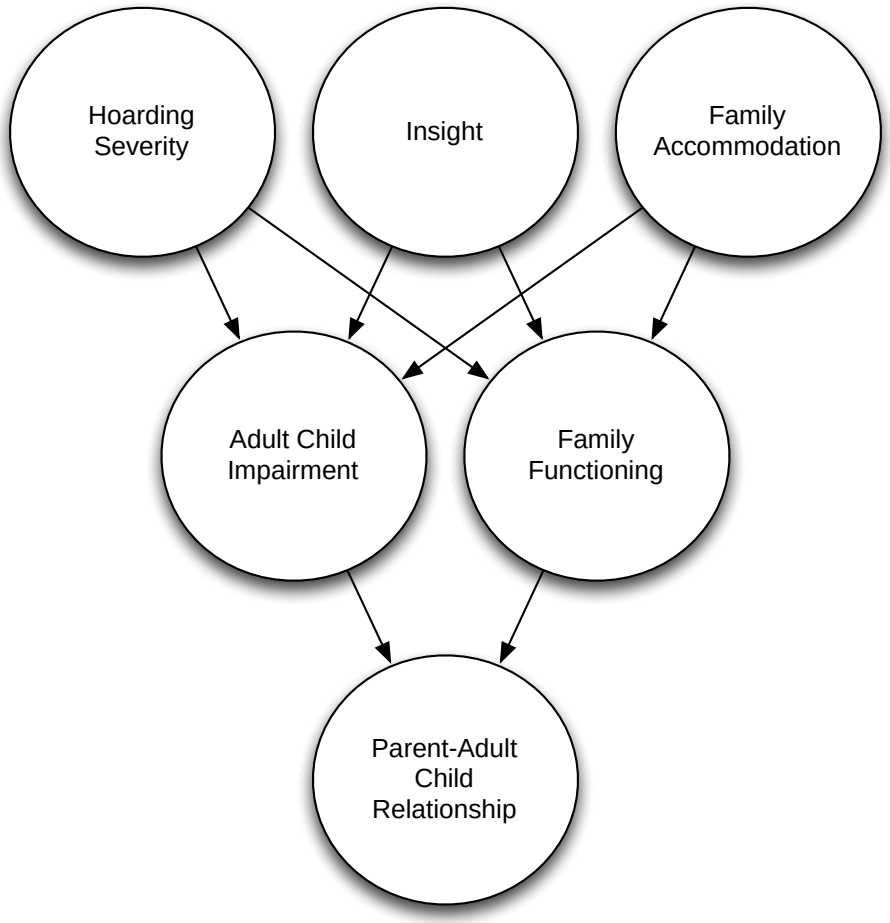


Figure 1. Model of adult child and parent hoarding variables related to parent-adult child relationship

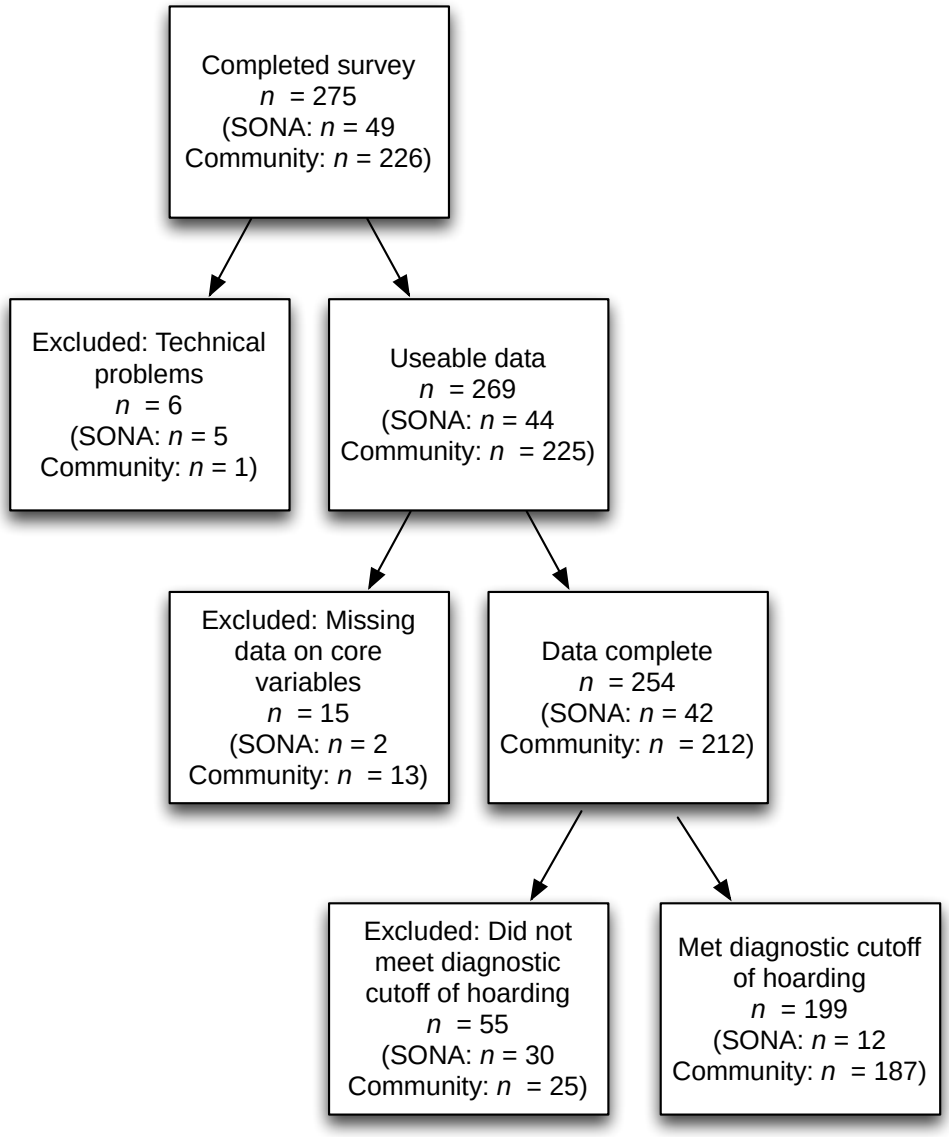
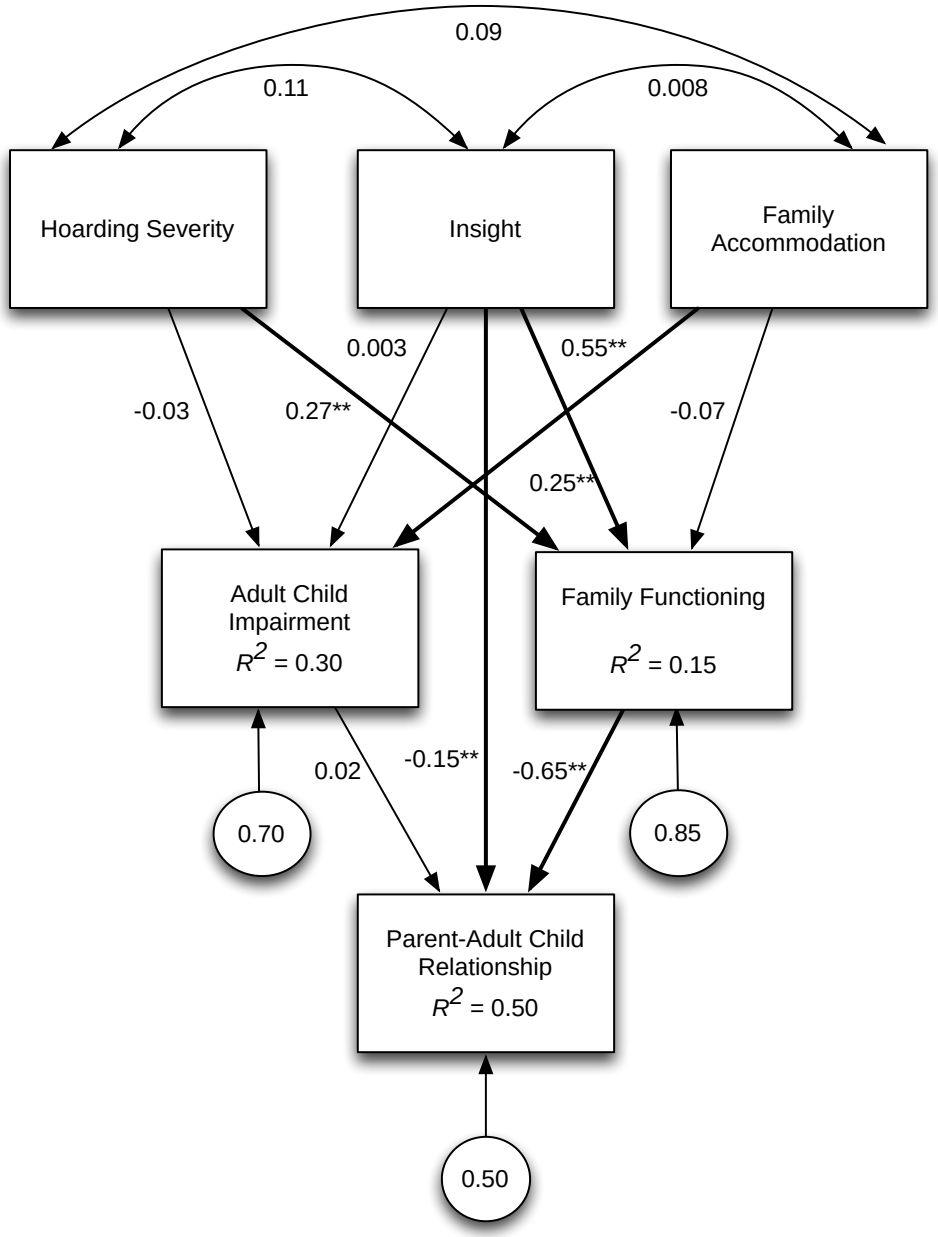


Figure 2. Flowchart of Participants



Note. * $p < .05$, ** $p < .001$

Figure 3. Final path analysis model with standardized path estimates, standardized residuals, R^2 estimates for endogenous variables and correlations of exogenous variables

References

Abramowitz, J. S., Franklin, M. E., Schwartz, S. A., & Furr, J. M. (2003). Symptom presentation and outcome of cognitive-behavioral therapy for obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology, 71*(6), 1049-1057.

Albert, U., Bogetto, F., Maina, G., Saracco, P., Brunatto, C., & Mataix-Cols, D. (2010). Family accommodation in obsessive-compulsive disorder: Relation to symptom dimensions, clinical and family characteristics. *Psychiatry Research, 179*(2), 204-211. doi: 10.1016/j.psychres.2009.06.008

Amato, P. R., & Sobolewski, J. M. (2001). The effects of divoce and marital discord on adult children's psychological well-being. *American Sociological Review, 66,* 900-921.

American Psychiatric Assocation. (2000). *Diagnostic and statistical manual of mental disorders (DSM-IV-TR).* Washington, D.C.: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5*. Arlington, VA: American Psychiatric Publishing.

Amir, N., Freshman, M., & Foa, E. B. (2000). Family distress and involvement in relatives of obsessive-compulsive disorder patients. *Journal of Anxiety Disorders, 14*(3), 209-217.

Armsden, G. C., & Greenberg, M. T. (1987). The Inventory of Parent and Peer Attachment: Individual differences and their relationship to psychological well-being in adolescence. *Journal of Youth and Adolescence, 16,* 427-453.

Ashton, W. A., & Fuehrer, A. (1993). Effects of gender and gender role identification of participant and type of social support resource on support seeking. *Sex Roles, 28,* 461-476.

Beardslee, W. R., Versage, E. M., & Gladstone, T. R. (1998). Children of affectively ill parents: a review of the past 10 years. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*(11), 1134-1141.

Bentler, P. M. (1988). Comparative fit indexes in structural models. *Psychological Bulletin, 107,* 238-246.

Beşiroğlua, L., Çillib, A. S., & Aşkı nb, R. (2004). The predictors of healthcare seeking behavior in obsessive-compulsive disorder. *Comprehensive Psychiatry, 45,* 99-108.

Black, D. W., Gaffney, G., Schlosser, S., & Gabel, J. (1998). The impact of obsessive-compulsive disorder on the family: Preliminary findings. *Journal of Nervous Mental Disorders, 186*(7), 440-442.

Black, D. W., Gaffney, G. R., Schlosser, S., & Gabel, J. (2003). Children of parents with obsessive-compulsive disorder -- a 2-year follow-up study. *Acta Psychiatica .Scandinavica, 107*(4), 305-313.

Bollen, K. A., & Long, J. S. (1993). *Testing Structural Equation Models*. Newbury Park, CA: Sage.

Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. In K. A. B. a. J. S. L. (Eds) (Ed.), *Testing Structural Models*. Newbury Park, CA: Sage Publications.

Calvocoressi, L., Lewis, B., Harris, M., Trufan, S. J., Goodman, W. K., McDougle, C. J., et al. (1995). Family accommodation in obsessive-compulsive disorder. *American Journal of Psychiatry, 152*(3), 441-443.

Calvocoressi, L., Mazure, C. M., Kasl, S. V., Skolnick, J., Fisk, D., Vegso, S. J., et al. (1999). Family accommodation of obsessive-compulsive symptoms: instrument development and assessment of family behavior. *Journal of Nervous Mental Disorders, 187*(10), 636-642.

Catapano, F., Sperandeo, R., Perris, F., Lanzaro, M., & Maj, M. (2001). Insight and resistance in patients with obsessive-compulsive disorder. *Psychopathology, 34*(2), 62-68.

Cermele, J. A., Melendez-Pallitto, L., & Pandina, G. J. (2001). Intervention in compulsive hoarding. A case study. *Behavior Modification, 25*(2), 214-232.

Christensen, D. D., & Greist, J. H. (2001). The challenge of obsessive-compulsive disorder hoarding. *Primary Psychiatry, 8*, 79-86.

Clarke, E. J., Preston, M., Raksin, J., & Bengston, V. L. (1999). Types of conflicts and tensions between older parents and adult children. *The Gerontologist, 39*, 261-270.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences (2nd Ed.).* Hillsdale: Erlbaum.

David, A. S. (1990). Insight and psychosis. *British Journal of Psychiatry, 156*, 798-808.

De Berardis, D., Campanella, D., Gambi, F., Sepede, G., Salini, G., Carano, A., et al. (2005). Insight and alexithymia in adult outpatients with obsessive-compulsive disorder. *European Archives of Psychiatry and Clinical Neuroscience, 255*(5), 350-358. doi: 10.1007/s00406-005-0573-y

DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology, 23*(2), 207-218. doi: 10.1037/0278-6133.23.2.207

Epstein, N., Baldwin, L., & Bishop, D. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy, 9* 171-180.

Foa, E. B. (1979). Failure in treating obsessive-compulsives. *Behaviour Research Therapy, 17*(3), 169-176.

Foa, E. B., Abramowitz, J. S., Franklin, M. E., & Kozak, M. J. (1999). Feared consequences, fixity of belief, and treatment outcome in patients with obsessive-compulsive disorder. *Behavior Therapy, 30* 717-724.

Foa, E. B., & Kozak, M. J. (1997). *Mastery of Obsessive-Compulsive Diorder: A Cognitive-Behavioral Approach. Therapist Guide.* San Antonio, TX: The Psychological Corporation.

Formoso, D., Gonzales, N. A., & Aiken, L. S. (2000). Family conflict and children's internalizing and externalizing behavior: Protective factors. *American Journal of Community Psychology, 28*(2), 175-199.

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

Frost, R. O., & Hartl, T. L. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research Therapy, 34*(4), 341-350.

Frost, R. O., Hartl, T. L., Christian, R., & Williams, N. (1995). The value of possessions in compulsive hoarding: patterns of use and attachment. *Behaviour Research Therapy, 33*(8), 897-902.

Frost, R. O., Krause, M. S., & Steketee, G. (1996). Hoarding and obsessive-compulsive symptoms. *Behavior Modification, 20*(1), 116-132.

Frost, R. O., Sketetee, G., Tolin, D. F., & Renaud, S. (2008). Development and validation of the Clutter Image Rating. *Journal of Psychopathology of Behavioral Assessment, 30,* 193-203.

Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: Saving Inventory-Revised. *Behaviour Research and Therapy*, *42*(10), 1163-1182. doi: 10.1016/j.brat.2003.07.006

Frost, R. O., Steketee, G., Tolin, D. F., & Brown, T. A. (2006). *Comorbidity and diagnostic issues in compulsive hoarding*. Paper presented at the Annal Meeting of the Anxiety Disorders Association of America, Miami, FL.

Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: A community health problem. *Health Social Care Community, 8*(4), 229-234.

Frost, R. O., Steketee, G., Williams, L. F., & Warren, R. (2000). Mood, personality disorder symptoms and disability in obsessive compulsive hoarders: a comparison with clinical and nonclinical controls. *Behaviour Research and Therapy, 38*(11), 1071-1081.

Frost, R. O., Tolin, D. F., & Maltby, N. (2010). Insight-related challenges in the treatment of hoarding. *Cognitive and Behavioral Practice, 17*, 404-413.

Frost, R. O., Tolin, D. F., Steketee, G., Fitch, K. E., & Selbo-Bruns, A. (2009). Excessive acquisition in hoarding. *Journal of Anxiety Disorders, 23*(5), 632-639. doi: 10.1016/j.janxdis.2009.01.013

Fullana, M. A., Vilagut, G., Rojas-Farreras, S., Mataix-Cols, D., de Graaf, R., Demyttenaere, K., et al. (2010). Obsessive-compulsive symptom dimensions in the general population: Results from an epidemiological study in six European countries. *Journal of Affective Disorders, 124*(3), 291-299. doi: 10.1016/j.jad.2009.11.020

Geffken, G. R., Storch, E. A., Duke, D. C., Monaco, L., Lewin, A. B., & Goodman, W. K. (2006). Hope and coping in family members of patients with obsessive-compulsive disorder. *Journal of Anxiety Disorders, 20*(5), 614-629.

Goodman, W. K., Price, L. H., Rasmussen, S. A., Mazure, C., Fleischmann, R. L., Hill, C. L., et al. (1989). The Yale-Brown Obsessive Compulsive Scale. I. Development, use, and reliability. *Archives of General Psychiatry, 46*(11), 1006-1011.

Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *American Psychologist, 59*(2), 93-104. doi: 10.1037/0003-066X.59.2.93

Greenberg, M. T. (1982). *Reliability and validity of the inventory of adolescent attachments*. University of Washington.

Grisham, J. R., Frost, R. O., Steketee, G., Kim, H. J., & Hood, S. (2006). Age of onset of compulsive hoarding. *Journal of Anxiety Disorders, 20*(5), 675-686. doi: 10.1016/j.janxdis.2005.07.004

Grisham, J. R., Frost, R. O., Steketee, G., Kim, H. J., Tarkoff, A., & Hood, S. (2009). Formation of attachment to possessions in compulsive hoarding. *Journal of Anxiety Disorders, 23*(3), 357-361. doi: 10.1016/j.janxdis.2008.12.006

Hanna, G. L., Yuwiler, A., & Coates, J. K. (1995). Whole blood serotonin and disruptive behaviors in juvenile obsessive-compulsive disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, *34*(1), 28-35.

Hu, L., & Bentler, P. M. (1995). Evaluating model fit. In R. H. Hoyle (Ed.), *Structural Equation Modeling. Concepts, Issues, and Applications* (pp. 76-99). London: Sage.

Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure and analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling, 6*, 1-55.

Jackson, D. L. (2003). Revisiting sample size and number of parameter estimates: Some suppor for the *N*:*q* hypothesis. *Structural Equation Modeling, 10*, 128-141.

Johnson, J. A. (2001). *Screening massively large data sets for non-responsiveness in web based personalitiy inventories.* Paper presented at the Invited talk to joint the Bielefeld-Groningen Personality Research Group, University of Groningen, The Netherlands.

Kessler, R. C., McGonagle, K. A., Zhao, S., Nelson, C. B., Hughes, M., Eshleman, S., et al. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. Results from the National Comorbidity Survey. *Archives of General Psychiatry, 51*(1), 8-19.

Kessler, R. C., Mickelson, K. D., Barber, C. B., & Wang, P. S. (2001). The effects of chronic medical condisitions on work impairment. In A. S. Rossi (Ed.), *Caring and doing for others: Social responsibility in the domains of th family, work, and community* (pp. 403-426). Chicago: University of Chicago Press.

Kim, H. J., Steketee, G., & Frost, R. O. (2001). Hoarding by elderly people. *Health and Social Work, 26*(3), 176-184.

Kline, R. B. (2005). *Principles and Practice of Structural Equation Modeling, 2nd Edition*. New York, NY: Guildford Press.

Kline, R. B. (2011). *Principles and Pratice of Structural Equation Modeling, 3rd Edition*. New York: Guilford Press.

Kohli, M., & Kunemund, H. (2001). Give and take: The elderly in intergenerational relation. *Zeitschrift fur Erziehungswissenschaft, 4*, 513-528.

Kreisman, D. E., Simmens, S. J., & Joy, V. D. (1979). Rejecting the patient: Preliminary validation of a self-report scale. *Schizophrenia Bulletin, 5*(220-222).

Kyrios, M., Frost, R., & Steketee, G. (2004). Cognitions in compulsive buying and acquisition. *Cognitive Therarpy Researchs, 28*, 241-258.

Lawton, L., Silverstein, M., & Bengston, V. L. (1994). Affection, social contact and geographic distance between adult children and their parents. *Journal of Marriage and Family, 56*, 57-68.

Lawton, L., Silverstein, M., & Bengtson, V. L. (1994). Solidarity between generations in families. In R. A. H. V.L. Bengtson (Ed.), *Intergenerational Linkages: Hidden Connections in American Society* (pp. 19-42). New York: Springer.

Leon, A. C., Olfson, M., Portera, L., Farber, L., & Sheehan, D. V. (1997). Assessing psychiatric impairment in primary care with the Sheehan Disability Scale. *International Journal of Psychiatry Medicine, 27*(2), 93-105.

Lewis, F. M., Woods, N. F., & Ellison, E. (1987). *Family impact study*. University of Washing, R01-NUO1000, Division ofNrusing, Public Health Service.

Lochner, C., Kinnear, C. J., Hemmings, S. M., Seller, C., Niehaus, D. J., Knowles, J. A., et al. (2005). Hoarding in obsessive-compulsive disorder: clinical and genetic correlates. *Journal of Clinical Psychiatry, 66*(9), 1155-1160.

Lye, D. N. (1996). Adult child-parent relationships. *Annu Rev Sociol, 22*, 79-102.

Mardia, K. V. (1970). Measures of multivariate skewness and kurtosis with applications. *Biometrika, 57*, 519-530.

Mardia, K. V. (1985). Mardia's test of multivariate normality. In S. K. N. L. Johnson (Ed.), *Encyclopedia of statistical sciences* (Vol. 5, pp. 217-222). New York, NY: Wiley.

Marks, N. F. (1995). Midlife marital status differences in social support relationships with adult children and psychological well-being. *Journal of Family Issues, 16*, 5-28.

Mataix-Cols, D., Baer, L., Rauch, S. L., & Jenike, M. A. (2000). Relation of factor-analyzed symptom dimensions of obsessive-compulsive disorder to personality disorders. *Acta Psychiatrica Scandinavia, 102*(3), 199-202.

Mataix-Cols, D., Frost, R. O., Pertusa, A., Clark, L. A., Saxena, S., Leckman, J. F., et al. (2010). Hoarding disorder: a new diagnosis for DSM-V? *Depression and Anxiety, 27*(6), 556-572. doi: 10.1002/da.20693

Mataix-Cols, D., Marks, I. M., Greist, J. H., Kobak, K. A., & Baer, L. (2002). Obsessive-compulsive symptom dimensions as predictors of compliance with and response to behaviour therapy: results from a controlled trial. *Psychotherapy and Psychosomatics, 71*(5), 255-262. doi: pps71255

Mataix-Cols, D., Rauch, S. L., Manzo, P. A., Jenike, M. A., & Baer, L. (1999). Use of factor-analyzed symptom dimensions to predict outcome with serotonin reuptake inhibitors and placebo in the treatment of obsessive-compulsive disorder. *American Journal of Psychiatry, 156*(9), 1409-1416.

Matsunaga, H., Kiriike, N., Matsui, T., Oya, K., Iwasaki, Y., Koshimune, K., et al. (2002). Obsessive-compulsive disorder with poor insight. *Comprehensive Psychiatry, 43*(2), 150-157.

McGuire, J. F., Kaercher, L., Park, J. M., Frost, R. O., & Storch, E. A. (2012). Hoarding in the community. A code enforcement and social service perspective. *Journal of Social Service Research, 39*(3), 335-344.

Merlo, L. J., Lehmkuhl, H. D., Geffken, G. R., & Storch, E. A. (2009). Decreased family accommodation associated with improved therapy outcome in pediatric obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology, 77*(2), 355-360.

Meunier, S. A., Tolin, D. F., Frost, R., Steketee, G., & Brady, R. E. (2006). *Prealence of hoarding symptoms across the anxiety disorders*. Paper presented at the Annaul Meeting of the Anxiety Disorders Association of America, Miami, FL.

Mueller, A., Mitchell, J. E., Crosby, R. D., Glaesmer, H., & de Zwaan, M. (2009). The prevalence of compulsive hoarding and its association with compulsive buying in a German population-based sample. *Behaviour Research and Therapy, 47*(8), 705-709. doi: 10.1016/j.brat.2009.04.005

Muthen, L. K., & Muthen, B. O. (2007). *Mplus User's Guide. Sixth Edition*. Los Angeles, CA: Muthen & Muthen.

O'Connor, K. P., Aardema, F., Bouthillier, D., Fournier, S., Guay, S., Robillard, S., et al. (2005). Evaluation of an inference-based approach to treating obsessive-compulsive disorder. *Cognitive and Behaviour Therapy, 34*(3), 148-163. doi: 10.1080/16506070510041211

Peris, T. S., Bergman, R. L., Langley, A., Chang, S., McCracken, J. T., & Piacentini, J. (2008). Correlates of accommodation of pediatric obsessive-compulsive disorder: Parent, child, and family characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(10), 1173.

Perrig-Chiello, P., & Hopflinger, F. (2001). *In between the generations: Women and men in middle adulthood*. Zurich, Switzerland: Seismo Verlag.

Pertusa, A., Fullana, M. A., Singh, S., Alonso, P., Menchon, J. M., & Mataix-Cols, D. (2008). Compulsive hoarding: OCD symptom, distinct clinical syndrome, or both? *American Journal of Psychiatry, 165*(10), 1289-1298. doi: 10.1176/appi.ajp.2008.07111730

Pinto, A., Eisen, J. L., Macebo, M., Dyck, I., Edelen, M., & Rasmusse, S. (2007). *A 2-year follow up study of the course of obsessive-compulsive disorder*. Paper presented at the Meeting of the Association of Behavioral and Cognitive Therapies, Philadelphia, PA.

Rasmussen, S. A., & Eisen, J. L. (1992). The epidemiology and clinical features of obsessive compulsive disorder. *Psychiatric Clinica of North America, 15*(4), 743-758.

Ravi Kishore, V., Samar, R., Janardhan Reddy, Y. C., Chandrasekhar, C. R., & Thennarasu, K. (2004). Clinical characteristics and treatment response in poor and good insight obsessive-compulsive disorder. *European Psychiatry, 19*(4), 202-208.

Renshaw, K. D., Steketee, G., & Chambless, D. L. (2005). Involving family members in the treatment of OCD. *Cognitive Behaviour and Therapy, 34*(3), 164-175.

Ridenour, T. A., Daley, J. G., & Reich, W. (1999). Factor analyses of the family assessment device. *Family Process, 38*(4), 497-510.

Rossi, A. S., & Rossi, P. H. (1990). *Of Human Bonding: Parent-Child Relations Across the Life Course*. New York: Aldine de Gruyter.

Rufer, M., Fricke, S., Moritz, S., Kloss, M., & Hand, I. (2006). Symptom dimensions in obsessive-compulsive disorder: Prediction of cognitive-behavior therapy outcome. *Acta Psychiatrica Scandinavia, 113*(5), 440-446. doi: 10.1111/j.1600-0447.2005.00682.x

Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K. Y., et al. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behaviour Research and Therapy, 46*(7), 836-844. doi: 10.1016/j.brat.2008.04.004

Samuels, J. F., Bienvenu, O. J., Pinto, A., Fyer, A. J., McCracken, J. T., Rauch, S. L., et al. (2007). Hoarding in obsessive-compulsive disorder: Results from the OCD Collaborative Genetics Study. *Behaviour Research and Therapy, 45*(4), 673-686.

Samuels, J. F., Bienvenu, O. J., Riddle, M. A., Cullen, B. A., Grados, M. A., Liang, K. Y., et al. (2002). Hoarding in obsessive compulsive disorder: Results from a case-control study. *Behaviour Research and Therapy, 40*(5), 517-528.

Samuels, J. F., Shugart, Y. Y., Grados, M. A., Willour, V. L., Bienvenu, O. J., Greenberg, B. D., et al. (2007). Significant linkage to compulsive hoarding on chromosome 14 in families with obsessive-compulsive disorder: results from the OCD Collaborative Genetics Study. *American Journal of Psychiatry, 164*(3), 493-499.

Saxena, S., Maidment, K. M., Vapnik, T., Golden, G., Rishwain, T., Rosen, R. M., et al. (2002). Obsessive-compulsive hoarding: symptom severity and response to multimodal treatment. *Journal of Clinical Psychiatry, 63*(1), 21-27.

Schreier, A., Wittchen, H. U., Hofler, M., & Lieb, R. (2008). Anxiety disorders in mothers and their children: Prospective longitudinal community study. *British Journal of Psychiatry, 192*(4), 308-309. doi: 10.1192/bjp.bp.106.033589

Schwarz, B., Trommsdorff, G., Albert, I., & Mayer, B. (2005). Adult parent-child relationships: Relationship quality, support, and reciprocity. *Applied Psychology: An International Review, 3*, 396-417.

Seedat, S., & Stein, D. J. (2002). Hoarding in obsessive-compulsive disorder and related disorders: a preliminary report of 15 cases. *Psychiatry and Clinical Neuroscience, 56*(1), 17-23. doi: 10.1046/j.1440-1819.2002.00926.x

Sheehan, D. V., Harnett-Sheehan, K., & Raj, B. A. (1996). The measurement of disability. *International Clinical Psychopharmacology, 11 Suppl 3*, 89-95.

Steketee, G., & Frost, R. (2006). *Compulsive Hoarding and Acquiring: Therapist Guide*. New York, USA: Oxford University Press.

Steketee, G., Frost, R. O., Tolin, D. F., Rasmussen, J., & Brown, T. A. (2010). Waitlist-controlled trial of cognitive behavior therapy for hoarding disorder. *Depression and Anxiety, 27*(5), 476-484. doi: 10.1002/da.20673

Steketee, G., Frost, R. O., Wincze, J., Greene, K., & Douglass, H. (2000). Group and individual treatment of compulsive hoarding: A pilot study. *Behavioural and Cognitive Psychotherapy, 28*, 259-268.

Stewart, S. E., Beresin, C., Haddad, S., Egan Stack, D., Fama, J., & Jenike, M. (2008). Predictors of family accommodation in obsessive-compulsive disorder.. *Annals of Clinical Psychiatry, 20*(2), 65-70. doi: 10.1080/10401230802017043

Timpano, K. R., Exner, C., Glaesmer, H., Rief, W., Keshaviah, A., Brahler, E., et al. (2011). The epidemiology of the proposed DSM-5 hoarding disorder: Exploration of the acquisition specifier, associated features, and distress. *Journal of Clinical Psychiatry, 72*(6), 780-786; quiz 878-789. doi: 10.4088/JCP.10m06380

Tolin, D. F., Fitch, K. E., Frost, R., & Steketee, G. (2010). Family informants' perceptions of insight in compulsive hoarding. *Cognitive Therapy and Research, 34*, 69-81.

Tolin, D. F., Frost, R. O., & Steketee, G. (2007). An open trial of cognitive-behavioral therapy for compulsive hoarding. *Behaviour Research and Therapy, 45*(7), 1461-1470. doi: 10.1016/j.brat.2007.01.001

Tolin, D. F., Frost, R. O., & Steketee, G. (2010). A brief interview for assessing compulsive hoarding: The Hoarding Rating Scale-Interview. *Psychiatry Research, 178*(1), 147-152. doi: 10.1016/j.psychres.2009.05.001

Tolin, D. F., Frost, R. O., Steketee, G., & Fitch, K. E. (2008). Family burden of compulsive hoarding: Results of an internet survey. *Behaviour Research and Therapy, 46*(3), 334-344. doi: 10.1016/j.brat.2007.12.008

Tolin, D. F., Frost, R. O., Steketee, G., Gray, K. D., & Fitch, K. E. (2008). The economic and social burden of compulsive hoarding. *Psychiatry Research, 160*(2), 200-211. doi: 10.1016/j.psychres.2007.08.008

Tolin, D. F., Kiehl, K. A., Worhunsky, P., Book, G. A., & Maltby, N. (2009). An exploratory study of the neural mechanisms of decision making in compulsive hoarding. *Psychological Medicine, 39*(2), 325-336. doi: 10.1017/S0033291708003371

Umberson, D. (1992). Relationships between adult children and their parents: Psychological consequences for both generations. *Journal of Marriage and Family, 45*, 841-849.

Weissman, M. M., Wickramaratne, P., Nomura, Y., Warner, V., Pilowsky, D., & Verdeli, H. (2006). Offspring of depressed parents: 20 years later. *American Journal of Psychiatry, 163*(6), 1001-1008. doi: 10.1176/appi.ajp.163.6.1001

Wilbram, M., Kellett, S., & Beail, N. (2008). Compulsive hoarding: A qualitative investigation of partner and carer perspectives. *British Journal of Clinical Psychology, 47*(Pt 1), 59-73. doi: 10.1348/014466507X240740

Winsberg, M. E., Cassic, K. S., & Koran, L. M. (1999). Hoarding in obsessive-compulsive disorder: A report of 20 cases. *Journal of Clinical Psychiatry, 60*(9), 591-597.

Wu, K. D., & Watson, D. (2005). Hoarding and its relation to obsessive-compulsive disorder. *Behaviour Research and Therapy, 43*(7), 897-921. doi: 10.1016/j.brat.2004.06.013

Yang, L., Levine, E., Xu, X., & Lopez Rivas, G. E. (2009). Surveying via the next vs hard copy: A cautionary note. *Ergometrika, 6*(1), 20-39.

Appendices

Appendix A

Consent form – Community/Hoarding Websites

IRB# 00009495
Dear Appreciated Volunteer:

Thank you for your interest in this study. The title of this study is "An Examination of the Impact of Hoarding on Parent-Adult Child Relationships and Family Functioning". The purpose of this study is to examine the impact of parental hoarding in adult-aged children.
We are examining familial relationships – via adult-aged child reports – in up to 300 individuals. To participate, you must be over the age of 18 years old and you must have a parent who engages in hoarding behaviors. Hoarding behaviors refer to any of the following: excessively collecting items or acquiring, difficulty discarding items (especially seemingly valueless items), and/or experiencing significant distress, anger, or anxiety when items are lost or discarded. The survey will take approximately 45 minutes to complete.

You will be asked to complete a questionnaire about your parent's hoarding behaviors, relationships with your family and hoarding parent, and impairment associated with the hoarding behaviors. Your answers to the questions will be kept confidential and will only be seen by myself and members of the research team. In addition, your identity will be anonymous, as no identifying information from you will be associated with your answers. Finally, participation is voluntary – you may stop participating in the study at any time with no penalty.

While we do not anticipate any risks associated with study participation, some people may feel uncomfortable answering questions about their relationship with their parents and aspects about their family that may be private. You will not receive any compensation for the completion of the study. If the results of this research are published or presented at scientific meetings, your identity and your parent's identity will not be disclosed at any time. No data regarding your internet address will be collected, thus ensuring your anonymity.

If you feel distressed about answering questions, you may contact Jennifer Park at 727-767-8230 or via email at jmpark@mail.usf.edu

Please understand that by selecting "continue" that you are indicating that you have read the description of the study and agree to participate.

Thank you for your consideration. If you have any questions about your participation, you may call Jennifer Park or Dr. Eric Storch or University of South Florida Institutional Review Board at 813-974-5638. Also, please feel free to print out this form if you prefer to keep it for your records or read a hard copy.

Sincerely,

Jennifer Park, M.A.
University of South Florida
4202 E Fowler Ave, PCD 4118G
Tampa, FL 33620
Jmpark@mail.usf.edu

Eric Storch, Ph.D.
Departments of Pediatrics and Psychiatry

Appendix B

Consent form – Sona

IRB#00009495

Dear Appreciated Volunteer:

Thank you for your interest in this study. The title of this study is "An Examination of the Impact of Hoarding on Parent-Adult Child Relationships and Family Functioning". The purpose of this study is to examine the impact of parental hoarding adult-aged children. We are examining familial relationships – via adult-aged child reports – in up to 300 individuals. To participate, you must be over the age of 18 years old and you must have a parent who engages in hoarding behaviors. Hoarding behaviors refer to any of the following: excessively collecting items, difficulty discarding items (especially seemingly valueless items), and/or experiencing significant distress, anger, or anxiety when items are lost or discarded. The survey will take approximately 45 minutes to complete.

You will be asked to complete a questionnaire about your parent's hoarding behaviors, relationships with your family and hoarding parent, and impairment associated with the hoarding behaviors. Your answers to the questions will be kept confidential and will only be seen by myself and members of the research team. In addition, your identity will be anonymous, as no identifying information from you will be associated with your answers. Finally, participation is voluntary – you may stop participating in the study at any time with no penalty.

While we do not anticipate any risks associated with study participation, some people may feel uncomfortable answering questions about their relationship with their parents and aspects about their family that may be private. You will receive 1 research credit for your participation in this study. If you choose to withdraw consent and discontinue the study at any point, you will receive 0.5 research credit for your participation. If the results of this research are published or presented at scientific meetings, your identity and your parent's identity will not be disclosed at any time. No data regarding your internet address will be collected, thus ensuring your anonymity.

If you feel distressed about answering questions, you may contact Jennifer Park at 727-767-8230 or via email at jmpark@mail.usf.edu

Please understand that by selecting "continue" that you are indicating that you have read the description of the study and agree to participate.

Thank you for your consideration. If you have any questions about your participation, you may call Jennifer Park or Dr. Eric Storch or University of South Florida Institutional Review Board at 813-974-5638. Also, please feel free to print out this form if you prefer to keep it for your records or read a hard copy.

Sincerely,

Jennifer Park, M.A.
University of South Florida
4202 E Fowler Ave, PCD 4118G
Tampa, FL 33620
Jmpark@mail.usf.edu

Eric Storch, Ph.D.
Departments of Pediatrics and Psychiatry

Appendix C

Demographic Form

1. Your Age: _____/_____
   years months
2. Your Gender: Male / Female
3. Your Race: □ Hispanic or Latino □ not Hispanic or Latino
4. Your Ethnicity: □ White □ Black or African American □ Asian

□ American Indian or Alaska Native □ Native Hawaiian or Other Pacific Islander

5. Please identify which of your parents hoard:

___Mother

___Father

___Both

Please note: If both of your parents exhibit hoarding behaviors, please fill out this survey regarding the parent who exhibits these behaviors the most. If both parents hoard equally, please choose one and focus on that parent for the rest of this survey. Please only focus on ONE parent throughout the entire survey.

6. Age of parent who hoards: _____/_____
   years months
7. Race of parent who hoards: □ Hispanic or Latino □ not Hispanic or Latino
8. Ethnicity of parent who hoards: □ White □ Black or African American □ Asian

□ American Indian or Alaska Native □ Native Hawaiian or Other Pacific Islander

9. Family income of hoarding parent:
   ___below $25,000
   ___$25,000-$50,000
   ___$50,000-$75,000
   ___$75,000-$100,000
   ___more than $100,000
10. Marital status of parent who hoards (mark one):
    ___ single, never married

___ single, divorced separated
___ widowed
___ married/cohabiting

11. What is the highest level of education for your parent who hoards?

___ 5th grade or less ___ 7th through 9th grade

___ GED ___ high school diploma

___ at least one year of college ___ 4-year college/university degree

___ graduate degree (M.A./M.S.; Ph.D.)

12. What is the employment status of your parent who hoards?:
___ unemployed
___ employed – if so, what is his/her current occupation?_____
___ homemaker
___ retired – if so, what was his/her most recent occupation?_____

13. How old were you when your parent's hoarding first began (or first became noticeable to you)?___

14. How old was your parent when he/she began to hoard? ___

15. Did your parent engage in hoarding behaviors while you lived in the same home? Yes or No

If yes:

a. How long did you live in the home while your parent engaged in hoarding behaviors?

___ Less than 6 months
___ 6 months-1 year
___ 2-5 years
___ 6-10 years
___ 10-15 years
___ Over 15-20 years
___ Over 20 years

16. Has your parent who hoards ever received treatment for his/her hoarding behaviors? Yes or No

If yes:
What type of treatment did he/she receive (choose all that apply)?

___Psychotherapy
Duration:
___Medication
Duration:
___Other (Please specify):_____
Duration:

17. What is the approximate distance between where you and your parent who hoards reside?
    ___ Reside in same home
    ___ 0-30 miles
    ___ 31-60 miles
    ___ 61-120 miles
    ___ Same state but over 120 miles
    ___ Different state
    ___ Different country

18. What is the frequency of your contact with your parent (face to face and/or telephone contact)?
    ___ Daily, or every other day
    ___ 1-3 times per week
    ___ 1-3 times per month
    ___ Once every other month
    ___ Once every 3-6 months
    ___ Once a year
    ___ Once every 2-3 years
    ___ Never

Appendix D

Hoarding Rating Scale – Self Report (HRS-SR)

Please respond to the following questions regarding your parent who hoards.

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

0	1	2	3	4	5	6	7	8
Not at all Difficult		Mild		Moderate		Severe		Extremely Difficult

2. To what extent does your parent have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?

0	1	2	3	4	5	6	7	8
Not at all Difficult		Mild		Moderate		Severe		Extremely Difficult

3. To what extent does your parent currently have a problem with collecting free things or buying more things than he/she needs or can use or can afford?

0	1	2	3	4	5	6	7	8
None								Extreme

0 = no problem
2 = mild problem, occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items
4 = moderate, regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items
6 = severe, frequently (several times per week) acquires items not needed, or acquires many unneeded items
8 = extreme, very often (daily) acquires items not needed, or acquires large numbers of unneeded items

4. To what extent does your parent experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?

0	1	2	3	4	5	6	7	8
None/ Not at all		Mild		Moderate		Severe		Extreme

5. To what extent does your parent experience impairment in his/her life (daily routine, job / school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

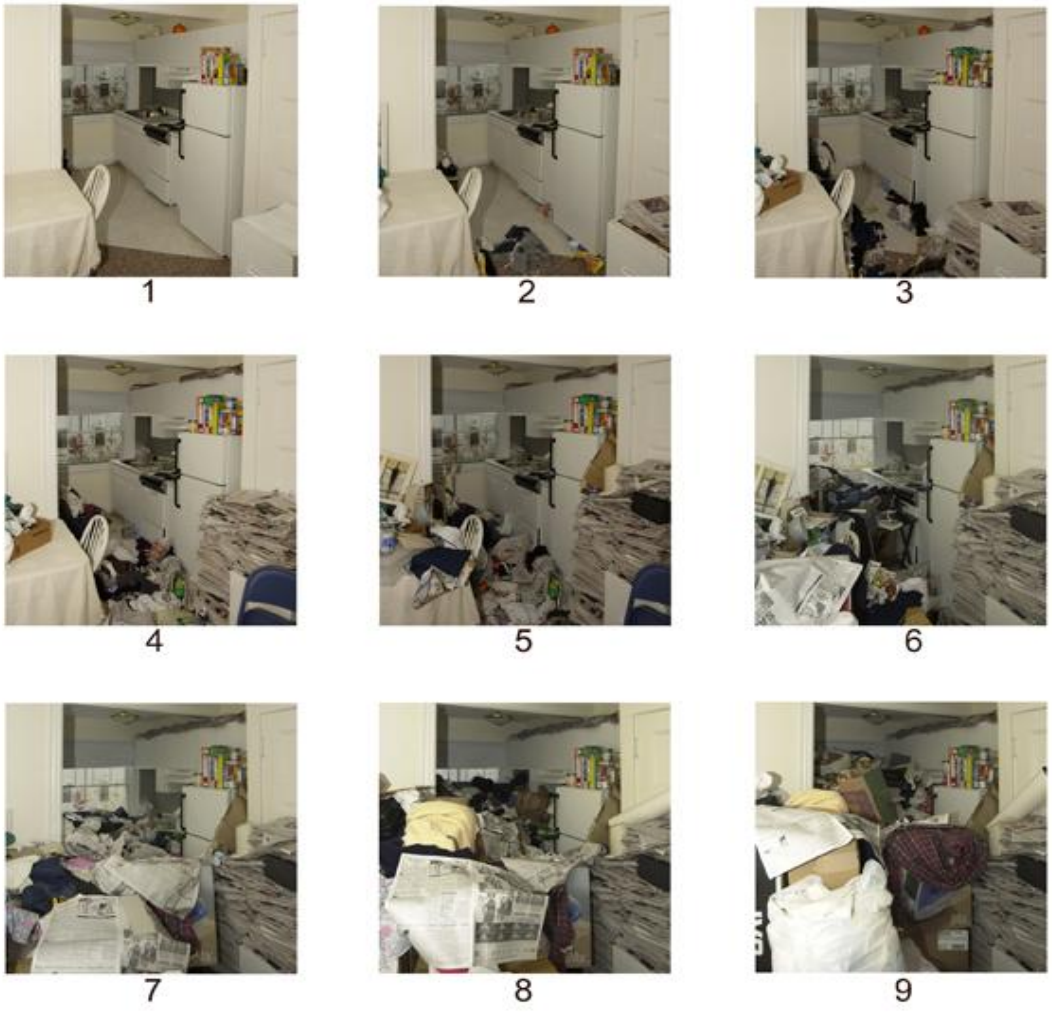
0	1	2	3	4	5	6	7	8
None/ Not at all		Mild		Moderate		Severe		Extreme

Appendix E

Clutter Image Ratings (CIR)

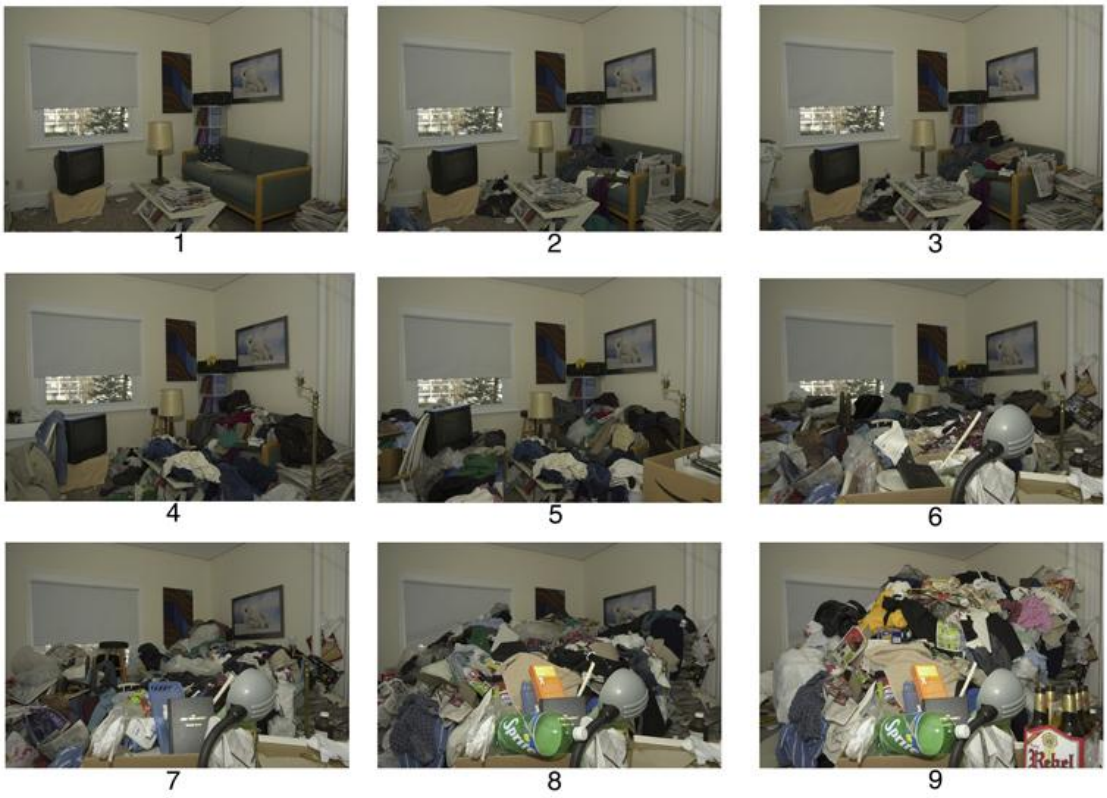
Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.



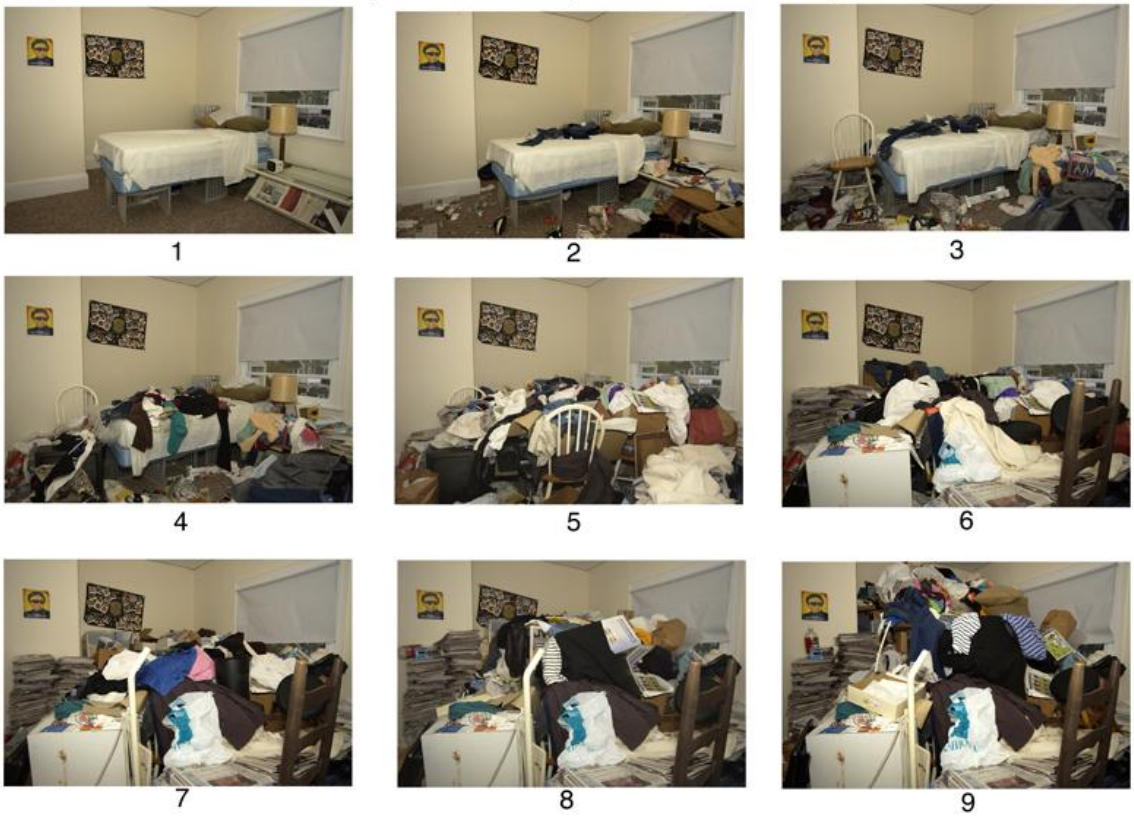
Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.



Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.



Appendix F

Insight Ratings

Please choose one item which best represents the awareness or insight you parent who hoards has regarding his/her hoarding behaviors.

(0) Excellent insight, fully rational. Parent's hoarding behaviors may have been bad, but he/she fully recognized that they were a problem

(1) Good insight. Parent readily acknowledges that his/her acquisition, clutter and/or difficulty discarding is a problem. However, when at home or out shopping/acquiring, parent has difficulty seeing the problem with acquiring or not discarding items.

(2) Fair insight. Parent may admit clutter is a problem, but only reluctantly admits that his/her behavior (such as acquiring too many things, or failing to discard things) has caused the problem. When at home or out shopping/acquiring, parent has difficulty seeing that he/she has a problem with acquiring or not discarding things

(3) Poor insight. Parent maintains that acquisition, difficulty discarding, and clutter are under control or not a problem. When someone discusses the problem with him/her, parent acknowledges that he/she might have a problem, but still underestimates the severity of the problem

(4) Lacks insight, delusional. Parent was convinced that he/she had no problems with acquisition, clutter, or difficulty discarding. He/she would argue that there is no problem, despite contrary evidence or arguments

Appendix G

Inventory of Parent and Peer Attachment (IPPA)

This questionnaire asks about your relationship with your *parent who hoards.*

Please read each statement and circle the ONE number that tells how true the statement is for you
now.

	Almost Never or Never True	Not Very Often True	Some-times True	Often True	Almost Always or Always True
1. My parent respects my feeling.	1	2	3	4	5
2. I feel my parent does a good job as my parent.	1	2	3	4	5
3. I wish I had a different parent.	1	2	3	4	5
4. My parent accepts me as I am.	1	2	3	4	5
5. I like to get my parent's point of view on things I'm concerned about.	1	2	3	4	5
6. I feel it's no use letting my feelings show around my parent.	1	2	3	4	5
7. My parent can tell when I'm upset about something.	1	2	3	4	5
8. Talking over my problems with my parent makes me feel ashamed or foolish.	1	2	3	4	5
9. My parent expects too much from me.	1	2	3	4	5
10. I get upset easily around my parent.	1	2	3	4	5
11. I get upset a lot more than my parent knows about.	1	2	3	4	5

12. When we discuss things, my parent cares about my point of view.	1	2	3	4	5
13. My parent trusts my judgment.	1	2	3	4	5
14. My parent has his/her own problems, so I don't bother him/her with mine.	1	2	3	4	5
15. My parent helps me to understand myself better.	1	2	3	4	5
16. I tell my parent about my problems and troubles.	1	2	3	4	5
17. I feel angry with my parent.	1	2	3	4	5
18. I don't get much attention from my parent.	1	2	3	4	5
19. My parent helps me to talk about my difficulties.	1	2	3	4	5
20. My parent understands me.	1	2	3	4	5
21. When I am angry about something, my parent tries to be understanding.	1	2	3	4	5
22. I trust my parent.	1	2	3	4	5
23. My parent doesn't understand what I'm going through these days.	1	2	3	4	5
24. I can count on my parent when I need to get something off my chest.	1	2	3	4	5
25. If my parent knows something is bothering me, he/she asks me about it.	1	2	3	4	5

Appendix H

Family Assessment Device

This assessment contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family, **which includes parents and siblings**. **These questions do NOT refer to spouses and children.** You should answer according to how you see your family.

For each statement are four (4) possible responses:

Strongly agree (SA) Check SA if you feel that the statement describes your family very accurately.

Agree (A) Check A if you feel that the statement describes your family for the most part.

Disagree (D) Check D if you feel that the statement **does not** describe your family for the most part.

Strongly disagree (SD) Check SD if you feel that the statement **does not** describe your family at all.

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have difficulty, answer with your first reaction. Please be sure to answer *every* statement and mark all your answers in the space provided *below* each statement.

1. Planning family activities is difficult because we misunderstand each other.

____SA ____A ____D _____SD _____

2. We resolve most everyday problems in the family.

____SA ____A ____D _____SD _____

3. When someone is upset the others know why.

____SA ____A ____D _____SD _____

4. If someone is in trouble, the others become too involved.

____SA ____A ____D _____SD _____

5. In times of crisis we can turn to each other for support.

____SA ____A ____D _____SD _____

6. We are reluctant to show our affection for each other.

____SA ____A ____D _____SD _____

7. We cannot talk to each other about the sadness we feel.

____SA ____A ____D _____SD _____

8. We usually act on our decisions regarding problems.

____SA ____A ____D _____SD _____

9. You only get the interest of others when something is important to them.

____SA ____A ____D _____SD _____

10. You can't tell how a person is feeling from what they are saying.

____SA ____A ____D _____SD _____

11. Individuals are accepted for what they are.

____SA ____A ____D _____SD _____

12. People come right out and say things instead of hinting at them.

____SA ____A ____D _____SD _____

13. Some of us just don't respond emotionally.

____SA ____A ____D _____SD _____

14. We avoid discussing our fears and concerns.

____SA ____A ____D _____SD _____

15. It is difficult to talk to each other about tender feelings.

____SA ____A ____D _____SD _____

16. After our family tries to solve a problem, we usually discuss whether it worked or not.

____SA ____A ____D _____SD _____

17. We are too self-centred.

____SA ____A ____D _____SD _____

18. We can express feelings to each other.

____SA ____A ____D _____SD _____

19. We do not show our love for each other.

____SA ____A ____D _____SD _____

20. We talk to people directly rather than through go-betweens.

____SA ____A ____D _____SD _____

21. There are lots of bad feelings in the family.

____SA ____A ____D _____SD _____

22. We get involved with each other only when something interests us.

____SA ____A ____D _____SD _____

23. We often don't say what we mean.

____SA ____A ____D _____SD _____

24. We feel accepted for what we are.

____SA ____A ____D _____SD _____

25. We show interest in each other when we can get something out of it personally.

____SA ____A ____D _____SD _____

26. We resolve most emotional upsets that come up.

____SA ____A ____D _____SD _____

27. Tenderness takes second place to other things in our family.

____SA ____A ____D _____SD _____

28. Making decisions is a problem for our family.

____SA ____A ____D _____SD _____

29. Our family shows interest in each other only when they can get something out of it.

____SA ____A ____D _____SD _____

30. We are frank(direct, straightforward) with each other.

____SA ____A ____D _____SD _____

31. We are able to make decisions about how to solve problems.

____SA ____A ____D _____SD _____

32. We express tenderness.

____SA ____A ____D _____SD _____

33. We confront problems involving feelings.

____SA ____A ____D _____SD _____

34. We don't get along well together.

____SA ____A ____D _____SD _____

35. We don't talk to each other when we are angry.

____SA ____A ____D _____SD _____

36. Even though we mean well, we intrude too much into each other's lives.

____SA ____A ____D _____SD _____

37. We confide in each other.

____SA ____A ____D _____SD _____

38. We cry openly.

____SA ____A ____D _____SD _____

39. When we don't like what someone has done, we tell them.

____SA ____A ____D _____SD _____

40. We try to think of different ways to solve problems.

____SA ____A ____D _____SD _____

Appendix I

Family Accommodation Scale (FAS)

This questionnaire measures the extent to which you may accommodate, or change your personal routine or behaviors to enable your parent's hoarding behavior or avoid causing distress in your parent who hoards.

Examples of accommodation may be (but are not limited):

Acquisition

Purchase items for parent that they will put in their "collection"; bring parent to places where he/she can acquire items (flea market, second hand store, mall); give parent items by request

Clutter

Provide parent storage space for their items; make different accommodations so that family gatherings/parties will not occur at parent's hme

Discarding

Refrain from discarding items in parent's home; make decisions for parents on which items to discard

Distress

Help parent avoid situations that may cause parent to become distressed, such as conversations regarding hoarding behaviors, entering parent's home, discarding items in parent's home

During the past month,

1) How often did you reassure your parent who hoards?

(Reassurance refers to the act of removing anxiety, fear or doubt, such as (but not limited to) telling your parent that items have not been discarded, comforting parent that lost items will be found, assuring parent that items will not be discarded, telling/reminding parents where items are located)

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

2) During the past month, how many times did you watch your parent acquire hoarding items or have difficulty discarding items?

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

3) During the past month did you wait for your parent to complete hoarding behaviors resulting in interference with plans you had made? For example, look for items, order and arrange items, make decisions about what to do with certain items (discard, organize, etc.)

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

4) During the past month, were there things that you did not do or say because of your parent's hoarding? For example, avoid talking about hoarding behaviors, refrain from discussion regarding need to discard items.

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

5) How many times did you directly participate in your parent's hoarding behaviors. For example, provide storage for their items, purchase items for your parent that he/she will subsequently hoard, give parent items that they request to keep

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

6) Were there times in this past month how many times did you do something that helped your parent engage in hoarding behaviors.? For example, bring parent to places where parent may acquire items (e.g., thrift stores, malls, flea market), join them for shopping trip, offer encouragement in seeking out opportunities to acquire new items.

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

7) How often did you assist your parent who hoards in avoiding doing things, going places or being with certain people because of your parent's hoarding? For example, refrain yourself from discarding items that are in parent's home (or other cluttered areas, such as office or car), make decisions for your parent on whether to discard items, avoid discussion of hoarding behaviors, avoid going to your parent's home or inviting people into your parent's home

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

8) To what extent did you tolerate off behaviors or unusual conditions in your home (or your parent's home) because of your parent's hoarding. For example, tolerate clutter in parent's home, allow parent to store items at areas around your home

0 = None
1 = Mild (tolerated slightly unusual hoarding behaviors/conditions)
2 = Moderate (tolerated somewhat unusual hoarding behaviors/conditions)
3 = Severe (tolerated very unusual hoarding behaviors/conditions)
4 = Extreme (tolerated extremely aberrant hoarding behaviors/conditions)

9) On how many occasions did you help your parent with simple tasks or decision because he/she was impaired by his/her hoarding symptoms? For example, make decisions on which pieces of mail tor trash o discard

0 (Never) 1 (1 time /week) 2 (2-3 times/week) 3 (4-6 times/week)4 (Everyday)

10) To what extent did you take on your parent's responsibilities due to his/her hoarding behaviors? For example, clean parent's home, pay parent's bills, take out parent's trash, lawn care, remove clutter, cook meals and complete other daily living activities that clutter and/or hoarding behaviors have prohibited from occurring in their own home.

0 = Not at all
1 = Mild (occasionally handles one of parent's responsibilities, but there has been no substantial change in your role)
2 = Moderate (has assumed parent's responsibilities in one area)

3 = Severe (has assumed parent's responsibilities in more than one area)
4 = Extreme (has assumed most or all of parent's responsibilities)

11) To what extent did you modify your personal routine (your leisure time, your work/family relationships) because of your parent's hoarding behaviors? For example, stay at a hotel or friend's home rather than staying at parent's home when visiting, use leisure time to take care of and/or clean parent's home, use free time to take care of the responsibilities of your parent who hoards.

0 = Not at all
1 = Mild (slightly modified routine, but was able to fulfill family and/or work responsibilities and to engage in leisure time activities)
2 = Moderate (definitely modified routine in one area – family work, or leisure time)
3 = Severe (definitely modified routine in more than one area)
4 = Extreme (unable to attend to work or family responsibilities or to have any leisure time because of relative's OCD)

12) To what extent did you modify the family routine because of your parent's hoarding behaviors? To what degree has your parent's hoarding necessitated changes in family activities or practices?

0 = Not at all
1 = Mild (slightly modified routine, but was able to fulfill family and/or work responsibilities and to engage in leisure time activities)
2 = Moderate (definitely modified routine in one area – family work, or leisure time)
3 = Severe (definitely modified routine in more than one area)
4 = Extreme (unable to attend to work or family responsibilities or to have any leisure time because of relative's OCD)

Appendix J

Sheehan Disability Scale (SDS)

Please circle the **number** indicating how much your parent's hoarding symptoms are currently interfering with various areas of *your* life:

The symptoms have disrupted <u>your</u> **work**:

0 1 2 3 4 5 6 7 8 9 10

Not at all A little bit Some A lot very, very much

The symptoms have disrupted <u>your</u> **social life**:

0 1 2 3 4 5 6 7 8 9 10

Not at all A little bit Some A lot very, very much

The symptoms have disrupted <u>your</u> **family's home**:

0 1 2 3 4 5 6 7 8 9 10

Not at all A little bit Some A lot very, very much

Appendix K

Saving Inventory-Revised (SI-R)

Please complete this questionnaire regarding YOURSELF

1. **To what extent do you have difficulty throwing things away?**
   - 0 = Not at all
   - 1 = To a mild extent
   - 2 = To a moderate extent
   - 3 = To a considerable extent
   - 4 = Very much so

2. **How distressing do you find the task of throwing things away?**
   - 0 = No distress
   - 1 = Mild distress
   - 2 = Moderate distress
   - 3 = Severe distress
   - 4 = Extreme distress

3. **To what extent do you have so many things that your room(s) are cluttered?**
   - 0 = Not at all
   - 1 = To a mild extent
   - 2 = To a moderate extent
   - 3 = To a considerable extent
   - 4 = Very much so

4. **How often do you avoid trying to discard possessions because it is too stressful or time-consuming?**
   - 0 = Never avoid, easily able to discard items
   - 1 = Rarely avoid, can discard with a little difficulty
   - 2 = Sometimes avoid
   - 3 = Frequently avoid, can discard items occasionally
   - 4 = Almost always avoid, rarely able to discard items

5. **How distressed or uncomfortable would you feel if you could not acquire something you wanted?**
   - 0 = Not at all
   - 1 = Mild, only slightly anxious
   - 2 = Moderate, distress would mount but remain manageable
   - 3 = Severe, prominent and very disturbing increase in distress
   - 4 = Extreme, incapacitating discomfort from any such effort

6. **How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms or other rooms.)**
   - 0 = None of the living area is cluttered
   - 1 = Some of the living area is cluttered
   - 2 = Much of the living area is cluttered

3 = Most of the living area is cluttered
4 = All or almost all of the living area is cluttered

7. How much does the clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter.

0 = Not at all
1 = Mild, slight interference, but overall functioning not impaired
2 = Moderate, definite interference, but still manageable
3 = Severe, causes substantial interference
4 = Extreme, incapacitating

8. How often do you feel compelled to acquire something you see (e.g., when shopping or offered free things)?

0 = Never feel compelled
1 = Rarely feel compelled
2 = Sometimes feel compelled
3 = Frequently feel compelled
4 = Almost always feel compelled

9. **How strong is your urge to buy or acquire free things for which you have no immediate use?**

0 = Urge is not at all strong
1 = Mild urge
2 = Moderate urge
3 = Strong urge
4 = Very strong urge

10. **How much control do you have over your urges to acquire possessions?**

0 = Complete control
1 = Much control, usually able to control urges to acquire
2 = Some control, can control urges to acquire only with difficulty
3 = Little control, can only delay urges to acquire only with great difficulty
4 = No control, unable to stop urges to acquire possessions

11. **How often do you decide to keep things you do not need and have little space for?**

0 = Never keep such things
1 = Rarely
2 = Occasionally
3 = Frequently
4 = Almost always keep such possessions

12. **To what extent does clutter prevent you from using parts of your home?**

0 = All parts of the home are usable
1 = A few parts of the home are not usable
2 = Some parts of the home are not usable
3 = Many parts of the home are not usable
4 = Nearly all parts of the home are not usable

13. **To what extent does the clutter in your home cause you distress?**
    0 = No feelings of distress or discomfort
    1 = Mild feelings of distress or discomfort
    2 = Moderate feelings of distress or discomfort
    3 = Severe feelings of distress or discomfort
    4 = Extreme feelings of distress or discomfort

14. **How frequently does the clutter in your home prevent you from inviting people to visit?**
    0 = Not at all
    1 = Rarely
    2 = Sometimes
    3 = Often
    4 = Very often or nearly always

15. **How often do you actually buy (or acquire for free) things for which you have no immediate use or need?**
    0 = Never
    1 = Rarely
    2 = Sometimes
    3 = Frequently
    4 = Almost always

16. **How strong is your urge to save something you know you may never use?**
    0 = Not at all strong
    1 = Mild urge
    2 = Moderate urge
    3 = Strong Urge
    4 = Very strong urge

17. **How much control do you have over your urges to save possessions?**
    0 = Complete control
    1 = Much control, usually able to control urges to save
    2 = Some control, can control urges to save only with difficulty
    3 = Little control, can only stop urges with great difficulty
    4 = No control, unable to stop urges to save possessions

18. **How much of your home is difficult to walk through because of clutter?**
    0 = None of it is difficult to walk through
    1 = Some of it is difficult to walk through
    2 = Much of it is difficult to walk through
    3 = Most of it is difficult to walk through
    4 = All or nearly all of it is difficult to walk through

19. **How upset or distressed do you feel about your acquiring habits?**
    0 = Not at all upset
    1 = Mildly upset
    2 = Moderately upset
    3 = Severely upset
    4 = Extreme embarrassment

20. **To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc.?)**

0 = Never
1 = Rarely
2 = Sometimes
3 = Frequently
4 = Very frequently or almost all the time

21. **To what extent do you feel unable to control the clutter in your home?**

0 = Not at all
1 = To a mild extent
2 = To a moderate extent
3 = To a considerable extent
4 = Very much so

22. **To what extent has your saving or compulsive buying resulted in financial difficulties for you?**

0 = Not at all
1 = A little financial difficulty
2 = Some financial difficulty
3 = Quite a lot of financial difficulty
4 = An extreme amount of financial difficulty

23. How often are you unable to discard a possession you would like to get rid of?

0 = Never have a problem discarding possessions
1 = Rarely
2 = Occasionally
3 = Frequently
4 = Almost always unable to discard possessions

Appendix L

Dissertation Timeline

Proposal: September 7

IRB submitted: September 10

IRB approval anticipated by October 15

Data collection begins by November (with 20 participants expected per month, for a total of 8 months

Data collection expected to be completed by July 2013

Data analyses expected to be completed by August 2013

First draft of complete dissertation expected by September 2013

Final draft of completed dissertation expected to go to committee by November 2013

Dissertation expected to be defended by December 2013

Appendix M

IRB Approval

Institutional Review Board
All Children's Hospital
ACH Box #9496
FWA# 00000977
IRB# 00001642
727.767.4275

October 08, 2012

Eric A Storch, Ph.D.
880 6th Street, South
Suite 460
USF Pediatrics
St. Petersburg, FL 33701

Dear Dr. Storch,

Your new protocol entitled, "An Examination of the Impact of Hoarding on Parent-Adult Child Relationships and Family Functioning" IRB# 12-0522, Ref# 107160 was approved under the expedited review process pending recommended changes. Those changes have been received, reviewed and found to be appropriate. This will be reported at the 11/14/2012 meeting of the All Children's Hospital Institutional Review Board. This protocol meets the criteria 45 CFR 46.404, research not involving greater than minimal risk. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b) (1).

The initial approval period is for a maximum of one year. The IRB approval for this protocol will expire on 10/7/2013. Please submit your continuation request by 9/9/2013 in order to avoid lapses in approval of your research and possible suspension of subject enrollment. If during the course of the study, there are any changes or amendments, or you decide to terminate the study, please notify the All Children's Hospital Institutional Review Board.

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists or other healthcare providers not directly involved with this study.

Per Hospital Administrative Policy No. 014-0024-9581-000-A *Research Administrative Review Process*, your protocol must receive administrative approval prior to commencing the study. For administrative review questions, please contact the Department of Research Administration at (727) 767-4813.

Thank you for your participation in the All Children's Institutional Review Board process. If you have any questions, please contact the office of the ACH Institutional Review Board at (727) 767-4275.

Sincerely,

Signature applied by Dawn A. Bruton on 10/08/2012 10:51:23 AM EDT

Dawn Bruton, BSN, CCRP
Member, ACH Institutional Review Board

DB:se