

THE LIVED EXPERIENCE OF FAMILY MEMBERS OF PERSONS WHO COMPULSIVELY HOARD: A QUALITATIVE STUDY

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The current study took an Interpretive Phenomenological Analysis approach to investigate the lived experiences of 12 family members of persons who hoard to better understand family members' cognitions, emotions, perceptions, experiences, and responses in their interactions with their loved ones who hoard. Five overarching themes for the participants' experiences of having a person who hoards in the family emerged: negative feelings toward the persons who hoard; lack of understanding of hoarding behavior; experiences of loss; internal barriers to seeking support; and internal conflicts. Clinical implications and recommendations for future research are discussed, including a proposed application of an ambiguous loss framework for understanding and working with the experiences of family members of persons who hoard.

Compulsive hoarding has been sensationalized in the recent media through reality television series and daytime talk shows, calling attention to a relatively misunderstood phenomenon. Despite this current attention, little focus has been placed on how family members of persons who hoard are affected by this peculiar malady.

Compulsive hoarding has been defined as (a) the acquisition of, and failure to discard, a large number of possessions, (b) clutter that precludes activities for which living spaces were designed, and (c) significant distress and impairment in functioning caused by the hoarding (Frost & Hartl, 1996). Although psychiatric literature has linked hoarding with several other comorbid diagnoses, including schizophrenia and other psychiatric disorders (Luchins, Goldman, Lieb, & Hanrahan, 1992; Lysaker et al., 2000), eating disorders (Frankenburg, 1984), dementia (Hwang, Tsai, Yang, Liu, & Lirng, 1998), obsessive-compulsive disorder (Christensen & Greist, 2001; Winsberg, Cassic, & Korran, 1999), major depression (Steketee, Frost, Wincze, Greene, & Douglass, 2000), and personality disorders, such as OCPD, avoidant, dependent, and paranoid personality disorders (Mataix-Cols, Baer, Rauch, & Jenike, 2000), compulsive hoarding has evaded its own diagnostic label (Mataix-Cols et al., 2010). The majority of attempted clinical interventions, including psychotropic medications and cognitive-behavioral treatments, have had poor outcomes (Abramowitz, Franklin, Schwartz, & Furr, 2003; Mataix-Cols, Marks, Greist, Kobak, & Baer, 2002; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999). With estimates in the U.S. of around 6 million individuals who compulsively hoard (Frost & Steketee, 2010), the need for an understanding of the disorder is vital for developing effective clinical treatment and support for people who hoard and their families.

Currently, research on this behavior has largely been embedded in biological (e.g., Stern & Passingham, 1994) or cognitive-behavioral (e.g., Frost & Hartl, 1996) frameworks of thought and study, emerging across a range of research fields, including neuropsychology (Lawrence, 2006), cognitive psychology (Kyrios, Steketee, Frost, & Oh, 2002), and brain imaging and genetics (Anderson, Damasio, & Damasio, 2005; Saxena et al., 2004). To date, outcome and treatment research has been focused largely on the individuals struggling with compulsive hoarding to the exclusion of their family members, despite social research that has found hoarding to be a serious threat to people living with or near the person who hoards (Frost, Steketee, & Williams, 2000). One self-report study of 94 people who hoard found that

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two-thirds of hoarding participants stated that their behavior constituted a problem for family members (Frost & Gross, 1993). Currently, there seem to be no relational or family intervention studies for the treatment of compulsive hoarding, despite findings that family focused interventions can be advantageous for the treatment of various compulsive behaviors (Chambliss et al., 1998; Eisler et al., 2000; Pincus & Foa, 1995).

In general, researchers have paid little attention to understanding how hoarding behavior affects the family. A thorough review of the family based literature yielded only two studies to date that have examined how family members are impacted by the compulsive hoarding of a loved one. In one study on this topic, Tolin, Frost, Steketee, and Fitch (2007) examined the burden of hoarding on family members of persons who hoard in a retrospective, self-report internet survey of 665 individuals reporting to have family members or friends with compulsive hoarding problems. The study found that living in a severely cluttered environment as a child is associated with increased levels of childhood distress, which includes less happiness, more difficulty making friends, reduced social contact in the home, increased intra-familial strain, and embarrassment about the condition of the home. The investigation also found that family members' feelings of rejection toward the person who hoards are associated with a variety of factors that are linked with hoarding, including severity of the problem and lack of insight displayed by the persons who hoard, as reported by the family members. Although this project offered contributions to the research on how family members are impacted by compulsive hoarding, the scope of the survey did not include other factors of family burden, including the experience having multiple family members with hoarding problems or the systemic effects of hoarding behaviors on family relationships. Further research is needed to explore the idea of family burden at a deeper level to better understand the experiences of these individuals.

The second study took place in the United Kingdom, qualitatively examining the perspectives of caretakers of persons who compulsively hoard (Wilbram, Kellett, & Beail, 2008). Ten caretakers of a hoarding family member were interviewed using an Interpretive Phenomenological Analysis (IPA) approach, and the major themes that emerged included "loss of normal family life," "the need for understanding," "coping with the situation," "impact on relationships," and "marginalization." This investigation offered a deeper level of understanding of caregiver experiences, but because of the scope of participants was limited only to caretakers, further research is needed to also understand the experiences of family members who do not directly care for the person who hoards, which is important given the findings from Tolin and colleagues' study (2007) which found these family members to also be affected by the behavior.

While each of the previously described studies greatly contributed to the scant knowledge base about how family members are impacted by compulsive hoarding behavior, the future implications of both articles landed on the focus of the individual person who hoards, suggesting that family members simply be educated about the disorder and their role and contribution in the treatment of hoarding (Van Noppen & Steketee, 2003); however, it is clear that family members are also experiencing distress around this issue (Tolin et al., 2007; Wilbram et al., 2008) and may also need to be offered support based on research findings. Because of this, it is important for researchers to investigate further the experiences of noncaretaking family members in order for a deeper understanding of their experiences to inform more effective interventions for them.

AMBIGUOUS LOSS THEORY

The application of ambiguous loss theory (Boss, 1999) can provide a framework for understanding the experience of family members who are be dealing with the compulsive hoarding behaviors of a loved one. Developed by Pauline Boss in the mid-1970s, the concept of *ambiguous loss* refers to a loss or trauma situation that remains incomplete, confusing, or uncertain for family members. According to Boss (1999), events that involve ambiguity, such as divorce, miscarriage, or mental illness, are the most difficult and stressful situations with which people may deal. When ambiguous loss presents in a family system, it may affect individuals' perceptions of their relationships, the resources they use, and the degree of stress and trauma that they experience.

An ambiguous loss arises from a psychological incongruence between the physical and the psychological presence of a person, leading to stress and difficulty with effective coping strategies (Boss, 1999, Boss, 2004; Boss & Couden, 2002). Theoretically speaking, in the case of compulsive hoarding, a person who presents with hoarding behavior may be physically present in the lives of the family members, but as the hoarding symptoms progress and worsen, the individual's psychological presence for the family members may deteriorate (Steketee & Frost, 2003), leading to distress within the family system (Tolin et al., 2007).

In the case of compulsive hoarding, family members may not understand the person who hoard's behavior (Wilbram et al., 2008), and this lack of clarity may prevent families from tangibly defining their situation and coping with and managing their distress effectively (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007). Boss (1993) suggested that when there exists a lack of cognitive understanding about a family member's disorder, including not knowing its cause, it can lead to difficulty in their dealing with the ambiguity of the situation (Boss, 1999).

The loss of family rituals may also be a source of ambiguous loss (Boss, 2006). When "normal" family events (Wilbram et al., 2008), such as holidays, are disrupted, perhaps because of the experience of compulsive hoarding, it can pose serious threats to the sense of identity to the family (Boss, 2002), leading to feelings of ambiguity and distress in the family members. Boss (2002) found that these high levels of ambiguity may put families at risk for deterioration of individual and relational well-being.

STATEMENT OF PURPOSE

Previous research has shown that family members of persons who hoard carry a large burden related to their family members' hoarding behaviors (Tolin et al., 2007), along with feelings of loss and relational conflicts (Wilbram et al., 2008). No qualitative research currently exists investigating the lived experiences of noncaretaking family members who deal with one or more people who compulsively hoard in their family, though previous research suggests that this sample is affected by hoarding behavior (Tolin et al., 2007). Further examination is needed to expand the work in this area in its exploratory and descriptive stages of study.

The current study uses Interpretative Phenomenological Analysis (IPA; Smith, 1996), a method used for analyzing qualitative data, to explore the lived experiences of family members of persons who hoard to better understand their cognitions, emotions, perceptions, experiences, and responses in their interactions with their family members who hoard. In this project, 12 semi-structured interviews were conducted in a qualitative study to investigate the phenomenological question: "What is the lived experience of a family member of a person who hoards?" The study contributes to the existing literature by helping to reach a phenomenological understanding of participants' experiences of having a person who hoards in his or her family and providing clinical implications for working with family members of persons who hoard.

METHODOLOGY

Design

An Interpretative Phenomenological Analysis (IPA; Smith, 1996) methodology was selected as the research method and analysis for this project. An increasingly popular form of qualitative analysis, IPA was chosen as the most appropriate research method for this study based on its roots in both phenomenological and interpretative approaches. It is phenomenological in that it explores the unique experiences between individuals, in lieu of making general statements about them (Smith, 1996). At the same time, while attempting to closely understand the participant's personal world, IPA considers that this cannot be done without depending on the researcher's own conceptions which are required to make sense of the participant's experiences through interpretative activity (Smith, Jarman, & Osborn, 1999). In this case, the investigation of the participants' lived experience was designed to add deeper meaning to the experiences of family members when dealing with compulsive hoarding in their families through gaining an understanding of the participants' personal worlds (Smith & Osborn, 2003).

Participants, Recruitment, and Setting

Family members of persons who hoard were considered for participation in this study. Prior to beginning this research, this study was approved by the Institutional Review Board at the University of Minnesota. Because of the relative difficulty in locating individuals who would meet criteria for this project for a variety of reasons (e.g., there are no professional services directly aimed at family members of persons who hoard), participants were recruited through Craigslist, an internet forum featuring free online classified advertisements. The advertisement was placed in the “volunteer” section of Craigslist in three different metropolitan cities, two in the Midwest and one on the West Coast, requesting volunteers for an interview study investigating the experiences of family members of persons who hoard. The ad was run concurrently in each of the cities until the desired number of participants was met.

Approximately 40 individuals responded to the advertisement and expressed interest in participation. Individuals were sent a copy of the informed consent to review before agreeing to volunteer for the project, which included general information about confidentiality and participants’ rights to refuse participation or stop the interview process at any time. The potential subjects were also informed of the potential risk that the study may bring up difficult emotions and that a professional referral list for the participant would be provided if he or she requested one. Following this, less than half expressed continued interest. These 16 individuals were contacted by phone to assess whether they met the selection criteria. To qualify for participation, subjects had to report at least one immediate family member (e.g., parent, spouse, sibling) whose hoarding has caused the participant to experience personal distress, and the participant could not him or herself be a person who hoards. The definition of hoarding was determined during the phone conversations in which people were asked to briefly describe their family member’s hoarding behavior. Individuals whose brief narrative of the behavior seemed to meet criteria guided by the Hoarding Rating Scale Interview (HRS-I; Tolin, Frost, & Steketee, 2010), focused on excessive acquisition, difficulty discarding, clutter, and distress, met criteria for the study. From this, 12 followed through with participation in the study. Interviews were scheduled at mutually agreeable times and neutral locations (e.g., local coffee shops). In two cases, participants’ situations did not allow for in-person interviews, in which cases telephone interviews were conducted. Although these two interviews were conducted via different medium, they did not significantly differ in content or structure.

A sample of 12 participants (10 women and two men; 11 Caucasian, one Chinese) ranging in age from 20 to 63 were interviewed for this study. See Table 1 for a description of the participants. The sample size was directed by previous research stating that this number is adequate for the exploratory nature of the qualitative research (Turpin et al., 1997) and is commensurate with other recent IPA-based investigations (Kellert, Greenhalgh, Beail, & Ridgway, 2010; Wilbram et al., 2008).

Data Collection

The investigator conducted and taped 11 semi-structured, open-ended interviews with the participants in which participants’ lived experiences of having a family member who compulsively hoards were assessed, and interview recordings were transcribed verbatim by the author. The interviews ranged from 45 to 150 min in-length; nine interviews took place in-person and two took place over the telephone. In one of the interviews, two related participants were interviewed together. All of the interviews were conducted and analyzed by the author. The semi-structured interview was designed to be a free-flowing discussion, led by the narrative of the interviewees to include their interests, concerns, and experiences. The interviewer encouraged description, depth, and detail of responses about the participants’ experiences, perceptions, and feelings about having a family member who hoards. While no participants expressed overwhelming emotions or distress during the interviews, each person was monitored for distress or discomfort during the process and procedures were outlined as additional assurances of participant safety prior to the start of the interview, including a referral list for mental health services. The purpose of the project was explained again to the participants, which is to understand the lived experiences of a family member of a person who hoards. The interview schedule, guided by IPA methodology to “[explore] the lived experience” (Reid, Flowers, & Larkin, 2005, p. 20),

Table 1
Participant Description

Interview No.	Gender	Age	Family member(s) who hoard
1	F	63	Husband; sibling; cousin
2	F	48	Mother; sibling
3	F	30	Mother; sibling; grandmother; grandfather
4	F	35	Mother; sibling; maternal great-aunt (2)
4	F	25	Mother; sibling; maternal great-aunt (2)
5	F	20	Father; step-mother
7	F	45	Maternal uncle; maternal grandmother
8	F	34	Mother
9	F	28	Father
10	M	33	Mother; father
11	M	24	Mother
12	F	45	Mother; maternal aunt

included the following questions: “Can you start by telling me about your experience with each of the people in your family who you would identify as a person who hoards?” “Can you describe what the interactions in your family are like in dealing with the hoarding behavior?” “Can you discuss any experiences of trying to deal with the hoarding behavior?” “What is your experience of how your family members’ hoarding behavior has influenced you personally?” “What is your experience of how your family members’ hoarding has impacted your relationship with him or her?” “In your experience, how do you make sense of why your family member hoards?” and “What is your experience like talking to others about dealing with your family members’ hoarding behavior?”

Analysis

Analysis of the interview transcripts was conducted using IPA procedures (Smith & Osborn, 2003), as outlined here: (a) each transcript was initially read and then reread, noting observations, looking for themes, and interpreting the narrative of the participants; (b) the preliminary ideas were translated into themes, and the themes were coded using NVivo 8 qualitative data analysis software; (c) emergent themes were connected and grouped through the process of coding and writing, and an overarching group of themes was created once all of the interviews had been coded and analyzed; (d) previously coded transcripts were again read to ensure the themes were existent across a majority of the interviews. Themes emerged within and across the individual interviews; themes that appeared in a majority of the transcripts were included as super-ordinate themes (Smith, 1996); subthemes were found to also exist within two of the super-ordinate themes.

Validation Methods

The IPA conceptions method provides the researchers with the allowance to interpret the data based on his or her conceptions, to make sense of the participants’ experiences (Smith, 1996). Interpretative phenomenological analysis requires a high degree of subjectivity as it is shaped by the researcher’s interpretive worldview. Because subjectivity requires a departure from the traditional criteria for evaluating research, which are based in researcher objectivity and disengagement from the analytic process, validation of the researcher’s interpretation of the data in IPA is an important part of the analysis process to ensure that the interpretations are as trustworthy as possible.

Bracketing was used as an initial step prior to beginning the data collection and analysis (Strauss & Corbin, 1998). Bracketing involves a thorough examination of the researcher’s thoughts and experiences about the phenomenon being studied to avoid possible contamination

of the findings because of the researcher's bias. As part of this, the basis for the study was fully explained, presumptions about the phenomenon based on the researcher's personal experiences were identified, and a review of the literature on the area of compulsive hoarding and family members' experiences was journaled about prior to beginning the research interviews. The use of these procedures increases the credibility of the current study by minimizing the researcher bias within data collection and analysis. Throughout the data collection, analysis, and writing process, the author consulted with colleagues and supervisors about the findings and emergent themes to best ensure that a personal experience, hypotheses, and other biases of the researcher were bracketed successfully (Strauss & Corbin, 1998).

The author also used a member checking procedure which included checking information and interpretations with the respondents, both within an interview and across interviews to ensure the credibility of findings (Lincoln & Guba, 1985) by summarizing to the participants how the researcher was understanding the main themes and points of their experience at the end of each interview. Most often, the participants confirmed that the researcher had accurately interpreted their experience; in some situations, the participants offered clarification about their comments. This feedback was used to develop member-checking questions for subsequent interviews; later, participants were asked near the end of the conversation whether previous participants' themes were relevant to their situations, and whether they had not already addressed them in their interviews. Participant feedback helped to adapt future interviews as well and was considered in coding and clustering of the themes during analysis. An additional measure taken to focus on transferability of findings included the use of the author's self-reflexive journaling throughout the study. Following each interview, notes were taken, containing initial impressions about potential questions, emerging themes, and possible biases. These notes were used as data for analyses, aiding in the development of categories and themes.

RESULTS

Five discrete and interrelated super-ordinate themes emerged from the data: negative feelings toward the family member who hoards; lack of understanding of hoarding behavior; experiences of loss; internal barriers to seeking support; and internal conflicts. These major themes are described with interpretive comment, emphasizing the shared commonalities between interviews. Verbatim quotes from the transcripts are used to demonstrate the themes, and the names of the interviewees have been changed for each interview extract. The results are organized in a way that reflects the order in which the themes naturally emerged as the participants talked about their experiences in the interviews.

Negative Feelings Toward Family Member Who Hoards

All of the participants began the interview with a lengthy description of the extent of the clutter in their family members' homes. The tone and language used by participants to describe the "stuff" was overwhelmingly negative and even disdainful. Even so, it seemed important to the participants that the researcher got a thorough idea of the extent of the clutter, as if sharing the nature of their family members' hoarding would justify the "craziness" or their lack of comprehension around the behavior.

My brother's really into science, tools, machine shopping (sic) stuff. So, for example, he probably has an entire wood working shop. You know, all the big fancy commercial equipment. But he doesn't wood work. Never has wood worked ... But it's the stuff he likes, and then he'll go to an auction or sale ... He buys stuff he's *gonna* do something with but then never does ... Do you see how crazy this is? (Lisa)

In spite of the attempts at understanding their family members' behavior, all of the participants described feelings of frustration and pointlessness as a result of a variety of failed attempts at helping their family member organize his or her belongings. This process seemed to be quite trying for the participants, who many times were met with excuses or defensiveness from their family member who hoards.

I'd suggest like, 'Let me help you clean up that, let me help you address the house. You know, let's work on the house and sort through things.' It would be ... just a deflection for my mother, to be- She would start an argument about, you know, something like, "Look at you, all you wanna do is fight with me now about the house. It's none of your business! It's not hurting anybody else. What's the matter with you? Something must be wrong with you.' And *anything* to make the fight so big that, a topic that would deflect from talking about the house. (Chloe)

As a result of negative interactions around attempting to handle the family members' hoarding behaviors, 11 of the 12 participants reported becoming resigned to the situation and stated that they had given up in their attempts at helping their loved one.

We brought a dozen boxes or so to my brother's house and we sat in the garage to go through it, and a hoarder needs to touch everything and relive through all of their things ... So we probably touched a thousand things and got rid of three. It's created a lot of anger and tension in our family ... Hoarders don't go through things, and they don't get rid of things. It's just an exercise in futility. (Lisa)

A sense of hopelessness filled the interviews when participants discussed how they might help their family member. Through their experiences with attempts at helping the person who hoards and the reactions and choices made by those family members, participants discussed their intense frustration and anger with their loved one who hoards. Becoming strongly aggravated and discouraged about dealing with their loved ones, each of the participants described several strong emotions, including feelings of anger, frustration, not being appreciated, disgust, disrespect, embarrassment, and defeat about their family members' hoarding.

We've tried for so long [to help my brother with his hoarding, but the end of the day, it's like nothing's going to change ... We're so angry at him ... We've gotten to the point where, especially with him, everybody's kind of disgusted. And it's like, you know what, don't even bother wasting your air. (Emma)

These negative feelings seemed to result in participants emotionally and physically separating themselves from the persons who hoard as a way to cope with the feelings of hurt and anger, resulting in the deterioration or loss of relationships with the hoarding family members.

Lack of Understanding of Hoarding Behavior

A second overarching theme in the interviews revolved around the desire to better understand compulsive hoarding behavior. The inability to cognitively understand why their family members hoard seemed to create a large amount of distress and anxiety within the participants. When asked about how they understood their family members' hoarding behaviors, a strong majority (11 of 12) of the participants said that they simply could not make sense of the actions that their loved one was taking, and it was this inability to understand the problem that made life difficult for them; the one who reported a relative level of understanding about hoarding had done a significant amount of research on the subject itself.

There has been a lot of misunderstanding. If someone had given me a book ... and said "read this book, it'll explain your stepmom to you", that would be great ... I don't understand her hoarding. I've had to white knuckle it through and figure it out and that's a lot harder ... I just don't understand it. I understand depression, I understand anxiety, I don't understand hoarding. And that makes it hard. (Emma)

Despite the general lack of cognitive knowledge that most of the participants claimed to have on hoarding behavior, when they took the time to reflect on contextual factors in the lives of their family members who hoard during the interviews, the participants seemed to come to their own conclusions about reasons for the behavior. Although apparently frustrating and

confusing to the participants, the connections that the person who hoards had to their possessions seemed to make sense to the subjects on some level. Almost all of the participants (10 of 12) offered some form of meaning for their loved ones' otherwise inexplicable behavior.

The stuff is very important. And for my mom, I think the best years of her life are captured by those things. She was young and married and had a family, and the longer that she lives, the more importance those things take on to her, so she really can't let go of them. (Lisa)

The descriptions and meanings that the participants offered seemed to play an important part in the creation of their internal experience of having a person who hoards in their family by providing a sense of logic or rationale to an otherwise unexplainable phenomenon that has created distress in the lives of participants, and it was only during this time of the interviews that the author sensed a sort of compassion from the participants when talking about the hoarding behavior.

Experiences of Loss

Over and over, each of the participants discussed a variety of losses they experienced in dealing with the hoarding behavior in their families. The participants talked about a variety of experiences centered on relational, social, and physical losses encountered as a result of the hoarding, and through these discussions, feelings associated with grief began to surface.

Loss of relationships. Beyond family rituals, many of the participants spoke about the loss of the relationship between themselves and their family member who hoards, expressing sadness and grief about the "loss" of a person and a relationship that was once so meaningful to them. One of the most striking and heartfelt themes that arose about the participants' experiences was the confusion and hurt that surrounded the intense response to attempts at cleaning or organizing by the persons who hoard. Even at the expense of losing family relationships, 11 of the 12 participants described their family members who hoard often times choosing their possessions over any other option.

The fact that I don't- that I *can't* have a relationship with my parents [because of their hoarding] is extremely sad to me. It's like they died or something. It'd probably be easier if they had died, because they're actually *here*, but I can't have a relationship with them because their stuff just has taken over. (David)

Perhaps not surprisingly, the intense connection to these objects triggered emotional responses in the participants, relating to the sense that the persons who hoard were choosing his or her possessions over the family. This seemed to lead participants to feel immensely rejected by the person who hoards, creating disbelief and further confusion in family members; 11 of the 12 reported current feelings of rejection.

The impacts with my brother have almost been worse than the ones with my mom. Partly just because, he had a great wife. He had a great wife and a good family, and he just completely screwed it up. And I think, from our whole family's perspective, it's like, oh my god, you picked aquariums over your family. (Lisa)

Loss of family rituals. Ten of the participants reported how normal family events and rituals, such as holiday traditions, were impacted by the hoarding person's messes, resulting in feelings of sadness and anger toward the person who hoards.

Like even outside of the hoarding ... I mean we would at least be able to like have a semblance of a family because maybe Christmas would come, and we would be able to go down there or something. And then I wouldn't have to like dread holidays. But as it is, I dread every single freaking holiday because of this horrible obligation to have to go down there, and this really uncomfortable thing about, ok well we can't have holiday dinner at her house, obviously, because it's like a disgusting filth-pit. (Chloe)

While some of the participants seemed angry, most of those who spoke about the topic gave the impression that he or she was quite sad about the role that the hoarding behavior had taken in the loss of these family events.

Loss of future opportunities. Not only did the interviewees talk about the loss of their own relationships with the person who hoards, but they also experienced grief around the loss of future relationships that their children would miss. Eight of the participants discussed this theme.

I mean, my Dad's pretty mobile so he's good at going to see the grandkids, rather than needing the kids to come see him but ... I don't know ... that kinda stinks. I have really fond memories of going to visit my grandparents ... And you know, [my kids] will miss out on comfortable, warm memories of the house rather than a crazy grandfather that has all kinds of crap all over the floor, you know. (Betty)

Sadness around the loss of future hopes and dreams seemed to permeate the experience of the participants, as if they felt that they had lost a piece of their future in a way.

Loss of a sense of "home". Beyond the loss of relationships, another theme of loss associated with compulsive hoarding was the idea of a loss of "home". Because of the excessive amount of material goods in the home of the person who hoards, nine of the participants' childhood homes had reportedly become the object of much grief and loss because of being hoarded. Although structurally present, the feelings associated with what a participant identified as his or her childhood home seemed to be no longer present, which the author perceived as distressing for the participants.

It wasn't familiar, and it wasn't comfortable anymore ... to the point where I didn't like being there ... I would come home and it was-, I really-, I hated [it] ... So that was *super* hard, and I would just cry ... it wasn't home anymore ... [it was] not the house that I knew and grew up with. So, like I said, I lost this childhood memory, the fond memories of my childhood home. (Betty)

With "home" being so central to a "family", in physicality and in emotionality, the loss of it seemed to be the "last straw" for many participants who spoke of it when discussing why their relationships are strained with their family member who hoards. It was as if the loss of the home was equated with the loss of their sense of "family" in ways, and much sadness and anger was expressed around this loss.

Internal Barriers to Seeking Support

Eight of the participants discussed experiencing stress relating to a lack of social support in dealing with their family members' hoarding behaviors, and despite the consistent mention of their personal need for social and professional support, none of the participants reported seeking out any help related to this issue prior to being interviewed. Although professional support around these issues is indeed lacking, participants seemed hesitant to seek out any kind of support, either professionally or socially because of perceived feelings of judgment associated with their family members' hoarding behavior.

Social invisibility. A theme that became apparent in a majority of the interviews (11 of 12) was the idea that outside of the family system, a person might never know that a hoarding problem existed. With the person who hoards being able to function "normally" in day-to-day social interactions outside the home, often with upstanding jobs such as engineers, physicians, or teachers, the participants seemed to feel that an outsider would be unsuspecting about their loved ones' hoarding, which seemed to create difficulty for the participants in attempting to talk with others about it.

I feel like with my mom, she could function in the real world and be fine and nobody would ever know it. Like nobody. People would come to their house and be shocked ... I think people would be like, 'Are you kidding me? This is what your house is [like]?!' (Sara)

The “social invisibility” around a family member’s hoarding behavior may contribute to the participants feeling unable to talk about the family “secret” for fear of others not believing them. The lack of a visible presence of the problem within the family seemed to compound the level of difficulty associated with talking to others about the family issue. Because the disorder is not one that is obviously noticeable from an outside perspective, some of the participants seemed further hesitant to want to seek support from others for fear of others not understanding.

Feelings of shame. For each of the participants, the issue of embarrassment came up several times throughout the interviews, in discussions about how they might be perceived by people outside the family system. Participants reported being so embarrassed by their loved one’s behavior that it impacted how they interacted with other people outside of the immediate family, referring to a sort of stigma-like feeling that was attached to hoarding behavior.

It’s one of those issues too that there’s so much embarrassment and shame attached to it, that unlike other addictions, people don’t talk about it. So people will say, my brother’s a really bad alcoholic, he just got his third DWI. But people will never say, ‘Yeah, my brother’s a hoarder.’ (Lisa)

This embarrassment seemed to keep these participants from reaching out to others, which may in effect isolate them in their dealing with their distress because of the hoarding behavior in their family.

Internal Conflicts

Most of the participants also described internal battles they experience as a result of the hoarding behavior in the family. Nine of the participants described having behavioral urges that they considered to be similar to the hoarding behaviors displayed by their family members. They talked about how they experienced some urges to hold on to possessions that they felt were unimportant, equating this behavior to their loved one’s hoarding. The decision over whether or not to discard an item was often times reported to be a struggle.

I think that part of my issue is that I know [the object I want to keep] is unimportant, and it makes it worse almost because I know I’m doing it and so I have that internal struggle. Like, ‘You should not keep this, you should not keep it.’ But I want to keep it. And I can’t throw it away. You know, so inside my head I’m fighting. (Sara)

The fear that one might “turn into a hoarder” seemed to permeate the thoughts of several of the interviewees, and each of the individuals who discussed this also spoke about organizing their own actions and behaviors to avoid becoming like their family members who hoard. Most of those who discussed this internal struggle spoke about it as a constant source of anxiety in their lives, one for which they resented themselves.

I just beat myself up for feeling like this. And I blame my mom too. I shouldn’t have to have this hard of a time throwing out an old brochure. (Betty).

These participants further discussed the influence that hoarding behavior has had on their feelings toward themselves in terms of experiencing guilt about how they have handled their interactions with the people who hoard in their family. Several of the participants expressed guilt for talking about their family members “behind their backs,” and this seemed to be related to the negative emotions they held toward their family member around their hoarding behavior.

I’m ashamed and embarrassed and disappointed that I want my mother to be different than she is ... and I don’t want to tell people because I don’t want to deal with feeling crappy [about myself]. (Tanya)

The guilt that the participants experienced seemed to serve as yet another reason for not seeking out help from others, as if doing so would solidify their feelings of shame and embarrassment.

DISCUSSION

The current study qualitatively explored the lived experiences of 12 family members of persons who hoard to better understand participants' cognitions, emotions, perceptions, experiences, and responses in their interactions with their family members who hoard. In this study, participants overwhelmingly discussed being majorly affected by compulsive hoarding behavior, both individually and relationally. Five overarching themes for the participants' experiences emerged: negative feelings toward the family member who hoards; lack of understanding of hoarding behavior; experiences of loss; internal barriers to seeking support; and internal conflicts.

A major contribution of this article is the application of ambiguous loss theory (Boss, 1999) to the experiences of family members of persons who hoard, which will be applied throughout this section. As Boss (1999) argued, events that involve ambiguity, like living with compulsive hoarding, are extremely difficult and stressful events for a family. Ambiguous loss within a family system, when unaddressed, may affect individuals' perceptions of their relationships, resources, and the degree of stress experienced, and this seemed to be the case for the participants in this study.

In the current project, participants told intimate stories of the difficulties that they associated with attempting to deal with or manage their family members' hoarding behavior. Problems seemed to stem from communication with their loved one in general and particularly around their hoarding. The participants' attempts at helping clean and organize the clutter were reportedly most often met with defensiveness, avoidance, and resistance from their hoarding family member; when they were allowed to help, the process was reported to feel "futile" and pointless, as the lack of productivity and follow-through on the part of the person who hoards seemed to stand in the way of things getting organized.

Many of the participants reported a lack of understanding of their family members' hoarding behavior, which can be considered a type of ambiguous loss (Boss, 1993). The lack of a cognitive understanding about a loved one's behavior, its causes, or what to do about it, seemed to prevent participants from tangibly defining their situation, coping, and managing it effectively. According to previous ambiguous loss literature (Blieszner et al., 2007), it may also contribute to negative feelings toward the hoarding family member, which was further discussed by participants.

The experience of Ambiguous Loss can have systemic effects on the family (Boss, 2006). High levels of ambiguity can put families at risk for deterioration of individual and relational well-being by immobilizing individuals in their relationships, resulting in conflict within the family (Boss, 2002), and the findings from this study seemed to validate this. In this study, participants reported conflict that ensued as a result of family interactions about hoarding, and that, coupled with the lack of understanding of hoarding behavior and how to effectively deal with it, seemed to lead the participants to hold a myriad of negative feelings toward their family member who hoards; these negative feelings support findings from previous research (Tolin et al., 2007). Feelings, such as anger, frustration, disgust, and resentment, seemed to fuel interactions, many times leading to reported hopelessness about change, increased conflict, and emotional disengagement on the part of the participants, and resulting in rifts within family relationships.

Participants in the current study also talked about a variety of losses that they experienced as a result of hoarding behavior in their families, including social, relational, and physical losses, which were different from "ordinary losses", like death. Instead, almost all of the relationships between the participant and their hoarding family member were intact, albeit strained, which seemed to cause a level of ambiguity in their experiences. Many of the participants reported a large amount of sadness around "wanting a relationship" with the person who hoards, but felt that it would be "impossible if the hoarding continued". The feelings of loss around relationship were shown in comments like, "I'm sad and angry that I'm not getting the mother that I want to have because of the hoarding." These kinds of statements strongly support the application of an ambiguous loss framework.

Further ambiguous loss was demonstrated in participants who currently live or once lived in the now-hoarded home, with reported feelings of sadness around "not having a place to call

'home'." This type of loss reflects the psychological incongruence between physical and emotional presence discussed by Boss (1999); although the hoarded home was still physically present, the psychological feelings associated with one's childhood home were no longer available to the participants, leading to ambiguous loss about the situation.

Another loss discussed by participants was the loss of "normal family life," which has also been previously described by Wilbram et al. (2008). The disruption of family rituals and other meaningful life events is another type of ambiguous loss discussed by Boss (2002). Because these events contribute to a sense of identity within the family, the loss of them as a result of hoarding behavior may lead to deterioration of a family's identity; this can cause much grief and distress among family members and seemed to in the cases of the participants in this study.

In discussing feelings of loss, family members also described feelings of shame and embarrassment related to talking about their loved one who hoards. They reported experiencing a social stigma attached to hoarding behavior that seemed to prevent them from seeking out support outside their families; this also supports findings from previous research (Wilbram et al., 2008). Additionally, fear that the participants themselves might "turn into a hoarder" also seemed to serve as motivation for not discussing the problems with others. This seeming unwillingness to talk to others about the hoarding in their family further appeared to perpetuate the "secret" and "invisibility" of the problem; these types of unspoken concerns may also contribute to the ambiguity of the situation.

CLINICAL IMPLICATIONS

This study offers some important clinical implications for working with family members of persons who hoard. The current study has shown that participants may carry a large burden associated with having a family member who hoards, supporting previous research findings (Tolin et al., 2007; Wilbram et al., 2008). The data from this study further maintain the need for professional support for family members of persons who hoard, through the forms of psychoeducation and clinical training for working with this presenting problem in families. It is imperative that professionals become up-to-date in their knowledge about compulsive hoarding and its effects on family members to provide help where it is sorely needed. By understanding some contributing factors to the disorder of compulsive hoarding, it may assist clinicians in providing necessary psychoeducation to family members of persons who hoard about hoarding behavior along with clinical help for overcoming the feelings related to the shame and embarrassment that hold them back from seeking out social and professional support.

Further, previous qualitative research supports the idea that persons who hoard may come from families in which emotional expression is suppressed (Kellett et al., 2010); one may deduce that, because emotional expression is influenced by the emotional expressiveness of one's family of origin environment (Halberstadt, 1986), that it might be particularly difficult for family members of persons who hoard to express their emotional distress about the hoarding behavior within their family. However, this needs to be examined in future research. In the meantime, clinicians may benefit by keeping in mind the potential struggle that some clients may have with emotional expression in the therapy room.

Clinicians working with this presenting issue could also benefit from a conceptual framework which allows for areas of possible intervention. Based on the themes that arose in the interviews, the author proposes the application of Pauline Boss's (1999, 2006) ambiguous loss theory as a framework from which clinicians may conceptualize and work with clients whose loved ones hoard in a therapeutic setting.

Boss (2006) writes that the key to working with the presentation of ambiguous loss in clients is to understand that

With ambiguous loss, hope must be discovered despite imperfect endings and unclear terminations. But such endings can be symbolically understood and, through narrative and relational therapies, reconstructed so as to renew hope. To discover hope is to embrace the ambiguity and then find meaning in it. The paradox becomes easier to live with that holding on to what was- an impossible hope (p. 195).

Boss's (2006) cyclical model offers tools for clinicians in the form of six guidelines for resiliency while having to live with ambiguous loss. They are: (a) finding meaning; (b) tempering mastery; (c) reconstructing identity; (d) normalizing ambivalence; (e) revising attachment; and (f) discovering hope. Therapists may educate clients about ambiguous loss and work with them to utilize these tools for living with the ambiguity that having a family member who hoards might entail. See Boss (2006) for a more detailed explanation and application of each of these six tools in practice.

Given the systemic nature of ambiguous loss theory, this framework may shed light on how to work with compulsive hoarding in a family therapy setting. However, given the limited sample size of the current study upon which the application of this framework is proposed, it is important for clinicians to consider these recommendations tentatively until further research can be done to confirm the appropriateness of ambiguous loss theory for the experience of the family members of persons who hoard.

LIMITATIONS

As a qualitative study with a small self-selected sample size, this project has some methodological limitations to be highlighted. Although the sample size may be small, it corresponds to the recommended sample size for IPA work (Smith et al., 1999). The sample size should not be seen as representative of all family members of persons who hoard; however, achieving a representative sample is not the goal of most approaches to qualitative research. Rather, the aim is to produce an in-depth analysis of the accounts of a small number of participants, and any conclusions gained from the study are specific to this group; any generalization to groups beyond this sample should be taken tentatively.

Another limitation related to the sample is the overrepresentation of women in the participant group ($n = 10$). While all of the participants discussed similar themes in the interviews, regardless of gender, the men ($n = 2$) focused slightly more around distress related to being unable to "solve" the hoarding "problem", while the women focused more distress around the emotional impact of hoarding on relationships. Future studies could benefit by examining these gender differences more closely.

This study was also limited in ethnic overrepresentation of Caucasian participants. The one Chinese participant specifically discussed issues related to culturally related shame around hoarding, which held her back from seeking out support from others, more so than other participants. Ethnic differences related to family member experiences of hoarding are certainly an area for future study.

Another limitation of the current study relates to the use of purposive sampling. Because of the selection criteria based in the research question, participants shared the common characteristic of being a family member of a person who hoards, resulting in the need for purposive sampling. Such a sampling selection may have created a bias in participants being motivated by elevated levels of distress relating to their family members' hoarding behavior. The use of Craigslist as a recruitment tool also limited participants to those family members who had internet access. Future research should consider the use of larger samples to generalize the findings to a greater population.

CONCLUSION

In conclusion, this study has provided a detailed exploration of 12 people's lived experiences of having a family member who hoards. The qualitative methodology echoed many of the findings of previous studies on this subject (Tolin et al., 2007; Wilbram et al., 2008). The current study has furthered the knowledge in this subject area by expanding previous research to include a deeper perspective of the lived experience of these participants. Additionally, this article provides an application of a theoretical framework for this population, enabling professionals to have a clearer conceptual approach from which to work with these individuals in clinical work. Applying ambiguous loss theory in this way is a novel use of the framework, which has been previously applied in very specific populations, such as caregivers of Alzheimer's

patients or family members of prisoners of war. Clinical practice may benefit greatly from further research of the appropriateness of an ambiguous loss framework for this population.

The current research has examined how compulsive hoarding behavior can influence a family system. Building on the relational-systemic approach taken in this project, it would also make sense for future research to also examine the how hoarding behavior may be influenced by the various systems in which it is embedded. With such obvious emotional and relational underpinnings to hoarding behavior as discussed in these interviews and in previous research, further studies are needed to expand the work in this area in exploratory and descriptive stages of study.

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*, 1049–1057.
- Anderson, S. W., Damasio, H., & Damasio, A. R. (2005). A neural basis for collecting behavior in humans. *Brain, 128*, 201–212.
- Blieszner, R., Roberto, K. A., Wilcox, K. L., Barham, E. J., & Winston, B. L. (2007). Dimensions of ambiguous loss in couples coping with mild cognitive impairment. *Family Relations, 56*, 196–209.
- Boss, P. (1993). The recognition of family life with Alzheimer's disease: Generating theory to lower family stress from ambiguous loss. In P. Boss, W. Doughtry, R. LaRossa, W. Schumm & S. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 163–166). New York: Plenum Press.
- Boss, P. G. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P., & Couden, B. A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples, and families. *Journal of Clinical Psychology, 58*(11), 1351–1360.
- Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflection after 9/11. *Journal of Marriage and Family, 66*, 551–566.
- Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. New York: W. W. Norton.
- Chambless, D. L., Baker, M. J., Baucom, D. H., Beutler, L. E., Calhoun, K. S., Crits-Christoph, P., et al. (1998). Update on empirically validated therapies, II. *The Clinical Psychologist, 51*(1), 3–16.
- Christensen, D. D., & Greist, J. H. (2001). The challenge of obsessive-compulsive disorder hoarding. *Primary Psychiatry, 8*, 79–86.
- Eisler, I., Dare, C., Hodes, M., Russell, G., Dodge, E., & Le Grange, D. (2000). Family therapy for adolescent anorexia nervosa: The results of a controlled comparison of two family interventions. *Journal of Child Psychology and Psychiatry, 41*, 726–736.
- Frankenburg, F. (1984). Hoarding in anorexia nervosa. *British Journal of Medical Psychology, 57*, 57–60.
- Frost, R. O., & Gross, R. C. (1993). The hoarding of possessions. *Behaviour Research and Therapy, 31*(4), 367–381.
- Frost, R. O., & Hartl, T. L. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research and Therapy, 34*(4), 341–350.
- Frost, R. O., & Steketee, G. (2010). *Stuff: Compulsive hoarding and the meaning of things*. Boston: Houghton Mifflin Harcourt.
- Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: A community health problem. *Health and Social Care in the Community, 8*, 229–234.
- Halberstadt, A. G. (1986). Family socialization of emotional expression and nonverbal communication styles and skills. *Journal of Personality and Social Psychology, 51*(4), 827–836.
- Hwang, J. P., Tsai, S. J., Yang, C. H., Liu, K. M., & Lirng, J. F. (1998). Hoarding behavior in dementia: A preliminary report. *American Journal of Geriatric Psychiatry, 6*(4), 285–289.
- Kellett, S., Greenhalgh, R., Beail, N., & Ridgway, N. (2010). Compulsive hoarding: An interpretive phenomenological analysis. *Behavioral and Cognitive Psychotherapy, 38*, 141–155.
- Kyrios, M., Steketee, G., Frost, R. O., & Oh, S. (2002). Cognitions in compulsive hoarding. In R. O. Frost & G. Steketee (Eds.), *Cognitive approaches to obsessions and compulsions: Theory, assessment, and treatment* (pp. 269–289). Oxford: Elsevier.
- Lawrence, N. S. (2006). Decision making and set shifting impairments are associated with distinct symptom dimensions in obsessive-compulsive disorder. *Neuropsychology, 20*(4), 409.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park: Sage.
- Luchins, D., Goldman, M. B., Lieb, M., & Hanrahan, P. (1992). Repetitive behaviors in chronically institutionalized schizophrenic patients. *Schizophrenia Research, 8*, 119–123.

- Lysaker, P. H., Marks, K. A., Picone, J. B., Rollins, A. L., Fastenau, P. S., & Bond, G. R. (2000). Obsessive and compulsive symptoms in schizophrenia: Clinical and neurocognitive correlates. *The Journal of Nervous and Mental Disease, 188*, 78–83.
- Mataix-Cols, D., Frost, R. O., Pertusa, M. D., Clark, L. A., Saxena, S., Leckman, J. F., et al. (2010). Hoarding disorder: A new diagnosis for DSM-V? *Depression and Anxiety, 27*, 556–572.
- 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 behavior therapy: Results from a controlled trial. *Psychotherapy and Psychosomatics, 71*, 255–262.
- 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. *The American Journal of Psychiatry, 156*, 1409–1416.
- Mataix-Cols, D., Baer, L., Rauch, S., & Jenike, M. (2000). Relation to factor-analyzed symptom dimensions of obsessive-compulsive disorder to personality disorders. *Acta Psychiatrica Scandinavica, 102*, 199–202.
- Pinsof, W. M., & Wynne, L. C. (1995). The efficacy of marital and family therapy: An empirical overview, conclusions, and recommendations. *Journal of Marital and Family Therapy, 21*(4), 585–613.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20–23.
- Saxena, S., Brody, A. L., Maidment, K. M., Smith, E. C., Zohrabi, N., Katz, E., et al. (2004). Cerebral glucose metabolism in obsessive-compulsive hoarding. *American Journal of Psychiatry, 161*, 1038–1048.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretive phenomenological analysis in health psychology. *Psychology & Health, 11*, 261–271.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretive phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: theories and methods* (pp. 218–240). London: Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretive phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods* (pp. 51–81). London: Sage.
- Steketee, G., & Frost, R. O. (2003). Compulsive hoarding: Current status of the research. *Clinical Psychology Review, 23*, 905–927.
- 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.
- Stern, C. E., & Passingham, R. E. (1994). The nucleus accumbens of monkeys (*Macaca fascicularis*): The organization of behavior. *Brain Behaviour Research, 61*, 9–21.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Tolin, D. R., Frost, R. O., & Steketee, G. (2010). A brief interview for assessing compulsive hoarding: The Hoarding Rating Scale-Interview. *Psychiatry Research, 178*(1), 147–152.
- Tolin, D. F., Frost, R. O., Steketee, G., & Fitch, K. E. (2007). Family burden of compulsive hoarding: Results of an internet survey. *Behaviour Research and Therapy, 46*, 334–344.
- Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., & Smith, J. A. (1997). Standards for research projects and theses involving qualitative methods; suggested guidelines for trainees and courses. *Clinical Psychology Forum, 108*, 3–7.
- Van Noppen, B. L., & Steketee, G. (2003). Family responses and multifamily behavioral treatment for obsessive-compulsive disorder. *Brief Treatment and Crisis Intervention, 3*, 231–247.
- Wilbram, M., Kellett, S., & Beail, N. (2008). Compulsive hoarding: A qualitative investigation of partner and carer perspectives. *British Journal of Clinical Psychology, 47*, 59–73.
- Winsberg, M. E., Cassic, K. S., & Korran, L. M. (1999). Hoarding in obsessive-compulsive disorder: A report of 20 cases. *Journal of Clinical Psychiatry, 60*, 591–597.