Empowering families to help a loved one with Hoarding Disorder: Pilot study of Family-As-Motivators training

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**Abstract**

Individuals with Hoarding Disorder (HD)—a dangerous problem and public health concern—are often ambivalent about treatment. Furthermore, family members of those with HD report high levels of distress and often attempt to intervene unsuccessfully. The current study reports outcome data from a pilot study of a new training package—designed exclusively for empowering family members to address a loved one’s treatment ambivalence—called Family-As-Motivators (FAM) training. Nine family members of a loved one with HD initiated 14 sessions of FAM Training and were measured at pre-, mid-, and post-training on a comprehensive outcome battery. Results over the course of training suggested that family members improved in the use of certain coping strategies and in the application of motivational interviewing techniques. They also exhibited increased hopefulness, reported a reduced negative impact of HD on the family, rated a reduction in family accommodation of HD behaviors, and displayed boosts in HD and motivational interviewing knowledge. According to participants who completed the program, FAM Training was rated as highly acceptable. Although only preliminary, the current pilot study suggests that FAM Training is palatable for participants and shows promise for improving the lives of family members of those with HD.

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Now recognized in the Diagnostic and Statistical Manual of Mental Disorders (5th Edition; American Psychiatric Association, 2013) as a discrete psychiatric condition, Hoarding Disorder (HD) is characterized by clinically significant distress associated with the discarding of possessions. This difficulty with discarding often results in high levels of clutter that preclude the intended functional use of living space (American Psychiatric Association, 2013). Affecting 2–6% of the population (American Psychiatric Association, 2013), HD is dangerous, as individuals living in a cluttered environment are at increased risk of illness from unsanitary conditions, as well as injury and death from falls and fire (Steketee & Frost, 2003). Such risks also extend to neighbors (e.g., a cluttered condominium causing the floor to cave in) and emergency personnel (e.g., firefighters, emergency medical technicians, police officers), who are often required to enter the homes of those with HD.

Hoarding also negatively influences family dynamics, as relatives of a patient with hoarding report considerable distress and tend to exhibit high levels of patient rejection (Tolin, Frost, Steketee, & Fitch, 2008). In fact, according to evidence from Tolin, Frost, Steketee, and Fitch (2008), family rejection of a loved one with hoarding may be higher than family rejection for OCD and comparable to levels of family rejection for schizophrenia. Higher rejection by a family member was associated with higher patient levels of hoarding severity and clutter, as well as lower insight (Tolin, Frost, Steketee, and Fitch, 2008). Additionally this patient rejection may be related to a tendency for family members to exaggerate a patient’s level of hoarding severity (DiMauro, Tolin, Frost, & Steketee, 2013).

Fortunately, studies of specialized cognitive-behavioral therapy (CBT) for HD have reported considerable reduction of hoarding behaviors (Steketee, Frost, Tolin, Rasmussen, & Brown, 2010; Tolin, Frost, & Steketee, 2007a). According to one study, however, fewer than 45% of individuals with HD sought mental health treatment within the last year, despite 84% reporting a need (Tolin, Frost, Steketee, Gray, & Fitch, 2008). Such treatment ambivalence seems to further frustrate family members. Indeed, anecdotally, family members often compound the problem by trying to arrange hoarding treatment with a provider, frequently unbeknownst to the individual with HD.

Based on this strong family desire to help loved ones with HD, multiple programs have been developed to leverage this
motivation. For example, Tompkins (2011) and Tompkins and Hartl (2009) have discussed a comprehensive model for aiding family members of those with HD—called Community Reinforcement and Family Training—which includes multiple elements such as harm reduction techniques, communication training, and self-care. Although focused on the entire spectrum of obsessive-compulsive disorder conditions and not exclusive to HD, Pollard and colleagues (Pollard, 2013; VanDyke & Pollard, 2005) have presented on promising preliminary results of their program—called Consultation to Families of Treatment-Refusers—for helping relatives address a loved one’s treatment ambivalence. This program includes many elements, such as educating family, helping them address their own psychological distress, reducing family accommodation of rituals, and incentivizing treatment-seeking behavior. These promising approaches from Tompkins and colleagues and Pollard and colleagues are grounded in theory and based on empirical support in non-HD populations (e.g., harm reduction in substance abuse populations; Logan & Marlett, 2010).

Despite the promise of these approaches, to our knowledge, only one study to date has published research data supporting family techniques in this clinical population. Using a qualitative methodology with eight families, Sampson, Yeats, and Harris (2012) published data on a six-week (12 total hours) psycho-education program designed for family members of those with HD. The results of the qualitative analysis suggested that family members exhibited an increase in the understanding of HD and its impact on the family. Results also suggested that family members benefited from the psychoeducation groups, including lowered distress and improved interactions with the loved one with HD.

There is a growing interest from researchers and clinicians in leveraging family motivation to facilitate recovery from HD, but published, quantitative research on family techniques for addressing this condition is clearly lacking. The current study was designed to fill this void by offering quantitative pilot data on a new training package—designed exclusively for empowering family members—called Family-As-Motivators (FAM) Training. The goal of FAM Training consists of increasing treatment-seeking behavior and readiness among individuals with HD, as well as increasing the well-being of their family members, given the high levels of distress associated with having a loved one with hoarding (Tolin, Frost, Steketee, & Fitch, 2008). FAM Training was a manualized seven-week protocol based on 14 sessions across four modules: psycho-education (two sessions), motivational interviewing training (six sessions), harm reduction (four sessions), and family accommodation prevention (two sessions). A comprehensive battery of measures, designed to capture various elements theoretically addressed by FAM Training, was administered to a small sample of family members of those with HD at pre-training, mid-training, and post-training. We hypothesized that family members who participated in FAM Training would report increases in positive coping strategies, decreases in negative coping strategies, increased hopefulness, less negative impact of HD on the family, reduced family accommodation of hoarding behaviors, boosts in HD knowledge, and increases in the use and knowledge of motivational interviewing techniques. We also hypothesized that FAM Training would be associated with positive acceptability ratings. As an exploratory aim, we also expected family-report of hoarding severity to decrease, even though the loved one with HD was not enrolled in the study.

**Method**

**Participants**

Nine adult family members of a loved one with HD participated in the pilot study. The sample contained seven females, had a mean age of 46.22 (SD = 13.10), and was 89% Caucasian (n = 1 Asian American). Three of the participants were adult children of a parent with HD (two daughters of a female with HD and one daughter of a male with HD), three of the participants were siblings of the individual with HD (two sisters of a female with HD and one sister of a male with HD), two of the participants were husbands of a female hoarder, and one participant was the mother of an adult daughter with HD.

Five of the families completed the full training, with four dropping out before the mid-training assessment and one before the post-training assessment. Reasons for dropout were as follows: one participant cited time constraints due to dealing with the housing crisis of a mother with HD, one husband started the process of separating from his wife with HD, one sister dropped out because she believed that she already had all of the information and skills, and the last case dropped out for unknown reasons.

**Procedure**

Participants were recruited from the first author’s specialized group practice geared toward CBT for obsessive-compulsive disorder and related conditions. The study was voluntary, and participants did not receive monetary incentives for participation, although FAM Training and university parking were free of charge. The research was approved by the university’s Internal Review Board for human subject research.

Before initiating FAM Training, all participants completed a pre-training assessment battery, after which each family member participated in FAM Training. The 14 sessions of FAM Training were administered for two hours per week (either two one-hour sessions or one two-hour session), although given the voluntary, non-incentivized, and preliminary nature of the study, this administration format varied on occasion to accommodate participant scheduling needs. Designed as a one-to-one program with a trainer, FAM Training was standardized using a 200-page implementation manual (Chasson, Ewing, Gibby, & Carpenter, 2013). The training was implemented by first- and second-year graduate students in a clinical psychology Masters program. All students had previous experience delivering psychosocial treatments and were clinically supervised by the first author, a licensed psychologist. After the eighth session, which marked the end of the Motivational Interviewing Training module, participants received a mid-training assessment battery. Similarly, upon completing the 14th session of FAM Training, participants completed the post-training battery. All three assessment batteries were identical, except the post-training battery also included the measure of training acceptability.

**FAM training modules**

**Psychoeducation**

This module was created using pre-existing educational material (Steketeet, Frost, Steketee, & Fitch, 2008). These materials were supplemented with information from the research literature on HD, such as findings pertaining to epidemiology (Samuels et al., 2008), family factors (Tolin, Frost, Steketee, & Fitch, 2008), economic burden (Tolin, Frost, Steketee, Gray, et al., 2008), and clinical correlates (e.g., information processing deficits; Grisham, Norberg, Williams, Certoma, & Kadib, 2010). During the first FAM Training session, family members received an outline of local hoarding resources.

**Harm reduction**

Derived from the substance abuse treatment literature, in which it has demonstrated positive outcomes with illicit drug users (Logan & Marlett, 2010), harm reduction techniques have recently
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