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The psychological, relational and social impact in adult offspring of parents with hoarding disorder

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Abstract

Hoarding disorder (HD) is a psychiatric condition that negatively impacts individual sufferers, their families and the larger community. The disorder goes beyond problems with excessive clutter; it also presents with deficits in executive functioning, attachment and affect regulation deficits. This paper focusses on the needs of adult children of parents with HD, who directly experience the consequences of the disorder throughout their life cycle. We explore the existing research on the psychological, relational and social impact of parental hoarding on adult offspring. We discuss the clinical implications of these findings and offer possible psychological interventions that may be of help in this vulnerable population.

Introduction

Hoarding disorder (HD) is a debilitating psychiatric condition, categorised in the *Diagnostic and Statistical Manual of Mental Disorders* (5th edn.) as an obsessive compulsive and related disorder (OCRD; American Psychiatric Association [APS], 2013). It is defined by an inability to part with objects, irrespective of their value, due to an experience of distress associated with the discarding process. This is often accompanied by excessive acquisition and leads to significant levels of clutter compromising the ability to access and successfully use living spaces (APS, 2013). HD frequently involves poor insight on the part of the person who hoards, which makes it difficult to successfully treat (Tolin et al., 2010).

This condition cannot simply be reduced to problems with excessive clutter. Cognitive deficits involving informational processing and ineffective emotional attachments to objects lead to distress around discarding, which is managed through avoiding (Frost & Hartl, 1996; Steketee et al., 2003). Although initial formulations focused primarily on the cognitive aspects of the disorder (Frost & Hartl, 1996; Steketee et al., 2003; Tolin, Hallion et al., 2018), recent research has drawn attention to the extreme emotional reactivity triggering the hoarding behaviour (Shaw et al., 2015; Tolin, Levy et al., 2018). These reactions are not just related to the items but also globalise into more general emotion regulation issues impacting everyday life (Shaw et al., 2015; Tolin, Levy et al., 2018). This aspect of the disorder is believed to be so significant that Shaw et al. (2015) encourage further research exploring to what extent HD should be classified with the affective disorders.

Hoarding behaviour has significant consequences for the person who hoards, the community and the family. The focus of this paper will be to review the impact of parental hoarding on adult offspring. We will then discuss the clinical implications of the research and use this information to explore specific therapeutic techniques that can assist in helping this very vulnerable population.

The impact of parental hoarding for adult children can be categorised into three overarching themes: psychological, relational and social. The psychological aspect can be understood in terms of the emotional impact the hoarding behaviour has on the adult child. The relational aspect focuses on assessing how this disorder affects the relationship between the adult child and the hoarding parent. Understanding the social impact involves exploring the feelings of isolation and difficulties accessing services experienced by many adult children of persons with HD. Lastly, many offspring have grown up in unsafe or unsanitary environments. The long-term impacts of those have yet to be explored sufficiently.

Psychological impact

HD is a chronic condition that can have a lifetime impact on offspring, with different challenges at each life stage. Children and adolescents live with daily disruptions, including loss of functional living space, familial tension, financial hardship, social isolation or unsanitary conditions. The degree of psychological impact may be contingent upon the offspring's age at the onset of the parental hoarding and severity. Research demonstrates that those who lived with moderate or higher levels of clutter before age 10 experience more distress (Tolin et al., 2008). Younger children also may have a larger cumulative psychological impact since they live with the clutter and disruption for a longer period of their development. Even though offspring may no longer live directly with clutter, as they age the psychological distress and other challenges are experienced into adulthood.

As their parents age, offspring may bear additional responsibilities as caregivers. They live with the increased concern and anxiety for their parent's safety, for instance, concern about injuries from falls resulting from unsafe living conditions (Rees et al., 2018; Tompkins, 2011). Concerns about the well-being of an ageing parent with HD are very real. A study by Kim et al. (2001) of elderly people who hoard found significant issues regarding mobility and safety in the home, self-care, health risks as well as high rates of suspected mental health issues. The emotional and social impact of caregiver burden on adult relatives (80% of whom were offspring) of individuals with HD is similar to that found in individuals suffering from HD (Drury et al., 2014). Caregiver burden was at a level similar to those caring for people with dementia and increased as the person with HD aged (Drury et al., 2014). This was coupled with concerns about how they would address the clutter when the parent passes away (Rees et al., 2018). Severe clutter can also result in complaints from neighbours, possible eviction and intervention by local authorities, placing additional burdens on family members to manage and resolve.

Feelings of loss are a common experience for adult children of persons with HD. Offspring struggle with the feelings of grief around the loss of the relationship with the person who hoards, loss of cultural rituals and holidays as well as a belief that their loved one chose their possessions over family relationships, leading to feelings of rejection and anger (Sampson, 2013). The loss is felt not just for the past but also for future relationships and experiences, such as continuing traditions for the next generation including grandchildren. These experiences lead to a more existential sense of loss in terms of not having a sense of home and family identity. Sampson (2013) reports that it feels as if the family member and the experience of being a family were no longer really present. The ambiguity of this loss makes it harder to understand and process.

Wilbram et al. (2008) also explored the experience of caring for family members and caretakers with HD. Participants similarly reported the loss of family life. Participants reported comparing their present situation to a time before the hoarding behaviour began, as well as comparing their current situation to families who do not experience hoarding. Similar to the findings of Sampson (2013), family members talked about the loss of opportunities to be together as a family and the loss of the experience of being able to celebrate holidays together.

The experience of having a parent with HD can lead to feelings of shame and embarrassment which has a negative impact on selfesteem (Rees et al., 2018; Sampson, 2013; Tolin et al., 2008; Wilbram et al., 2008). The study by Wilbram et al. (2008) suggests that family members blame themselves for the HD, believing they somehow helped to create the situation. Furthermore, children live with the fear that their peers, neighbours or even extended family members may find out about the hoarding.

Offspring also worry about their own risk in developing hoarding. In Sampson's (2013) qualitative study of 12 individuals, the vast majority of whom were adult children of hoarders, 9 of the participants talked about having urges associated with hoarding behaviour with regard to difficulty discarding. This led them to worry that they, themselves, would develop HD and caused them to resent themselves (Sampson, 2013).

Often, when offspring attempt to convince their parent to seek treatment, the person declines the help (Park et al., 2014; Rees et al., 2018; Wilbram et al., 2008). This may result in ongoing feelings of powerlessness and hopelessness and negatively impact the parent–child relationship (Park et al., 2014). At times, the offspring's struggle with feelings of powerlessness, hopelessness and victimisation lead to a strong desire to understand the reasons for the hoarding behaviour (Rees et al., 2018; Sampson, 2013; Wilbram et al., 2008). Individuals believe that gaining an understanding will help them develop an ability to effectively address the issue, and as a result, obtain a sense of control and agency (Wilbram et al., 2008).

In summary, the psychological impact of having a parent with hoarding results in a complex reaction that includes a conflicting desire to understand the hoarding and help their parent and, at the same time, experiences anger, resentment, shame, embarrassment and anxiety. Loss and grief over past familial experiences and the possibility of those same feelings in the future are also experienced by offspring. The psychological impact may be influenced by the child's age and severity of the hoarding.

Relational impact

Parental hoarding negatively affects the parent-child relationship into adulthood. People with HD use objects to regulate emotions and, as a result, are less emotionally available as a parent (Rees et al., 2018). The significant issues with emotion reactivity can also have an impact on the parent-child relationship (Rees et al., 2018; Shaw et al., 2015; Tolin, Levy et al., 2018; Wilbram et al., 2008). Consequently, children of people who hoard demonstrate very high levels of expressed emotion, including anger towards, and rejection of, the person who hoards (Rees et al., 2018; Sampson, 2013; Tolin et al., 2008). Negative emotions are greater when parental hoarding is present during childhood (Tolin et al., 2008). Those who grow up in homes with hoarding also report difficulty forming relationships in general, beginning in childhood and adolescence and continuing into adulthood (Rees et al., 2018). Females report more impairment in the relationship than men (Tolin et al., 2008). A significant factor contributing to increased levels of anger and rejection is a lack of insight on the part of the hoarding parent (Park et al., 2014; Tolin et al., 2008). This may be because a lack of insight interferes with the parent understanding the adult child's feelings and needs and contributes to the person who hoards undermining efforts to address the issue (Park et al., 2014). This would understandably lead to feelings of anger and frustration. Furthermore, those with hoarding behaviour may lack interpersonal skills resulting in difficulties repairing conflict and maintaining effective relationships with family (Grisham et al., 2008).

Another dynamic factoring into this is the hoarding parent reacting with hostility when the adult child does try to intervene (Rees et al., 2018; Wilbram et al., 2008). Part of the issue seems to be a lack of knowledge of effective ways to intervene (Sampson, 2013; Wilbram et al., 2008). This lack of knowing how to address the issue can lead to family members cleaning the clutter without the person's knowledge or consent, which frequently leads to greater conflict (Wilbram et al., 2008).

Not knowing how to respond to the hoarding behaviour can lead the adult children to attempt to reduce conflict through avoiding the parent by distancing themselves physically and emotionally (Rees et al., 2018; Sampson, 2013). Although understandable, this way of coping with the issue contributes to the experience of loss described earlier (Sampson, 2013; Wilbram et al., 2008). Many times, family members feel they have no choice but to accommodate the hoarding behaviour through participating in and facilitating it (Drury et al., 2014). This is done in an effort to reduce conflict, but may have the opposite effect by creating higher levels of family conflict and emotional distress (Park et al., 2014).

Social impact

Children of people with HD report feelings of isolation and invisibility due to the experience shame, embarrassment and social stigma (Sampson, 2013; Wilbram et al., 2008). Offspring often live in secrecy, as the larger community is unaware of the hoarding since the parent may function well in other areas, including work (Sampson, 2013).

For those living with the hoarding parent, feelings of shame and embarrassment may interfere with the ability to make friends and have people visit, resulting in social isolation (Wilbram et al., 2008). Also, a fear of being judged and misunderstood has been known to interfere with people accessing needed support (Sampson, 2013; Wilbram et al., 2008). These feelings are reinforced by actual experiences with service providers, such as social service workers and medical professionals, not adequately understanding the issue. As a result, individuals may be reluctant to involve agencies and other providers out of concerns as to how they will respond (Wilbram et al., 2008). Often, adult children need to interact with the community agencies or housing boards that are trying to evict their parents. The situation is compounded by the tremendous shame and powerlessness experienced by the adult children as well as the lack of training and resources of agencies to adequately respond. Sometimes, assisted living facilities or nursing homes face similar difficulties with their inability to cope with the hoarding, requiring family members to intervene and resolve the situation. Threats of eviction create an ongoing burden on offspring. These situations are often difficult to share with friends and extended family due to continued embarrassment and shame.

Clinical implications

The small amount of research investigating adult children of parental hoarding suggests that this population is vulnerable and requires specific support and psychological interventions. There are several areas of need in this population. The development of psycho-education interventions, family therapy, teaching specific communication strategies, support and general coping skills could greatly improve both the parent–adult child dynamic and the psychological well-being of the adult offspring. Given the complex psychological experiences, research efforts to identify specific disorders within this population, including trauma, depression and anxiety, would be of value to increase resources to this population.

Psycho-education on the nature of HD, as well as the impact it has on families, may help to reduce feelings of stigma, anger, rejection, shame and embarrassment in offspring. This also may help to provide individuals with a sense of agency and a starting point in developing effective strategies to manage the hoarding behaviour. A common theme in several of the studies was the participants' desire to understand the behaviour in order to develop a sense of control and an ability to more successfully address the issue (Rees et al., 2018; Sampson, 2013; Wilbram et al., 2008). Given this, there is also a need to educate community service workers and providers on this issue to increase the likelihood that effective support and outreach will be available to families.

In many ways, the research points to the need to teach family members effective coping skills. This would include techniques to constructively manage the negative emotions elicited by the hoarding behaviour. An essential aspect of this is teaching interpersonal skills to assist with addressing family accommodation. As noted earlier, due to unsuccessful attempts at addressing the behaviour, many family members can come to view accommodation as the path of least resistance. However, evidence suggests the negative impact of this on the family member and his or her relationship with the hoarding person (Park et al., 2014).

Similar to other OCD-related disorders, family members may vacillate between accommodation and antagonistic response styles (Van Noppen et al., 1997). Accommodation refers to family members supporting and facilitating loved one's rituals and avoidance while an antagonistic style refers to reacting to a loved one's symptoms with criticism, blame and hostility. Psycho-education regarding these patterns of responses can lead the way for coaching family members on effective responses to support and encourage their loved one to seek help. The OCD literature suggests that parental accommodation in children with OCD can lead to greater severity and impairment while decreasing accommodation can predict treatment outcome in children with OCD (Merlo et al., 2009). Decreasing family accommodation may also increase the likelihood that the hoarding parent will become aware of the consequences of their behaviour. This may provide motivation for them to address the issue (Park et al., 2014; Sampson, 2013; Wilbram et al., 2008). Further research may help clarify the similarities and differences in OCD versus HD family styles.

Clinical interventions

Teaching effective coping and interpersonal skills best occurs in an emotionally validating environment, and a cornerstone of emotional validation is a phenomenological empathy (Linehan, 1993). This means understanding that people are doing the best they can, and that there are reasons behind their actions, which from their perspective, make perfect sense.

Before teaching specific skills, the first step then is for the therapist to help the adult child understand that the hoarding parent is not intentionally trying to be rejecting or 'selfish', but rather doing his or her best to cope with intense feelings of distress and anxiety. This can provide an opportunity for the adult child to respond from a place of empathy, rather than from feelings of hurt and anger. As noted earlier, people with HD are known to be lacking emotion regulation skills (Shaw et al., 2015; Tolin, Levy et al., 2018), and therefore responding in a way that communicates an understanding of their situation is essential for an effective, non-combative interaction.

This perspective can also help to reduce feelings of shame and embarrassment around having a parent with HD, since it provides the adult child a non-judgemental way to understand their own, as well as their parent's situation. It is important for adult children of people with HD to view themselves with empathy. The research suggests that adult children of people with HD can feel guilty for their critical and rejecting behaviour toward the hoarding parent (Sampson, 2013). It is essential for them to understand that their feelings and reactions make sense given how they view the situation. However, learning to be phenomenologically empathic provides them with the opportunity to explore other, more effective, ways of understanding and addressing the issues they are encountering with their parent. This perspective is foundational and will be revisited as we explore specific techniques.

It is interesting that to date we have no research on how to clinically intervene with adult children of hoarders. The below suggested strategies will need systematic investigation. The proposed intervention strategy and motivational interviewing (MI) are techniques geared not for offspring's own distress, but as methods to help loved one's seek treatment. Ultimately, the successful treatment for the hoarding behaviour would address the adult child's own struggle and improve their well-being.

Intervention strategy

Neziroglu et al. (2004) proposed the use of a strategy based on the Johnson model of intervention (Johnson, 1986; Loneck et al., 2009) often used in substance abuse treatment to confront a person who is refusing to engage in treatment. The Johnson intervention strategy essentially gathers a person's closest family and friends to confront and persuade him/her to seek treatment. Its applicability for HD is based on a similar lack of insight and lack of recognition for the necessity of treatment (Tolin et al., 2010). Often when treatment is suggested, individuals with hoarding get angry and upset (Rees et al., 2018; Wilbram et al., 2008), leading to greater relationship discord. They may assert they can do it on their own, which the adult child will most likely suspect is futile. However, most individuals with hoarding require outside intervention to seek treatment. In a study, only 3% of individuals with hoarding were self-referred (Kim et al., 2001), supporting the critical need for family involvement.

Effective use of an intervention requires careful planning and rehearsal. A hoarding specialist can serve as an interventionist to coordinate the meeting and coach family members on its effective execution. The specialist meets with the family and friends prior to their intervention to discuss effective confrontation strategies, which include using a validating and non-judgmental approach. Family members learn how to express the personal impact of the hoarding behaviour without placing blame or creating guilt for their loved one. It is advisable for the involved individuals to write down and practice what they will say to their loved one.

The goal of the intervention is to convince their loved one to agree to an initial consultation/evaluation with a hoarding expert. The most successful interventions involve a pre-arranged scheduled appointment with the hoarding expert within the same day or within a very short period of time. It is the responsibility of the expert to convince the patient to agree to follow-up therapy. It is advisable for an adult child or family member to accompany their loved one to the initial consultation.

If the parent with hoarding refuses to attend the pre-arranged session or seeks to delay treatment, it is advisable for the family to stay as firm as possible. If that is unsuccessful, the family can agree to a time-limited delay with compassionate but firm reminders to encourage follow through. Family members are coached to continue expressing the impact of hoarding on the individual and loved ones. Initial commitment to treatment is often possible, but attrition rates in HD range around 20% to 30% (Tolin et al., 2007; Turner et al., 2010). Many of those who do engage in treatment are resistant to discarding a significant number of belongings, resulting in continued symptoms. Ongoing familial involvement is a necessary component not only for the initiation of treatment but also for long-term commitment and follow through.

Motivational interviewing (MI)

People with HD are usually unmotivated to change, or stated another way, they are not ready for change. Prochaska and DiClemente (1983) proposed a transtheoretical model suggesting that individuals go through stages of change to modify problematic behaviours. Measuring readiness for change that can help identify the amount of treatment motivation, engagement and preparation is required to increase treatment outcome. Family members can be a valuable assistance to increase the likelihood of treatment engagement. Several motivational strategies are found to be helpful such as giving advice; removing barriers; providing choice; decreasing desirability; practicing empathy; providing feedback; clarifying goals and active helping. It is not the purpose of this paper to go into depth on readiness for change or MI styles but to indicate its value in providing strategies for the adult child.

Similar to the Johnson intervention strategy suggested above, MI (Miller & Rollnick, 1991) is a strategy developed to engage individuals with addiction to participate in treatment and commit to change. Clients who are at the earlier stages of change may benefit from addressing motivation before engaging in cognitive behavioural techniques to reduce clutter. Teaching offspring these therapeutic tools can empower them with a sense of control and purpose.

MI is a conversation style that promotes change by encouraging individuals to recognise their own obstacles and ambivalence for change. It adopts a collaborative approach and helps individuals strengthen their own motivation and commitment to change (Miller & Rollnick, 2013). MI suggests a way to help people examine and acknowledge the reality of their situation, particularly when insight is limited. Individuals with HD have high overvalued ideation and therefore are less likely to engage in treatment (Neziroglu et al., 2012). In a study (Ayers et al., 2015) examining the recruitment of a geriatric group with HD, the treating clinicians and research assistants engaged in informal MI to increase participation commitment. This resulted in lower than typically reported attrition rates (Ayers et al., 2015), supporting the potential applicability of MI as a successful communication style for family members of someone with HD to implement for treatment engagement.

Although there may be great value in offspring learning to implement these strategies, clinicians need to proceed with caution by being cognizant of balancing the family's needs with the vulnerable individuals with HD.

Assertion training skills

Adult children resort to accommodation, antagonistic behaviour or ignoring the situation as coping styles. As mentioned above, accommodation refers to efforts made by the adult child to pacify, live with or tolerate the dysfunctional lifestyle of the parent. Whereas, antagonism refers to yelling, screaming or dismissive behaviour such as insisting the family member just clean up, demonstrate an insensitivity for the desires of the parent or ignore and distance from the parent altogether. Assertive communication skills are a more effective way to express one's needs in a firm and balanced way limiting high expressed emotion. Offspring using assertiveness skills may have a greater chance for success by clearly expressing the problem behaviour, their emotional experience as a result of the behaviour, followed by clear requests for change. Assertiveness communication can be implemented for a variety of scenarios, including limiting the parent requests with help to acquire more items. It can also be used in the course of the intervention approach to persuade a parent to seek help.

Psycho-education

Psycho-education is an essential component of cognitive behavioural interventions. It is often the first strategy introduced in treatment. Adult children of those with HD are seeking an understanding of the disorder in order to better understand their parents. It also gives them a way to conceptualise their life experiences within the context of the condition. Psycho-education can reduce shame, guilt and responsibility and is an important intervention for adult children. It also helps with recognising symptoms associated with HD beyond the actual clutter. Children may benefit from understanding that HD has associated cognitive impairment and how that impacts their daily functioning. Deficits in executive functioning in HD include difficulties in organisation, planning, problem-solving, decision-making, sustained attention and memory (Grisham et al., 2010; Tolin, Hallion et al., 2018; Woody et al., 2014), as well as visual domains, including visual memory, visual detection and visual categorisation (Mackin et al., 2016).

Acceptance and commitment therapy strategies

Adult children have two options in responding to their parent's hoarding behaviour: either pursuing attempts to change the problem or learn ways to accept the situation as it is. Many of the above strategies involve change strategies via persuasive communication skills. Although there are practical intervention methods that may increase treatment seeking in HD, often the attempts are unsuccessful. HD can be a chronic disorder and unchanging aspect of family life. When problem-solving and intervention are unsuccessful, offspring could benefit from letting go of a desire to change the parent's behaviour, and instead learn acceptance strategies.

Acceptance and commitment therapy (ACT; Hayes et al., 1999) is applicable in dealing with the adult child's frustration and negative feelings. In ACT, the adult child is asked to accept her/his feelings, stay in the present and be willing to behave in accordance with his/her values, for example, learning to value the relationship with the parent regardless of the clutter, leading to specific changes in behaviour. This may include a willingness to meet the parent at a restaurant for dinner because the home is too cluttered rather than choosing to distance from the parent. Some strategies discussed specifically for adult children of hoarders that use ACT principles are acceptance/willingness, mindfulness, cognitive defusion, values clarification and committed action and self as context (Neziroglu & Donnelly, 2013).

ACT provides many specific techniques including distancing from the negative thoughts, via cognitive defusion. For example, instead of thinking 'My father loves his possessions more than me', say 'I am having the thought that my father loves his possessions more than me'. Neziroglu and Donnelly (2013) suggest observing the thoughts, being mindful of them and letting them go through various mindfulness techniques are applicable methods for adult children to reduce their distress. In addition, they suggest not identifying with labels such as 'child of a hoarder' because this identification may either move the person towards enmeshment or total distancing from the parent. When the child identifies with mentally assigned labels be it for him/herself or for the parent 'hoarder', it is hard not to act in accordance with the label. The thoughts, emotions and behaviours are tied to the label. It is important to defuse from these labels and commit to actions that are in accordance to one's values. ACT provides strategies for offspring to accept the hoarding behaviour in their parent.

Group family therapy

Van Noppen and colleagues (1997) developed a family intervention for OCD called 'multi-family behaviour therapy' consisting of a group treatment with family members alongside the individual with OCD. The goal of the group is to teach family members how to participate in treatment by understanding the disorder, managing the symptoms, learning coping strategies and improving life quality (Van Noppen, 2002).

Given the impact and involvement on families in HD, adapting Van Noppen and colleagues' group treatment to those with HD and their family members could increase treatment outcome and improve family relationships. With the high levels of possible distress in adult children and conflict with their parent, initial group sessions may be structured differently, so that parents and their children meet separately at first before families and parents engage in joint group therapy.

Exposure and response prevention

Children of hoarders commonly feel pain, frustration, hurt, anger and resentment. These emotions lead to hostile and aggressive styles of communication. Exposure therapy may be a helpful way to face these negative thoughts and memories. An anxiety hierarchy can be constructed of painful thoughts, images and expressions of the parent that trigger anger. The adult child is exposed to the thought, image or expression in a gradual manner and imagines not responding with anger. This can be practiced in imagination and then later in vivo whereby the therapist may actually take the adult child to the house or have the parent and the child speak to one another in the therapist's office or elsewhere. Therapists target disruptive behaviours including yelling, screaming and expressing hostility via exposures. Teaching offspring to react differently to their parents using exposure therapy may be another method to improve communication and the relationship between the child and their parent.

Furthermore, adult children's childhood experiences, especially in cases of severe hoarding, may result in trauma and post-traumatic stress symptoms. Exposure therapy in these circumstances may be especially applicable. As are other cognitive behavioural approaches to consider, such as cognitive processing therapy (Resick et al., 2017). Further research would clarify the incidence and likelihood of trauma in this population.

Summary

HD is a significant psychiatric issue that goes well beyond simply having problems with clutter. People with HD have issues with executive functioning, ineffective attachments to objects and emotional dysregulation that can impact the lives of many people. Especially vulnerable are children of hoarders, who suffer the consequences of the disorder irrespective of where they are in the life cycle. As noted, there is limited research of the effect this has on adult children of hoarders; however, studies which have been done show concerns in the areas of psychological, relational and social functioning. It is likely that this population may struggle with psychological disorders influenced by their life experiences, including difficulty with relationships, trauma, depression, hoarding behaviour and social anxiety. Clinical studies in this population would be valuable. Several strategies for helping the children of hoarders cope with their distress have been suggested. These approaches need to be investigated. To date, we have no research data on treating the aftermath of living with someone who has HD.

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