



Compulsive hoarding: A qualitative investigation of partner and carer perspectives

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Objective. This study explores the experiences of family members caring for a person who compulsively hoards.

Design. Ten participants, all 'key carers' for a hoarding family member, were interviewed using a semi-structured interview schedule designed for the purpose of the study.

Methods. Transcribed interviews were analysed using interpretive phenomenological analysis.

Results. Five superordinate, discrete but interconnecting themes were identified: 'loss of normal family life'; 'the need for understanding'; 'coping with the situation'; 'impact on relationships'; and 'marginalization'. Carers' accommodation of hoarding behaviours and role isolation were examined in drawing connections between themes. Outlying themes suggesting factors protective of relationships and facilitating coping were also identified.

Conclusion. Carers struggled to cope with both the environmental and interpersonal impacts of the hoarding. Lacking both formal and informal networks of support, carers are in need of information and treatment options for themselves and their families. Possible avenues for future clinical and theoretical research are suggested.

Families often perform vital roles in supporting members with mental health problems (Derisley, Libby, Clark, & Reynolds, 2005). Carers' needs have become a focus of concern as potential 'risks' to well-being, arising from the role, have been identified (Taylor, Ford, & Dunbar, 1995). Evidence is most developed in relation to difficulties experienced in families living with a member with schizophrenia (Saunders, 2003). Investigation of the impact of anxiety disorders in families forms a smaller yet expanding area of related work (Lochner *et al.*, 2003). Research suggests that anxiety disorders similarly negatively impact the quality of family life (Lochner *et al.*, 2003), with only

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modest quantitative and qualitative differences in 'burden of care' when compared to severe mental illness (Veltro, Magliano, Lobraccio, & Morosini, 1994).

The impact on families living with obsessive-compulsive disorder (OCD), of the spectrum of anxiety disorders, has received the greatest research attention. A review of family burden in OCD noted the consensus (although most evidence is anecdotal, observational, or correlational) for a coexisting high degree of family dysfunction, particularly relating to conflict, distress, and marital discord (Steketee, 1997). When studies have compared families with an OCD member to matched controls, key differences have emerged. Black, Gaffney, Schlosser, and Gabel (1998a) reported increased disruption to family, social and personal life, anger, conflict, fatigue, and marital discord in the OCD group, whilst Derisley *et al.* (2005) found parents with an OCD child had poorer mental health and used more avoidant coping strategies. Surveys report a common perception of negative impact on family life, where OCD is a feature, both by the individual with OCD (Hollander *et al.*, 1996) and the wider family, including parents, partners, children, and siblings (Cooper, 1996). The main problems described by carers are the negative effects on marital relationships and home management issues (Laidlaw, Falloon, Barnfather, & Coverdale, 1999). A key finding in the OCD family literature is the concept of 'accommodation' of OCD symptoms (Cooper, 1993), whereby family members feel forced to collude with compulsive rituals. Calvocoressi *et al.* (1995) reported some degree of family 'accommodation' in 30 of 34 caregiving relatives, noting that threats of violence ensured 'accommodation' in some families.

Hoarding is one of a range of symptoms of OCD, found in 20–31% of sufferers (Frost & Hartl, 1996; Leckman *et al.*, 1997; Samuels *et al.*, 2002) and compulsive hoarding can exist in its own right (Frost & Gross, 1993). Although hoarding behaviour has most often been associated in the literature with OCD, exclusive links have been recently contended. Research findings cite co-occurrence with other psychiatric and physical disorders, albeit with inconsistencies in reliable associations across studies (Steketee & Frost, 2003). Wu and Watson (2004), for instance, propose that hoarding be considered among disorders sharing certain features of obsessionality, not OCD *per se*, finding no higher prevalence of hoarding symptoms in OCD patients than in out-patient and student controls.

Maier (2004), in a review of the phenomenology and classification of hoarding, also notes the clinical heterogeneity of the behaviour. Studies suggest an association between hoarding and a range of disorders, in addition to its attribution as a possible symptom of OCD. These have included schizophrenia and other psychiatric disorders (Luchins, Goldman, Lieb, & Hanrahan, 1992; Lysaker *et al.*, 2000), eating disorder (Frankenburg, 1984), brain injury (Eslinger & Damasio, 1985), autism (Greenberg, Witzum, & Levy, 1990), and dementia (Hwang, Tsai, Yang, Liu, & Lirng, 1998). In populations of older adults, hoarding has been found to pose a significant threat to self-care and engagement with services (Steketee, Frost, & Kim, 2001) and appears particularly closely associated with severe self-neglect (Lauder, Anderson, & Barclay, 2005).

Compulsive hoarding is defined as 'the acquisition of and failure to discard possessions that appear to be useless or are of limited value. Living spaces are sufficiently cluttered so as to preclude the activities for which those spaces were designed and significant distress is caused by the hoarding' (Frost & Hartl, 1996, p. 341). Decisions to dispose of objects appear to be fraught with anxiety, resulting in the development of avoidance behaviours to preserve possessions (Kyrios, Steketee, Frost, & Oh, 2002), whilst living spaces become overwhelmed by accumulated clutter.

Rooms may be piled to the ceiling with apparently useless possessions and traversed using narrow pathways, or may never be entered due to the sheer volume of clutter (Frost & Hartl, 1996). Crucially, compulsive hoarding is an environmental issue (Kellett, *in press*) compared to the purely behavioural or mental rituals of other compulsions. Additional risks to safety and hygiene can occur, as homes become increasingly uninhabitable and fall into disrepair (Thomas, 1997).

Hoarders demonstrate a lack of insight into their problems (Frost, Steketee, & Williams, 2000; Greenberg, 1987), view hoarding in an ego-syntonic manner, and appear to lack anxieties relating to the behaviour, compared to sufferers of other compulsions (Black *et al.*, 1998b). Considerable dysfunction can result from the gross disorganization (Steketee & Frost, 2003) attracting complaints to public health departments of unsanitary conditions and hazards to community health (Frost *et al.*, 2000). Such factors, associated with hoarding, necessarily raise questions of impact on the carers and the wider family system. No research currently exists investigating carers' perspectives in compulsive hoarding and the difficulties they may face in their role. This study reports an analysis of interviews with 10 individuals who care for a family member who compulsively hoards.

Method

Participants

A purposive sample of 10 participants (four males and six females) contributed to the study. Participants' ages ranged from 37 to 71 years (mean 56 years). One daughter cared for her mother, one brother for his retired sister, two mothers for their offspring (both dependent adults), and six individuals for their partner. Duration of the caring role ranged from 3 to 35 years. Currently 7 of 10 participants shared their home with the hoarder, two had recently moved out whilst retaining the caring role, and one had always cared 'from a distance'.

Recruitment

Participants were a self-selected sample recruited through 'OCD Action', a UK charity providing information, advice and support to sufferers of OCD and their families. Participants identified themselves as a partner or family member, acting as key carer for a person who compulsively hoards. 'Key carer' describes the family member most involved in the everyday care of the symptomatic relative (Falloon, Graham-Hole, & Woodroffe, 1993).

All participants emphasized caring as an integral aspect of their role in the family. Care provided was in relation to a range of activities of daily living otherwise neglected by the hoarder: managing personal and family finances; encouraging discard of clutter; overseeing self-care (personal hygiene, physical safety, adequate diet); and help with (or assumption of full responsibility for) contact with services in the outside world (such as appointments with GP).

Without exception, homes were cluttered to the extent that it was difficult to navigate rooms and make space to conduct interviews, closely resembling Frost and Hartl's (1996) descriptions of chronicity. Hoarded items, in loose piles and contained in boxes, bin bags, and carrier bags, occupied furniture and floor space to waist and (in some instances) chest height. The clutter made it impossible to gain unimpeded entry and use these rooms for their intended purpose. Cleaning and maintaining rooms was

reported to be impossible, leading to problems with hygiene and disrepair, creating the potential for living spaces to become hazardous to health.

Hoarding family members had not tended to have received a clinical diagnosis of compulsive hoarding or OCD. Participants were therefore included in the study on the basis of their descriptions (and investigators observations) of the severity and environmental impact of the hoarder's behaviour.

Data collection

The principal investigator conducted and audiotaped 10 previously piloted semi-structured interviews, each limited to 1 hour. The taped interviews were transcribed verbatim. Nine participants were interviewed in the family home and one at the first author's NHS base. The researchers had no contact with the hoarding family members who were not present at the interview. Participants were asked to comment on their relationship with the hoarding family member and perceptions of the hoarding behaviour. Designed to facilitate a free exchange in discussion, guided by the narrative of the participant, questions were only used as prompts. The purpose of the interview, as explained to participants, was to discuss their experience of living with hoarding in the context of family life. Interviews followed the interests, concerns, views and experiences of each participant.

Interview schedule:

- Can you tell me about (hoarder's name) and what they do?
- Can you describe to me what its like living with (name)?
- What have you noticed about their hoarding? For example, what kinds of items?
- Can you tell me about your relationship with (name)?
- Have you and/or (name) had any contact with services or voluntary groups?

There was no offer of services to participants (or hoarding family members) following interview, although time was taken to discuss participants' concerns and referral pathways to local services wherever necessary.

Analysis

Interpretative phenomenological analysis (IPA; Smith, 1996) was chosen as the most appropriate research method for this study. An ideographic approach to analysis, IPA is concerned with the exploration of unique individual experiences, rather than seeking to make general or universal statements. IPA allows the researcher to interpret (using their own conceptions) to make sense of the participant's personal world (Smith, Jarman, & Osborn, 1999). An investigation of 'lived experience' was designed to add meaning to the current understandings of compulsive hoarding (Stiles, 2003). The recommendations of Smith and Osborn (2003), for conducting research using an IPA framework, helped to guide the process of analysis.

Each interview transcript was initially engaged with separately (in a process of reading and rereading) noting observations, interpreting the narrative, and looking for themes which were grouped as they emerged. Connections between themes were then identified, allowing the combination of previously separate categories into overarching superordinate themes. A masterlist of themes was created for each interview and combined with themes of subsequent interviews as the analysis progressed.

In a circular process, newly emerging themes were tested against earlier transcripts to inform, modify, or become subordinate or superordinate (determined by degree of replication across participants) to previously elicited themes. Outliers, viewed as aiding overall understanding, were also identified and reported while other subordinate themes were discarded in the process of analysis.

Validation methods

As IPA relies on the researcher's interpretation of data, it was important to ensure that such interpretations were as trustworthy as possible. Standards for the conduct of good qualitative research, including considerations of validation (e.g. Stiles, 2003; Turpin *et al.*, 1997), were adhered to in this study. Validation methods included: the completion of a research diary to create an audit trail (ensuring transparency of process) moving from data collection to final interpretations; supervision to provide an ongoing critique of the work and confirm adequate inter-rater reliability of emergent themes; participant theme validation (testimonial validity) via feedback prior to write up on themes emergent from individual interviews and the masterlist; triangulation of evidence (raw data, supervision and observation); and the identification and inclusion of negative cases and outliers.

Results

Five superordinate, discrete but interconnecting themes emerged from the data: (i) loss of 'normal' family life: living space and social life; (ii) the need for understanding: searching for a meaningful explanation and needing to feel understood; (iii) coping with the situation: strategies and secrecy, weight of responsibility and distress. Outlying theme: support and role division; (iv) impact on relationships: anger, frustration and conflict. Outlying theme: protective positive qualities; and (v) marginalization: social, emotional, and physical. Figure 1 provides a visual representation of the connections between themes and outliers. The relationship of participant to the hoarding family member is provided for each interview extract.

The seminal definition of compulsive hoarding by Frost and Hartl (1996) specifies that clinical significance is achieved when clutter renders living spaces unusable for their intended function. It is unsurprising, therefore, that participants described the scale and scope of clutter and its impact on everyday life. All manner of items were reportedly hoarded, including: furniture and electrical items (often broken beyond repair); clothing, reading material, and paper of all sorts; bags and wrappers; food; household refuse; and body waste. Clutter was stored in apparently arbitrary stacks and mounds of varying depth, throughout rooms, whole properties and occasionally extending into outbuildings and gardens.

Loss of 'normal' family life

All participants described the extent and scale of clutter, in addition to the range of items hoarded by the individual. It is useful, therefore, as a starting-point in understanding the impact on family life, to report participants' descriptions of the chronicity of the hoarding and the associated impact on 'normality':

Several of the rooms are now completely inaccessible with unwanted furniture, erm, all sorts of things . . . chaotic heaps, lot of papers, just even wrappings, you know, cellophane off clothing and carrier bags, brochures, programmes . . . We've quite a big landing upstairs

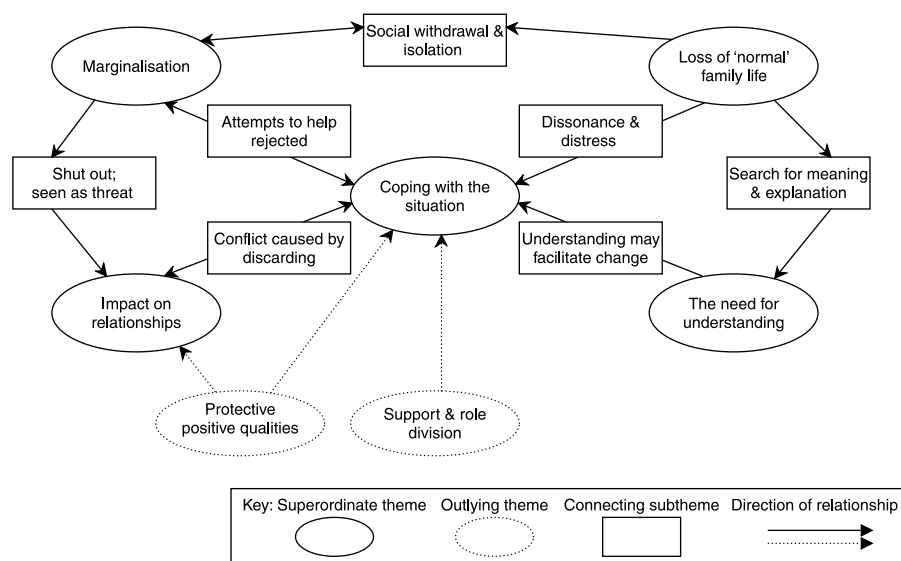


Figure 1. Illustration of connections between superordinate themes and outliers.

which is completely obstructed, just a narrow pathway round from the stairs to our bedroom (Wife).

This extract is typical of descriptions used early in interviews to contextualize the difficulties faced by carers. Geographical metaphors (such as ‘avalanches’, ‘landslides’ and ‘mountains’ of clutter) were commonly used to convey the scale of the problem. Accounts suggested considerable dissonance between the reality of living with hoarding and the desire to live as a ‘normal’ family. Comparisons (between past and present and between self and others) were used to highlight the losses experienced by the whole family. Discussing the development of the problem, the following extract introduces these issues:

There was nowhere we could sit, you had to eat standing up in the kitchen, erm, or my son, in his bedroom. I used to be so determined that I wouldn’t give up some sort of values, you know, I wouldn’t give up altogether but my daughter and now my son-in-law used to come and sit in (our son’s) room and eat on trays . . . Christmas has always been a nightmare here. When the children were small I used to make it, have . . . decorations and love, you know, everything was really nice. But as more and more of the space got used up you couldn’t do anything. So (our son) would have a little Christmas tree in his bedroom, but he had such a small bedroom that there wasn’t much room for anything in there either (Wife).

This extract was taken to illustrate the relationship between the spread of clutter in the family home and departure from norms and values. This departure contributed, in part, to the distress experienced by participants described in ‘coping with the situation’. In addition to precluding the necessary servicing of utilities and repairs to properties, the volume of clutter in living spaces and the associated embarrassment felt by participants prevented many from seeking out new friends or inviting anyone to visit:

I avoid any kind of closeness. I rarely accept offers to go and visit them because I might have to reciprocate – I haven’t got any close friends in the area . . . it’s almost unconscious but there’s definitely that distancing . . . I don’t follow up friendships and let them really develop because I know I can’t keep up my end of it by inviting them here . . . we’ve

become very withdrawn, introvert . . . and there's very little impact from outside . . . we've defended it, kept it out (Husband).

The need for understanding

In the context of disruption to family and social functioning, 'the need for understanding' describes participants' search for a meaningful explanation of hoarding behaviour. Participants appeared to have spent considerable time trying to formulate their family member's behaviour. Hoarding as a compensation strategy for physical impoverishment, loss and trauma in earlier life were all examples of speculation regarding precipitative factors:

R: Why do you think (partner) hoards?

P: Because its . . . er . . . a way of escaping, isn't it? Erm . . . do you know her medical history?

R: I don't.

P: Oh, right. Erm . . . she was raped when she was little like, you know what I mean? She was a little girl, so I suppose this is an offset of it? I don't know, I don't know why it causes people to . . . erm . . . have OCD like, I don't know (Partner)

Participants believed that with some understanding of the reasons why, a degree of control over the spread of clutter might be achieved:

I don't know, I guess if I figured out what it really was with (him) . . . I feel that it's a lack of something that he's making up for. If I could work out what the lack, in the past . . . it's too late now. If I could have worked out what the lack was, you know, life might have been different (Partner).

However, having sought information and reflected on possible explanations, most participants felt defeated in their attempts to achieve an understanding that might facilitate change. Participants recognized hoarders' lack of insight and saw this as a barrier to achieving change, irrespective of their gaining an adequate understanding:

He can't see the illogicality of keeping so much, that life becomes a misery for all of us (Wife).

The illness makes you think that you want to be like that, that's the illness, and so you don't challenge your own assumptions, you challenge the rest of the world (Partner).

'The need for understanding' also encapsulates carers' need to have their situation understood by others. Participants reported encountering little sympathy from service providers. From the participants' perspective, priorities for service provision should be recognition, support and collaboration with those providing the individual's day-to-day care:

I think that this thing of saying 'unless the person wants it' isn't the right approach at all. The carer is the feedback to the practitioner of actually what is happening. The reality check is the carer (Daughter).

I was desperate for something . . . people with experience to guide, you know . . . what's available, what not to fear, what's what. Because definitely at the moment I am in such a pit of complete feeling, you know, hopeless . . . there's just nothing there to even connect to. Recently, finally I got to tell the GP what was going on . . . I was pretty much fobbed off. I went to ask, could she please, you know, what support could she offer, but sectioning was the only solution she had. I rang up (social services) but was afraid to give my mother's name because of this fear that they'll come and section her (Daughter).

Coping with the situation

In the absence of adequate external support, 'coping with the situation' emerged as the central theme. Participants described searching for strategies that might stop or stem the flow of clutter into the home, such as negotiating, modelling behaviour and using recycling as a rationale for discarding. Such strategies were typically met with opposition and provided incomplete and limited lasting change. Many expressed a view that tackling the problem in this way felt overwhelming:

It feels like emptying a leaking boat with a teaspoon (Wife).

I feel like Gulliver, with all those little ropes holding him down . . . and they stop us moving forward (Husband).

Resignation and feelings of disempowerment, in the face of the continued spread of clutter, caused some to avoid raising the issue of discarding, whilst others coped by denial. The following extract is illustrative of this, perhaps necessary, mechanism of participants' ability to live within such clutter:

I know it was all there . . . but I didn't actually look at it. Erm, it sounds a very strange thing to say but if I'd allowed myself to actually acknowledge how appalling it was, I wouldn't have survived it . . . I'd do things like have flowers on the kitchen windowsill, even though there was hundreds and thousands of things on the kitchen windowsill . . . I could look at the flowers (Wife).

Where all attempts to implement strategies to cope with the situation proved unsuccessful, secret discarding of clutter represented the strategy of last resort:

I don't put things in the dustbin . . . he doesn't put things in the dustbin so he notices if I do and he's quite likely to go ferreting through, wondering what I've thrown away. So I keep dustbin sacks in strategic places in the house and when they get full, I put them in the car when he's not looking and I take them straight to the tip (Wife).

The 'key carer' was also frequently the *sole* source of care and support for the hoarding family member. Non-availability of information and support from services and withdrawal (through fear or shame) from other potential networks of support, left participants with a strong sense of entrapment in the caring role:

I know, quite clearly that she can't turn to anybody else (Brother).

One of the things that I think carers desperately need is respite . . . I've just no escape, and I think that's how a lot of carers feel (Mother).

Most did not perceive their sole caring role as entirely one of choice. Comments such as '*. . . it's life, shut up, get on with it*' contrasted with the expressed need for space and support, suggesting a stoic resignation to 'duty'. Carers' financial loss (through inability to work), social loss (through isolation), and psychological distress (such as anxiety, depression, and 'breakdown') were reported. Loss of positive self-regard and agency contributed to the distress described by those struggling to cope:

I mean I just, I, I feel ashamed of myself, I suppose really, for, for living in a place like this (Partner).

I was very well respected when I worked for (local authority). My credibility just went out the window and I became very nervous. Even though I'm a forthright person. I remember when I was trying to explain to this very confrontational teacher and she was awful, she was awful. I wanted to just slither down the door crying (Mother).

'Distress' is a subordinate theme which can be related to all five superordinate themes. It is included here, however, being most strongly linked by participants with a perceived inability to manage the situation faced by the family. The metaphor used below, of clutter as despair, highlights distress in relation to helplessness regarding the pervasive environmental impact of the hoarding:

I just got sucked into despair, in the house, the house was full of despair and you'd come in and you were sucked into the despair because, I mean you couldn't sort of, erm, override it and just get on with everyday things that you had to do. It was where we slept, it was where we ate . . . (Daughter).

Support and role division

Narratives of coping and containment of the hoarding behaviour were few but formed an outlying theme. It is interesting to note that both outlying themes were most evident in interviews with those family members who did not share their home with the hoarder. Where participants discussed adaptive coping, this was in the context of availability of external networks of support, such as an 'understanding' GP or helpful voluntary organization. Collaborative problem solving and the availability of a range of complementary skills (among a close and trusted group) spread the weight of responsibility and reportedly served to reduce anxiety regarding the future. The ability to access informal networks of support was central to one carer's narrative of adaptive coping:

They've got skills that will enable support to be maintained . . . and I think R is a key player in that. But that's why she's a trustee of the house. R's got the financial acumen that I haven't got (Brother).

Impact on relationships

'Impact on relationships' captures the anger and frustration, conflict, and (in some cases) subsequent breakdown of family relationships. The inexorable flow of clutter into the home and the carers' (and wider family's) inability to live a 'normal' life amongst it resulted in frequent feelings of anger and frustration. Such emotions often stood in stark contrast with the love expressed for the individual as a partner or relation:

I felt that desperate. I've hated my son, hated him, despised him. You know, you sort of, you've got this dual feeling of intense love and this intense hate . . . because he was very aggressive, and also would say the nastiest of things (Mother).

Described by one carer as '*an insane way to live*', the hoarder's behaviour was viewed as damaging to family relationships, representing a singular disregard for the needs of other family members:

Any sort of compulsive illness probably destroys relationships because it's a very selfish thing. I've held on to mine and I hope it can change back, you know, I hope there's some redemption . . . because I don't believe that he's a selfish man really. But the hoarding is very selfish, very. It takes from everybody . . . but I don't know that he can face that . . . and I don't really think now that he's got a relationship with his children either, at all . . . certainly not with our son (Wife).

Participants often carefully used language to distinguish the behaviour from the individual. One mother described '*calling OCD a name . . . to have a go at the thing*,

rather than the person', experiencing intense negative emotions but recognizing the futility and potential for harm to the relationship of blame. Conflicts most often arose in relation to the issue of discarding items, whether using collaborative strategies (described in 'coping with the situation') or taking unilateral action:

P: I threw a couple away the other day and he got very, very angry when he discovered that I'd done it. Fortunately I hadn't thrown them right away, they were still in the house . . . he became very, very angry, and, erm, was actually quite violent.

R: Is that a common occurrence?

P: It's not a common occurrence for him to become physically violent, but there's a fair amount of verbal violence (Wife)

Conflict concerning the clutter, leading to some degree of breakdown in family relationships, was a common subordinate theme. In those cases where relationships had broken down, participants attributed the breakdown to hoarding behaviour:

It got to the point where you were actually climbing into the house as opposed to walking through the door. Erm, and then I had to keep my word at Christmas, and that's where unfortunately I did move out (Daughter).

Protective positive qualities

This outlying theme (with connections to 'impact on relationships' and 'coping with the situation') describes factors protective of relationships. In contrast to the narratives of negative impact, two participants notably balanced their descriptions with positive qualities in the hoarding individual. The following are extracts taken from those interviews where a theme of positive qualities was emphasized. The excluded daughter of her mother:

There's a tremendous depth there which sometimes . . . a lot of counselling and wisdom that, when we talk, sometimes it comes out (Daughter)

and another participant of his partner:

I think we're very strong as a couple. I think we need to be . . . if we hadn't been we would have split a long time ago (Husband).

The ability to externalize blame (locating it in behaviour, not personality) was highlighted as an important protective factor in some carer/hoarder relationships:

I would much rather live with the stuff and (my wife) than cause aggro and upset her, you know. There's a lot more to her than the hoarding (Husband).

Externalization allowed some carers to cement or preserve the relationship by acknowledging its positive qualities, conveying a conviction that the label 'hoarder' did not adequately describe the individual.

Marginalization

'Marginalization', as an overarching theme, emerged out of participants' discussion of withdrawal from social life and the distancing, developed over time, in their relationship with the hoarder. The interpretations underpinning this theme were also made using participants' descriptions of emotional distance (created by the hoarder to defend against carers' efforts to manage the clutter) and the experience of being forced into occupying an increasingly smaller portion of their home.

Families became marginalized socially as friends and neighbours failed to understand the hoarding, feared the behaviour of hoarder, or were unable to tolerate it in their lives. Social relationships with neighbours deteriorated as houses fell into disrepair (access by tradesmen being impossible) or when clutter spread into gardens. Others were marginalized as a result of stigma and prejudice:

When he got to school and his OCD kicked in, you know, we were isolated. Off you go to a birthday party, er, when he was six and he'd have to bring every paper cup, the table cloths, everything. And all the packing from the presents, he'd have to bring it home. Now you try and explain that to a parent (Mother).

The sibling of this child was teased by peers at school about his brother's behaviour:

I mean like my youngest son said . . . 'mummy, they call us the Addams Family'. They just thought we were totally barmy (Mother).

Participants also noted how they felt emotionally '*squeezed out*' of the relationship:

The house being barricaded up is almost symbolic of how . . . you know, we are together (Daughter).

Hoarding family members were reported to be mistrustful of carers' intentions to help. This proved particularly problematic for the relationships of those living separately from the hoarder. These carers were often more easily excluded from the property and the 'threat' of their help thereby neutralized:

She turned on me and said, I don't want you in here, this is my house and everything is mine, and you're to go. And so I had to leave the house. I think she thought I meant . . . can I have some of this? (Brother).

Where carer and hoarder lived together, *physical* marginalization was due to the expansion of clutter and consequent reduction in living space:

There was so much stuff in our bedroom at one point that we were sleeping on two thirds of the bed (Wife).

Whilst this extract provides a description of how clutter physically presses in around the couple, it is also a reflexive discussion of the marginalizing effect of hoarding behaviour on the marital relationship. Feelings of marginalization motivated participants and other family members to attempt to demarcate an area to be preserved clutter free, an additional reference to maintaining values:

We used to have a table we put up in here, a folding table . . . for years I kept that up . . . as long as I possibly could. Especially Sunday dinner, we would sit down together and eat . . . I was determined to keep some sort of semblance of normality, what I thought was normality (Wife).

For some, the sanctuary of a small demarcated area allowed escape from the distress surrounding the hoarding behaviour. Speaking of her son:

. . . his room was like a cocoon . . . that was his protection (Wife).

Conclusions

This study presents a detailed exploration of 10 participants' experiences of caring for a hoarding family member. Although the aim was not to test previously hypothesized associations between family dysfunction and compulsive behaviour, such as those

proposed by Black *et al.* (1998a, 1998b) and Steketee (1997), it was anticipated that hoarding behaviour would predict some disruption to family relationships and functioning.

Disruption was indeed evident across interviews, extending from family and social relationships to the basic day-to-day activities of family life, such as moving through the house, cleaning, cooking and sleeping. Family functioning became incrementally compromised, as clutter increased and spread over time. The wide range of emergent themes reflects the multifaceted nature of participants' experiences, whilst combining to present a picture of families struggling to understand and cope (often in isolation) with the effects of hoarding behaviour. Presenting a systemic problem, hoarding not only impacts the carer/hoarder relationship but also the wider family and community. In the context of family life, as has been suggested by previous outcome research (Steketee, Frost, Wincke, Greene, & Douglass, 2000), carers reported substantial discord.

The concept of 'accommodation', developed to describe OCD families' reluctant participation in the rituals of OCD (Calvocoressi *et al.*, 1995; Calvocoressi *et al.*, 1999), seems particularly relevant to carers' experiences of hoarding. In OCD, accommodation involves (for example) submitting to decontamination rituals, assisting with checking or providing constant reassurance (Calvocoressi *et al.*, 1995). This was also relevant to the present group of carers, who reported walking '*on eggshells*' around the home, in fear of disturbing clutter with the resultant conflict and distress. For these carers and their families, however, accommodation extended beyond 'tolerating' the continued acquisition of clutter, to *physically* accommodating the clutter in their homes. The current study therefore extends the theme of accommodation in the context of hoarding to that of a psychological *and* an environmental concept. Comparisons drawn in interviews, between past and present, self and other, served to highlight the incongruity of this 'dual accommodation' with a strong desire to maintain norms and values.

Carers' stated need to develop an understanding of hoarding behaviour was linked closely in the narrative with perceptions of coping. Without such an understanding this group expressed little sense of agency or hope of effecting meaningful change. However, for hoarding (Maier, 2004) as for other presentations of severe self-neglect in the community (Lauder *et al.*, 2005), a lack of definitive diagnosis means there are no clear pathways for resources, interventions or social care. Feeling unheard and misunderstood by services reportedly compounded carers' alienation from potential sources of support and served to increase their isolation.

The co-morbid presence of hoarding in autism (Greenberg *et al.*, 1990), dementia (Hwang *et al.*, 1998), schizophrenia (Luchins *et al.*, 1992), eating disorder (Fankenburg, 1984), and brain injury (Eslinger & Damasio, 1985) may go some way towards helping families, for whom these difficulties coexist, to contextualize and understand the hoarding behaviour. In the absence of obvious co-morbidity, however, there is a risk that families living with hoarding may attribute blame to themselves for having 'allowed' the behaviour to develop and continue unabated and unchecked. In the current study, similar perceptions led many participants to express what were interpreted as feelings of hopelessness, loss of agency and entrapment in the caring role, with consequent potential for a negative impact on psychological well-being.

As a qualitative study employing a small sample, this research has several methodological limitations. IPA makes assumptions about the participant's ability to articulate thoughts, feelings and perceptions of a given phenomenon (Smith, 1996). It may be argued that conveying such abstract and subjective concepts is fraught with problems, particularly for a group having had little previous opportunity to discuss their experiences. However, participants in this investigation used many means to communicate complex

internal processes, including emotive language, metaphor and non-verbal communication (showing photographs). The value of such strategies to assist communication is widely accepted. In therapeutic relationships, where the therapist similarly seeks to understand the individual's internal world, metaphor has been seen as analogous (or even fundamental) to the analytic concept of transference (Legowski & Brownlee, 2001). A further assumption of qualitative methodologies relates to the researcher's ability to make valid interpretations of the data. IPA recognizes that, alongside considerations of validation, analysis depends on and is achieved through the researcher's own conceptual framework.

An isolated opportunity to recruit a group of participants, homogenous in their experience of caring for a hoarding family member, led to the employment of purposive sampling. It may be that those agreeing to take part were motivated by greater levels of psychological distress or experienced more difficulties managing hoarding behaviour than other potential participants. Similarly, such sampling may have unintentionally excluded carers with heightened levels of shame. Interviewing carers at home, in the context of the hoarding behaviour, may additionally have contributed to distress saturated narratives. The environmental presence of clutter and 'intrusion' of the researcher, whilst informative for the purposes of analysis, may have served to heighten participants' anxiety or feelings of embarrassment. Future work regarding carer perspectives should consider the relative benefits of neutrally located interviews.

Notwithstanding these potential limitations, participants were very clear in expressing their distress and the need for information and support in the caring role. The need for psychoeducation, recommended by Cooper (1993) for family members, to reduce (in this instance) the conflict surrounding attempts to resist hoarding behaviour, is clear. The reported lack of professional awareness of hoarding behaviour presented a barrier to carers' access of services, highlighting a need for education within services. Lack of theoretical awareness, however, should not preclude services from relating and responding to the real lived experience and needs of clients (Lauder *et al.*, 2005). Service providers, particularly those involved in community work (such as community mental health teams), require better training and support in order to help families cope with the conflicts, pressures and dilemmas of caring for hoarding individuals. A better understanding of compulsive hoarding is additionally required, in order to support carers in implementing clutter management strategies and crucially, effective self-care in the caring role.

Compulsive hoarding in the family context remains under-researched, although current understandings are beginning to identify factors predicting additional vulnerabilities for families. In terms of future research, exploration of the concept of 'dual accommodation' in families living with hoarding appears both clinically and theoretically indicated, in order to better understand these co-dependent relationships. Perhaps the next step, following the findings of this study, should be a closer investigation of the factors influencing psychological adjustment and adaptive coping in family members living with compulsive hoarding. A shift from a model of 'stress response' to one of 'health behaviour' may additionally empower family members towards coping and adjustment in the caring role.

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