

Compulsive Hoarding – a study of the experiences of family members caring for people who hoard compulsively.

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Families often perform vital roles in supporting members with mental health problems. Carers' needs have become a focus of concern as there are potential 'risks' to well-being. Evidence is most developed in relation to schizophrenia, but anxiety disorders, OCD etc. also feature.

Hoarding occurs in up to a third of OCD sufferers, but it can also exist in its own right, or in conjunction with other psychiatric (e.g. eating disorders, brain injury, autism, and dementia,) and physical disorders. Particularly in older adults, it can be linked with problems of self-care (sometimes severe self-neglect). Sufferers are often reluctant to engage with services.

People who hoard can become extremely anxious about disposing of objects and therefore find ways of avoiding doing so. On the other hand, they often display a lack of insight into their problems. Living spaces can be overwhelmed with possessions piled high to the ceiling, so that they can only be crossed via narrow pathways, or not at all, which can cause risks to safety and hygiene as homes become increasingly uninhabitable and fall into disrepair. Cleaning and maintenance can be impossible. Complaints to public health departments are often made about unsanitary conditions and hazards to community health. This must raise questions about the impact on carers and the wider family system.

Recruitment and methods. 10 'key' carers, (i.e. family members most involved in the everyday care of the person in question,) siblings, partners, parents and children, ranging in age from 37 – 71 years, contributed to the study. 4 were male, 6 female, 7 shared a home with the hoarder, 3 did not. The duration of the caring role ranged from 3 – 35 years. Participants were self-selected. Care of the hoarder was provided in relation to managing personal and family finances, encouraging discarding of clutter, overseeing self care (e.g. personal hygiene, physical safety and adequate diet) and helping with (or taking full responsibility for) making contact with services in the outside world.

Items hoarded included furniture and electrical items (often broken beyond repair), clothing, reading material, paper of all sorts, bags and wrappers, food, household refuse and body waste. They were stored in loose piles, boxes, bin bags, carrier bags, occupied furniture and floor space to waist or even chest height throughout rooms, whole properties and occasionally extending into outbuildings and gardens.

Data collection. Participants were interviewed, and the results analysed afterwards. The questions asked were: -

- Can you tell about.....and what they do?
- Can you describe to me what it is like living with.....?
- What have you noticed about their hoarding?
- Can you tell me about your relationship with
- Have you and/or.....had any contact with services or voluntary groups?

Results. Five themes emerged: -

1. Loss of 'normal' family life:

a. living space and social life.

Words such as 'avalanches', 'landslides' and 'mountains' were used to convey the scale of the problem.

Clutter precludes the necessary servicing of utilities and repairs to properties and the associated embarrassment felt by participants prevented many from seeking out new friends or inviting anyone to visit.

2. The need for understanding; searching for a meaningful explanation and needing to feel understood.

Participants appeared to have spent considerable time trying to understand their family member's behaviour (possibly a compensation strategy for physical poverty, loss and trauma in early life). They believed that such understanding might give them a degree of control over the spread of clutter, but many felt defeated. They recognised the hoarder's lack of insight and saw this as a barrier to achieving change. Participants reported encountering little sympathy from service providers and regarded priorities as recognition, support and collaboration.

3. Coping with the situation:

a. strategies and secrecy,

b. weight of responsibility

c. distress

d. (support and role division)

Participants described searching for ways of stopping clutter coming into the home e.g. negotiating, modelling behaviour and using recycling as a rationale for discarding, but these were typically met with opposition and provided incomplete and limited lasting change. This felt overwhelming and disempowering and either caused avoidance of raising the issue of discarding, or denial. When all other strategies failed, the last resort was secret discarding.

Non-availability of information and support from services and withdrawal (through fear or shame) from potential networks of support, left participants with a strong sense of entrapment in the caring role and a stoic resignation to 'duty.' Carers also reported financial loss (through inability to work), psychological distress (anxiety, depression and 'breakdown'), and loss of positive self-regard.

In a minority of cases, collaborative problem-solving (with a close and trusted person or group) spread the weight of responsibility, thus serving to reduce anxiety regarding the future.

4. Impact on relationships:

a. anger,

b. frustration

c. conflict

d. (protective positive qualities).

Feelings of anger and frustration stand in stark contrast with the love expressed for the individual as a partner or relation, despite the hoarder's disregard for the needs of other family members. Participants sometimes attributed breakdowns in relationships to hoarding behaviour.

The ability to externalise blame was highlighted as an important factor in protecting some relationships.

5. Marginalisation:

a. social,

b. emotional

c. physical

This included withdrawal from social life, a distancing in the relationship with the hoarder (defending against carer's efforts to manage the clutter), and the experience of being forced into occupying an increasingly smaller portion of the home.

Families became socially marginalised, as friends and neighbours failed to understand the hoarding, or were unable to tolerate it in their lives. Relationships deteriorated as houses fell into disrepair or clutter spread into gardens. Others were the subjects of stigma or prejudice. The sibling of one child was teased by peers about his brother's behaviour. Carers living separately from hoarders were often excluded from the property, thus 'neutralising' the threat perceived by the hoarder to their possessions. Some family members attempted to demarcate an area to be preserved clutter-free.

Conclusions. Carers struggle to cope (often in isolation) with the environmental impact of hoarding and its effects on relationships and functioning. They need networks of support, information and treatment options for themselves and their families. Research undertaken in connection with Obsessive Compulsive Disorder (OCD) would indicate that it can result in disruption to individual and wider family life, problems with home management, anger, conflict, fatigue and marital discord. Family members often feel it necessary to collude with compulsive rituals because of fear of violence.

A lack of definitive diagnosis means that there are no clear pathways for resources, interventions or social care. Feeling unheard and misunderstood by services reportedly compounded carers' alienation from potential source of support, and served to increase their isolation. Co-morbidity (where it exists) with autism, schizophrenia, eating disorder and brain injury might help families to understand the hoarding behaviour, but in their absence there is a risk that they might attribute blame to themselves for having 'allowed' the behaviour to develop and continue.

The reported lack of professional awareness presented a barrier to carers' access of services, highlighting the need for education. Those involved in community work require better training and support in order to help families cope with the conflicts, pressures and dilemmas, clutter management strategies, and with self-care in the caring role.

Future research should explore the concept of 'dual accommodation' in order to understand these co-dependent relationships better. A closer investigation of factors influencing psychological adjustment and adaptive coping in family members living with compulsive hoarding is also suggested.