A qualitative exploration into opportunities for earlier therapeutic intervention in hoarding disorder

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Abstract

Hoarding disorder is characterised as excessive acquisition of possessions and difficulties disposing of items resulting in excessive clutter. Hoarding can be stigmatising, causing the person with hoarding behaviours significant distress and can put a strain on family relationships, finances and physical and mental health.

As the treatments for hoarding are low in efficacy it makes them slow and expensive. This study qualitatively explores the possibilities for earlier interventions by interviewing six participants with significant hoarding behaviours. They were asked to talk about triggering events, as well as awareness of the hoarding and the time taken to seek help and support.

Many of the participants had childhood trauma events. All had multiple losses over a 10-year period that were concurrent with or preceded the hoarding escalation. They generally took up to two years to seek help after they realised that they had a hoarding problem and that help might be available for it.

The main barriers to help-seeking were shame, fear of judgement, lack of services and lack of funds. They had all previously accessed help for other mental health issues such as anxiety and depression but the therapies for these had little effect on their hoarding behaviours.

All participants had events in their childhood that may have caused a shame reaction and the beginnings of a shame spiral. This sensitivity to shame may be a contributing factor to resistance to help, and denial of problem, at early stages of hoarding.

Any opportunities for earlier interventions would have been dependant on the participants own awareness of their hoarding problem and willingness to accept help if offered. They all came to seek help later on their own accord but found coherent and continual services for hoarding support was lacking.

Earlier interventions might be including questions about hoarding behaviours within assessments for depression and anxiety. It might also include better training for counselling for bereavement and depression, especially around the links to shame and abandonment.

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Introduction

According to the DSM-5-TR, hoarding disorder is characterised by a persistent difficulty and distress in discarding possessions regardless of their actual value. Along with excessive accumulation of possessions which causes clutter to impede the intended use of a living area. The excessive accumulation combined with discarding distress can cause both social and functional impairment. Although hoarding has often been seen as a sub-type of obsessive-compulsive disorder (OCD), it is now seen as a separate, anxiety-based disorder (American Psychiatric Association, 2022). It has also been strongly linked to other anxiety disorders, chronic depressive disorders and attention deficit hyperactivity disorder (ADHD) (Steketee and Frost, 2014). Typically, people with hoarding disorder are more disabled than other people, and are at greater risk of fire, falling and poor sanitation (Hooley, Nock, and Butcher, 2021). The research on hoarding disorder has mostly taken place in the last 30 years despite it being a condition which has been mentioned in literature for centuries so it is not a new phenomenon (Chasson and Siev, 2019). It is estimated that the occurrence of hoarding behaviours in the general population is between 1-5% (Timpano *et al*, 2011; Nordsletten *et al*, 2013). Talking therapies alone have had relatively low efficacy compared to treatments of other disorders, however the combination of cognitive behavioural therapy (CBT) and on-site declutter coaching has been found to be most effective. This therapy method tends to last around 6-12 months so the treatment can be slow and costly (Steketee and Frost, 2014).

People with hoarding behaviours typically have been shown to have problems with attention, decision-making, memory and categorisation which promotes disorganisation (Tolin, Frost and Steketee, 2014; Davidson *et al,* 2019). The onset of hoarding behaviours has often been linked to past traumatic experiences or bereavements. Furthermore, research studies have shown strong links to traumatic experiences, interpersonal attachment insecurity and early family environments, but has not been able to prove causality and remains inconclusive (Hombali *et al*, 2019; Chia *et al*, 2021; Kehoe and Egan, 2018; Chou *et al*, 2018). Some studies do suggest early traumas during childhood may impact attachment regulation (Fontenelle *et al*, 2021) which may have a bearing on the strong links to increased hoarding after bereavements.

Researchers have suggested that people with hoarding behaviours have poor insight into their condition and low motivation to seek help. It is thought that a person with compulsive hoarding behaviours feels that the retention of objects is “desirable, justifiable and even necessary” (Rachman and DeSilva, 2009, p.38). This lack of awareness can often be frustrating to family and friends who want to help the person with hoarding behaviours but meet with resistance (Tolin, Frost and Steketee, 2014). People with hoarding behaviours tend to live alone and some suffer from social phobias. This possible lack of connection may mean that they also lack feedback from others about their living conditions and this may reduce insight and motivation (Steketee and Frost, 2014). In one study of intra psychic conflict within people with hoarding disorder, one theme that emerged was a state of ambivalence, indicating a level of inaction due to a suspension of decision-making, which may also contribute to resistance to accepting or seeking help (Brien and Russell-Carroll, 2018).

Counterproductive interventions previously have been to see hoarding as a lifestyle choice and has often been dealt with by local authorities as a housing issue. Evictions and forced house clearances have often been used as their main solution. This approach has often re-traumatised the person who has hoarding behaviours as they have been shown to have strong defensive reactions to attempts, by other people, to remove their possessions (Steketee and Frost, 2014). When re-traumatised by enforced decluttering, the hoarding behaviours have continued, sometime worse than before (Cooke, 2017). This means that a slow and steady approach with mixed therapeutic and practical involvement is the only treatment that currently works, but this is still prohibitively expensive. Therefore, a preventative model where interventions can happen earlier, preventing the extreme clutter levels often seen in severe cases, would be preferable both in terms of distress levels to the person with hoarding behaviours and the financial costs involved in rectifying the situation.

There have been studies into onset of hoarding which indicates it begins mostly in adolescence, between the ages of 10-20 (Dozier, Porter and Ayres, 2015). There have been very few studies into earlier interventions for hoarding. The majority were assessments for hoarding tendencies using college students, showing that problem insight had a positive association with a willingness to reduce acquiring behaviours (O’Flynn and Grisham, 2021). One paper stated the possible tools available for assessing hoarding behaviours in children.

By its own admission it was not able to tell if these hoarding tendencies were likely to lead to extreme or chronic hoarding in adulthood or were just age-appropriate collecting (Højgaard and Skarphedinsson, 2020). Without a longitudinal study on hoarding starting in childhood, we can only speculate what triggers a child to begin hoarding behaviours and whether this will escalate in adulthood to the extreme levels seen in hoarding disorder.

One study into early interventions of OCD suggests the mean interval between disorder onset and help-seeking was seven years. It also suggested there was a case for screening patients for OCD symptoms in high-risk groups such as new mothers (Fineberg *et al*, 2019). Clearly, they had identified a high-risk group and were therefore able to suggest a protocol for OCD that may work. Without a clear understanding of the causes of hoarding it is difficult to treat it effectively and makes a similar prevention protocol and early screening for symptoms very difficult.

In another study the average timeframe between symptoms and treatment in hoarding disorder was 16.75 years. Barriers to help-seeking were; treatment costs, lack of knowledge about available treatments and a belief that people should work out their own problems. But the strongest predictor of help-seeking for hoarding disorder was accessing previous treatments (Robertson, Paparo and Wootton, 2020). One study where patients sought treatment for anxiety had a high percentage of hoarding behaviours, but the hoarding behaviours were only admitted when the subjects were questioned directly about them (Tolin *et al,* 2010). These two studies suggest an inconsistency with previous assumptions that people with hoarding behaviours are resistant to help-seeking. If people with hoarding behaviours seek help for other co-morbid conditions it suggests that the stigma around hoarding may be an inhibiting factor to help-seeking.

Consequently, this study aims to test the premise that people with hoarding behaviours are resistant to help-seeking and explore what the barriers to help-seeking might be. It aims to find out if there are any earlier opportunities to intervene therapeutically that may prevent hoarding from escalating to an extreme level. These opportunities might be linked to earlier traumas or bereavements, ADHD diagnoses or incorporated into assessments for depression. If we can identify opportunities then perhaps this can go some way towards a

prevention model or can at the very least help to reduce costs and the extreme level of distress caused by high levels of hoarding and clutter.

Methodology

Design

It was thought that the best way to ascertain if there had been missed opportunities for early intervention was to ask people who had been hoarding for some time and therefore had some insight into their own hoarding behaviours. The research would be carried out by using thematic analysis of interview transcripts. Although interviews inevitably include a level of bias from the interviewer, they should provide a detailed and interesting account of the participants experiences (Cooper, 2008).

A hoarding support organisation was contacted to see if any of their existing support group participants were interested in volunteering to be interviewed. The interviews were carried out using a mixture of open and closed questions (Appendix 1). The participants were able to talk at length about their experiences as the interview was semi-structured. Interviews lasted between 40 to 150 minutes.

Subjects were asked to provide biographical information about their socioeconomic background and family life. They were asked about health issues they had or any diagnosed neurodivergent conditions. They were then asked to specify any life events that had negatively impacted them, about how their hoarding behaviours manifested themselves, when they first noticed the behaviours and when they started to become a problem. Where it was possible, timings for events were ascertained so that a timeline could be constructed to use in the eventual analysis. The participants were asked about their experiences in reaching out for support for any other mental health conditions as well as hoarding, any treatments they had received and if there were any barriers to help-seeking.

Participants

Initially there was a total of eight volunteers, one of which dropped out before consenting, and one (Person 5) who completed the interview but the researcher was unable to use the interview due to a technical problem with the recording. The data from all six of the remaining participants are used for the basis of this report.

The age range of participants was from 39 to 70 - the average age being 56. There were four women and two men. The participants were from a range of socioeconomic backgrounds and geographical areas in the UK. All six participants are white British. Two of the participants were currently working, three were out of work due to ill health and one was retired.

The participants had either been diagnosed with hoarding disorder by a professional clinician or were self-diagnosed as having hoarding behaviours.

Ethics

All participants were provided with a participant information sheet (Appendix 2) and signed a consent form (Appendix 3) before they agreed to an interview. The interviews were recorded on the Zoom platform, transcribed onto a word document by the researcher and any identifying details removed to preserve the participants anonymity. All interviews and personal information were subsequently deleted.

Analysis

The data was analysed for possible common themes. When several general themes were identified, they were then analysed again for sub themes. A timeline for each individual participant was also constructed using details provided within the interview. This was used to explore time gaps between life events and help-seeking and the time gaps between awareness of hoarding and help-seeking.

Results

Using the interview data, the main themes identified were: Co-Morbidities; Awareness of Hoarding; Onset and Triggers for Hoarding; Barriers to Help-seeking; Support Accessed; and Early Opportunities.

Co-Morbidities

All the participants have cited at least one other co-morbid mental or physical health condition, namely:

- 4 with depression, including 1 with bipolar depression;
- 4 with anxiety;
- 2 with OCD;
- 2 had developed agoraphobia during lockdown but were coping better with it 3 years on;
- 2 had been suicidal on more than one occasion;
- 1 of them had a diagnosis of ADHD; and
- 4 of them had other significant medical issues that may have periodically affected their cognitive or physical abilities such as: persistent urinary infections, epilepsy, asthma, arthritis, leg injury, vertigo or migraines.

Awareness of Hoarding

There appears to be two distinct phases of hoarding awareness. The first is surface level where the person is aware that they have a lot of possessions and their home is cluttered. It may have been pointed out to them by others that they have a problem that needs addressing, but generally they are resistant to accepting help or do not believe they have a big enough problem, as they should be able to handle it alone. One participant had been told by friends and family that she had a problem years earlier but as she says “I had not made the mental leap at that point, I was in denial, and I was resistant, and the more they said it to me, the more I would argue the opposite and do the opposite” (Person 3).

The second type of awareness is when the person gets a deeper understanding of what hoarding is and that it is causing them significant distress. In this stage the person accepts

that they have a problem and that it needs addressing. At this stage they are more likely to reach out for help or accept help when it is offered. At least two of the participants said that their deeper awareness was because they had seen hoarding shows on the television; “I’d only started becoming aware of the hoarding when the sensationalist programs came on the telly, so it was well past the year 2000 before I even realised it was a thing that you could get help for” (Person 3).

The analysis of the timeline data suggests that of the six participants, half of them had sought help within 2 years of becoming fully aware of the hoarding problem. Two others took longer or it was not clear when they definitely became aware of their hoarding condition as it was more gradual, but they indicated that help was sought within 15 years of initial realisation of there being a problem. One said she had never sought professional help for hoarding but did get support from a family member and was heavily involved in a support group for hoarding.

Onset and Triggers of Hoarding behaviours

This theme splits into five sub-themes of: Interpersonal Injury; Bereavements and Losses; Identity; Living Alone; and Lack of Control.

With the benefit of hindsight, the participants were able to confirm when the onset of the hoarding started for them. Two of the participants believe that the hoarding began in adolescence. The remaining four participants believe it began in adulthood, varying from ages 21 to 41.

Four of the participants have identified older family members that also had hoarding behaviours which may have had an influence.

<u>Interpersonal Injury</u>

Interpersonal injury is a psychological injury to self, caused by another person. Three of the participants have said they were bullied by peers during childhood or adolescence. Another had been physically and psychologically abused during childhood and one other had been sexually abused during childhood. This suggests that interpersonal injury of the kind such as physical or sexual abuse, or psychological abuse such as bullying might be a contributory risk

factor in hoarding. People who have been bullied in childhood are also vulnerable to bullying as adults, and this is upheld by at least three of the participants' stories of bullying in adulthood.

One participant cited an event of bullying by a neighbour as the catalyst for her hoarding. This happened not long after she moved into her first home and said that "I didn't realise how frightened I'd become in there, and I was frightened to go home" (Person 2); she would stay out and buy things just to avoid coming home. These events preceded several other losses over a 10-year period, including bereavements and a job loss. This participant's childhood was described as traumatic, as her father bullied her using physical and psychological abuse. Consequently, the bullying by a neighbour years later was a vivid reminder of her earlier unsafe environment.

Bereavements and Losses

Multiple losses that effect the sense of self are present with all of the participants. Losses include; enforced separation from loved ones, bereavements, job losses, poor health, marriage breakdown and estrangement from parents. They all seem to have had at least two of these significant losses within a 10-year period that were concurrent with or preceding the escalation of hoarding behaviours. At least five out of the six participants have stated that significant bereavements have had a large triggering effect for hoarding. Although they have not all been able to state that those bereavements were the sole cause of the hoarding, they all believe it to be a contributing factor. "The deaths absolutely pushed it forward. Massive triggers made it worse" (Person 3).

Separations from family are in the same category as losses, as they are about relationships that affect a sense of self. One participant has stated that although she believed for many years that a significant bereavement was the beginning of hoarding behaviour, she has come to believe it began when she was sent to boarding school at aged 11. "I felt separate from the rest of my family". She started to amass items at boarding school and said of the items, "I suppose they started to become my family in a way" (Person 1). Her hoarding behaviours escalated after a significant bereavement 10 years later but were clearly present much earlier.

Identity

Identity is tied into the types of objects that are collected or hoarded and can be an extension of a person's personality. One participant is clear that he has a collection of certain items linked to things he enjoys and are a part of his identity and is separate from his hoard which is made up of items of general clutter and rubbish. He is aware that "there is a fine line between the two, I try to keep them separate, at least in my head" (Person 7).

Another link to bereavement is in the inheritance of objects from deceased loved ones and the connection to that person through those objects. Three of the participants have stated that collecting objects from deceased loved ones had caused a significant and sudden rise in the volume of objects cluttering their home. One of the participants has said of those inherited items that "It's a part of my identity, my relationship with them is intrinsically part of me. I don't want her forgotten, she's in all of those things"(Person 3). The relationship to the objects was seen as a continuation of the relationship with the person that had died.

Living Alone

Living alone seems to increase the risk of hoarding. Some participants have described their hoarding behaviours escalating after they gained financial or physical independence with their first home or first job. One participant said about being isolated "If I don't have connection, for me it's a danger because I will go out and buy to feel better" (Person 4).

For some it was living with others that helped the management of the hoarding. One of the participants was very clear that she had been able to keep on top of the hoarding while she was living with her children and husband in the house. After the children left home and she divorced her husband, the hoarding escalated. "The thing is I had children and you can't have their rooms full. The minute they moved out though, that changed a bit, but I had to keep on top of the house to some degree for when my son or daughter came home. Since covid they haven't been coming home. Their rooms are full now and I know I'm losing out on these relationships as a result" (Person 6).

Lack of Control

Four of the participants have cited controlling or judgemental behaviour on the part of parental figures or partners as a contributory factor to the hoarding and the fact that they feel they had no control over their lives. “I know the reason I hoard is because my brain is trying to get control, because other people have taken it” (Person 6).

The other two participants felt they had no control in their lives but did not link this to specific behaviour from others. “The only thing I have control over is my possessions, my belongings, my home. It’s the only place I feel I’ve got control. The funny thing is I am no longer fully in control, the hoard controls me” (Person 7).

Barriers to Help-seeking

This theme can be separated into sub themes of: Stigma and Judgement; Funding; and Lack of Services.

Stigma and Judgement

All of the participants cited a fear of judgment, stigma, shame and embarrassment as potential barriers to help-seeking for hoarding. One participant said “you don’t want to admit the problem and be seen as dirty or smelly, you don’t want to promote that stereotype that you see on television” (Person 1). Another said “the stigma of going to a support group and thinking, I’m not one of these people or that there’s something wrong with you” (Person 2). Another participant says “I found it easier to seek help for depression. But for hoarding I’ve found it a lot more difficult to admit I had a hoarding problem. Up until lockdown I wouldn’t have admitted it” (Person 4).

Three of the participants have had either family members or professional helpers in their home to help with decluttering and experienced a level of judgement from the person that was unhelpful. It caused additional resistance from the participant in co-operating with them or moving forward. “My friend went through all my books and laughed at the titles and things and I just felt really diminished, yes, bad experiences when I did ask for help” (Person 3). “I felt like I was being challenged too much, like why do you need this? Why is that

useful? Like being told what to do with my own stuff. I was relinquishing some of the control to someone else who didn't even know me" (Person 7).

Funding

All of the participants have cited lack of funding as a barrier to seeking help. Either their own lack of funds or that of the local authority. One had his local council withdraw a hoarding support service as the council had gone bankrupt (Person 4). Several have said that they are out of work due to ill health and rely on benefits, but these do not cover additional expenses like private treatment or travel to support groups. One participant, currently in work, was able to access a private counsellor once a week but could not find one that had much experience of supporting people with hoarding behaviours. She did have a declutter coach for a few days and said it was a great experience that a family member paid for, but it was so expensive neither she or her family can afford to do it again (Person 3).

Lack of Services

Several participants have been disheartened by the lack of treatments and services available specifically for hoarding. One participant said, "I just don't think there's any support for hoarding. Theres just no pathway. You only get support if you are causing problems for your landlord or neighbours" (Person 3). When asked whether she had actively sought help for hoarding another participant said " I think getting involved in support, this made me realise there isn't a lot out there. So, there's not much point" (Person 1).

Support Accessed

All the participants have accessed some kind of talking therapy in the past, but most support has been for bereavement, depression, anxiety or OCD, rather than being specific to hoarding. The services accessed for depression were generally through primary care or local charities and accessed relatively quickly. Access to bereavement counselling was generally through charitable organisations and accessed within 1-2 years of the bereavement. All of the participants had accessed online support groups for hoarding, a couple had managed to access face-to-face hoarding support groups.

Four of the participants have been to bereavement counselling, which had mixed reviews of its effectiveness “the counsellor was nice but it didn’t really do anything for me” (Person 3). Three of the participants have accessed 12 sessions of CBT for depression and anxiety but said “it still didn’t feel like that was enough, with all the problems I was facing” (Person 4). One had accessed exposure therapy for agoraphobia which was deemed to be successful and two had accessed therapy for OCD which was less successful. Most of the participants had a positive experience and said that the therapies feel helpful, most wanted the sessions to last longer.

Two participants had accessed psychiatric help for general depression, anxiety and hoarding. One of these participants found it helpful to understand her own hoarding behaviours and the insights were really valuable “I wished I’d been referred quicker to a clinical psychologist because I am really amazed at their skills, it not always easy or pleasant but it’s a brilliant service. I think it’s almost like an intervention, like coaching life skills” (Person 2).

Most participants agreed that the talking therapies had not affected the management or control of the hoarding behaviours for a sustained time but the ones that had access to psychiatrists or clinical psychologists said they were more effective than counsellors, but in those cases the therapy was more likely to have been targeted towards hoarding.

Participants describe a lack of continuity with treatment programs for any mental health problem. There is also a post code lottery element to treatments. Participants that live in large towns or cities have been more likely to find services specific to hoarding than those living in smaller towns or rural areas. Covid has also disrupted the provision of services for hoarding as many that existed before Covid are no longer running.

Early Opportunities

Some participants identified specific incidents where professionals such as paramedics or trades people had come to their home. They identified that those professionals could have reported the hoarding problem using safeguarding procedures but did not.

Some participants seeing counsellors for depression or anxiety thought that the counsellors lacked training and knowledge about hoarding and saw it as a missed opportunity.

Several participants wished that people around them had noticed the problem earlier and had said something.

Most participants when challenged on the timings of the possible earlier opportunities agreed that at the time they may not have been receptive to receiving help from others due to being in a state of denial.

Discussion

The results suggest parity with previous studies in hoarding behaviours with regards to age of onset, co-morbid conditions, social and economic backgrounds, gender distribution, barriers to help-seeking and links to traumatic events and bereavements. It also suggests that the level of awareness of their hoarding problem is key to help-seeking and any possible earlier interventions. Fear of judgement and shame give clues to the motivating factors around hoarding behaviours and the resistance to help or help-seeking that has also been seen in previous research.

All the participants had events in childhood that involved abuse, bullying or enforced separation from family. These are all situations that could be classed as traumatic (Davies and Frawley, 1994) and can evoke feeling of shame and abandonment, distressing enough for a child to create survival defence strategies such as flight, fight or freeze responses. Bowlby (1973/1998) observed that certain possessions can provide a measure of comfort if a child is separated from its main caregiver. Winnicott (1971) theorised that this was a transitional object that helped to ease separation anxiety when a child is starting to separate from its parent with the beginnings of understanding the concepts of self and others. If growing in a healthy way, the child learns to soothe itself through the process of becoming a separate person. A traumatic event or threat during this time can disrupt that ability to self soothe and the child seeks external ways to soothe itself, often, paradoxically by way of relationships with others (Jacoby, 1994). But if trust is broken, relationships with possessions could be seen as a safer option than relationships with people (Masterson, 1988; Hartl *et al*, 2004).

Most coping strategies emerge during childhood and adolescence and research has suggested that hoarding behaviours mostly begin before the age of 20 (Dozier, Porter and Ayres, 2015). It's not clear why the accumulation of objects would be chosen as a comfort over that of, for example; overeating or obsessive-compulsive behaviours, which are also defensive strategies to aid numbing of psychological pain. Perhaps the fact that more than half of the participants claimed to have an older relative that also had hoarding behaviours may be a clue to this as a learned behaviour, and this prevalence for family members with hoarding behaviours mirrors previous research (Samuels *et al*, 2002). Identity is also formed in childhood and adolescence (Alsaker and Kroger, 2006) so if attachments to objects are formed at this time as a defence mechanism, this may also explain the heightened link to identity that hoarders have with their possessions

The main identifiable defence mechanisms that come from shame-inducing events include; fight, which can be rage and attack; flight which can be withdrawal, secrecy and hiding; and freeze which can be avoidance and dissociation (Sanderson, 2015). Avoidance is prevalent in hoarding behaviours and could be seen as a form of dissociation from reality, numbing the person and protecting them from further feelings of shame or abandonment. The pursuit of pleasure can also deaden psychological pain and typically leads to addictions or compulsive behaviours such as compulsive shopping or acquiring (Sanderson, 2015). Dissociation is a form of splitting of the personality and a well-known protection from trauma (Davies and Frawley, 1994). Wurmser states that the aim of shame anxiety is to hide (Wurmser, 1981, cited in Mollon, 1993, p.48), hoarding could also be seen as a physical barrier to protect from the outside world, so perhaps hoarding is also a way of being invisible, of hiding from shame. Accumulating possessions may also be a "display of worth" to hide shame using a superficial display of status (Sanderson, 2015, p.113).

Although this research was not designed to prove causality of hoarding, the commonalities of abuse, bullying and separation in childhood could explain the beginnings of a shame cycle that could lead to hoarding. With these participants, the severity of the abuse or bullying is unknown and it seems that those early events alone did not cause escalation in hoarding but the interpersonal injuries or separations may explain the participants' feeling of a lack of control in their own lives, consistent with the shaming effect of bullying, abuse or abandonment (Sanderson, 2013). This could cause them to look outside themselves for

conditions of worth and validation and this can continue well into adulthood and lead to "narcissistic vulnerability" (Jacoby, 1994, p.50).

Narcissistically vulnerable individuals show a strong reaction to "being slighted, ignored or treated without respect or empathy" and can lead to "illusions of self-sufficiency" (Mollon, 1993, p.65, p.76). It may explain the resistance to help when judgements are vocalised by those around them. This resistance may also be interpreted as counter-shame, where there is a denial of shame in order to avoid feeling it (Mollon, 1993). Resistance to change can also be a feature of not losing a set of firmly held beliefs about who we are, our personal construct of self (Button, 1993). Events that "do not fit with previous conceptions of oneself would be likely to be ignored or distorted" (Alsaker and Kroger, 2006, p. 100). This means that a person already susceptible to shame can be hypervigilant to criticism or more shame, and resistant to shameful admissions of responsibility. If shame can lead to hoarding and hoarding can lead to feelings of shame it could create a self-perpetuating cycle of shame (Sanderson, 2015).

It was clear that all participants had suffered multiple losses of different types within a 10-year period. There seems to be a dual aspect to hoarding where an earlier interpersonal injury is followed by multiple losses, such as bereavements in order for the excessive hoarding to be triggered. This suggests a level of disordered mourning, this is mourning described as leading to physical or mental ill health and an impaired ability to order one's life or maintain relationships (Bowlby, 1980/1998). Depression is a prime symptom of disordered mourning and is often combined with anxiety or agoraphobia. It has also been described as "abandonment depression" (Masterson, 1988, p.59) as losses can be experienced as the shame of rejection (Mollon, 1993) and probably stem from embedded separation anxiety. When looking at the participants' co-morbidities, it was clear that all of them had either chronic depression or chronic anxiety or both which fits with this description of disordered mourning and also fits the definition of complex grief (Shear, 2012). We do not see ourselves in isolation, in constructing ourselves we do so in relation to our understanding of relationships with others (Button, 1993). When our loved ones die, it is inevitable that this loss has a profound effect on our sense of self. Risk of danger increases when we are alone (Bowlby, 1973/1998) therefore this increase in anxiety linked to being

alone or being abandoned may also explain why the hoarding behaviours escalated for many of the participants when they started living alone or had a significant bereavement.

Motivation is crushed by depression, as all the participants had potentially debilitating co-morbid conditions such as anxiety, depression and OCD, those conditions could be reducing motivation to help them to get on top of their problems or seek help. Possible trauma symptoms can include cognitive dysfunction, lack of focus and poor memory, all of which can impair a person's ability to organise their life or home and cope with additional stresses (Van Der Kolk, 2014; Maté, 2012). It would be useful to screen for hoarding behaviours during assessments for anxiety and depression as these conditions are all strongly linked together. Often these co-morbid conditions are treated in isolation, but as people with hoarding behaviours generally have multiple health issues and multiple life events and losses that all appear to be interacting, perhaps a more holistic approach to screening and treatments would be more effective.

It was clear from all the participants that they were not afraid to ask for help when they felt they needed it. The main pivotal point in asking for help seems to be the level of awareness in the person that they have a hoarding problem. When that is acknowledged, help-seeking for hoarding tends to happen within 2 years. This suggests that there is not enough awareness of what hoarding is or what it looks like, other than the programs on television. With names like "buried alive" (IMDB, 2024), "no room to move" (My5, 2024) or "Britain's biggest hoarders" (BBC, 2024), these programs are all sensationalising the squalor that some hoarders end up living in. It is highlighting the extreme end of the problem and is more interested in the clean-up rather than the psychological reasons behind hoarding and how to overcome it. Most of the participants felt that the demonisation of hoarders in the media added to the shame of being a hoarder, and was an inhibiting factor in help-seeking, although paradoxically they did often help with gaining a deeper insight into the problem. Perhaps if hoarding was on an equal standing with addiction or eating disorders in how we view it and treat it, it would not have as much stigma attached to it and it would be immediately seen as a mental health issue and not a housing or lifestyle problem.

Limitations to Research

The main limitations of this research were:

- The reliance on the accuracy of participant recall;
- The small participant number, a larger group would have given more accurate and comprehensive data;
- The analysis was subject to the interviewer's own biases and interpretations; and
- This study only included individuals who had already looked for support for hoarding disorder, this excludes any individuals who are not ready to accept help and therefore is from a narrow perspective in the overall field of hoarding behaviours.

Conclusion

Although many hoarders reach out for help earlier for bereavements and depression, it seems that counselling for such single events and illnesses does not prevent escalation of hoarding. A person-centred approach would be vital to working with a person with a high sensitivity to shame and judgement. However, some counselling modalities may not be flexible enough or not trauma-informed enough to help if their shame spiral is so deeply embedded and sometimes outside of consciousness. Perhaps counsellors and psychotherapists could be better trained to spot the risk factors involved in hoarding and its links to shame and abandonment. Appropriate signposting to more specialist mental health teams, similar to addictions or eating disorders would be more helpful and would provide a recognisable treatment pathway for hoarding. Additional questions included in the assessments for depression and anxiety would help with early screening for hoarding behaviours.

Despite the belief that people with hoarding behaviours are resistant to treatment or help-seeking, this research indicates that this is not true as they have accessed multiple treatments for anxiety, depression, OCD and agoraphobia. Awareness of their own problem is, however, clearly a factor in help-seeking for hoarding. If pushed by others before they have made the connection themselves, this is where resistance to help is seen as they are

sensitive to shame and judgement. Better general awareness of hoarding as a mental health problem would help with this, both by making the person with hoarding behaviours more aware of their own problem, reducing stigma and perhaps making those around them less judgemental and more sympathetic to the situation that they find themselves in. It is not clear that early opportunities for interventions in hoarding would arise without this higher level of awareness from the person with hoarding behaviours, or a greater capacity for empathy and tact on the part of the person trying to intervene.

Clearly better and more longitudinal research is needed to clarify the risk factors in hoarding, especially around the links to shame and separation anxiety during childhood and adolescence. With that clarity, early opportunities would be easier to identify and treatments would be more effective than they currently are. At present, shame reduction is probably the only way to prevent hoarding from escalating but that would involve better mental health provision for childhood traumas and bullying, and in bereavement and loss support, as well as increased hoarding awareness for the general population and a clearly defined treatment pathway for hoarding behaviours available on the NHS.

Word Count 6577

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Appendix 1

Semi-structured Interview Questions

The information in brackets was to assist the interviewer in asking the questions and not meant as specific prompts for the interviewee.

1. How old are you?
2. What part of the country did you grow up in?
3. What sort of community was it, (small town, rural, big city, etc)?
4. What sort of community do you live in now? Is it the same part of the country?
5. Do you have any siblings? are you the youngest, oldest etc?
6. Did you grow up with both your parents?
7. What did your parents do for a living?
8. What was your homelife like when you were growing up? (was it:- happy/unhappy/challenging/violent/uneventful/calm/dull, etc)
9. How old were you when you left home?
10. What do you do for a living? Or have done in the past?
11. Do you live alone? If so, have you always lived alone or have you had periods of time when you shared with a partner, friend or flat mate?
12. Have you ever been diagnosed with a neurodiverse condition such as Autism or ADHD or had a brain injury in the past?
13. Have you ever suffered from a mental or physical illness that has affected your day-to-day life? How old were you when this happened?
14. Have you ever been negatively affected by global or local events? (This could include things like 9-11, covid lockdowns, global warming, death of a public figure, wars, politics, local incidents etc).
15. Can you describe any personal life events that have had a negative effect on you either physically, mentally or emotionally? How old you were when they happened? (This could include accidents, illnesses, bereavements, relationship breakdowns, job losses, house losses, pet losses, abuse, witnessing of a traumatic event etc).

16. Have you ever reached out for help or support after any of these events (global or personal)? If so, can you tell me about this experience? Was it helpful? (could be to friends, family, GP, local authority, social worker, counsellor, alternative therapists such as hypnotherapy, acupuncture, raiki, spiritualists etc).
17. What would you say prompted you to reach out for help at those times?
18. How did the experience of asking for help make you feel?
19. Were there any times when you wanted to reach out for help but something stopped you?
20. If so, can you describe what sort of barriers were there that stopped you seeking help?
21. Can you briefly describe your own hoarding behaviours?
22. When did you first notice them?
23. When would you say the hoarding behaviours became a problem for you?
24. What in your opinion was the main cause or trigger for the hoarding behaviours?
25. At what point in time did you decide to seek help for the hoarding behaviours and what prompted it?
26. What was your experience of seeking help? How did it make you feel? Has it been helpful?
27. What sort of barriers have you encountered with regards to seeking help and support for the hoarding behaviours? (This can be internal or external barriers).
28. Have you received any therapeutic support for hoarding behaviours? If so, what was your experience of this therapy? Have they helped in any way, what was most successful?
29. Have you been resistant to accepting help in the past? If so, what were the main causes of the resistance?
30. In your own experience, was there a time when you think a therapeutic intervention, such as counselling, would have prevented the hoarding behaviours from escalating?
31. If so, what could have been different to have made this kind of intervention possible?
32. Do you have any other experiences with accessing mental health services that you think might be relevant to my research that we haven't already covered?

Appendix 2

Participant Information Sheet

Project Background:

This research is being done as part of a dissertation for a BA in Counselling Studies at NESCOT college.

The aim of this research is to find out if people with hoarding behaviours ever reach out for help for any mental health conditions or traumatic events to GP's, Counsellors, support organisations or friends and family. If they have asked for help, what were their experiences of this help and what have been the main barriers to seeking help.

If you are concerned about what you will be asked about:

You may be asked to provide some basic details about your hoarding behaviours, but you will not be asked to go into detail about these behaviours.

You may be asked to provide some basic information about any traumatic events in your life, but you will not be asked to go into detail about these events.

If you feel you may be triggered or unduly upset by talking about anything in your past, please be aware you can discuss it before the interview to see if it is something you still wish to do. You can also withdraw consent or change your mind about participating.

If you agree to take part in this research:

You will be asked to sign a consent form to take part in this research. It is important that you are aware that you can withdraw your consent at any time up to the 1st May 2024, after this time it will be too late to remove data from the dissertation.

You will be asked to participate in a one-to-one interview either by phone or online. The interview will last approximately 1 hour and will be recorded and transcribed. The original recording will be destroyed after the transcription has been completed.

You can ask to see the final report.

Confidentiality:

Your personal details will not be included in the dissertation and therefore you will remain anonymous. No details that might cause you to be identified will be included in the dissertation.

Your words may be quoted in the dissertation but will not contain any identifying details.

Data Protection:

Your personal details will be held in a secure computer file according to GDPR regulations, this is in case we need to contact you for clarification of any of the data. When the project has ended and marking has been completed, all data files, original recordings and contact details will be destroyed.

You have the right to complain to the Information Commissioners Office (ICO).

Contact details:

You can ask to speak to the researcher to discuss the project or the interview. You can also contact them if you wish to withdraw your consent.

Researcher details are: Christine Ashworth cashworth30@gmail.com

Thank you for your participation in this study, you are helping to widen the knowledge base and understanding of counsellors and other practitioners within the field of Hoarding disorder.

Appendix 3

Consent Form

Study Title: **Are there opportunities for earlier therapeutic interventions in hoarding disorder?**

I have read and understood the participant information sheet provided.

I am aware that the information I provide is for an undergraduate dissertation at NESCOT college.

I understand that my participation is voluntary and I can withdraw consent at any time.

I consent to the interview being audio/video recorded and understand this will be transcribed and then destroyed.

I understand that I will be anonymised within the dissertation and any personal information collected will not be shared with anyone outside of the researcher, NESCOT course tutors and anyone involved with marking.

I understand that all data held will be stored in a secure computer file and will be destroyed within 2 months of the dissertation going through marking.

Name of Participant (please print): ……..

Signature of Participant: ……

Date: ……