



“Scared of the emptiness”
Exploring the therapeutic experiences
of people with hoarding disorder:
an interpretative phenomenological study.

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University of Wales Trinity Saint David School of Psychology
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for the degree of MA in Advanced Counselling Theory and Research



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**University of Wales Trinity Saint David School of Psychology
MA Advanced Counselling Theory and Research
Part 2 Research Dissertation**

DECLARATION:

I declare that this dissertation has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree.

Except where stated by reference or acknowledgment, the work presented is entirely my own.

I confirm that I have not used any AI tools in the research and creation of this assignment. I confirm that I have not presented any AI generated materials as my own work.

I confirm I have copies of my drafts, notes, and other resources I used, which I may be asked to provide in evidence.

SIGNED BY HARRY BEER

DATE

March 2025



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WORD COUNTS (minus abstracts and tables):

Chapter 1	488
Chapter 2	4808
Chapter 3	4795
Chapter 4	2697
<i>TOTAL:</i>	<i>12,788</i>

Chapter 1: Plain English Summary

INTRODUCTION AND BACKGROUND

Hoarding disorder (HD) is a mental health condition. It involves a strong urge to gather and keep all sorts of possessions, regardless of value. Letting things go causes anxiety so the home fills up, making day-to-day life very hard. Rooms become unusable and things like cooking and washing become difficult or impossible.

Around 2.5% of the population are affected. There is a lack of research into their experiences, especially with therapeutic support.

Many studies report that cognitive behavioural therapy (CBT) is effective for HD. However, questions remain, especially about how suitable it is for this group and whether it brings long-term success.

This research aimed to better understand how to help people with HD by answering a simple question:

What are the experiences and effects of talking therapy on people who have hoarding disorder?

RESEARCH METHOD

Four people with HD, (two women and two men), were recruited and interviewed individually. These were found through two UK hoarding organisations and by emailing people who run support groups.

The interviews lasted around an hour and between them totalled over forty thousand words. Each interview was recorded and analysed using an established method. Themes were found which were backed up by quotes. Individual themes were then considered as a whole to reflect the group experience.

FINDINGS

- People with HD are stuck and feel unable to change
- They avoid making decisions because of the fear of getting things wrong
- Hoarding can be a way to feel safe or in control when these things are missing

- The hoard is connected to their sense of identity so letting things go can feel unbearable

The participants were all positive about the idea of therapy and had received many different kinds. The benefits include being seen and understood and feeling less isolated.

Nevertheless, talking therapy did not lead to long-term positive outcomes. One participant had seen 23 professionals and did not feel any had helped.

CBT was described as useful in terms of feeling normal and understood, but not for delivering change. Three participants described having disorganised minds and struggled with the tasks and homework of CBT. This is backed up by other research but more work is needed to find the best way to help people overcome hoarding.

The wrong kind of help can be damaging. One participant reported feeling bullied by two different professionals. If a person with HD is made to feel stressed or upset, they may cling to behaviours which they find soothing, so bad help for hoarding can make the problem worse.

SUMMARY

- Therapy is considered a good thing by people with HD
- It has positive impacts on well-being but does not reduce hoarding
- Good help involves therapists who have empathy but also expertise
- The wrong kind of help can make things worse

More studies are needed so that help for people with HD can be as appropriate and effective as possible and lead to long term change.

Word count: 488

Chapter 2: Systematic Literature Review

ABSTRACT

This systematic review of qualitative literature is an exploration of the therapeutic experiences of people with hoarding disorder (HD).

BACKGROUND

HD involves the compulsive gathering and retaining of possessions to the point that day to day life is negatively affected. It is not fully understood what causes this condition, nor how best to treat it. CBT is the recommended intervention but there is a lack of research into what therapy is like for those with HD.

AIMS AND OBJECTIVES

The aim of this review was to look for, pull together and analyse research relating to the therapeutic experiences of people who have HD.

The objectives were to:

- Find out what the intervention was like and if it had any impact on the hoarding
- See if the process led to any improvements or changes for the person
- Look at things that might help or hinder any therapeutic change
- Think about long-term effective support for people with HD

METHODS

A detailed search was carried out to find relevant studies using academic databases. Six papers were chosen, carefully read and analysed leading to valuable conclusions.

RESULTS

The core themes include the importance of the relationship in therapy and the desire of people with HD to be understood and listened to free of judgement.

CONCLUSIONS

There is a lack of research into treatment and support for hoarding which comes from the perspective of the person affected.

Decluttering is a therapeutic process, the success of which depends on the quality of the relationship.

Effective support for people with hoarding disorder requires that they be in control of the process, to have a relationship of trust with any therapist or helper and be treated without judgement.

IMPLICATIONS

CBT may not lead to lasting changes in HD. Research is needed to find out if it works in the long-term. Other approaches should be considered, possibly involving a mix of therapy, group support and volunteer-led decluttering.

INTRODUCTION AND BACKGROUND

Hoarding Disorder (HD) came into existence with the publication of DSM V (APA) in 2013 and consequently the ICD 11 (WHO, 2019). The following are the accepted defining characteristics (APA, 2013):

- Compulsive accumulation and retention of items
- Persistent difficulty disposing of possessions, irrespective of value
- Resulting distress / negative impact on normal day-to-day functioning

Prevalence in the UK population is around 2.5% (Postlethwaite *et al*, 2019), but as a consequence of the associated shame, as few as one in 20 cases come to light (BPS, 2024). HD is heavily stigmatised and associated with negative and critical attitudes from the public and among many professionals (Prosser *et al*, 2024).

The etiological basis of HD resides in a complex intersection of biopsychosocial factors (Jagannathan and Chasson, 2023). Issues such as genetic predisposition and executive functioning are considered important variables (Dozier and Ayres, 2017). Traumatic experiences are also contributory factors (Shaw, Witcraft and Timpano, 2016, Landau *et al*, 2011). ADHD symptoms are often seen in individuals with HD but are not a diagnostic requirement (Worden and Tolin, 2023). Likewise, certain autistic traits are observed in some people with HD but no more than psychiatric controls (Pertusa *et al*, 2012).

CBT is the recommended treatment for HD according to the NHS (2024), The Royal College of Psychiatrists (2024) and MIND (2024) among others. A brief search in the online academic library of The University of Wales Trinity Saint David (UWTSD) brings up 31 peer-reviewed studies into CBT for hoarding in the last five years.

The most recent meta-analysis (O'Brien and Laws, 2025) encompasses studies into 41 psychological interventions for HD. The authors report impressive pre-post effect sizes across the board with "no discernible distinctions" between CBT and other interventions. Of the 41 studies, 32 were CBT (78%) and only 15 reported follow-up scores, ranging from one month to a year. More detail on this crucial element would be illuminating but lacking.

Despite the eye-catching headline, only three studies could be categorised as associated with *recovery* and three with *improvement*. The ultimate test would be to ascertain if the

change was lasting. The authors acknowledge the shortage of non-CBT studies available for inclusion and the need for “cautious interpretation”. Bias is also an issue; the participants as a whole are younger (mean age 55) and disproportionality more female (76.5%) than typical. It is also possible that, as research participants, they were highly motivated to see results from the intervention and conceivably influenced by the Hawthorne effect.

A previous meta-analysis (Rodgers, McDonald and Wootton, 2021) also declared CBT effective for HD while recognising the need to examine long-term effects. This echoes an earlier review by Tolin *et al* (2015) which reported similar effect sizes but, critically, clutter levels did not continue to decrease once treatment had concluded.

The subjective world of a distressed individual is difficult to fit into the straitjacket of traditional quantitative empiricism. The paucity of longitudinal, qualitative evidence is problematic, constituting a gap in understanding of the efficacy of therapeutic interventions for HD. It is to that gap, through the voices of those with relevant experience, that the present study seeks to speak.

AIM AND OBJECTIVES

The aim of this review is to collate, analyse and synthesise relevant literature relating to the therapeutic experiences of people who have HD. The objectives can be seen in table 1:

Table 1: Objectives of the review

1	Ascertain how interventions were received and what impact they had
2	Assess whether the process alleviated any distress and/or led to any change in terms of accumulation and/or discard of possessions
3	Identify barriers and facilitators to therapeutic change in people who have HD
4	Consider implications for effective, long-term support for people with HD

METHODS

SEARCH STRATEGY

This review focuses on qualitative research in accordance with its aim and objectives. Literature was searched using the online library of UWTSD. It was not necessary to exclude any databases as HD can encompass multiple domains including; housing, social work,

occupational therapy, psychology, counselling etc. PRISMA methodology provided a basic guide and the process was conducted in August 2024.

INCLUSION AND EXCLUSION CRITERIA

Studies had to include the views of participants who have HD. Purely quantitative reports were excluded as were systematic reviews, meta studies and RCTs. Each search was conducted with the following parameters: peer-reviewed articles in English published between 2004 and 2024. This 20-year range was selected after preliminary searches indicated a sparsity of qualitative literature. Additionally, for the purposes of this review, the concept of “therapeutic experiences” is extended to include decluttering support in the home. The necessity of this decision, while yielding fruitful data, further evidences the research gap. Table 2 details the search process.

Table 2 – search process

Search 1:	
TITLE CONTAINS:	"hoarding disorder" OR hoard* AND therap*
ANY FIELD:	qualitative
<i>Results: 18</i>	
Filtered for relevance removing duplicates: 14	
Search 2:	
TITLE CONTAINS:	hoard*
TITLE CONTAINS:	treat* OR therap*
ANY FIELD:	“self-reported”
<i>Results: 12</i>	
Filtered for relevance removing duplicates: 3	
Search 3:	
TITLE CONTAINS:	hoard*
TITLE CONTAINS:	treat* OR therap* OR intervention
ANY FIELD:	experiences
<i>Results: 24</i>	
Filtered for relevance removing duplicates: 1	

Other searches were conducted using variations of interv*, therap*, treat* and qualitative but yielded only duplicates and irrelevant studies. The process was repeated ten days later with the same results.

Abstracts and conclusions were read of the 18-strong shortlist and manually filtered to a final six. See appendix 1 for a full list and reasons for exclusion.

OVERVIEW OF THE STUDIES

The papers comprise three each from the UK and the USA. These are presented and numbered alphabetically. Names of the publications are recorded in appendix 2.

The CASP qualitative studies checklist (2023) provided a useful guide while papers were reviewed for methodological rigour and relevance.

In the interest of brevity and clarity this review adopts the phrase, “people with HD”, to refer to participants speaking from personal experience of hoarding, regardless of formal diagnosis or use of any established scale.

The six papers for this review are introduced below in table 3.

Table 3 – Summary of papers

NO	TITLE OF PAPER	YEAR	FROM	DETAIL
1	A ‘Friendly Visitor’ Volunteer Intervention for Hoarding Disorder: Participants’ Perceptions	2024	USA	Relates to at-home support (including decluttering) and has the voices of both volunteers and clients
2	‘A more human approach... I haven’t found that really’: experiences of hoarding difficulties and seeking help	2024	UK	Explores the experiences of people with HD with seeking support
3	Acceptability of treatments and services for individuals with hoarding behaviours	2016	USA	Considers which treatments and services are acceptable to people with HD.
4	Older adult hoarders’ experiences of being helped by volunteers and volunteers’ experiences of helping	2018	UK	As paper 1, relates to at-home support, including decluttering, has voices of both volunteers and clients
5	Therapist and patient perspectives on cognitive behavioural therapy for older adults with hoarding disorder: A collective case study	2012	USA	Details the experiences with therapy of people with HD, the context being a collective case study of a CBT intervention
6	Working together when the problem is multi-faceted: understanding inter-agency	2022	UK	Pertains to multi-agency working and includes the views of people with HD

	working for the benefit of people with hoarding problems			
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A table detailing the authors, aims, populations and designs of the studies can be found in appendix 3 and a summary of themes and conclusions in appendix 4.

The papers were sought and selected to meet the objectives of this review. As table 4 shows, none met all the objectives and half only satisfied two of the four. This graphically evidences a gap in research pertaining to the therapeutic experiences of people with HD.

Table 4: Review of objectives by paper

OBJECTIVE	P'R 1	P'R 2	P'R 3	P'R 4	P'R 5	P'R 6
1) Ascertain how the therapeutic interventions were received and what impact they had	✓	×	×	✓	✓	×
2) Assess whether the process alleviated any distress and/or led to any change in terms of accumulation and/or discard of possessions	×	×	×	×	×	×
3) Identify barriers and facilitators to therapeutic change in people who have HD	✓	✓	✓	✓	✓	✓
4) Consider implications for effective, long-term support for people with HD	✓	✓	✓	✓	✓	✓

The six papers represent a systematic and replicable process serving to emphasise the need for the proposed research, while simultaneously presenting a coherent overview of that which exists.

RESULTS: SUMMARY AND CRITIQUE OF EACH PAPER

PAPER 1: A 'Friendly Visitor' Volunteer Intervention for Hoarding Disorder: Participants' Perceptions.

This American research published in 2024 discusses a volunteer-delivered home-based decluttering intervention for hoarding; the Friendly Visitor Programme (FVP). Participants included six volunteers and three clients with HD.

While this research does not pertain to therapy per-se, it does relate to a type of intervention that is often available to people with HD; decluttering. The relationship with the

helper is shown to be of vital importance, as is the case with formal therapeutic interventions (Noyce and Simpson, 2018). The programme was instigated by an occupational therapy (OT) team and the FVP volunteers were mostly master's level OT students. Training was offered but its content and duration are not detailed which is unfortunate given the complexity of HD and the attendant co-morbidities which can include schizophrenia (Schou *et al*, 2020).

Researchers collected data through semi-structured interviews (SSI) which were recorded and transcribed. Codes were derived then manually grouped and categorised. It is not explained if this was according to any particular methodology, nor is any example offered to illustrate the process.

The resultant three themes relate to decluttering; the relationship with helper, the physical demands of the process and practical strategies. The most prominent (and salient to the present study) is the first which is easily relatable to the therapeutic field. Decluttering carries the added pressure of allowing a stranger to enter the home. As one client says, "... to let someone in is a big, big deal."

The volunteers adopted a person-centred style, guided by the client with opinions and advice withheld. While not stated as such, this also supports the client towards meeting the psychological needs of self-determination theory (Ryan and Deci, 1985) namely; autonomy, competence and connectedness. For the clients this means being shown respect and treated with dignity.

Some of the volunteers felt they were not achieving much which may be because their measure was visual (volume of discard) rather than emotional wellbeing. This is unfortunately not elucidated in the research and would require a longitudinal study to address.

Being in the home afforded the volunteers insight into the reality of having HD. This would be hard to achieve in the therapy room and possibly facilitated the forming of trusting relationships. One volunteer said she could, "... feel the agony for her of making these decisions."

Clients' difficulties with decision-making, planning and organising are referred to, as are the importance of routine and consistency. The authors note that positive outcomes in the study were achieved using client-centred approaches. This has an obvious therapeutic equivalence, i.e., people with HD respond to a humanistic, non-directive attitude.

The authors cite as limitations that the volunteers' training likely influenced interactions with clients and the lead researcher being faculty supervisor to most of the volunteers meant they had access to regular guidance. These could be argued as strengths, affording an optimally ethical environment in which to explore the effects of an intervention on a vulnerable group.

The study is worthwhile but lacking in detail such as the duration of the intervention, the number of client hours and whether participants felt it was successful and if so, in what way?

PAPER 2: 'A more human approach: I haven't found that really': experiences of hoarding difficulties and seeking help.

Eight people with HD took part in this British research, published in 2024. Interviews were conducted remotely by phone or online and subjected to interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin, 2022).

This research relates to the experiences of seeking help rather than any actual intervention. In terms of available support, practical versus therapeutic offerings are not differentiated. SSIs covered areas including; motivation, perceptions of support and barriers and facilitators.

The researchers attend to matters of quality, rigour and validity in various ways; use of Yardley's principles (Yardley, 2000), engaging in a reflective interview to mitigate bias and a solid defence of the need for their research.

This study offers valuable insights into individual relationships with clutter, demonstrated by the use of emotive language such as; fortress, prison, security net, trapped etc.

Trust is a significant theme, exemplified in difficulties participants experienced in telling anyone about the hoarding. This links with the fear of judgement, criticism and rejection, all of which feed the shame felt by people with HD (BPS, 2024). Participants expressed a lack of

faith in what services could offer and this came across in low confidence born of experiences in which they did not feel heard.

Six of the eight participants had opened up to others in a support group. This is a significant finding; sharing is therapeutic, acceptance from others dissolves shame and the comfort of being understood is uplifting (Beard *et al*, 2024).

All eight people found it difficult to access help. Barriers included; not fitting what was on offer, lack of internet access, not meeting thresholds, not being ill enough or there not being any funding available.

It is clear from this study that services are inept at providing interventions for this group. Participants reported too much focus on pharmacological routes. One individual had received CBT and described it as unhelpful, not geared towards them.

Decluttering services were desired but failed to meet needs appropriately. Participants reported an over-emphasis on the stuff, leaving them feeling overlooked as people. The antidote to these barriers according to this study, is for a compassionate, caring, human approach.

Interestingly, most participants had accessed therapy for other issues. The authors suggest that the stigma attached to the label, 'hoarder' is a barrier to self-awareness and appropriate help-seeking. This point is exacerbated by a mistrust of services, crippling shame and fear of judgement which negatively impact on motivation.

The penultimate sentence of the report calls for clinicians to be more person-centred. The conclusion that professionals should strive to build a non-judgmental and compassionate relationship is consistent with the Rogerian (1951) approach to counselling. Focusing on the person and not the clutter is the central message from this study.

The researchers did not use any established tools to gauge the degree of the hoarding such as the Clutter Image Rating Scale (CIR) (Frost *et al*, 2008) or the Saving Inventory Revised (SIR) (Frost *et al*, 2004). These might have clarified some participants' uncertainty over whether their hoarding was a problem or not. This ambiguity calls for further research as there may be a connection between self-description in this regard and the type / frequency of help seeking.

Suggestions for further research include exploring the therapeutic relationship in delivering treatments; this is consistent with the aim of the present research.

PAPER 3: Acceptability of treatments and services for individuals with hoarding behaviours.

This 2016 American paper is anomalous with 203 participants with HD and a questionnaire approach. The cohort being 80 percent female with a mean age of 47 is unrepresentative of general presentation of the disorder.

A Likert scale questionnaire offered descriptions of 11 treatments and services. The three most preferred were; CBT, professional organiser and use of a self-help book. Notably, these barely made the cutoff score of six, suggesting a lack of enthusiasm or even ambivalence among participants.

Established self-report scales were used including the CIR (Frost *et al*, 2008) and the SIR (Frost *et al*, 2004) relating to hoarding, and the Depression Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1993) to assess mood. The authors undertook a thorough, systematic search to decide upon the 11 options offered to participants. A focus group of experts was convened to agree the wording of the questionnaire in order to obviate bias. All these points are explained in detail in the article, affording it an air of robustness and validity.

The qualitative data were coded by two of the researchers. The process is not attributed to any established methodology and is not elaborated in the text which is unfortunate given the standards previously alluded to. A supporting quote is offered for all but one of the 11 treatments and services under consideration, however none are particularly illuminating.

The participants' mean score on the CIR was three point six out of a possible nine which many practitioners would not consider to be clinically significant. For instance, the authors of paper 4 do not regard anything under four to represent a problematic level. This is a flaw as the researchers do not extrapolate whether those more severely affected have different attitudes to the acceptability of services and treatments.

A third of participants had not experienced any of the 11 services and treatments and of the rest, the most commonly tried were; a self-help book, medication and CBT.

The factors which made a service or treatment acceptable include; it being personalised and specific, the participant being held accountable and belief that it works. Factors which

influenced a service or treatment being unacceptable include; if it entailed the prospect of emotional pain, doubts about efficacy and lack of control over the process.

The outcomes would have more value if the research focused on people who had experienced at least one of the 11 services or treatments. There is ambiguity in the findings e.g. does being held accountable mean being challenged? If so, that may lead to a power imbalance and loss of autonomy. The use of a Likert scale questionnaire was inevitably prescriptive and precluded any subjective expression of distress.

The authors are diligent with their awareness of limitations, in particular the need for in-person evaluation of clutter to ascertain whether the HD is clinically significant which the study claims to be the case based on self-reported scales.

The report contradicts itself claiming in 2.1.3. in respect of the 11 treatments and services, "Each description included information about risks, benefits, cost, and time commitment." However, the discussion section states the descriptions "did not include information on relative cost or quantify the amount of time spent on behavioural interventions". This is significant as such information may have impacted on participants opinions.

Arguably, this study would have proved more fruitful with far fewer participants and a qualitative methodology seeking, without limit or constraint, to understand the treatment and support preferences of people with HD. Participants could only choose from the 11 options presented, basing decisions on descriptions rather than experience.

PAPER 4: Older adult hoarders' experiences of being helped by volunteers and volunteers' experiences of helping.

In common with paper 1, this 2018 British study considers the experiences of people with HD being helped by volunteers. While this is not formal, professional, nor therapy it is arguably therapeutic and the findings relevant to the aim and objectives of this review.

Seven volunteer helpers and four people with HD made up the participant cohort. As with paper 1, the balance would arguably be more impactful reversed. Interviews were conducted and analysed using IPA (Smith, Flowers and Larkin, 2022). Again, the importance of the relationship between client and volunteer is paramount. This was built through talking and allowing clients to have control of their process.

Volunteers received a half-day training on hoarding and while decluttering could be involved, the focus of the support was client-led. Notably, the three researchers all hailed from a cognitive behavioural background which is acknowledged as an inevitable interpretive lens.

Offering space to talk proved highly valuable while the freedom from any corporate constraints was facilitative of relationship building. Both groups felt the support benefited from the absence of any results-based pressures. It also engendered an egalitarian atmosphere as the volunteers had no powers of sanction or enforcement.

The study suggests this model helps instigate virtuous circles of positive reinforcement. Building trust and allowing clients to direct the process led to improvements through sorting and decluttering. Positive consequences reported include increased self-esteem.

Decluttering is presented as a therapeutic process. The authors note the need to focus on the person rather than the hoarded items as vital. The unconditionality of the volunteers was conducive for therapeutic change and brought quality of life benefits.

With this indicating that professional status may be a barrier for people with HD, the authors suggest collaboration with third sector / voluntary organisations could be a productive addition to any multi-disciplinary provision.

The four participants with HD had a mean age of 75, were retired and two were married (therefore likely less socially isolated though this is not explored). It is possible they chose to take part in the research due to the positive feelings they had about the support. The volunteers who were interviewed had worked with many other clients and encountered barriers such as paranoia, suspicion, lying and being kept at arms-length. This is a stark counterpoint to the favourable quotes from the four clients who were interviewed.

This study positions itself as the first to explore the experiences of people with HD receiving support. It offers a valuable contribution with findings that are relevant to the present review of literature.

PAPER 5: Therapist and patient perspectives on cognitive behavioural therapy for older adults with hoarding disorder: A collective case study.

This 2012 American paper was published prior to the inclusion of HD in the DSM V (APA) in 2013. It earned its place because it offers a qualitative view of CBT which, as already

established, is the only intervention recommended for HD. This represents a gap in which the voice of the client remains unheard amid a sea of quantitative evidence.

The research is a collective case study and differentiates itself by the variety of data it absorbs including observation, treatment notes, feedback and a focus group. The authors explain the methodology thoroughly, in particular the triangulation and analysis which afford the findings an air of reliability.

Seven women and five men with a mean age of 73 made up the participant cohort. It is notable that the authors refer to the participants as patients rather than clients. While this is a cultural norm for the USA, the inherent power imbalance it implies juxtaposes poorly against the other studies.

In common with the other papers, participants cited the therapeutic relationship as an important aspect. Exposure exercises were also considered to be useful. Completing homework is a central aspect of CBT but compliance here was poor. Three of the 12 made no attempt and nine tried but failed to complete tasks. The authors do not hypothesise whether this might be because of a condition (e.g. ADHD) or possibly a subconscious recoiling from negative associations with school days. These notions are perhaps supported by the reported embarrassment and guilt the participants felt about their inability to complete set tasks. Whatever the reason, this suggests that the homework demands of CBT may not be compatible with HD.

Three participants were not compliant with the session agendas, refusing to complete exercises. The study discusses the use of psychoeducation and redirection in the case of "Ruth" who wished to discuss abandonment issues. It is possible that the therapist's dogged adherence to the CBT script may have made this participant feel disempowered and unheard; this is not considered.

The researchers acknowledge that people with HD struggle with executive functioning, decision-making and acquiring and retaining new information. It is conceded that such facets may have contributed to non-compliance.

All participants failed at tasks which demanded cognitive agility and were unable to alter any belief or behaviour despite evidence. Irrespective of this, the authors do not consider that

CBT may be unsuitable for people with HD. In fact, all 12 participants indicated that the concepts, strategies and tools offered were too abstract for them.

On a more positive note, the direct exposure exercises were deemed the most helpful element of the treatment. Ten participants reported feelings of accomplishment and three were amazed they could tolerate discarding of possessions. While this is encouraging and doubtless beneficial, the success was not maintained and six months later there was no change.

The human elements of the experience proved valuable to the participants. Encouragement, support, trust and being non-judgmental are all referred to as facilitative. Home visits were the other component which participants valued. The reasons are not considered but might relate to relief; for three of those taking part, no-one else had seen inside their home in more than a decade.

Among the conclusions it is suggested that CBT should be modified for people with HD. The study also recommends providing motivational interviewing and psychoeducation at the start of therapy.

This study is thorough, it casts a wide net to incorporate multiple sources and triangulation to examine its subject. However, the authors repeatedly note how people with HD are neither comfortable with, nor cognitively suited to, the CBT approach. The suggestions for modifications they make do not appear to heed their own observations. The negative reports of the participants might help explain why there is such a paucity of qualitative studies into CBT for HD.

PAPER 6: Working together when the problem is multi-faceted: understanding inter-agency working for the benefit of people with hoarding problems.

Multi-agency working is the context of this British paper from 2022. Researchers evaluated outcomes of a conference set up to assist professionals in working with HD. The conference had a predominantly CBT focus, in line with the prevailing understanding, medical advice and guidance.

This is a mixed methods study; the qualitative aspect being the thematic analysis of a focus group of people with HD (or affected by it) considering the results of the conference. Of the

11 members, nine had personal experience of HD and two were family members or carers. The focus group lasted for 84 minutes with one member in person and the other ten online.

While this study meets only two of the objectives of the present review, the views of people with HD about how they want to be supported represents valuable data.

The focus group expressed the urgency for greater understanding of hoarding and a need to reduce stigma and judgement from professionals and society at large. Members also highlighted the shortage of funding for MH support and long wait times. The limitations of available help were considered, in particular the inappropriateness of local councils suggesting clearance as a type of support.

Other focus group findings include difficulties with accessing help from the third sector, lack of information-sharing between agencies and the importance of improving communication with the person with HD.

The authors emphasise how important it is that people with HD feel understood and believe that professionals are working together to support them.

These findings echo the other papers in that people with HD want to be understood and heard without judgement and to have access to practical and psychological support without long waiting lists or multiple referrals.

Limitations recorded include the lack of any measure to ascertain the level of the hoarding experienced by those in the focus group. Allowing participants to explain their own barriers and facilitators to support along with their preferences would have added to the findings.

Overall, the rigour and methodology are sound but the voices of those affected by HD is neither loud nor precise enough.

SYNTHESIS OF THEMES FROM THE SIX PAPERS

The consensus is that the therapeutic relationship is valued above all else. Establishing trust helps to dissolve the alienation and isolation experienced by people with HD as a result of the shame, guilt and judgement they feel. This is the case whether the intervention is therapeutic or decluttering with a volunteer.

Fear of judgement and the possibility of sanctions or enforcement (eviction, clear-out, fine etc) can be barriers to accessing help for people with HD. Papers 1 and 4 obviate these concerns with voluntary support in which professional roles, timescales, financial pressures and corporate targets are absent.

Individual CBT (paper 5) does not emerge from the review as optimally suited to people with HD. The homework and written tasks were roundly disparaged by participants, consistent with issues with executive functioning but also as a potential affront to autonomy.

People with HD want help but it has to be the right kind. Anything that disempowers, stigmatises or judges is unacceptable. Talking and compassion are vital, clients wish to feel understood and cared for. The label, 'hoarder' is seen as dehumanising, potentially equating the person with the accumulated clutter.

Person-centred qualities are desirable, including being non-judgemental, allowing the client to be in control and not imposing an agenda or timetable.

DISCUSSION

This review reveals the dearth of research into the therapeutic experiences of people with HD. Compromises had to be made to gather the six papers which serves to evidence the gap.

Only one paper could be found which specifically considers the therapeutic experiences of people with HD. This was limited to CBT and published in 2012, before HD appeared in the DSM V (APA, 2013).

The papers reviewed do not represent a level playing field. There is no consistency in definition of diagnosis nor measures of distress with varying thresholds for what constitutes clinically significant hoarding.

The unique phenomenology of a person with HD lends itself to qualitative study, yet this review shows how lacking that is in relation to therapeutic interventions.

The support that people with HD want is often at odds with the needs of services and their funders. The absence of time-limits and results-driven outcomes is beneficial but rare.

People with HD often have to wait a long time for therapy and then may receive CBT from which few will achieve clinically significant improvements (O'Brien and Laws, 2025).

IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

Clients want to be heard without judgement and to be supported with person-centred values towards their own individual resolutions, which cannot be externally imposed.

Building trust is paramount to a person with HD. They feel shame, guilt, isolation and self-loathing, all of which can be reduced through empathic communication (Hughes and Blundell, 2024).

This review suggests that clients with HD are ill-suited to the strictures of CBT and improvements tend to be short-term. This requires further study.

Research is needed to assess the long-term impacts of interventions and to consider alternative approaches, possibly combining therapy, group support and volunteer decluttering.

LIMITATIONS

Excluding quantitative reports and the small number of qualitative studies to review, inevitably allows only a thin slice of experience to emerge.

This review sought to illuminate the therapeutic experiences of people with HD, extending this to include decluttering and help-seeking is a dilution of intention and generalisability.

Participants in the reviewed papers are not representative, being more female and younger than typical presentation. The lack of consistency in the definition of problematic hoarding is a further limitation.

The theoretical bias of the author towards the person-centred approach is obvious throughout the analysis. A reflexive or bracketing statement would have been advantageous had the word count allowed.

CONCLUSION

This review highlights the lack of research into the therapeutic experiences of people with HD. This vulnerable group want support, but it has to be the right kind. In order to fully understand what that means, work must be done to explore their therapeutic experiences.

Word count total minus abstract and tables: 4808

Chapter 3: Research Paper

“SCARED OF THE EMPTINESS” - EXPLORING THE THERAPEUTIC EXPERIENCES OF PEOPLE WITH HOARDING DISORDER: AN INTERPRETATIVE PHENOMENOLOGICAL STUDY.

This manuscript has been written for submission to:
Counselling and Psychotherapy Research
following that journal’s instructions to authors.

ABSTRACT

BACKGROUND AND AIMS

Hoarding Disorder is a mental health condition defined by the compulsive acquisition of items, regardless of value, coupled with the inability to discard. This negatively impacts on day-to-day life and causes distress. It affects around 2.5% of the UK population.

This study set out to explore and evaluate the therapeutic experiences of a small group of people who have hoarding disorder, using their own words.

METHOD

Four people were recruited to take part through appeals via two established organisations along with direct approaches to hoarding support groups. Each was interviewed for approximately one hour by online video call. These were recorded, transcribed and analysed.

RESULTS

Participants described the loss of safety and certainty in their lives which contributed to the hoarding behaviours. The positive aspects of therapy include increasing self-awareness, understanding and compassion. The negative aspects include damaging experiences akin to being bullied as well as disappointment and unmet expectations.

CONCLUSION

People with hoarding disorder value the qualities of connection and validation offered by the therapeutic relationship. While participating in therapy helps reduce distress in the short term, this study indicates that it does not lead to lasting improvements in the hoarding behaviour either in terms of acquisition or discard.

KEYWORDS

Hoarding, hoarding disorder, therapy, counselling, therapeutic experiences, IPA

INTRODUCTION

Hoarding Disorder (HD) affects approximately 2.5% of the UK population (Postlethwaite *et al*, 2019). It leads to social isolation, difficulty with day-to-day functioning (Bedi and Woody, 2025) and is associated with co-morbidities including depression and anxiety disorders (Frost *et al*, 2011) as well as suicidal ideation (Gil-Hernandez, 2025). Often starting in childhood or adolescence it frequently does not come to light until decades later (Steketee, 2020), hence is usually associated with older people (BPS, 2024). The depth of attachment to the hoard can make it difficult for the person to differentiate their sense of self from it (Kings *et al*, 2020, Williams, 2016).

Since HD's addition to the DSM in 2013 (APA) and later the ICD (2019), understanding has improved and awareness increased. Inevitably, the research base is still young and incomprehensive. There is a lack of qualitative evidence pertaining to the experiences of people who have HD. Much of that which exists focuses on the behaviour itself, e.g. Mulligan-Rabbitt *et al*, (2023) and Brien *et al*, (2016), as opposed to the experiences and efficacy of support.

CBT is the favoured therapeutic intervention (NHS, 2024). A recent meta-analysis of 41 studies (O'Brien and Laws, 2025), 32 of which were CBT, points to impressive pre-post effects but with very little clinically significant improvement. This accords with earlier reviews carried out in 2021 (Rodgers *et al*) and prior in 2015 (Tolin *et al*) both of which reported encouraging effect sizes but with the latter conceding that post-treatment, improvements were not sustained. The small number of RCT's, longitudinal research and studies involving non-CBT interventions highlight how nascent understanding is in this field.

Trust emerges as crucial in a study by McGrath *et al* (2024) in which eight participants discussed their help-seeking experiences. All had struggled to find suitable support and felt unheard but six had benefitted from membership of a peer-support group. Negative experiences were reported with CBT and decluttering, further emphasising feelings of isolation and hopelessness.

A 2024 American study of a voluntary decluttering scheme (Noyes *et al*) emphasises the need for clients to be seen and heard, not judged, and to retain autonomy. These person-

centred attributes (Rogers, 1951) are reflected in a British report from 2019 (Ryninks *et al*) which emphasises the person as an individual rather than a problem to be solved.

While quantitative evidence supporting CBT as effective for hoarding is easy to find (e.g. Chandler *et al*, 2019, Pollock *et al*, 2014), experiential detail is far less prevalent. A 2012 American study (Ayers *et al*) highlights the difficulty clients have assimilating CBT concepts and tools. Discard successes were few and short-lived and the study indicates that CBT may not be a good fit for people with HD. Participants did however value the non-judgemental human contact considering it facilitative and validating.

Having identified the gap in research, this study aims to explore, consider and evaluate the therapeutic experiences of a small group of people who have HD.

The objectives are to:

- Ascertain how the intervention was received by, and impacted on, participants
- Assess whether the process alleviated distress and/or led to any change
- Identify barriers and facilitators to therapeutic change
- Consider implications for long-term support

In summary, the question this research seeks to answer is:

What are the experiences and effects of talking therapy on people who have hoarding disorder?

METHODS AND METHODOLOGY

RECRUITMENT

A purposive sample of between 3-6 adults was sought; the target population being adults who have:

- Lived with hoarding-related impairment of functioning for at least ten years
- Undergone any kind of therapeutic intervention

Homogeneity was not considered beyond these points and no constraints imposed in terms of defining the extent of the hoarding nor interpretation of the term, “therapeutic intervention”. Recruitment was conducted thus:

- An appeal on the website of Hoarding UK (see appendix 5)
- A request via the director of Hoarding Disorders UK
- Emails to facilitators of support groups

Four people (two female, two male, mean age 67) responded and met the inclusion criteria (see appendix 6). The participants were geographically disparate and unknown to each other.

METHODOLOGY

The lived-experience, meaning-making nature of the inquiry align well with the chosen methodology, IPA (Smith, Flowers and Larkin, 2022). With its emphasis on interpretation, IPA makes a virtue of researcher subjectivity. The double hermeneutic (Smith, Flowers and Larkin, 2022, p. 23) being influenced by the researcher's professional life as a hoarding support practitioner and a person-centred counsellor.

Living with HD has complex identity and existential repercussions (Tinlin *et al*, 2022) and can only be understood through a phenomenological lens (Braun and Clarke, 2013). IPA is iterative and inductive, offering a scientific underpinning within an interpretative frame (Finlay, 2015). These qualities underscore the intentions of the researcher.

The present study aims to meet the four indicators for IPA laid out by Nizza *et al* (2021) as shown in table 5 below.

Table 5 - The four quality indicators of good IPA

1	Constructing a compelling, unfolding narrative
2	Developing a vigorous experiential and/or existential account
3	Close analytic reading of participants' words
4	Attending to convergence and divergence

PROCEDURE AND ANALYSIS

The researcher applied for and received ethical approval from UWTSD (see appendix 7). Participants were emailed relevant documentation including an information sheet and consent form (appendices 8 and 9 respectively). An interview schedule (see appendix 10)

was developed with reference to the research question, aim and objectives. This was designed for flexibility to allow participants to lead (Flick, 2022) while retaining focus. Semi-structured interviews were conducted online with durations of 61-67 minutes and a mean of 64 minutes. Debriefing at the conclusion consisted of a checking-in with regards any impacts of the interview and offers of support or signposting. Transcriptions were pasted into Word and checked against the recordings for accuracy.

Analysis was conducted according to the steps laid out by Smith, Flowers and Larkin (2020). Initial exploratory noting was done by hand and then reproduced in electronic form. Experiential statements were added (see appendix 11), which were printed and cut out to facilitate creative dynamic grouping according to the qualities of the data (see appendix 12). Tables were generated of themes, subthemes and supporting quotes. Subsequent to the individual analyses, the process was repeated to discern group themes (see appendix 13) and ultimately inform the findings and conclusions of the research.

RESULTS

The analysis of the interviews resulted in four superordinate themes, each with sub themes as shown in table 6.

Table 6 – Themes and subthemes

SUPERORDINATE THEMES	SUBTHEMES
1. SEEKING SAFETY – FACTORS CONTRIBUTING TO THE HOARDING BEHAVIOUR	<p>1.1 Loss, distress and the permanence of possessions</p> <p>1.2. Inertia, fear, indecision and avoidance are blockages to change</p>
2. EXISTENTIAL ASPECTS OF HOARDING: IDENTITY, AGENCY AND CONTROL	<p>2.1 Worries about the future, death and legacy</p> <p>2.2 Feeling overwhelmed and powerless</p>

3. POSITIVE THERAPEUTIC EXPERIENCES AND THE QUALITIES OF EFFECTIVE SUPPORT	<p>3.1 Being seen and heard and feeling understood are beneficial even if the hoarding persists</p> <p>3.2 Effective therapeutic support is empathic, experienced and skilful</p>
4. POOR OUTCOMES, NEGATIVE OR UNHELPFUL THERAPEUTIC EXPERIENCES	<p>4.1 At its worst, therapy can be a damaging experience</p> <p>4.2 Disappointments and unmet expectations</p> <p>4.3 CBT did not deliver any benefit or change in the hoarding</p>

Group themes were identified according to convergence but also to represent significant features and honour individual experience (Smith, Flowers and Larkin, 2022).

The first two themes offer contextual background and describe the multi-factorial nature of HD. The analysis shows that the quality of the relationship is key as are being seen, heard and understood, but these things do not translate to long-term resolution of hoarding.

THEME 1: SEEKING SAFETY – FACTORS CONTRIBUTING TO THE HOARDING BEHAVIOUR

1.1 Loss, distress and the permanence of possessions

Loss is central for all participants and contributes to how they understand the hoarding instinct. Objects can be calming when confusion and chaos abounds and this often starts at a young age.

Kate: "... my coping mechanism was that I got out all the stuff that was in the bottom of my wardrobe and I spread it all over the floor."

Yvonne: "... it was difficult to make sense of my home environment..."

Losses are compounded by life events and bereavement can be a catalyst for awareness that the clutter is in control. Losing autonomy over one's environment is a stressor, yet with HD the paradoxical response is a powerful drive to keep everything.

Simon: "... it really came to my attention in 2003 when my mum died. I was splitting up with my wife and I had two flats to clear."

Oliver: "... my father died and then my mother died and when the family home was cleared, I also accumulated some material from that..."

1.2. Inertia, fear, indecision and avoidance are blockages to change

The innate tendency to self-soothe is acknowledged in various ways in the transcripts. Regretting disposing of something is agonising but negative feelings are easy to assuage by keeping everything. In this way fear and indecision hold sway and the hoarding becomes reinforced.

Yvonne: "... there's an element of... safety that you use these possessions and this hoarding is about protecting yourself."

Simon: "Everything's got a value of nothing but at the same time it's got a value of priceless... if you don't know what to do with something, it's best just not to do anything."

Fear is a powerful motivator. Rational arguments for decluttering yield to a visceral dread; the risks are too great and the stakes too high.

Oliver: "I can think through things to the point of almost doing something, but then bottle out or lose my nerve, or, afraid of making the wrong decision..."

These responses speak to how complex HD is and how elusive change can be. When possessions represent identity and the avoidance of distress, it is logical their owners will be driven to keep them. So emotive is the issue that the wrong kind of help (e.g. overly-directive), can feel threatening and lead to further rigidity in the hoarding rather than loosening.

THEME 2: EXISTENTIAL ASPECTS OF HOARDING: IDENTITY, AGENCY AND CONTROL

The second superordinate theme encompasses the overwhelming nature of the disorder alongside the existential angst it inspires in relation to identity, legacy and impact.

2.1 Worries about the future, death and legacy

Hoarding entails a compromising of autonomy over one's environment. This is disempowering and depressing yet difficult to resolve while the possessions fulfil an important emotional purpose.

Simon: "I think I'm scared of the emptiness. I think that hoard represents me somehow and when it's gone, that'll be me gone..."

The sense of feeling trapped is evident in the interviews along with a profound dread in terms of legacy and environmental impact.

Oliver: "... looking in this heap of... stuff that's just dumped into this huge concrete pit with a big JCB just shovelling it away, I find... that's, that's, my impact, that's potentially my impact on the environment..."

Yvonne: "It would be terrible to leave all these things if, if, I were to get really ill or, you know, leave the planet..."

2.2 Feeling overwhelmed and powerless

Oliver (the oldest participant at 77) expressed his desire to "die tidy" however rumination and procrastination tempered his optimism:

"I overthink things and that's certainly what I do. So, I think a lot about things but never enact them."

Feeling overwhelmed is a common sentiment contributing to a resignation that things cannot improve.

Yvonne: "Let's face it, I have actually got so much stuff here and I don't know what I'm going to do really."

Simon: "I've gradually whittled it down. But now what I've got is, if you think... like the... the core of it, and I find it impossible to deal with."

These quotes illustrate another paradox of HD; keeping possessions is an act of control yet leaves the person feeling ashamed and powerless.

THEME 3: POSITIVE THERAPEUTIC EXPERIENCES AND THE QUALITIES OF EFFECTIVE SUPPORT

All the participants considered therapy worthwhile. This is despite only one interviewee reporting tangible results with regard to motivation for discarding.

3.1 Being seen, heard and understood are beneficial even if the hoarding persists

At the time of the interview, Simon was receiving online CBT and spoke effusively about how deep the learning and insights were:

“It makes me realise... not that I'm normal, but that the process is, you know, that you know, it's, it's documented. And so, I feel better. It's like I can see myself in these stages and I can, I can understand and know that this is normal.”

This points to how important it is to destigmatise hoarding. Simon struggles to see himself as “normal” but his therapist is encouraging movement in that direction. Simon also gains from therapy a sense that change is possible; he feels understood and therefore has confidence in her:

“... it's giving me hope that things can be achieved. It helps that I've got somebody else that absolutely understands the problem.”

And this hope does galvanise, at least in the immediate aftermath of sessions, into action:

“... she's gave me a bit of self-belief that I can do this, that even if I do it in little amounts, it's doable... and then at the end of our session, nine times out of ten, I'll actually go in there straight away and do something.”

The other participants had also received CBT. While none considered it successful as the hoarding persisted, Oliver pointed out other benefits derived from the process:

“... she was kind, she was patient, she listened to me, you know? That... this, this thing of really getting into the other person.”

The value of being heard and having space for sharing deep feelings is a positive outcome across the board.

Yvonne: “... it's very helpful to talk now you know, because this is the, this is where I'm at and it's good to recognise that I've had these counsellors and this counselling which has been beneficial...”

Yvonne however struggled to specify how the counselling had helped. Her language at times suggesting a critical self-image hampers the process and impacts other areas of life:

“... it's good to share and I'd like to be more prepared to be able to, to, to engage in conversations with people and not be so, hoarding, you know, such a hoarder in the worst sense of the word.”

Oliver's recent therapeutic experience related to a peer support group, fostering self-awareness:

“... people provide you with the feedback you perhaps can't even see or don't want to see, makes you think about things. So, I have definitely on a number of occasions gained insight...”

3.2 Effective therapeutic support is empathic, experienced and skilful

The interviewees offered a clear vision of the qualities they desired from effective therapists. Many aspects of the person-centred approach (PCA) are evident, especially empathy and being non-judgemental (Rogers, 1951). However, one key facet is rejected in that the participants want to be in the hands of someone skilful, who has knowledge and experience, thereby offering expertise from which they can learn. This is antithetical to the PCA which attests the client is the only expert in their own experiencing (Rogers, 1957). Person-centred counsellors are non-directive and do not give guidance or advice, which is precisely what Simon valued from the person delivering his CBT:

“... somebody that I know that is accountable, that is reliable, that is there for me, is non-judgemental and is willing to offer great advice.”

Being good at listening and offering empathy is seen as a given, intrinsically valuable, approaching the person with no preconceptions or judgements.

Kate: “I think it was beneficial in the sense that I needed somebody to talk to...”

Yvonne: “... meeting somebody that... completely fresh approach, as though, you don't know me...”

But HD is complex and the sense from the interviews is that empathy and active listening are not enough to make a dent in the hoard.

Kate: "I have a very big problem with person-centred counsellors, and I think probably most of them have been person-centred, is they seem to have this theory that if they let me talk and talk and talk, I'm going to work it out for myself."

It is noteworthy that Kate's criticism is born of experience having seen more than 20 professionals. Consequently, she has a clear view of what good therapeutic support looks like for HD and that means knowing the subject:

"... they need to be experienced and qualified and not be doing it as an extra add-on to whatever else they do. They've got to be empathetic and they've got to understand hoarding."

Simon (having CBT at the time of the interview) felt strongly that his therapist was offering something bespoke and relevant:

"I think that's probably because of her skill. You know, she understands me, understands my requirements and it, and it is built around me."

Again, the suggestion is that HD is a speciality and to be effective the therapist requires subject-specific expertise. This notion extends to peer-support where a trained leader is considered essential.

Oliver: "... the person helping you needs to be qualified to understand all the subtleties... that's where the peer group fails because we don't have the understanding of people's psychology."

Kate has a poor opinion of the helping professions, considering many to be a waste of money. However, she retains a conviction that understanding the roots of an issue is important:

"I still believe that the place that you, you start is trying to sort the problem out, so counselling or therapy, you need somebody good who's, who knows what they're talking about, not CBT."

THEME 4: POOR OUTCOMES, NEGATIVE OR UNHELPFUL THERAPEUTIC EXPERIENCES

Oliver: "It's very, very difficult for hoarders to change. Very, very difficult."

Yvonne: "... it doesn't sort of solve everything. No, whatever solving is."

Kate: "I didn't find them helpful at all."

The interviewees express varying degrees of disappointment that therapy did not alleviate the hoarding. Yvonne is clearly ambivalent in terms of what the notion of "solving" might mean, Oliver is reflecting that positive change can be out of reach and Kate is unable to find a good word for any of her 23 professional helpers.

4.1 At its worst, therapy can be a damaging experience

Therapeutic support can be belittling, unpleasant and even traumatic. Kate described sessions with a psychologist who came to her home, of whom she states:

"I don't think he shouted at me but he did make me feel bullied. I felt like I was in front of the headmaster for doing something I shouldn't be doing..."

Kate described him in the interview as evangelical with a resolute self-belief which made her feel she was wrong. Despite the aforementioned desire for therapists to have expertise, this demonstrates how an unhealthy power dynamic can be counter therapeutic. Kate felt the psychologist had an agenda and was only interested in throwing things away. Eventually she told him that all she wanted was some support to which the dismissive reply was, "I don't do support".

This kind of unwelcome directivity was seen in other interviewees who had tried employing professional decluttering services. While not a specifically therapeutic transaction, the experiences are still relevant and revealing.

Simon: "... it didn't work for a number of reasons. She was quite bullish..." "... it almost felt quite threatening."

Yvonne: "... the guy that came, he was... quite... brutal... I was a bit... unhappy with the way he, he, sort of stormed in and wanted to take things..."

4.2 Disappointments and unmet expectations

Kate's 23 professionals inevitably blur into a mass but with a common thread encapsulated thus:

"... I went through the story from the beginning, you know, what had happened, and then I expected them to say something very profound, and they didn't."

Multiple therapeutic disappointments over decades led Kate to a reduced opinion of the profession which was at times disparaging:

“I had a lot of the sort of women who do it as a little part-time job. You know, they advertise in the paper or somewhere and I'd go and see them.”

“I'm not necessarily saying all counsellors are useless, but... I did go there with the object of getting some help which I didn't receive.”

Kate is directing some blame towards the counselling profession - for not having the skills, qualifications, experience or understanding to support someone with HD. Yvonne takes a different angle, seemingly blaming herself for lacking the eloquence or resources to articulate her inner world:

“... there's only so much that you can really say because there's some things that you can't put into words, aren't there?”

For Yvonne this combines with a feeling of frustration; she uses words like ‘worthwhile’ and ‘beneficial’ without explanation and then follows up with criticism as this quote demonstrates:

“I have had some good counselling experiences. You know, it's, it's, sometimes been expensive and difficult to get there and I feel angry sometimes, you know, with it, and wish I didn't have to have to have therapy all the time...”

The theme of unmet expectations continues with Oliver in his discussion of peer group support. Boundaries are hard to maintain and there is potential for informal support to become burdensome or ethically challenging:

“... we can help each other to a degree, but have we the professional expertise to do so? We don't.”

4.3 CBT did not deliver any benefit or change in the hoarding

As previously stated, research implies the requirements of CBT are poorly received by people with HD (Ayres *et al*, 2012). This can impact negatively, becoming something else the client feels they have failed at.

That said, Simon was receiving CBT at the time his interview was recorded and was ebullient about it. He praised the therapist and described being energised by the motivation it gave him in the moment. However, his testimony is included in this section because it highlights some shortcomings of the modality for this client group.

Simon: "... everything that we've done, I've sort of put in a little folder. So, I've got all that to go back to, but that's where, if I'm honest, I don't. I forget about it..."

"... she has gave me tools, but I can't remember them. It's on, on, on, the, the print outs that she's gave me."

"... she sent me things to do and then I failed miserably. I just haven't been able to do them either because I've forgotten where the things are or it's just too hard."

These downsides are incidental for Simon because for the first time he felt seen and understood. His quotes however suggest that the methods are transient, the homework not done, the tools soon forgotten and the paperwork lost in the hoard.

Simon's language is evocative of the experience of adults with ADHD, also reflected by the other participants (see the discussion section). Something comparable can be heard from Yvonne recalling her experience with CBT:

"I don't think it was very hugely effective, I mean, looking back, I can't see... other than I've got a file about it somewhere and I can't even find it..."

It is ironic that what endures from CBT for hoarding is a file of paperwork which has been subsumed into the clutter.

Oliver also spoke of his CBT experience as failure; articulated as a product of the chaos in the mind of a hoarder, reflected both in their physical and cognitive landscape:

"... the impression I have is that CBT can fail where the client or the patient doesn't fully engage in the process and do the homework and do the work, and I'm... and it's all about avoidance and I think people naturally avoid the discomforting things and they don't do it."

Kate reported an unpleasant experience with CBT, bad enough that she would actively avoid it in the future:

“... I didn't like that at all. I felt I was being bullied, which is basically what the original problem was, that I was being bullied...”

Inevitably this was not an experience which led to any constructive change. While not explicitly stated, it may have had the opposite effect, especially if Kate had been upset to the point of seeking refuge in comforting behaviours, specifically, hoarding.

DISCUSSION

LOSS

This study, along with many others (e.g. Fontenelle *et al*, 2021, O'Connor, 2014) points to loss as a contributory factor in the development and perpetuation of HD.

The participants describe possessions as representing sanctuary in childhood and permanence in bereavement. The drive for self-determination and safety is evident, extending to therapeutic support and whether or not it is deemed successful. Qualities which soothe are welcomed; being seen and heard, understood, not judged, while those which are experienced as controlling or directive are eschewed. Interventions which symbolise or amplify loss are undesirable, sometimes even traumatic. This underlying mechanism, evident in all four interviewees, suggests elements of unprocessed emotion to which any therapeutic intervention for HD must be attuned.

CBT

The findings of this study challenge the hegemony of CBT as the de-facto support for HD. All participants reported difficulties with three alluding specifically to discomfort / avoidance with its demands. None reported long-term change to the hoarding behaviour (notwithstanding the participant who was receiving CBT at the time of the interview).

Unprompted by the researcher, three participants referred to either a diagnosis or suspicion of ADHD (see appendix 14) and the fourth displayed patterns of speech which were noticeably tangential and rambling. This is consistent with research by Grassi *et al* (2023) which found adults with ADHD show a higher prevalence of HD than adults with OCD. Worden and Tolin (2023) also concluded that people with HD report more symptoms of ADHD in childhood than those with OCD.

The latest studies involving fMRI highlight the neural regions associated with maladaptive beliefs which can be affected by CBT (Knowles *et al*, 2024). It is possible that the HD brain may be predisposed to preventing the very engagement which is so vital for successful CBT (Worden *et al*, 2024).

EMPATHY IS NECESSARY BUT NOT SUFFICIENT

The therapeutic relationship is highly valued; feeling normal and understood help to alleviate distress. However, the findings suggest insight is gained from expertise, guidance and even advice, qualities not associated with the humanistic tradition (Wilkins, 2016). Conversely, more directive approaches can be experienced as over-bearing.

HD is complex and the present research suggests people with it want therapists with experience and understanding to help them, along with specific skills which they may feel they lack. Offering all this with empathy and non-judgementally is a formidable balance to achieve and, perhaps inevitably, most professionals will fall short.

IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

Research into treatment for HD is incomplete and potentially misleading without longitudinal perspective. This is relevant in terms of both intervention delivery and review and is an urgent gap to be addressed.

The wrong help can be worse than no help. If people with HD are not good candidates for CBT, long-term outcomes will always be poor. Indeed, the failure may be internalised and lead to self-blame, negative emotions and reversion to established patterns of self-soothing, i.e. hoarding. The suitability of CBT for HD should be revisited to incorporate the latest understanding of neurological structures, cognitive preferences and emotional tendencies.

The prevalence and effects of neurodivergence on people with HD requires further research. It is not yet definitively known if ADHD is a comorbidity or part of the disorder itself (Worden and Tolin, 2023). In his interview, Simon expressed a desire to try ADHD medication. What little research exists on this topic suggests ADHD medications can improve hoarding symptoms (Grassi *et al*, 2016) but further trials have yet to be undertaken.

People with HD want professionals who have subject-specific expertise and to be treated with compassion, understanding and empathy. The quality of the relationship is important but without appropriate support, it is not of enduring value.

Optimal therapeutic interventions for people with HD might be found within a pluralistic approach, something which would require testing. It may be possible to offer bespoke therapy for HD, tailored according to issues such as neurodivergence and the nature of past trauma. These are issues of which practitioners must be aware.

The idiographic nature of this study is inevitably tethered to IPA's "commitment to the particular" (Smith, Flowers and Larkin, 2022, p. 24). Next steps will necessarily involve more participants and a broader methodological scope.

LIMITATIONS

The researcher, being both a hoarding support practitioner and a person-centred counsellor, approached the study with a comprehensive set of pre-existing beliefs. While IPA accommodates researcher subjectivity, background and bias leave footprints; the interpretation and findings are inevitably impacted accordingly.

All four people who responded to the appeal took part in the research. This small, purposive sample cannot make any claims to represent the huge population of people in the UK with HD. IPA does not seek to make generalisations (Smith, Flowers and Larkin, 2022), something not made fully explicit in the present study.

No standardised measure of hoarding was used to discern the diagnosis of HD such as the Clutter Image Rating Scale (Frost *et al*, 2008). Self-identification and the criteria of having lived with hoarding-related impairment for a minimum of ten years was deemed adequate.

The interview schedule, while considered and discussed in supervision, was not piloted. More thorough preparation in this regard may have proven advantageous.

CONCLUSION

The experiences of talking therapy on people who have hoarding disorder are largely positive; feeling heard and understood can alleviate distress. Benefits include improving self-awareness and combating isolation; however this study reports no long-term change either

in reduction of distress or increased discard. CBT may not be suitable for people with HD who are naturally highly disorganised and struggle with paperwork and time-limited tasks.

Word count minus tables: 4795

Chapter 4: Reflective Chapter

GETTING HERE

Fascination is a better driver of research than boredom (Kasket, 2015). My motivation for embarking on master's level study was the irresistible prospect of undertaking primary research combining my twin professional passions, namely hoarding support and counselling.

As the child of a hoarder, my emotional investment in the subject is profound and fundamental to how I would collect and interpret the words of the participants. Being a person-centred counsellor furnished me with another lens which could not be handed in at the door. All of me was involved and all of me is evident in the finished product. From the outset I attempted to direct this self-awareness towards intentional reflexivity (Hennink, Hutter and Bailey, 2020).

This context informs the entire process, including each stage of Gibbs' (1988) reflective cycle, in particular the many times when feelings (stage 2) impacted on evaluation and analysis (3 and 4 respectively).

AT THE START OF PART 2 (AND EVEN BEFORE)

My primary emotion throughout was excitement. The challenge of the unknown coupled with the perfect balance of support and autonomy offered by my supervisor provided the ideal platform. The possibility of publication and contributing to the research base in my chosen field also continues to tantalise and motivate.

I do not like deadlines, preferring to set and adhere to my own, building in copious contingency time. To that end, my first step was to draft a timetable for the project which was printed and stuck on the wall along with the research question, aim and objectives. This would be referred to constantly, keeping me focused when I felt out of my depth or at risk of wandering off course.

The time contingency bore fruit at the end of January 2025. While checking a reference I stumbled upon a new meta-analysis into psychological interventions for HD (O'Brien and Laws, 2025). This contained pertinent detail which had to be included. As usual, I conferred

with my supervisor and made the necessary adjustments. This required more judicious editing which I hope led to disciplined, concise writing.

ETHICS, BIAS AND TOUGH QUESTIONS

As a BACP registered person-centred counsellor, its Ethical Framework (2018) was already very familiar. Its Ethical Guidelines for Research in the Counselling Professions (2019) were also indispensable along with UWTSD's Research Ethics and Integrity Code of Practice (2022). The overarching concern being the vital matter of informed consent.

Completing the ethics form raised many issues. Hoarding disorder (HD) is a mental health condition (AMA, 2013) therefore defining the target population as a vulnerable group (Flick, 2014, p. 56). This was addressed based on my relevant experience in the field. The context however was new to me; the interviews were research, not therapy and this process started me thinking about the real-world implications of my proposal.

People with HD often feel isolated and worthless. Being able to offer something positive by sharing their experience *could* help ameliorate these feelings. I felt a responsibility to be professional, attentive and honest with any potential participant.

I was worried that no one would come forward but at the same time that too many would be interested. Both concerns were considered; if too few people came forward, I would approach existing or former clients and if too many responded they would be handled on a first-come basis.

In theory, counsellors should be good at qualitative research; we are comfortable with one-to-one intense conversations and attuned to all manners of emotional communication such that the synchronicity can be an advantage (Bright and Harrison, 2013, p. 23). I expected the experience to change me; becoming a researcher involves an intellectual paradigmatic shift that inevitably informs future practice (Kegerreis *et al*, 2023). IPA (Smith, Flowers and Larkin, 2022) was ideal; not just tolerating my background, but incorporating it as integral to the fabric of the methodology itself.

Beyond the aims and objectives, all sorts of questions were arising:

- Would my findings closely resemble my established view and mirror my experience?
- Would it be possible to bracket out the bias of my professional life? Did I need to?

- Would I be any good as an interviewer or would it slip into counselling?
- Would I be open enough to discern anything novel and challenging from the process?

These points will be answered at the end of this chapter.

THE RESEARCH QUESTION

Being conscious of the researcher allegiance effect (Zimmerman and Marcus, 2024) I kept my research question away from therapeutic modalities per-se. While CBT has strong brand awareness, it seemed unlikely that I would be able to investigate purely person-centred specific support for HD. I knew I wanted to research the experience of *having* HD, not working with it.

The question settled on was therefore thus:

What are the experiences and effects of talking therapy on people who have hoarding disorder?

It wasn't until recruitment started that I began to have concerns about my wording. Firstly, "talking therapy", what is that? Should it be defined? Does it include support groups? What about peer support or chatting to the local vicar? Should I have stipulated it be a paid transaction? None of this was on my radar until it was too late. I felt worried and out of my depth.

Secondly, HD itself. My reading suggested that studies which used diagnostic tools like the Clutter Image Rating Scale (CIR) (Frost *et al*, 2008) appeared more credible and robust (e.g. Córcoles *et al*, 2024). I know all about the CIR, I've been using it for over a decade, why didn't I factor this in? What if a participant declared themselves to have HD when in fact, they did not?

All of this made me wobble and doubt myself. I reflected, I journalled, I took it to supervision. Concluding my inclusion criteria should cover these points, the only thing to do was plough on. My feelings at the time were self-critical but by the end of the process I was satisfied that the open wording of the question allowed for a kaleidoscope of therapeutic experience to emerge. This serendipity neatly encapsulates Gibbs' (1988) reflective cycle; it evoked strong feelings, it required objective evaluation and analysis and will benefit me in undertaking research in the future.

PARTICIPANTS AND INTERVIEWS

My drive to be organised and timely was unknown to the population I was seeking to engage with. Again, experience should have warned me. I know very well that ADHD symptoms and chronic procrastination are endemic in my client group. They are well-intentioned and altruistic people, but that rarely translates into action.

So, I waited.

And then I waited a bit more.

This stage was unpleasant with my predisposition for punctuality and fastidiousness. When the first respondent replied (Yvonne), I was delighted, she sounded ideal. We spoke by phone; she read and returned the research documentation and we set a date and time to record the interview. About ten minutes in, I started to worry. People with HD tend to have languorous ways of speaking, prone to rambling and tangents and this first interview was very hard to keep on track. Despite my best efforts I felt the content was falling short of my hopes. This extract from my reflective journal sums it up:

This is something I maybe should have anticipated; I know that hoarders have executive functioning issues and are often neurodiverse. I know they have had decades of avoidance patterns and rationalising to explain the issues.

This was a low point for me in terms of my enthusiasm and confidence. I journalled, reflected and emailed my supervisor. There was a lot of learning in there, but was it the kind that would yield a valid (let alone publishable) research paper? On that day, I was doubtful.

The second and third participants contacted me (independently) on the same day. One through his therapist who had seen my appeal online (Simon) and the other, Kate, I had emailed directly as the organiser of a support group.

Both, again, seemed ideal candidates. Simon was having CBT for HD at the time and had lots to say. Kate was battle-weary, cynical and vocal after seeing a total of 23 professionals over 35 years.

Simon's interview felt better than the first. He was responding well to the CBT and was able to articulate why and how it was benefitting him. Based on my professional experience, I had

not been expecting to hear glowing reports about CBT so my immediate response to this interview was surprise as it did not conform to expectations. From a reflective point of view, acknowledging this to myself felt important.

Interviewing Kate was a more combative affair. She asked a lot of questions, quite legitimately interrogating me and my knowledge. Interviewing skills were required to keep the focus on her experiences. She spoke fast; some detours, but mostly relevant, painting a picture of what it was like to be her, how the hoarding had taken root and why she felt let down by the counselling profession as a whole. This time I felt anxious that she had said so much I might miss something important in the analysis.

The final interviewee was Oliver, a thoughtful gentleman in his late 70s. He told his story clearly and made a host of excellent points. His most recent therapeutic experience had been within a peer-support group environment. What he said was great but did it fit the bill for my research question? Had I shot myself in the foot before I even started? These points would be resolved with reflection, journalling, supervision and, critically, the analysis.

All the interviewees had something to say about decluttering, but was that therapeutic? Three of the four raised the issue of ADHD, how would I incorporate that? One of them was outwardly hostile to the counselling profession, it was a strong but outlying sentiment so might it derail the group analysis?

Having the interviews recorded, transcribed, checked and double-checked was a great relief, but at this point I was mainly worried. I had just over 40,000 words of data but feared the group analysis would be agonising and potentially fruitless because the interviews were so different. Again, my reflective journal and patient supervisor kept me grounded. It would transpire that the ostensible differences merely disguised the convergences and the unique perspectives provided the heft which backed these up.

INDIVIDUAL ANALYSIS

I already knew I liked IPA; I found the process logical, enjoyable and creative. I decided to get hands-on using hard copy and highlighters for the first couple of reads. My initial thoughts led easily into exploratory notes. Once complete I turned to the electronic copies using

numbered lines and margins either side. I added my highlighted text and notes and started constructing experiential statements.

Throughout, I found it useful to refer to the IPA book (Smith, Flowers and Larkin, 2022) having re-read it a few weeks prior. My instinct was to lean on it as a manual but I gained confidence through experience and from my supervisor, appreciating that the 'interpretative' part presupposes flexibility and room for manoeuvre. Each analysis became iterative and fluid (Smith, Flowers and Larkin, 2022) as I relaxed into the task. Working on a large piece of cardboard, I cut out and moved around the statements, trying things out, using gut feelings to discern placings. Every fresh sweep of the data brought new clarity and coherence.

Often, I would refer to the research question, aim and objectives. At times it felt like the data would answer another question better. As a relative novice I had to find a balance between adherence to my aim and being fully true to the words, experiences and meanings laid out before me. The sequential nature of the endeavour proved reliable and the emerging analyses brought confidence and exhilaration.

GROUP ANALYSIS AND FINDINGS

Each of the interviews yielded approximately 10,000 words, culminating in around seventy experiential statements apiece. Not all were used and many were effectively duplicates.

At this stage I found the IPA book thin on detail. The few pages dedicated to group analysis were less a map than a signpost. I took this to mean there was probably no one right way to proceed, it depended on what the researcher had in front of them. I wanted to evidence everything and create an easy trail to follow. To that end I printed out all the statements, colour coded them with highlighters, cut them all out and dumped them on my cardboard sorting surface.

This process was daunting, then fun and then amazing. As columns appeared I could see from the colours what was important to which participant. As before, the iterative nature of IPA hit home, this could not be concluded in one sitting. I returned to the board over many days with fresh eyes. This stage is so idiosyncratic that it would be ludicrous to make any claims for objectivity (McLeod, 2015). Of course, any other person would have handled it

differently, the key thing was that I could justify my interpretation of the data. I am satisfied that I achieved that in the end. My previous worry about allegiance bias fell away – the understanding my background brought to this process afforded depth and insight.

Having created tables of themes, subthemes and supporting quotes for each of the interviews, I set about the same task at group level. This was also iterative and took multiple sweeps on separate days to evolve. One of the key themes only solidified on the final session with the data. This relates to the pitfalls of CBT for HD and had remained elusive to that point.

I decided it would be helpful to note how many of the four participants were represented in each subtheme. While this is not a stipulation of IPA, it engendered confidence that convergence does not mean compromising idiographic integrity. Some subthemes had quotes from all four, while another was only represented by one. As it happens, that is fine, the narrative inevitably moves from the group level to the individual (Smith, Flowers and Larkin, 2022), representing lived experience.

This is where my fears finally dissolved. With my supervisor I was able to summarise what I had found in simple terms that made sense. My research had *findings*.

STRENGTHS AND CHALLENGES

With hindsight, I am happy with the research question, however I should have considered all implications, semantic and practical, much earlier.

I wish it had been possible to fully reflect the richness of the data. The word count constraint necessitated tough choices which, while not diminishing the participant experience, inevitably compromised the extent of expression.

On a positive note, judicious time management afforded me all the space I needed to approach this complex task and complete it to the best of my ability. My life working with people with HD and as a counsellor informed the interviewing and the analysis. The double hermeneutic (Smith, Flowers and Larkin, 2022, p. 29) was that of researcher-with-experience and this facilitated the deeper connection with the data which I hoped it would.

The iterative nature of IPA (Smith, Flowers and Larkin, 2022) extends to the reflective process (Gibbs, 1988). Each part of the project required reflection, building towards the

next, coalescing into a whole. Paying attention to this contemporaneously proved to be at least advantageous if not pivotal.

CONCLUDING THOUGHTS

Challenging, sometimes stressful but also fun; I am sorry it's over. In attempting to present a trustworthy account I hope to have delivered credible and valid findings (Hanley, Lennie and West, 2013, p. 102).

I am happy to report how changed I am by this experience. It has given me new perspectives, self-awareness and an improved capacity for critical thinking. I feel this is about depth and clarity, things that feed into both of my jobs. My default position had always been to turn to books to deepen my knowledge and understanding, now my first thought is research.

Earlier, I posed four questions, table 1 below has my answers:

Table 7 – my four questions

QUESTION	ANSWER
Did the findings closely resemble my established view and mirror my experience?	Yes – I expected the healing qualities of empathy and connection to be recognised. No – I wasn't expecting positivity about CBT.
Would it be possible to bracket out the bias of my professional life, did I need to?	No on both counts. On reflection I feel the dual role was an advantage.
Was I any good as an interviewer or would it feel like counselling?	It didn't feel like counselling at all. I was focused on the research aims and the interview schedule.
Would I be open enough to discern anything novel and challenging from the process?	I <i>believe</i> so but must remain aware that there will be things I missed in the data.

The work is done, from idea to reflection. Dissemination is part of this experience, after all research without it is incomplete (Reeves, 2015, p. 229) and I hope my (and my participants) small contribution will help inform the hoarding support of the future.

Word count minus tables - 2697

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APPENDIX

Appendix 1 – table of shortlisted papers for review

NO	PAPER TITLE	Y/N	REASON
1	A 'Friendly Visitor' Volunteer Intervention for Hoarding Disorder: Participants' Perceptions	Y	Not about therapy but has qualt from HD participants
2	'A more human approach: I haven't found that really': experiences of hoarding difficulties and seeking help	Y	Qualt, relates to barriers to support, access etc
3	Acceptability of treatments and services for individuals with hoarding behaviors	Y	Explores clients' attitudes
4	Assessment and Treatment of Hoarding Disorder in Rural-Dwelling Older Adults	N	Not qualt
5	Augmenting group hoarding disorder treatment with virtual reality discarding: A pilot study in older adults	N	Negligible qualt element
6	Can cognitive analytic therapy treat hoarding disorder? An adjudicated hermeneutic single-case efficacy design evaluation	N	Not qualt
7	Coordinated Community-Based Hoarding Interventions: Evidence of Case Management Practices	N	No client data
8	Council tenancies and hoarding behaviours: A study with a large social landlord in England	N	Perspective of housing officers
9	Effectiveness of Group Cognitive Behavioral Therapy for Hoarding Disorder: Evaluation of Outcomes	N	Quant study
10	"In an ideal world that would be a multiagency service because you need everybody's expertise." Managing hoarding disorder: A qualitative investigation of existing procedures and practices	N	Nothing from the hoarders themselves
11	Multidisciplinary Teams' Practice Strategies With Older Adult Clients Who Hoard	N	Social workers' experiences
12	Older adult hoarders' experiences of being helped by volunteers and volunteers' experiences of helping	Y	Qualt experiences of being helped
13	Pilot trial of cognitive and behavioral treatment for hoarding disorder delivered via webcam: Feasibility and preliminary outcomes	N	Not qualt
14	Self-reported helpfulness of Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST) for hoarding disorder	N	Not qualt
15	Therapist and patient perspectives on CBT for older adults with hoarding disorder: A collective case study	Y	Qualt data from hoarders
16	Treating hoarding disorder with compassion focused therapy: A pilot study examining treatment feasibility, acceptability, and exploring treatment effects	N	Not qualt
17	Understanding barriers to treatment and treatment delivery preferences for individuals with symptoms of hoarding disorder: A preliminary study	Y	Relevant re barriers but all quant
18	Working together when the problem is multi-faceted: understanding inter-agency working for the benefit of people with hoarding problems	Y	Has qualt data from hoarders

Appendix 2 – Table of publications

NO	TITLE OF PAPER	PUBLICATION
1	A 'Friendly Visitor' Volunteer Intervention for Hoarding Disorder: Participants' Perceptions	The Open Journal of Occupational Therapy
2	'A more human approach... I haven't found that really': experiences of hoarding difficulties and seeking help	Behavioural and Cognitive Psychotherapy
3	Acceptability of treatments and services for individuals with hoarding behaviors	Journal of Obsessive Compulsive and Related Disorders
4	Older adult hoarders' experiences of being helped by volunteers and volunteers' experiences of helping	Behavioural and Cognitive Psychotherapy
5	Therapist and patient perspectives on cognitive behavioral therapy for older adults with hoarding disorder: A collective case study	Aging and Mental Health
6	Working together when the problem is multi-faceted: understanding inter-agency working for the benefit of people with hoarding problems	The Cognitive Behaviour Therapist

Appendix 3 – Table of authors, aims, populations and design

NO	AUTHOR	AIM	POPULATION	DESIGN
1	Noyes, S., van Houten, S., & Wilkins, E.	Not specified	3 clients with HD and 6 volunteers	Semi-structured interviews
2	McGrath M, Russell AM, and Masterson C	To explore the experiences of a sample of people who identify as engaging in hoarding behaviours and who are seeking support	8 individuals who self-identified as seeking help in relation to hoarding behaviours	SSI and IPA
3	Carolyn I. Rodriguez, Amanda Levinson, Sapana R. Patel, Kim Rottier, Jordana Zwerling, Susan Essock, Lee Shuer, Randy O. Frost, Helen Blair Simpson	To explore the acceptability of currently available treatments and services for individuals who self-report hoarding behaviors	203 participants who self-reported having hoarding behaviors	Statistical analyses and inductive coding
4	Kirsty Ryninks, Vuokko Wallace and James D. Gregory	To explore the experiences of older people with hoarding difficulties receiving help and volunteers providing support	7 volunteer helpers and 4 people with hoarding disorder	Interviews and IPA
5	Catherine R. Ayers, Christiana Bratiotis, Sanjaya Saxena & Julie Loebach Wetherell	To explore therapist and patient perspectives on a specialized CBT protocol for clinically significant hoarding in older adult patients	12 people aged 65 + (7f, 5m), mean age 73 with hoarding as their most severe psychiatric condition.	Case study
6	Sam G. French, Karen Lock, Tiago Zortea, Elaine Hassall, Victoria Bream, Kathryn Webb and Paul M. Salkovskis	3 aims including: To explore perceptions of improvements that could be made to multi-agency service provision from people with personal experience of HD.	26 conference delegates and 11 people with HD.	Thematic analysis

Appendix 4 – Table of themes, conclusions and notes

NO	THEMES	CONCLUSIONS	NOTES
1	Importance of the client-volunteer relationship. The demands of decluttering. Strategies for effective decluttering.	An in-home volunteer program contributes to motivation, accountability, and persistence in the work of decluttering. The strength of the relationship between clients and volunteers was shown to mediate the demands of decluttering.	Client-centred approach referred to as desirable.
2	Difficulty defining and addressing the HD Trust issues Falling between services Being dehumanised	There are both internal (e.g. fear of judgement; feeling overwhelmed) and external (e.g. service gaps) barriers that make finding useful help for hoarding behaviours very difficult.	Need a compassionate approach. Hoarder label is itself a barrier. Focus should be on the person
3	Personalisation of care One size does not fit all Need to believe treatment works	The three most acceptable treatments were: individual CBT, professional organizing service and use of a self-help book.	Preference for services / treatments to be personalised and specific.
4	Relationship between client and volunteer Space to live again Shame and uncertainty Needs of volunteers	Role of “professional” can be a barrier. Autonomy is vital as is building a relationship.	Importance of relationship with volunteer. Client needs to be in control of the process. Focus on the person, not the clutter.
5	People with HD struggle with the tasks of CBT.	Exposure therapy, therapist relationship and home visits were the most well received aspects.	CBT seems not to be a good fit for people who hoard.
6	Improved understanding of hoarding Need for improved resources Improved inter-agency working	A multi-agency conference increased confidence and understanding in professionals working with hoarding problems.	People with HD want nonjudgemental support, to be understood, heard, and to have access to practical and MH support.

Appendix 5 – screenshot of appeal for participants on website of Hoarding UK



[Home](#) [About Hoarding](#) [About HUK](#) [Support](#) [Events](#) [Training](#) [Support Us](#) [Opportunities](#) [Contact](#) 

Have you received any kind of talking therapy for hoarding disorder?

About the study

Hello, my name's Harry Beer, I'm a hoarding support practitioner and a practising person-centred counsellor.

I'm undertaking research towards an MA in Advanced Counselling Theory and Research at the University of Wales Trinity St. David (UWTSD) which seeks to answer the following question:

What are the experiences and effects of talking therapy on people who have hoarding disorder?

Who can take part?

I'm looking for UK residents who have lived with hoarding-related impairment of day-to-day functioning for a minimum of ten years and have ever had any kind of talking therapy.

What does taking part involve?

It'll be a one-to-one conversation with me; discussing your experiences and lasting around an hour, possibly longer. I'll be able to give you an idea of the kind of questions I'll be asking beforehand, but it'll be conversational and informal. This will take place either in person or online and will be recorded and analysed. It's anonymous, voluntary and there is no payment involved.

What will happen to the recordings?

Your data will be strictly confidential, only I, as the researcher, will have access to it. It'll be anonymised and saved on the university's cloud-based OneDrive. The information will be kept until the degree has been awarded, at which point it will be destroyed.

Has the research received ethical approval?

All aspects of this project have been submitted to and approved by the University's Research Ethics Committee.

I commit to adhering to the UWTSD Research Ethics and Integrity Code of Practice as well as those of the BACP (British Association for Counselling and Psychotherapy) and also to follow the legal requirements of GDPR and the Data Protection Act.

How can I get involved?

If you would like to help, please contact me by any of the methods below. Your experiences could help improve understanding of how useful therapy is for people who hoard.

The deadline for responses is 30th September 2024 with interviews taking place in October 2024.

Thank you,
Harry Beer

Appendix 6 – Table summary of participants

	PARTICIPANT 1	PARTICIPANT 2	PARTICIPANT 3	PARTICIPANT 4
PSEUDONYM	Yvonne	Simon	Kate	Oliver
10 YEARS + HD	Y	Y	Y	Y
THERAPY	Y	Y	Y	Y
GENDER	F	M	F	M
AGE	61	61	71	77
LOCATION	Devon	Kent	Bucks	Berks
1st CONTACT	16/09/24	23/09/24	23/09/24	14/10/24
I/V DATE	08/10/24	14/10/24	16/10/24	28/10/24
HOW HEARD	Hoarding UK website	Therapist saw appeal	Email to support group	HD UK support group
TOTAL DUR'N	1:04:52	1:01:14	1:07:13	1:06:31
I/V DURATION	58:52	55:45	59:37	58:43
TOTAL WORDS	8720	9816	11797	10410
I/V WORDS	7507	8635	10221	8609

Appendix 7 – Ethics form as approved by UWTSD**APPLICATION FOR ETHICAL APPROVAL****RESEARCH STUDENTS**

This form is to be completed by the student within **SIX** months for full-time students and **TWELVE** months for part time students, after the commencement of the research degree or following progression to Part Two of your course.

Once complete, submit this form via the ***MyTSD Doctoral College Portal*** at (<https://mytsd.uwtsd.ac.uk>).

This document is also available in Welsh.

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk, with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

In order for research to result in benefit and minimise risk of harm, it must be conducted ethically. A researcher may not be covered by the University's insurance if ethical approval has not been obtained prior to commencement.

The University follows the OECD Frascati manual definition of **research activity**: "creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man, culture and society, and the use of this stock of knowledge to devise new applications". As such this covers activities undertaken by members of staff, postgraduate research students, and both taught postgraduate and undergraduate students working on dissertations/projects.

The individual undertaking the research activity is known as the "principal researcher".

Ethical approval is not required for routine audits, performance reviews, quality assurance studies, testing within normal educational requirements, and literary or artistic criticism.

Please read the notes for guidance before completing ALL sections of the form.

This form must be completed and approved prior to undertaking any research activity.

Please see Checklist for details of process for different categories of application.

SECTION A: About You (Principal Researcher)

1	Full Name:	Harry Beer			
2	Tick all boxes that apply:	Member of staff:	<input type="checkbox"/>	Honorary research fellow:	<input type="checkbox"/>
	Undergraduate Student	<input type="checkbox"/>	Taught Postgraduate Student	<input type="checkbox"/>	Postgraduate Research Student <input checked="" type="checkbox"/>

3	Institute/Academic Discipline/Centre:	Institute of Education and Humanities Academic Discipline: Psychology and Counselling
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4	Campus:	Swansea
5	E-mail address:	2307835@student.uwtsd.ac.uk
6	Contact Telephone Number:	0775 226 9815
For students:		
7	Student Number:	2307835
8	Programme of Study:	Advanced Counselling Theory and Research
9	Director of Studies/Supervisor:	Dr Ceri Phelps / Dr Beverly Cole

SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)	YES	<input checked="" type="checkbox"/>	NO	<input checked="" type="checkbox"/>
					Date
2	If Yes, please indicate source of approval (and date where known): Approval in principle must be obtained from the relevant source prior to seeking ethical approval	Research Degrees Committee	<input type="checkbox"/>		
Institute Research Committee		<input type="checkbox"/>			
Other (write in) Research Proposal originally submitted on 15/01/24 as part of an assignment, and subsequently agreed in principle for MA research by Dr Beverly Cole in May 2024.		<input checked="" type="checkbox"/>			

SECTION C: Internal and External Ethical Guidance Materials

	Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, location-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines. You may add rows to this table if needed.
1	<u>UWTSD Research Ethics & Integrity Code of Practice</u> <input checked="" type="checkbox"/>
2	UWTSD Research Data Management Policy <input checked="" type="checkbox"/>
3	BACP (2019) Ethical Guidelines for Research in the Counselling Professions <input checked="" type="checkbox"/>
4	BACP (2018) Ethical Framework for the Counselling Professions <input checked="" type="checkbox"/>

SECTION D: External Collaborative Research Activity NA

If there are external collaborators then you should gain consent from the contact persons to share their personal data with the university. If there are no external collaborators then leave this section blank and continue to section E.

1	Institution					
2	Contact person name					
3	Contact person e-mail address					
4	Is your research externally funded?	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>	
5	Are you in receipt of a KESS scholarship?	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>	
6	Are you specifically employed to undertake this research in either a paid or voluntary capacity?	Voluntary	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
7		Employed	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
8	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)?	If YES then the permission question below does not need to be answered.	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
9	Has permission to undertake the research has been provided by the partner organisation?	(If YES attach copy) If NO the application cannot continue	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>

Where research activity is carried out in collaboration with an external organisation NA

10	Does this organisation have its own ethics approval system?	YES	<input type="checkbox"/>	NO	<input type="checkbox"/>
	If Yes, please attach a copy of any final approval (or interim approval) from the organisation (this may be a copy of an email if appropriate).				

SECTION E: Details of Research Activity

1	Indicative title:	Exploring the Therapeutic Experiences of People with Hoarding Disorder: An Interpretative Phenomenological Study.		
2	Proposed start date:	Summer 2024 – Once ethical approval has been granted	Proposed end date:	Easter 2025
	Introduction to the Research (maximum 300 words per section) Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the points below: <i>Purpose of Research Activity</i> <i>Proposed Research Question</i> <i>Aims of Research Activity</i> <i>Objectives of Research Activity</i>			

	<p>Demonstrate, briefly, how Existing Research has informed the proposed activity and explain <i>What the research activity will add to the body of knowledge</i> <i>How it addresses an area of importance.</i></p>
3	<p>Purpose of Research Activity</p> <p>The purpose of this research project is to take a detailed look at how talking therapy impacts on people who have hoarding disorder (HD). This little-understood mental health condition affects between 2-6% of the population (BPS, 2015) and is associated with a host of health and safety risks.</p> <p>HD is often a response to trauma and leads to shame, guilt and social isolation. The vast majority of sufferers also have other mental and physical health problems. In 2022, London Fire Brigade attended 1,036 hoarding-related fires which led to approximately 186 injuries and 10 deaths (LFB, 2023).</p> <p>Research suggests that CBT is an effective treatment for HD (Rodgers et al, 2021), however few studies follow up beyond 6 months. There is an absence of evidence for other therapeutic approaches and a gap in terms of qualitative assessment of client experience. There is also a need for a longer-term review on the reported benefits of CBT for HD.</p> <p>Hoarding Disorder became a distinct diagnosable condition in 2013. Since then, awareness has grown and more cases come to light every day. Specialised, bespoke support is rare and there is still a stigma attached to the word, 'hoarder', which is sometimes used as an insult.</p> <p>This study seeks to fill the gap in research by giving voice to the people at the heart of an issue which society frowns upon.</p> <p>Questions posed by this study will include:</p> <ul style="list-style-type: none"> • Is talking therapy successful in treating HD in the long term? • What was it like for clients to receive? Did they feel understood? • Was the support relevant, useful and did it bring any improvements in the hoarding? • What works, what doesn't and why? <p>(this box should expand as you type)</p>
4	<p>Research Question</p> <p>What are the experiences and effects of talking therapy on people who have hoarding disorder?</p> <p>(this box should expand as you type)</p>
5	<p>Aims of Research Activity</p> <p>The overarching aim of this study is to explore and evaluate the therapeutic experiences of a small cohort of individuals who live with hoarding disorder.</p> <p>(this box should expand as you type)</p>
6	<p>Objectives of Research Activity</p> <p>The objectives of this study are to:</p> <ul style="list-style-type: none"> • ascertain how the thereapeutic intervention was received by the individual and how it impacted on them. • assess whether the process alleviated any distress and/or led to any long-term change in terms of accumulation and/or discard of possessions.

	<ul style="list-style-type: none"> • identify barriers and facilitators to therapeutic change in people who have HD. • consider implications for effective, long-term support for people with HD. <p>(this box should expand as you type)</p>
	<p>Proposed methods (maximum 600 words)</p> <p>Provide a brief summary of all the methods that may be used in the research activity, making it clear what specific techniques may be used. If methods other than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed. You do not need to justify the methods here but should instead describe how you intend to collect the data necessary for you to complete your project.</p>
7	<p>A suitable number of participants will be in the range of 3-6. Homogeneity of the group is significant only in relation to the hoarding disorder, beyond that diversity will be an advantage.</p> <p>The target population for this research is adults of any age or gender who:</p> <ul style="list-style-type: none"> • have hoarding disorder as defined by the diagnostic criteria of DSM V and ICD 11. • have lived with impairment of day-to-day functioning for a minimum of ten years. • have undergone any kind of therapeutic intervention within the preceding 5 years. <p>Participants will be recruited through the researchers own contacts and also with the assistance of organisations such as Hoarding UK and Hoarding Disorders UK.</p> <p>Recruitment will not involve any incentive or remuneration. Informed consent will be addressed at every stage and embodied in the openness and accountability of the researcher who is both a hoarding support practitioner and a qualified person-centred counsellor. Specifically, this means the researcher will offer explanations of each aspect, encourage the asking of questions and ensure that participants understand their right to withdraw at any time up to the point at which analysis begins. Should any participant withdraw after data collection, this recording will not be the subject of analysis and will not be included within findings.</p> <p>All individuals who respond to the call for participants will be contacted for an informal phone conversation (or email exchange as preferred). This will be followed up with an information pack (available upon request) containing a covering letter, information sheet, consent form and interview schedule. The researcher will endeavour to ensure the best possible understanding of the nature of the commitment and all aspects of informed consent including right to withdraw.</p> <p>In the event that too many qualifying participants wish to take part, the first (up to six) will be recruited, with any remaining making up a reserve list to allow for unforeseen circumstances.</p> <p>Data will be collected through semi-structured interviews, one per participant, of approximately 60 minutes (but possibly up to 90) in duration. Participant validation will be sought and opportunities offered for additional comments to be added up to 6 weeks post the interview. Interviews will be conducted either face to face or online. Due to the practical difficulties of recording in a hoarded environment and the associated shame and stigma, it is vital that participants experience autonomy over this aspect.</p> <p>The semi structured interviews will be thoroughly prepared for with the use of a piloted interview schedule and supervisory guidance. Face to face interviews will be recorded using a battery-operated digital recording device with the audio files saved to a micro-SD card and transferred to a password protected external hard drive. Online interviews will be conducted via MS Teams and the</p>

	<p>recording saved and transferred as above. As a failsafe, online interviews will also be recorded using a battery-operated digital recording device with the audio files saved to a micro-SD card and transferred as above. Original recordings on a micro-SD card will be retained until submission date as a back-up and kept in a locked drawer in the home of the researcher. The audio will be transferred to an external hard drive and MS365 will be used for the initial transcription. Audio and transcription files will be transferred to the university's OneDrive, which is password protected, subject to double authentication processes and the university firewalls. All data will be anonymised using pseudonyms and retained until the degree has been awarded, at which point it will be deleted / sensitively destroyed. All data will be kept separately from consent forms.</p> <p>Participant validation will be welcomed however the right to withdraw will be time limited as it would not be possible to remove specific data at analysis stage without corrupting or compromising the integrity of the corpus. This will be an important element of the informed consent process.</p> <p>The research question and aims and objectives of this study make it ideally suited for IPA (Smith et al, 2022). The plan to explore subjective experiences of persons-in-context is entirely consistent with IPA which acknowledges and utilises the double hermeneutic as a fundamental element.</p> <p>Debrief for participants will be offered at the conclusion of the interview with a follow up at 1 and 4 weeks later. It should be noted that as a qualified and practicing counsellor who is in regular weekly contact with people who struggle with hoarding, the researcher is confident in being able to quickly identify and address any participant discomfort, whether this be within the interview itself or the debriefing process.</p> <p>(this box should expand as you type)</p>
	<p>Location of research activity</p> <p>Identify all locations where research activity will take place.</p>
8	<p>Online interviews will be conducted from the researcher's home in Colchester, Essex. If possible, some interviews will take place in the homes of participants which could be in any part of the UK. It should be noted that such activity is part of the researcher's daily working practice and therefore any risk (e.g. lone working) will be mitigated by his training and years of professional experience.</p> <p>(this box should expand as you type)</p>
	<p>Research activity outside of the UK</p> <p>If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants. If you live in the country where you will do the research then please state this.</p>
9	<p>NA</p> <p>(this box should expand as you type)</p>

10	Use of documentation not in the public domain: Are any documents NOT publicly available?	NO	<input checked="" type="checkbox"/>
		YES	<input type="checkbox"/>
11	If Yes, please provide details here of how you will gain access to specific documentation that is not in the public domain and that this is in accordance with the current data protection law of the country in question and that of England and Wales. <i>(this box should expand as you type)</i>		

	Does your research relate to one or more of the seven aims of the Well-being of Future Generations (Wales) Act 2015?	YES	NO
12	A prosperous Wales	<input type="checkbox"/>	<input checked="" type="checkbox"/>
13	A resilient Wales	<input checked="" type="checkbox"/>	<input type="checkbox"/>
14	A healthier Wales	<input checked="" type="checkbox"/>	<input type="checkbox"/>
15	A more equal Wales	<input checked="" type="checkbox"/>	<input type="checkbox"/>
16	A Wales of cohesive communities	<input type="checkbox"/>	<input checked="" type="checkbox"/>
17	A Wales of vibrant culture and thriving Welsh language	<input type="checkbox"/>	<input checked="" type="checkbox"/>
18	A globally responsible Wales	<input type="checkbox"/>	<input checked="" type="checkbox"/>
19	If YES to any of the above, please give details:		
	<p>With respect to each of the aims indicated above:</p> <p><u>A resilient Wales:</u> The findings will contribute to the understanding of hoarding in the words of those affected by it. The desired insights into therapeutic interventions will deepen understanding and awareness of the resilience shown by participants both in terms of living in highly challenging conditions but also in seeking to overcome this little understood condition.</p> <p><u>A healthier Wales:</u> The vast majority of people with HD have co-morbidities, the most common being depressive and anxiety disorders (Wheaton and Van Meter, 2014). This research hopes to contribute knowledge and information which will benefit practitioners, help destigmatise the condition and promote health and welfare.</p> <p><u>A more equal Wales:</u> Hoarding is still not widely understood as a mental health condition and is often used a pejorative, judgemental slur. This study hopes to increase awareness and empathy and dispel some of the accumulated shame and guilt which the condition inspires in those affected.</p> <p><i>(this box should expand as you type)</i></p>		

SECTION F: Scope of Research Activity

	Will the research activity include:	YES	NO
1	Use of a questionnaire or similar research instrument?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2	Use of interviews?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3	Use of focus groups?	<input type="checkbox"/>	<input checked="" type="checkbox"/>

4	Use of participant diaries?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5	Use of video or audio recording?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
6	Use of computer-generated log files?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7	Participant observation with their knowledge?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
8	Participant observation without their knowledge?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9	Access to personal or confidential information without the participants' specific consent?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
10	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
11	Performance of any acts which may cause embarrassment or affect self-esteem?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
12	Investigation of participants involved in illegal activities?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
13	Use of procedures that involve deception?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
14	Administration of any substance, agent or placebo?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
15	Working with live vertebrate animals?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
16	Procedures that may have a negative impact on the environment?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
17	Other primary data collection methods. Please indicate the type of data collection method(s) below.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	Details of any other primary data collection method: (this box should expand as you type)		

If NO to every question, then the research activity is (ethically) low risk and **may** be exempt from **some** of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

If there are no participants then do not complete this section, but go directly to section H.

	Who are the intended participants:	YES	NO
1	Students or staff at the University?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2	Adults (over the age of 18 and competent to give consent)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3	Vulnerable adults? NOTE: Clients who hoard are vulnerable by definition: past trauma, anxiety, complex needs etc. As a practicing counsellor and hoarding support practitioner the researcher is sensitive to vulnerability and will be fully attentive to individual responses and needs at all times.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5	Prisoners?	<input type="checkbox"/>	<input checked="" type="checkbox"/>

6	Young offenders?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper? NOTE: It is possible (though not inevitable) that one or more participants will be recruited from the researcher's client base. The BACP principles of autonomy and justice will guide the process and the researcher commits to ensuring involvement will not be of detriment to any existing or future therapeutic relationship.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
8	People engaged in illegal activities?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9	Others. Please indicate the participants below, and specifically any group who may be unable to give consent.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	Details of any other participant groups: (this box should expand as you type)		

	Participant numbers and source Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?	
10	How many participants are expected?	3-6 (this box should expand as you type)
11	Who will the participants be?	Adults who have received any kind of therapeutic intervention in relation to hoarding disorder. (this box should expand as you type)
12	How will you identify the participants?	Through the researchers own client base and wider contacts and those of Hoarding UK and Hoarding Disorders UK CIC. (this box should expand as you type)

	Information for participants:	YES	NO	N/A
13	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Will you tell participants that their participation is voluntary?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Will you obtain written consent for participation?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	If the research is observational, will you ask participants for their consent to being observed?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
18	Will you tell participants that they may withdraw from the research at any time and for any reason?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
20	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	If NO to any of above questions, please give an explanation			
	<i>(this box should expand as you type)</i>			

	Information for participants:	YES	NO	N/A
24	Will participants be paid?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
25	Is specialist electrical or other equipment to be used with participants?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
26	Are there any financial or other interests to the investigator or University arising from this study?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
27	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
28	If YES to any question, please provide full details			
	<i>(this box should expand as you type)</i>			

SECTION H: Anticipated Risks

	Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them. If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.		
1	Full risk assessment completed and appended?	Yes	<input type="checkbox"/>
		No	<input checked="" type="checkbox"/>
2	Risks to participants For example: sector-specific health & safety, emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information		

Risk to participants:	How you will mitigate the risk to participants:
Emotional distress discussing personal issues	<p>Through the use of active listening, counselling skills and a consistent emphasis on autonomy and informed consent.</p> <p>The researcher is a BACP registered person-centred counsellor and experienced hoarding support practitioner. The years of training and experience greatly reduce possible issues regarding dependency or vulnerability of participants.</p> <p>As a qualified, practising counsellor, the researcher has the ability to be in the moment, quickly recognising and addressing any point where a participant might feel distressed or anxious and to address this. In addition, during the debriefing, signposting will be provided should participants require further support, and the researcher will make himself available for an arranged period, should participants need to discuss any emotional issues which may arise after the interview.</p> <p>In this way, and through pre-interview discussions, the information sheet, consent form and strong debriefing procedures,</p> <p>the researcher will ensure safe capacity for participants.</p>
Handling personal data. It is recognised that there is a possibility of risk to the participant as the result of the handling of personal data.	<p>As an MA student at UWTSD, the researcher has familiarised himself with the requirements of data handling as pertaining to the university itself, the BACP and the laws laid out by GDPR and the Data Protection Act. Full attention will be paid to these as an ethical responsibility and acknowledging how data protection considerations interact with research ethics. The collection and transfer of personal data will be limited as far as this is possible and all research activity will be in accordance with the relevant laws and guidelines.</p>
Potential confusion arising from dual relationship should any participant be an existing or past client of the researcher	<p>The risk in this regard should be minimal as the pre-existing relationship could contribute to a deeper level of sharing at the interview stage. The researcher will act with</p>

	<p><i>(this box should expand as you type)</i></p>	<p>professionalism at all times and transparency with regards to informed consent to ensure that no client or participant is disadvantaged in any way as a consequence of their involvement in this research.</p> <p><i>(this box should expand as you type)</i></p>
3	<p>If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities</p>	
	<p>As this research will be considering the subject of hoarding and therapeutic processes, there is always a possibility that sensitive, embarrassing or upsetting topics may arise. As previously stated, the researcher is a qualified person-centred counsellor and experienced in recognising, relating to, holding and dealing with emotions.</p> <p>It is also confirmed that consent procedures will make it clear that if, in the course of discussions something potentially or actually illegal, or of harm to self and/or others, is discovered, this will be disclosed to the appropriate authorities. As this is a routine part of all counselling contracts, the researcher is experienced in imparting this information and assessing risk.</p> <p>As indicated in previous sections, debriefing procedures will be sensitive and provide signposting suggestions.</p> <p><i>(this box should expand as you type)</i></p>	
4	<p>Risks to the investigator</p>	

	For example: personal health & safety, physical harm, emotional distress, risk of accusation of harm/impropriety, conflict of interest	
	<p>Risk to the investigator:</p> <p>Potential risk from being in hoarded environments e.g., trips, falls, cuts, contact with contaminated items etc</p> <p>Conflict of interest / impropriety</p> <p><i>(this box should expand as you type)</i></p>	<p><i>How you will mitigate the risk to the investigator:</i></p> <p>The researcher is an experienced hoarding support practitioner with all the necessary awareness and equipment. Visiting hoarding environments is part of his day to day working life and he is skilled in safety management.</p> <p>The researcher recognises the responsibility to be aware of, and address, any conflict of interest or impropriety which might arise. This will be mitigated through awareness of this possibility and a working knowledge of the BACP guidelines for research and UWTSD research documentation. The researcher commits to erring on the side of caution in this regard and seeking supervisory guidance when in doubt.</p> <p><i>(this box should expand as you type)</i></p>
5	University/institutional risks For example: adverse publicity, financial loss, data protection	
	<p>Risk to the University:</p> <p>Plagiarism</p> <p>Professionalism</p> <p>Reputational damage of the University</p>	<p><i>How you will mitigate the risk to the University:</i></p> <p>The researcher will ensure the work is his own via text matching/Turnitin and following the requirements of the Harvard Referencing System for citations and referencing.</p> <p>The researcher will adhere to the codes of conduct of UWTSD and the BACP code of ethics.</p> <p>The researcher is conscious that in carrying out this research he is acting as an agent of UWTSD and his professional body. He will therefore ensure the research is carried out in accordance with the guidance of these organisations.</p>

	<i>(this box should expand as you type)</i>	<i>(this box should expand as you type)</i>
6	Environmental risks For example: accidental spillage of pollutants, damage to local ecosystems	
	Risk to the environment: None identified <i>(this box should expand as you type)</i>	<i>How you will mitigate the risk to environment:</i> <i>(this box should expand as you type)</i>

	Disclosure and Barring Service			
	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	YES	NO	N/A
7	Does your research require you to hold a current DBS Certificate?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	If YES, please give the certificate number. If the certificate number is not available, please write "Pending"; in this case any ethical approval will be subject to providing the appropriate certificate number.	001812276484		

SECTION I: Feedback, Consent and Confidentiality

1	Feedback What de-briefing and feedback will be provided to participants, how will this be done and when?
	Debriefing will be offered at the end of each interview and the offer made of a further conversation in relation to any issues arising. In addition, each participant will be contacted one week and one month post interview as a courtesy. Signposting will be available should any participant need additional support. <i>(this box should expand as you type)</i>
2	Informed consent Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	The conduct of the research and the requirements of those taking part will be described in the appeal for participants. The researcher will speak with interested individuals to explain in detail the implications of taking part. Informed consent will be explained thoroughly at this stage. The researcher will check understanding and be careful to avoid jargon or academic language.

	<p>After this initial contact, if the individual is still interested, they will be sent (by post or email) an information pack (available upon request) containing a covering letter, information sheet, consent form, interview schedule and information about the debrief which will take place after the interview. These will be presented in plain English to avoid ambiguity with the key facts highlighted.</p> <p>The researcher will encourage the asking of questions and allow plenty of time for potential participants to consider the information before deciding whether to take part.</p> <p><i>(this box should expand as you type)</i></p>
3	<p>Confidentiality / Anonymity</p> <p>Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.</p>
	<p>The researcher will ensure participant autonomy and provide confidentiality through upholding GDPR regulations.</p> <p>Pseudonyms will be used, and any other potentially identifiable interview content will be redacted from the interview transcript. Consent forms will be kept separate from data.</p> <p>Participants may be from any part of the UK and it is unlikely any will be already known to each other. The possibility of deductive disclosure will be minimal.</p> <p>For interviews conducted via MStTeams, participants will be notified that the session will take place via Teams and will be recorded. This will be made clear on the consent form returned prior to the interview, where interviewees will be directed to Teams' most recent privacy policy (<u>Microsoft Privacy Statement – Microsoft privacy</u>).</p> <p><i>(this box should expand as you type)</i></p>

SECTION J: Data Protection and Storage

	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 "GDPR" and the Data Protection Act 2018 "DPA")?	YES	NO
1	"Personal data" means any information relating to an identified or identifiable natural person ('data subject'). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Any video or audio recordings of participants is considered to be personal data.	x	<input type="checkbox"/>
	If YES, provide a description of the data and explain why this data needs to be collected:		
2	All research will be in line with the requirements of the GDPR and the Data Protection Act to ensure that use of personal data is accurate, fair and secure. For example: minimising the use of personal data as much as possible. Personal data collected will include name, postal and email address and date of birth. This data is needed for the researcher to contact the participants and		

	<p>to be aware of how old they are. Only their ages will be mentioned in the final study, and any subsequent publication, and all other details will be disguised.</p> <p>Personal information will be pseudonymised so no name is alongside a record of address or phone number. This information will be stored as previously outlined using the university's OneDrive, which is password protected, subject to double authentication processes and the university firewalls. No personal information will be recorded manually using pen and paper to minimise risk. All data will be destroyed as soon as possible after the degree has been awarded.</p> <p>Interviews will be recorded using a battery operated, non wi-fi enabled, hand-held digital recording device. The audio (which will not contain identifying information) will be transferred and stored as above, making full use of the university's organisational and IT security procedures. After the degree has been awarded, data will be sensitively disposed of according to the requirements of GDPR</p> <p><i>(this box should expand as you type)</i></p>		
	Does it involve special category data (as defined by the GDPR)?	YES	NO
3	<p>“Special category data” means sensitive personal data consisting of information as to the data subjects’ –</p> <p>(a) racial or ethnic origin,</p> <p>(b) political opinions,</p> <p>(c) religious beliefs or other beliefs of a similar nature,</p> <p>(d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992),</p> <p>(e) physical or mental health or condition,</p> <p>(f) sexual life,</p> <p>(g) genetics,</p> <p>(h) biometric data (as used for ID purposes),</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	If YES, provide a description of the special category data and explain why this data needs to be collected:		
4	<p>Whilst there is no explicit aim to address any of the above, as the interviews will involve discussion around therapy/counselling and hoarding, it is possible that (e) mental health issues may be discussed.</p> <p>As previously mentioned, the researcher is a qualified and practicing counsellor who is experienced in discussing mental health issues as part of his day-to-day work.</p> <p><i>(this box should expand as you type)</i></p>		

	Will data from the research activity (collected data, drafts of the thesis, or materials for publication) be stored in any of the following ways?	YES	NO
5	Manual files (i.e. in paper form)?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6	University computers?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7	Private company computers?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
8	Home or other personal computers?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
10	“Cloud” storage or websites?	<input checked="" type="checkbox"/>	<input type="checkbox"/>

11	Other – specify:	<input type="checkbox"/>	<input checked="" type="checkbox"/>
12	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of backup procedures, password protection, encryption, anonymisation and pseudonymisation:		
	<p>Pseudonyms will be used and no digital record will contain corresponding identifying information, this will be known only to the researcher. Phone numbers of participants stored in the researcher's phone will be pseudonymised.</p> <p>Any information which might identify participants, e.g., consent forms, will be stored separately from data.</p> <p>Raw audio will be recorded on a micro-SD card and stored in a locked draw in the home of the researcher as a back up until submission at which point they will be deleted.</p> <p>Audio files will be transferred to the university's OneDrive, which is password protected, subject to double authentication processes and the university firewalls.</p> <p>Audio will be transcribed using MS365 and the resulting transcripts anonymised and, again, saved and worked on via the university's OneDrive.</p> <p>No audio or transcripts will be saved on any device such as laptop or PC which could be hacked, stolen or lost.</p> <p>For interviews conducted via MTeams, the consent form returned prior to the interview will cover the use of MTeams, and interviewees will be directed to Teams' most recent privacy and storage policies (<u>Microsoft Privacy Statement – Microsoft privacy</u>).</p> <p><i>(this box should expand as you type)</i></p>		

Data Protection			
	Will the research activity involve any of the following activities:	YES	NO
13	Electronic transfer of data in any form? NOTE: Interviews will be recorded onto a micro-SD card and the files transferred to the UWTSD OneDrive and then for transcription via MS365. Audio and transcripts will only be saved on OneDrive.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
14	Sharing of data with others at the University outside of the immediate research team?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
15	Sharing of data with other organisations?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
16	Export of data outside the UK or importing of data from outside the UK?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
17	Use of personal addresses, postcodes, faxes, emails or telephone numbers? NOTE: Participants may require a hard copy of the research documentation which would be sent using a signed-for service. Email and texting are likely to be used for discussion / planning; these will be deleted at the earliest practicable opportunity. Any device these are present on will be password protected and details anonymised if possible.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
18	Publication of data that might allow identification of individuals?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
19	Use of data management system?	<input type="checkbox"/>	<input checked="" type="checkbox"/>

20	Data archiving?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
21	If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and Data Protection Act (2018) (and any international equivalents, where appropriate):		
	<p>As previously outlined, interviews will be recorded using a digital device onto a micro-SD card. This data will be transferred to the UWTSD OneDrive, transcribed electronically via MS365 and the resulting transcripts anonymised and also saved to the OneDrive. At each stage the researcher commits to adhering to the guidelines of the university and the BACP as well as GDPR and the Data Protection Act. All measures will be taken to ensure the safe and ethical handling of personal information.</p> <p><i>(this box should expand as you type)</i></p>		
22	List all who will have access to the data generated by the research activity:		
	<p>The sole researcher, Harry Beer.</p> <p><i>(this box should expand as you type)</i></p>		
23	List who will have control of, and act as custodian(s) for, data generated by the research activity:		
	<p>The sole researcher, Harry Beer.</p> <p><i>(this box should expand as you type)</i></p>		
24	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.		
	<p>Raw interview data will be recorded on a micro-SD card and kept in a locked drawer as a back-up precaution while the researcher is preparing the dissertation. At submission, this material will be deleted.</p> <p>Data that is transferred via the researcher's laptop to an external hard drive (password protected) for purposes of transcription will be labelled anonymously and deleted immediately afterwards.</p> <p>The anonymised transcripts will be retained until the degree is awarded and then destroyed.</p> <p>For interviews conducted via MTeams, the consent form returned prior to the interview will cover the use of MTeams, and interviewees will be directed to Teams' most recent privacy and storage policies (Microsoft Privacy Statement – Microsoft privacy).</p> <p><i>(this box should expand as you type)</i></p>		
25	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtsd.ac.uk/). If so please explain. <i>(Most relevant to academic staff)</i>		
	<p>The data will not be stored in the UWTSD Research Data Repository.</p> <p><i>(this box should expand as you type)</i></p>		
26	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtsd.ac.uk/library/research-data-management/)	YES	<input checked="" type="checkbox"/>

27	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	YES	<input checked="" type="checkbox"/>
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SECTION K: Declaration

<p>The information which I have provided is correct and complete to the best of my knowledge. I have attempted to identify any risks and issues related to the research activity and acknowledge my obligations and the rights of the participants.</p> <p>In submitting this application I hereby confirm that I undertake to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice which is published on the website: https://www.uwtsd.ac.uk/research/research-ethics/</p>			
1	Signature of applicant:		Date: 09/06/24

For STUDENT Submissions:

2	Director of Studies/Supervisor:		Date:
3	Signature:		

For STAFF Submissions:

4	Academic Director/ Assistant Dean:		Date:
5	Signature:		

Checklist: Please complete the checklist below to ensure that you have completed the form according to the guidelines and attached any required documentation:

<input checked="" type="checkbox"/>	I have read the guidance notes supplied before completing the form.
<input checked="" type="checkbox"/>	I have completed ALL RELEVANT sections of the form in full.
<input checked="" type="checkbox"/>	I confirm that the research activity has received approval in principle
<input type="checkbox"/>	I have attached a copy of final/interim approval from external organisation (where appropriate)
<input type="checkbox"/>	I have attached a full risk assessment (where appropriate) ONLY TICK IF YOU HAVE ATTACHED A FULL RISK ASSESSMENT
<input checked="" type="checkbox"/>	I understand that it is my responsibility to ensure that the above-named research activity will meet the University's Research Ethics and Integrity Code of Practice.

<input checked="" type="checkbox"/>	I understand that before commencing data collection all documents aimed at respondents (including information sheets, consent forms, questionnaires, interview schedules etc.) must be confirmed by the DoS/Supervisor, module tutor or Academic Director.
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RESEARCH STUDENTS ONLY

Once complete, submit this form via the **MyTSD Doctoral College Portal** at (<https://mytsd.uwtsd.ac.uk>).

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk , with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

Appendix 8 – Information sheet for participants

Thank you for agreeing to take part in this research, the date and time of which we have now agreed.

Your involvement takes the form of a one-to-one conversation lasting for approximately one hour which will be conducted on MS Teams. This will be recorded and stored securely on a password protected hard drive which will not be accessible by anyone other than the named researcher.

The interview will be relaxed, open and informal. No other person will be involved either at the interview or later in the analysis.

While this is not counselling, it is confidential and boundaries will be maintained. Open ended general questions will be asked which will allow you to explore your views and perceptions of the topic.

If at any time you wish to draw the interview to a close you will be able to do so without giving a reason. No data supplied by you will then be used.

Our discussion will be transcribed and analysed, after which a copy of the transcript plus derived meanings will be returned to you (if you so wish). You will have the opportunity to check the content and make notes of anything you are not happy with or would like to change.

You will be reminded at the start of the interview of the consent form you signed and returned (attached), the anonymity of the information you share, the fact that the interview is being recorded and that participation can be terminated at any time up to the cut-off point.

Only the researcher will hear the recording and have sight of any notes. Recorded and written material will be kept securely and destroyed once research is complete. Involvement in the study will be confidential, data collected will be anonymised and no detail which could be directly connected to any participant will be identifiable.

As a member of the BACP the researcher adheres to its ethical frameworks and the legislative requirements of the Data Protection Act and GDPR.

Topics for discussion are provided on the interview schedule which is also attached. These will give some idea as to the structure; however, the interview will go where you lead. You can decline to answer any questions without explanation.

The interview will close with the researcher thanking you for your time and reminding you of the procedures should you feel distressed by taking part or have any concerns about the conduct or process of the research. You will be reminded that a copy of the interview transcript and derived meanings will be sent to you along with a copy of the signed consent form for your records (you can indicate at this time whether you want to receive these).

There will be a short 'cool down', or debriefing, period immediately following the interview where you will have the opportunity to reflect upon and discuss the research process.

Thank you.

Appendix 9 – Consent form for participants

PARTICIPANT CONSENT FORM.

TITLE OF RESEARCH STUDY:

Exploring the Therapeutic Experiences of People with Hoarding Disorder: An Interpretative Phenomenological Study.

		YES	NO
1	I have read (and retained) the information sheet for this study, have had details explained to me and have no reservations.		
2	My questions about the study have been answered and I understand that I may ask further questions at any point.		
3	I have a telephone number and email address for the researcher and details of the main project supervisor should I have any concerns.		
4	I understand that I can withdraw from this study at any time up to the designated cut-off point, without giving any reason. If I do so data collected relating to me will be destroyed and not used in the study.		
5	I understand that the interview will be conducted and recorded using MS Teams or face-to-face but my involvement in the study will be confidential and any data collected will be anonymised. Data collected will be destroyed when the research project is completed.		
6	I understand that quotations from my contributions may be used to support the research and that findings may be the subject of journal articles and/or any other related educational or research work and that names and any other identifiable information will be anonymised.		
7	I consent to participate in a face-to-face / online interview and to this being recorded.		

Participant's Name:

Participant's Signature:

Date:

Researcher's Name: Harry Beer

Researcher's Signature: H. Beer

Date:

Researcher's contact details:

2307835@student.uwtsd.ac.uk

If you return this form via email, you may be able to sign it electronically. If this is not the case, please note that receipt of this form via your email address will be taken as informed consent.

I would like to have sight of the research findings when these are produced **Yes/No**

Please keep your copy of the consent form and the information sheet together.

Appendix 10 – Interview schedule for participants

INTERVIEW SCHEDULE

RESEARCH TITLE:

Exploring the Therapeutic Experiences of People with Hoarding Disorder: An Interpretative Phenomenological Study.

Date:

Start:

Finish:

Venue/mode of interview:

Interview with participant:

INTRODUCTION:

Reminder of the project purpose and aims, study, recording, dissemination and withdrawal.

Ensure interviewee has copy of the information sheet and has signed consent form.

INTERVIEW OUTLINE (subject to change, not a verbatim guide):

- What impact has hoarding had on your life?
- Tell me about your experience of therapy.
- What impact did the therapy have on you?
- Can you assess whether the process alleviated any distress or led to any changes?
- Describe any aspect you felt was particularly good.
- Any element you feel was unhelpful?
- What is the biggest learning you take with you?
- Anything you wish could have been different?
- Is there anything you would like to add?

CLOSING NOTES AND DEBRIEF:

Thank you participating.

Your information will be anonymised and protected.

Any issues or concerns raised by taking part?

Do you have any questions?

Cut-off date for withdrawing: 31st October 2024.

Appendix 11 – Examples of transcript with exploratory noting and experiential statements

Appendix 11a - Yvonne

EXPERIENTIAL STATEMENTS	LINE	TEXT	EXPLORATORY NOTES
	1	Harry Beer (2307835) 4:41	
	2	So what I've written down is, what impact has hoarding had on	
	3	your life. And so, let's start with that, shall we?	
	4	Yvonne: 4:47	
Hoarding is not just one thing	5	Yeah. Well, first of all, I I'm a bit hesitant about the meanings of	Language, meanings, interpretations.
	6	words, so hoarding obviously has lots of sort of implications, so	
Childhood was unpredictable and confusing	7	it might be being greedy or it might mean... um... obviously	
	8	having mental problems. So in my case, so the question was,	
	9	what impact has it had, I think? From an early age I, I had quite	Lack of stability
	10	a chaotic beginning in life, in sort of psychological areas that	Art and dad
	11	may be relevant, but my father had was a kind of contemporary	important
Moved a lot so no time for roots	12	artist and um so it was difficult to make sense of my home	Confusing
	13	environment and so I'm so that's the background and then, you	
	14	know, years later... um... I moved. I lived in London and I moved	
Art is an important theme	15	from about seven or eight different places to live, I think over	No time to settle
	16	the years. And stayed with my own peer group age group, living	
	17	in shared accommodation and then a Co-op. And then... I	
	18	moved to Devon when I went to do a degree course in an arts	Art is huge in her life
Found it difficult to fit in and cope growing up	19	degree course... Which again, it's difficult to define. You know,	More confusion
	20	with contemporary artists, sort of... full of questionable	
	21	theories and.... Um... difficult to understand... analysis you	
	22	know, it's all kinds of different people that I met at school and	
	23	social, you know, differences between people and just coping as	Identity issues
	24	a young person. So, I went to do this degree quite late in life...	
No obvious line between rubbish and art	25	in the beautiful Devon area of Dartington and I stayed there for	
	26	three years, but I was 30 by the time I started, I was 30, 31... so.	
	27	There were issues in my family with the so-called art, which in	What is art and what is junk?
	28	some sense may have just been literally rubble, you know, so it	
	29	wasn't... easy to.... to see what was valuable and what was...	
	30	rubbish... really.... so... And, then I moved to this where I am	
Being a single parent was a struggle, authorities were involved	31	now because I had a child... In the year 2000, millennium and I	
	32	had social services involvement at the time. I had a sort of child	It was hard as a single parent
	33	safety child protection case for about 3 years intermittently. So	
	34	because I was on my own and... um... So I moved into this...	
	35	with council property house semi-detached 2 bedroomed	
	36	house with my 2 year old daughter... and brought her up here	
	37	till she was about 19 and went to do her degree in London and	
	38	she's not here now... she's... wants to stay in London, so she	Collecting things as a response
Counselling over the years has not just been about the hoarding	39	doesn't really.... This was her room and... But the hoarding is	
	40	just the way that I collect, and the way I, I, respond to this	
	41	particular house. And I've had lots of counsellors help trying to	Needed help with
	42	help me with not only with trying to sort out my stuff, but, you	lots of things in life

<p>A strong link between letting go of the deceased person and letting go of their possessions</p>	<p>43 44 45 46 47 48</p>	<p>know, supervising with and helping me being a mum and... socialising in it where I am and my my family, my extended family extended family, you know, and they've yeah, it's grown. And the years go by and normal things happen like they happen to everyone and it's all rather rather difficult and sad in some, you know, with... my parents passing away and then my brother's from organising that and the furniture that I've inherited, which is in his garage, which I'm paying for. It's not sort of very high valued furniture, it's just... furniture I quite liked and I wanted to try and use it at some point, but it's just been there for about nearly three years just... costing rent and... doing absolutely nothing. So that's a shame. And I collect things like newspapers and jars and some things for recycling. Obviously, I've got this.... awareness about recycling and not putting sending things to landfill and so it's a mix... a mixture of things.</p>	<p>Life can bring pain</p> <p>Difficult to let go of possessions belonging to deceased parents</p> <p>Environmentally aware</p>
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Appendix 11b – Simon

EXPERIENTIAL STATEMENTS	LINE	TEXT	EXPLORATORY NOTES
A learning relationship with therapist though details are hard to pin down	284	Right. So let's think. Let's go back to your CBT person then. Are	Relationship with therapist
	285	you doing that face to face?	
	286	Simon 26:39	
	287	No like this, teams.	
	288	Harry Beer (2307835) 26:40	
	289	Right, OK, but you, but but it sounds like you've got a good	
	290	connection with the person who's delivering the therapy?	
	291	Simon 26:42	
	292	Yeah, yeah. Yeah, yeah, definitely. Definitely. Definitely, yeah.	
	293	We get on. She's gave me lots of insight... diagrams about... I	
Therapy is validating, reassuring, empowering	294	can't remember what they're called now, but like it literally a	Vague description of a CBT tool
	295	circle where you might start off as quite enthusiastic, then you	
	295	start doing the drawer, then by the time it comes round to sort	
	296	of like 10 o'clock 11:00, you're waning a bit and getting fed up	
	297	and maybe being about a bit self-critical, people get stuck	
	298	there... they have a rest and then they get back to the 2:00	
	299	position, let's have another go and just little things like that	
	300	really helped me. It makes me realise... not that I'm normal, but	
	301	that the process is you know that you know it's, it's	
	302	documented. And so I feel better. It's like I can see myself in	
Failing to do CBT homework but that's ok, it's all self-awareness	303	these stages and I can, I can understand and know that this is	Therapy helps him relate to his own experience, feel normal
	304	normal and give it a week or two and I'll be back on task which	
	305	again is normal. That you can't just keep going at it and going at	
	306	it... She's also gave me lots of stuff just about oh, let me think,	
	307	emotions and how they affect you, fatigue, I can't remember	
	308	them all, but it's also been a good process in that she sent me	
	309	things to do and then I failed miserably. I just haven't been able	
	310	to do them either because I've forgotten where the things are,	
	311	or it's just been too hard, so that's that's been good as well for	
	312	me. And I think for her that she's seen, I really do struggle with	
Good intentions do not come to fruition	313	these things, you know, that I can't. Yeah...	Struggles with CBT homework
	314	Harry Beer (2307835) 28:36	
	315	That's interesting. Do you mean that that she sort of sets	
	316	homework and then you can't do it?	
	317	Simon 28:42	
	318	Yeah, yeah. Literally, literally, like, you know, I suppose more	
	319	often than not, I've bitten off more than I can chew. I've said,	
	320	oh, yeah, I'll do this and I'll declutter there, and I'm going to	
	321	keep the kitchen tidy as well. And a week later, yeah, the	
	322	kitchen's still a mess, and, you know, I've I've managed to throw	
	324	2 hard drives away. Nothing. Like, I I said I would. Again, I don't	
	324	know if it's normal, but time management is a huge problem	
	325	for me. I honestly don't know what I do with my time. I always	
			Intensions v reality
			Busy but ineffective

<p>Always busy but achieving nothing is frustrating</p> <p>Outwardly, all is well, the truth is hidden and shameful</p>	<p>326</p> <p>327</p> <p>328</p> <p>329</p>	<p>seem to be busy, but I don't seem to get anything done. Finding things, looking for things takes up a lot of time. Yeah, yeah. The way I feel is that I'm living within the confines of a mental health issue, and that's why it's so hard for me to to just get on with life. I'm really good outside, really good... and I can talk and, you know, people of all levels and, you know, but this is like, hidden. This is where I struggle and it's totally hidden.</p>	<p>Hidden - a dirty secret?</p> <p>Isolated, alone</p>
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Appendix 11c – Kate

EXPERIENTIAL STATEMENTS	LINE	TEXT	EXPLORATORY NOTES
Stressful home and using stuff to self-soothe	11 12 13 14 15 16 17 18 19 20 21 22	KATE 3:31 OK. I think I'm going to go back a little bit. Not at the time, but, in retrospect, when I look back at it, the first signs of hoarding was as a teenager . And so... the the thing that I used to do, which wasn't really hoarding, but I recognise it now as being the beginning of the problem, was I lived in a very stressful household . And so when I was very stressed, my coping mechanism was that I got out all the stuff that was in the bottom of my wardrobe and I spread it all over the floor . And that's somehow released the stress. I, I, don't know exactly how. I suppose it's a bit like self-harm , you don't really understand the connection between what you're doing and what you want to achieve, not that I've ever self-harmed , but...	Started in childhood Home was stressful Used stuff to self-soothe Comparing to self-harm
Preferred to have stuff out on the floor	23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53	and then I would leave it on the floor. It was a tidy house, there was no hoarding, for a long period of time, I couldn't clear it up , and that was what I recognised as a teenager, I don't know, 12/13, something like that, but it wasn't normal, was that in my head, I was tidying up, but I couldn't put it away . And that was what I recognised as a problem. And sometimes it was there for quite long periods of time. I had an auntie come to stay on one occasion and a piece of of sheet was put over the pile to hide it . She... there was two, there was twin beds in the room, my sister had a separate bedroom, and so she was sleeping in the other bed and this was... but strangely enough I don't remember my mother asking me why I did it, or in fact even saying to me, can you... I want you to go, you know, I want you to go and clean your bedroom up or you won't get any tea because that was the sort of thing she would say. I never remember her saying that . She must have been aware of the fact it was on the bedroom floor. And then it it progressed in my life to having larger and larger amounts of possessions . So I remember one job where I was moving from... I was a live-in nanny, and I was moving out into a flat with my husband to be... and there was a great big box of like papers like newspaper cuttings and that sort of thing... and I mean, I'd only been living with them for, I don't know, about 10 months, but was quite a bit of stuff. And it was a bit disorganised. So, I've been in this house for 45 years. I had... my problems started with my mother , which you know, you'll go back to in another question... and carried on with my ex-husband so... he left... 30... I don't know... 40 years ago, I suppose. He's been gone a long time anyway, and my house is cluttered ... if I... If you were on my phone, I could... I'm in my lounge at the moment, so I've	Couldn't put things away or clear up Her mess was hidden from visitors, shameful? Mother did not respond to her about it, good or bad It got worse
Hiding the mess, implying it was shameful or wrong			
Mum did not respond to the behaviour			
Hoarding relates to difficult relationships			
Mum is dead and husband gone but the hoarding persists			Mother is dead and husband long gone but the hoarding persists

House doesn't feel like a home	54	got stuff here on top of the piano... over here... there's no no	Not a homely feel
	55	comfortable chair to sit in. I have a settee. This is a, you know, a	
	56	comfortable chair, but it's got stuff in it. Here, I've got a brown	
This is not normal living	57	three-piece suite and then over here there's a coffee table on	Self-deprecating description, sarcastic
	58	top of the settee and a load of stuff that came back from my	
	59	dad's house, and I've got a dressing table in my lounge, which	
	60	of course is very normal. And I suppose on the edges of the	
Simple things are a daily challenge	61	room, it's tidier anyway. All the... whole house is full of stuff. I	
	62	can move around the house. My kitchen particularly is difficult	Daily challenges with simple things like preparing food
	63	because I've got a lot of... recycling is my problem... recycling on	
	64	the worktops... so it's difficult to get food. I have to... I'm	
The designated functions of the house are lost to the hoarding	65	constantly moving stuff so that I've got room to butter a piece	
	66	of bread or assemble a meal or something like that. And I've	
	67	got 3 dining, three dining tables, two down here, which you've	
	68	just seen, and one in the kitchen.	

Appendix 11d - Oliver

EXPERIENTIAL STATEMENTS	LINE	TEXT	EXPLORATORY NOTES
Deep emotional content is not seen often in the group	428	NB 39:04	
	429	I don't think I've shared... there have been one or two	
	430	occasions when I have... I have touched emotion, but I don't	Emotional connection is rare
	431	think it happens very often within our group. But there's	
	432	definitely been insight. Harry, I certainly, I'm... sorry... I'm now	
Group has helped to be honest about the hoarding	433	more confident in actually talking about the fact that I'm a	Can now say he is a hoarder
	434	hoarder and that's a major breakthrough. So one is	
	435	acknowledgement, and from one of the books I'm reading,	
	436	which I will mention while I can... is it at hand? Yes, it is at hand.	
	437	The notion of taking responsibility. I have to be responsible. It is	Taking responsibility, reality check
The reality is the issues must be faced, can't avoid it forever	438	my hoard. I've got to deal with it. I've got to own it. I also know	
	439	it's going to be painful and difficult. I can't avoid that... I can	
	440	keep on trying avoiding it, but to get to the other side, I have to	
	441	go through the resolving the issues I have, looking at the fact	
	442	that my house is falling apart, all those kinds of things, there's	
	443	going to be some money and expense involved, all those kinds	
	444	of things. So that's roughly where I'm at. There's a book which	
	445	will obviously be recorded, I found a book in the library called	
	446	Building your Resilience, and its subtitle is CBT mindful and	
	447	that's in stress management, survive and thrive in any situation	
	448	by a guy called Donald Robertson. And he talks about the fact	
	449	that... classical CBT, as perhaps 20 years ago, has kind of	
	450	evolved into ACT, Acceptance Commitment Therapy I believe	
	451	it's called. And I really believe from his explanation I can see	
	452	there's a truth in that. And this, the notion of people have	
	453	requiring an element of stoicism. Life's thrown shit at you,	
Therapy to find inner strength to face pain, alone against the hoard	454	you've got to handle it. You need that kind of inner strength to	
	455	think, not my doing or I've got that wrong... I've got to try to	
	456	put it right and try and get beyond it. And I think that's a key	On him to face the fear and do it anyway
	457	step in the therapeutic process. You've got to be able to say,	
	458	this is what I've got to do and then do it. And I'm I'm at like,	
	459	that's stage 4 of having to do it. I know, I know, but I'm going to	
	460	have to go through the pain and start doing it. To add another	
	461	dimension to the conversation. I'm 77, I was diagnosed with	
	462	prostate cancer four years ago. I had radiotherapy. I have been	
	463	on hormone treatment for a while, which they keep you on,	
	464	and then they try you... try taking you off it and they see what	
	465	then happens and my PSA levels now going back up again so	
	466	that means the cancer cells are beginning to divide again, so.	
	467	That adds another dimension. I'm also to an age where I've lost	
	468	one or two friends through various illnesses and so on. The	
	469	other motivating factor, this is probably quite a common theme	
	470	is I'm old, I'm getting towards the end of my life. I would like to	End of life issues

<p>Does not want to die leaving a hoarded house</p> <p>Regaining autonomy would lead to happiness</p> <p>The hoarding is standing between me and a better life</p>	471	<p>die tidy. I've read the book, the Swedish Art of Death Cleaning, which is a lovely book. Great thing for hoarders to read. I must simply do that I must... I know I'd live a much happier life if I'd actually... if I if I were in control of my environment again, that's the thing.... being in control of my environment. There's a... when I was younger, I loved mountain walking, walking. One of my dreams when I retired was that I'd do some long-distance walks. I haven't done so... I would love to do that. If you like in the future, if I can get on top of my hoarding, there's a potential for me living a different life from the one I'm living at the moment.</p>	<p>Wants autonomy</p> <p>Brighter future?</p>
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Appendix 12 - Example of grouping of statements into personal experiential themes (PETs)

1 CHILDHOOD + MARRIAGE SHADOWS OF ABUSE

15) Mum had a lot of rules

4) Mum was about rules rather than affection

63) Not all mums were like hers

2) Preferred to have stuff out on the floor

4) Mum did not respond to the behaviour

Hiding the mess, implying it was shameful or wrong

13) Life changed aged 6 when mum turned on her

4) No reason why mum turned on her aged 6

38) A tumultuous marriage, a row every weekend

42) Abuse became normalised, home then marriage

43) He treated her as he treated his mum – abusive

11) Her own and her ex's mother's both had MH issues

45) Mum gone and ex gone but problems not gone

Mum is dead and husband gone but the hoarding persists

2) ONLY FAMILY HAVE THE POWER TO HURT LIKE THIS

60) Only family have the power to hurt like this

48) Mother always treated her badly

52) As an adult mum would still turn on her

53) Sister turns on her for seemingly no reason

55) In adulthood, sister makes her feel small

54) Sister controlling and angry she doesn't "fit in the box"

56) Sense of self destroyed by criticism from mum and sister

61) Being punished for not meeting expectations, fitting in

58) Estranged from one daughter – sense of loss

DRAFT PETs 1, 2, 3

NOT SEEN NOT HEARD NOT HELPED THE IMPORTANCE OF AUTONOMY

27) Psychologist had his own agenda, not interested in hers

35) Psychologist made her feel she was somehow wrong or at fault

28) Psychologist approach was not tailored to her needs

24) Psychologist was a threat to autonomy

26) The psychologist made her feel like a naughty schoolgirl, humiliating

33) Psychologist was inflexible, had an agenda "persuading me..."

25) Felt unseen by the psychologist, knew what help she wanted

30) Psychologist imposed his process on her

31) Psychologist rejected her needs

22) CBT was almost re-traumatising, bullying

18) After 3.5 years, no improvement, felt rejected by counsellor

29) Loss of control, no help at all

DRAFT PETs 4+5

23 COUNSELLORS 0 SOLUTIONS A PLANNED PROFESSION?

12) Therapy has not helped despite having seen a total of 23 counsellors over 35 years

19) Cynical about the value of the PCA

36) Low opinion of some counsellors, somehow not expert enough

47) Lack of respect for counselling qualifications

39) Many counsellors a homogenous blur, disappointing experience

57) Counselling did not help her reach conclusions

20) Wanted counselling to give her answers

40) Expected counsellors to offer insights and connections

71) Counsellors need to have specific knowledge of hoarding

59) Wanted counselling to build resilience and self-esteem

62) Counsellors must do more than listen, offer something

44) Helpful to talk but no solutions, a waste of money

SOME POSITIVES RELATIONS AND PERSPECTIVES

50) OCD and ADHD diagnoses helpful

68) Six diagnoses, HD is only part of the story

67) Her MH needs are complex and require expertise

51) Believes her autism is central

49) Realisation – it's a disorder, not laziness

70) Maybe events before her birth are significant?

16) Counsellor suggested mum wanted obedience and also link to trauma

17) With one counsellor 3.5 years, useful but not transformative

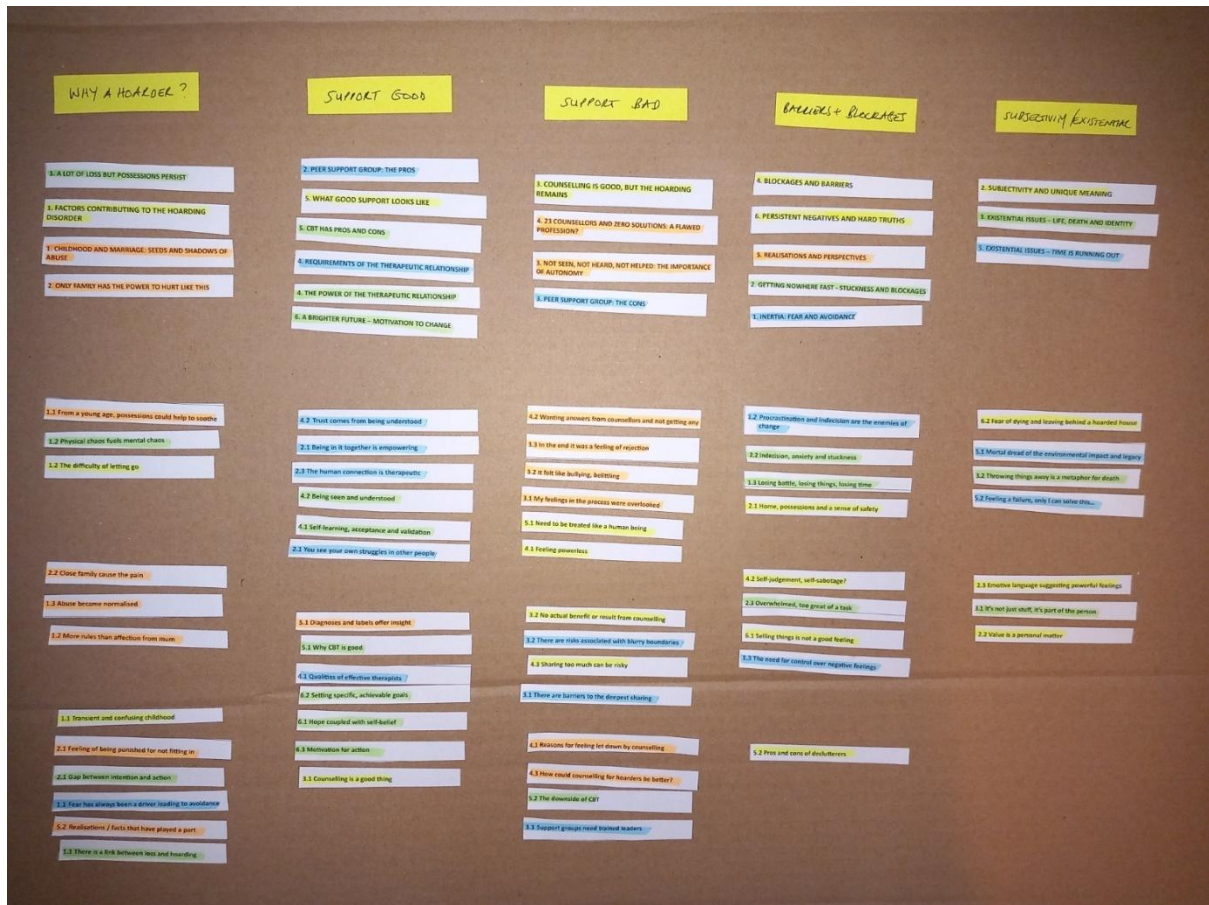
65) Some counsellors had empathy but no solutions

37) Female counsellors are more understanding

69) Declutterers get more done and do as she asks

72) Despite it all, believes counselling has a place

Appendix 13 – Example of sorting of PETs into group experiential themes



Appendix 14 – Participant quotes pertaining to ADHD/ADD

Simon: “I really do live within a mess. I, it's ADHD for sure. I just put things down all of the time, don't know where they are... I lose things all of the time and all of that takes up a lot of time.”

Oliver: “I think I suffer a little bit from ADD, you know, attention deficit disorder or I get distracted very easily...”

Kate: “I definitely have ADHD, but I don't think that's the primary problem, I think the primary problem is that I'm mildly autistic...”

Kate: “I've got OCD, but it's nowhere near as bad as the hoarding. And I also got a diagnosis for ADHD. Now, when I got the diagnosis for ADHD, I thought that that was the answer to the problem you know, I was rather loud and my mother didn't like it...”