Experiences of seeking help for hoarding difficulties: An IPA analysis

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The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Introduction: Difficulties related to hoarding behaviours can have a significant impact upon the life of the individual and those around them. Yet many individuals with hoarding behaviours struggle to engage with the interventions offered. This research aimed to explore the experiences of a sample of individuals who identify as engaging in hoarding behaviours and are seeking support in relation to them. Exploring motivation to seek support, the barriers those who hoard face in accessing support, and what can facilitate them to accept help may aid services in understanding how best to support individuals.

Method: Eight individuals who identified as seeking help in relation to hoarding behaviours participated. Interviews were conducted via telephone or videocall, before being transcribed and analysed using Interpretative Phenomenological Analysis.

Results: Four group experiential themes were identified across the data, with four, three, two and three subthemes respectively. Group experiential themes identified were Wrestling with identity, Who can I trust?, Services that don't fit and 'They just see the hoard, not the person': Overlooking the individual.

Discussion: Findings suggested complexity around the recognition of hoarding behaviours; participants described that they were continuing to grapple with whether their behaviour was protective or problematic. Difficulties trusting others and services were identified, although participants who had accessed peer support

described this as valuable. Some participants described difficulties accessing services because they were deemed not to fit clinical thresholds. All described a sense that the interventions available from statutory services were not suited to them, often because support focused on the clutter rather than the individual.

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1. Introduction

This chapter will begin by defining hoarding and exploring challenges related to insight which are commonly reported. An overview of the literature on the impact of hoarding will then be given. This is followed by a critical consideration of the social and cultural context of hoarding. A summary of treatment options for hoarding will be provided. Help seeking literature in relation to conditions with possible links to hoarding will be outlined. The final section of this chapter will detail the aims and research questions for this study.

Problems related to hoarding behaviours can have a significant impact upon the life of the individual and those around them. Yet many people with hoarding behaviours find it difficult to engage with the interventions offered. This research aims to explore the experiences of a sample of individuals who self-identify as engaging in hoarding behaviours and as seeking support in relation to them. It is hoped that by exploring motivation to seek support, a greater understanding of the barriers those who hoard face in accessing assistance, and what can facilitate them to accept help may aid services in understanding how best to support individuals.

In order to capture the most recent relevant literature, texts which summarise findings in relation to hoarding were examined (DCP, 2015; Frost and Steketee, 2014). A further review of the existing literature around help seeking in hoarding presentations was undertaken in January 2020, then updated in July 2022. Search terms used and results returned are outlined in Appendix A. Relevant publications have been incorporated into the summary below. Taking into consideration the view that the value of applying medical terms to presentations can be questionable, throughout this paper descriptions such as hoarding ‘behaviours’, ‘presentations’ or ‘difficulties’ will predominantly be used. Participants often simply referred to their

'hoarding'. However, where literature and diagnostic manuals discuss 'insight' and Hoarding Disorder (HD) these terms will be employed. In addition, the items acquired will be referred to as items or, often, 'stuff', echoing a phrase repeatedly used by participants. Whilst a broad, non-specific term, 'stuff' was also used because it was considered that items alone often don't result in distress and difficulties for individuals, rather it is the interaction between possessions and the space available.

1.1Defining hoarding

In terms of diagnostic categorisation, hoarding behaviours were previously considered part of an Obsessive-Compulsive Disorder (OCD) (American Psychiatric Association (APA), 2000). Clinicians later argued it should be considered independently of OCD (Mataix-Cols et al., 2010) due to growing evidence suggesting distinctions between the presentations (Samuels et al., 2008). It was not until the Diagnostic and Statistical Manual of Mental Health Disorders 5th edition (DSM-V) was published in 2013 that Hoarding Disorder (HD) was classified as a standalone diagnosis, although it continues to be listed as an OCD subtype within the draft of the International Classification of Diseases 11th Revision (ICD-11, World Health Organization, 2019). The diagnostic criteria within these manuals detail similar requirements, which will now be further outlined.

1.1.1 *Difficulty discarding*

Difficulty discarding items is an essential feature for diagnosis of Hoarding Disorder (HD) within both manuals, with this difficulty being due to a perceived need to save items and distress associated with discarding. Both the DSM-V (2013) and the ICD-11 (2019) outline that to meet diagnostic criteria, this difficulty leads to an accumulation of possessions which impacts upon function and causes significant

distress or impairment. The DSM-V explicitly outlines that items are kept irrespective of their monetary value, whilst the ICD-11 describes common motivations to retain items such as emotional associations, perceived usefulness, or aesthetic properties.

The DSM-V stipulates that it is key that the presentation should not be attributable to another medical condition (e.g. Prader-Willi syndrome or brain injury), or better explained by an alternative mental health disorder, such as obsessions within OCD, special interests as part of an autistic spectrum condition, or reduced energy as a result of a mood disorder. The ICD-11 acknowledges that hoarding behaviours are more common in some of these conditions but suggests there may be value in an additional diagnosis of HD if the presentation requires separate clinical consideration.

1.1.2 *Acquisition*

When considering the process of accumulating items, the manuals differ slightly. The ICD-11 details that both difficulty discarding and actions to amass items should be behind the accumulation of clutter, though the criteria states that this could be passive (e.g. the build-up of postal correspondence) as well as intended acquisition. Whereas the DSM-V does not comment upon acquisition within the essential criteria, but requests that clinicians specify whether excessive acquisition is evident within the presentation. The manual describes this trait to be very common and present in more than 80% of those who meet the criteria for HD.

1.1.3 *Insight*

A further specifier across diagnostic criteria within both manuals is in relation to the individual's insight into their hoarding behaviours, between good or fair insight into difficulties to poor or absent (both ICD-11 and DSM-V) with the

additional specifier of possible delusional beliefs in DSM-V only. The complexity of the concept of insight requires further analysis in the next section.

1.2 Further exploring insight

In relation to hoarding presentations Frost et al. (2010) outlined three possible areas of insight deficits: *anosognosia, overvalued ideation* and *defensiveness. Anosognosia,* or lacking awareness of a problem, may be relevant to those with hoarding difficulties who come to the attention of public services due to the social impact of their presentation. The authors suggest that anosognosia may be a common feature, however there is no research specifically exploring anosognosia in hoarding. Worden et al. (2014) discuss the application of literature around anosognosia in schizophrenia to hoarding difficulties. They outline possible neurobiological bases and note neuropsychological functioning deficits in people who experience psychosis alongside anosognosia, which appear to be commonly found in those with hoarding difficulties. These deficits primarily involve executive functioning which may influence attention, decision making and ability to categorise. Such deficits may increase the likelihood of acquisition and reduce an individual's ability to make a choice to discard items. Worden et al. (2014) also suggest that individuals who hoard are more likely to be socially isolated and therefore not receive feedback from others that their behaviours may be considered unacceptable.

Frost et al. (2010) describe *overvalued ideation* as an enduring belief that items have significant meaning, value or importance. They postulate that altering such beliefs is the biggest challenge in managing hoarding behaviours, noting that an individual may have insight into their difficulties, yet continue to have overvalued beliefs about possessions preventing them feeling able to discard objects.

They also suggest that those who hoard may not currently view an item as having high worth but be reluctant to discard it due to its potential opportunity to be useful or valuable.

Finally, the same authors (2010) suggest *defensiveness* limits the effectiveness of traditional approaches in response to hoarding. They describe that defensiveness and resisting suggested change may become a common response in therapy further to many years of this interpersonal pattern with family members, social care or housing agencies. Those who hoard may have intense beliefs around the need to feel control over their possessions (Steketee et al., 2003), therefore Frost et al. (2010) highlight the need for a therapeutic stance considerate of this; that the individual should make all decisions in relation to items and practitioners will only touch items when given explicit permission to do so. They also describe phrasing their collaborative aim as being to create space to live in, rather than discarding items.

1.2.1 *Understanding hoarding disorder from a psychological perspective*

It is key to note that low motivation is a discrete difficulty to lacking insight. An individual may see their hoarding as problematic yet still not be motivated to change. Miller and Rollnick (2002) defined motivation as a combination of an individual's *willingness, ability* and *readiness* to change. In relation to *willingness,* Worden et al. (2014) suggested that seemingly being unwilling to change might be associated with limited insight and anosognosia in hoarding. An individual may not have confidence in their *ability* to clear clutter due to the scale of the task or the distress associated with previous attempts to discard. They also suggested that individuals often speak of plans to manage their hoarding in future, which would link with Miller and Rollnick's dimension of *readiness*.

Tolin et al. (2010a) suggested that those who hoard are often in the 'precontemplative' stage of Prochaska and DiClemente's change model (1984), an interesting statement given Ayers et al.'s (2019) finding, mentioned below, that treatment success was associated with participants in the 'maintenance' stage. Generally, research on motivation in hoarding is limited though; there is no hoarding specific measure of motivation, and no evidence on whether levels of internal versus external motivation influence treatment outcomes (Worden et al., 2014). This shortcoming in the literature seems even more problematic when considering that motivation and insight may vary across the dimensions of hoarding criteria. For example, an individual may feel that they have a problem with accumulating clutter and be motivated to reduce this by trying not to acquire new items, but not feel they have any need or motivation to discard existing objects. Nonetheless, Frost et al. (2010) describe that some individuals who hoard do identify their behaviours as problematic and seek help, beginning treatment describing a desire to change.

1.3 Impact of hoarding

The negative impact of hoarding difficulties is well documented within the literature. In 2008, Tolin et al. explored the social and economic effect of hoarding with individuals who self-identified as having hoarding difficulties, as well as informants who described a family member exhibiting such behaviours. Their findings described occupational impairments, comorbid health issues, threats of eviction and in some cases children or vulnerable adults being removed from the home. This familial strain is also reflected in Büscher et al.'s thematic analysis (2014) which described themes of reduced quality of life, shattered families and attempts by the family to respond to the hoarding behaviour. Tolin et al. (2008) report the financial impact of hoarding behaviours, with those meeting diagnostic

criteria for Hoarding Disorder being more likely to report difficulty in paying bills. Frost and Steketee (2014) summarise studies which identify social phobia as a commonly reported comorbidity amongst those with hoarding difficulties.

Hoarding behaviours are likely to have a burden upon environmental and community services. The increased fire loading and restricted egress from properties containing hoarded objects can place individuals at significant risk. Investigations in some areas have found that while fires at properties containing hoarded objects accounted for less than 1% of residential fires, they account for 24% of fatalities by fire which were deemed preventable (Szlatenyi et al., 2009). Greater time investment, increased input of resources required and potential lack of understanding of hoarding difficulties were associated with the cases presenting the most complexity and challenge for fire services (Kwok et al. 2018). Rodriguez et al. (2012) suggests that hoarding behaviours may put individuals at an increased risk of homelessness due to housing providers seeking eviction proceedings.

Whilst the literature mentioned above largely focuses upon the system around the individual, there is a dearth of studies exploring the impact of hoarding difficulties upon the individual themselves. During exploration of the literature numerous studies sought the perspectives of people who hoard on treatment options, but only 3 papers were found which investigated hoarding individuals' lived experiences of their difficulties and the impact (Kellett et al., 2010; Subramaniam et al., 2020 and Ryninks et al., 2019). The wider shortage of subjective reporting of experience within the literature is likely reflective of a frequent observation that those with hoarding difficulties may lack insight and be reluctant to engage with interested agencies, as mentioned above.

Kellett et al. (2010) explored the lived experience of 11 individuals who describe hoarding behaviours. Themes included childhood relationships (with

parents, patterns of attachment and abuse), the relationship the individual has with hoarded items (emotions attached, uses for the object and the item as a direct link to a comforting memory), cognitive-behavioural aspects of the individual's avoidance of discarding, and finally the impact of hoarding upon themselves, others and the environment. Quoted examples within the interview data included anthropomorphising objects, including items being 'lonely' if on their own, and a sense of retaining objects due to fear that if discarded they may be needed in the future. In relation to discarding difficulties, the participants described moving items from room to room as a means of avoiding discarding, as well as ideas of perfectionism around order and decision making which make discarding more challenging. Participants disclosed fantasies of the perfect home, but that their current living situation has a significant negative impact upon themselves including shame, stigma and not feeling understood. Subthemes around both physical and psychological entrapment becoming overwhelming were noted, as well as a perception that hoarding changed the individuals' sense of identity.

This study is not without its shortcomings, as the authors identify the sample as being purposive and likely motivated to discuss their experiences. They also point out that no screening was undertaken to explore the extent to which participants met definitions at that time of hoarding behaviours. Nonetheless, the study bears a number of similarities to the planned research outlined below, and states that to include screening tools would not be consistent with an Interpretative Phenomenological Analysis approach (IPA, defined further within Chapter 2). However, Kellett et al. (2010) did not look specifically at the lived experience and meaning made of help-seeking for hoarding behaviours as this project proposes, although it is likely that an understanding of the themes established by Kellett's team may underpin findings around decisions to seek support.

1.4 Critiques of hoarding

1.4.1 *Difficulty calculating prevalence*

As mentioned previously, prior to the DSM-V in 2013 there was no agreed diagnostic definition for hoarding. There have also been a wide range of measurement tools used within the literature aiming to capture hoarding behaviours (Steketee & Frost, 2014a). These variations combined with the limited insight described have led to significant difficulties in establishing the prevalence of hoarding. Attempts to capture population prevalence of hoarding at a diagnosable level range between 2.3% to 6% of the population (Frost & Steketee, 2014), although research suggests prevalence within clinical populations may be higher (Tolin et al., 2010b; Novara et al., 2016).

1.4.2 *Social determinants of hoarding*

It may be anticipated that income and social status are likely to influence hoarding presentations – those living in larger properties who are unlikely to have experienced social deprivation would be expected to be less likely to hoard. However, as summarised by Frost and Steketee (2014) literature around this is conflicting with some studies suggesting hoarding was associated with difficulty paying bills and those receiving a lower income (Tolin et al., 2008; Samuels et al., 2008), whilst other research found no differences between in income between participants who hoarded and those did not (Mueller at al., 2009).

Seemingly the only research aiming to further explore sociodemographic factors since Steketee and Frost's summary in 2014 was a study in Brazil by da Cunha et al. (2021). The authors reported a finding that those who hoarded objects had lower incomes, however it is important to consider that this study explored both object and animal hoarding in a developing culture. Additionally, the sample was of individuals who were the subject of complaints from others about their hoarding,

suggesting a high level of severity and that the sample lived in close proximity to others where their behaviour could be observed and reported. This may suggest they did not live in larger more affluent, detached accommodation where hoarding behaviours may take place unreported and unobserved. Further research is required to understand the impact of social determinants of health in relation to hoarding.

1.4.3 *Culture and context*

The application of diagnostic criteria based on a medical model also overlooks the concept of hoarding as a cultural construct. Again, this is another area of the literature requiring further research, though studies have begun to suggest that cultural values may influence hoarding behaviours (Timpano et al., 2015).

Schaeffer (2017) and Herring (2014) provide interesting summaries considering sociocultural ideas including consumerism, collecting, how items are disposed of items and the growing industry of decluttering businesses.

There are public representations of those who hoard on media reality television shows. Though published over a decade ago, Lepselter (2011) summarises several of the shows broadcast before considering the impact such portrayals have upon the wider narratives in relation to those who hoard.

It is also interesting to note the context this research was undertaken in – shortly before recruitment the COVID-19 pandemic began, with early research beginning to explore the potential impact of this upon hoarding behaviours (Fontenelle et al., 2021a). And the culture and context of hoarding presentations is likely to continue to evolve amid the current global cost of living crisis.

1.5 Treatment

1.5.1 *Current provision in the UK*

The limitations within the evidence base also seem to mirror the challenges in the provision and availability of interventions offered in a national context. Despite now being a discrete diagnosis there are no hoarding specific guidelines from the National Institute for Health and Care Excellence (NICE), with hoarding briefly being mentioned as a possible complexity of OCD (NICE, 2005). These guidelines suggest that home-based treatment may be considered for adults who are unable to attend a clinic with hoarding cited as a possible example, and that where these difficulties may prevent a clinician attending for home-based treatment that telephone CBT may be considered. NICE guidelines relating to common mental health problems also list hoarding as an example of OCD with moderate to severe functional impairment and suggest home-based CBT be offered (NICE, 2011).

Online public guidance from the National Health Service (NHS) mentions CBT as a treatment option and encourages accessing support through attending a GP or self-referral to Improving Access to Psychological Therapies (IAPT) services but acknowledges challenges in finding appropriate intervention, as it signposts individuals to an OCD charity should they have difficulties accessing therapy (NHS, 2022).

There are hoarding-specific charitable agencies individuals may access, though much of the assistance they provide appears to be in a support group format (Hoarding UK, 2022a). Whilst some may have adopted remote mediums during the COVID-19 pandemic, face to face groups may limit availability due to travel and location. Given the limitations of the support available it may be that those who hoard do not seek help because they lack confidence in treatments or services, alongside the common challenges in relation to insight and motivation. Support

groups of this nature for the most part seem to offer informal support and a space to share experiences, rather than a structured intervention. There seems to be little evidence around this type of support, although a peer-facilitated support group workshop demonstrated effectiveness when compared to a waitlist control, as well as group CBT delivered by a psychologist (Frost et al. 2012; Mathews et al. 2018)

Previous literature on interventions for hoarding has highlighted the potential acceptability of non-statutory services, including support provided by volunteers or peers. Holmes et al. (2014) commented upon the importance of non-statutory support in engagement when developing a self-help group.

The non-professional status of volunteers was also commented upon as being valuable in a study by Ryninks et al. (2019). The authors explored the experiences of older adults receiving help for hoarding behaviours and found key themes including the relationship between client and volunteer, the client feeling in control, and the process feeling 'client-led'. Challenges to receiving help was also an identified theme, with subthemes including shame, embarrassment, and clients' difficulties in discarding items. The authors suggest that statutory services may benefit from making links with third sector or charitable organisations in order to promote non-professional support for those who hoard.

1.5.2 *CBT*

A Cognitive Behavioural Therapy (CBT) treatment programme for hoarding behaviours is the most widely recognised approach to the presentation, aiming to enhance motivation, develop skills in organising and problem solving, reduce acquisition, promote discarding and consider relapse prevention (Steketee and Frost, 2014b). This approach has also been adapted to be used in group treatment, and

Muroff (2014) provides a helpful summary of the evidence in relation to this. Nonetheless, the treatment does have some critiques.

A meta-analysis of 12 studies describing the results of CBT interventions for HD reported the approach to show promise, with pre to post treatment effect sizes of 0.82 and 0.70 for total hoarding severity and clutter respectively (Tolin et al., 2015). Despite the reductions in symptoms, many people may be leaving treatment with poor outcomes: whilst symptoms were reduced there were low levels of clinically significant change across all outcomes, particularly in relation to clutter where only 25.44% of cases demonstrated clinically significant change (Tolin, et al., 2015).

A further meta-analysis by Rodgers et al. (2021) sought to update this investigation. Across 16 studies they found a larger pre to post treatment effect size of 1.11 for CBT treatment for HD. Four studies within the sample also provided follow up data, which suggested a sustained large effect size of 1.25 from pre-treatment to follow up. The authors note that whilst there is a dearth of research on long term effects of CBT for HD follow up findings should be considered tentatively; hoarding presentations are often chronic and a follow up of six months was the longest period data was collected for. The updated meta-analysis also does not comment upon whether the samples examined demonstrated reliable or clinically significant change.

1.5.3 *Challenges in treatment*

1.5.3.1 Attrition and Non-Response.

There have also been procedural challenges in establishing an evidence base in treatments for hoarding difficulties. One study reported that high scores on a hoarding measure were a significant predictor of early discontinuation of treatment, with 27% of individuals with hoarding symptoms dropping out of the OCD trial early versus just 12% of participants without hoarding symptoms (Mataix-Cols et

al., 2002). In addition to high levels of drop out, low levels of compliance with treatment recommendations have also been described. This has been evidenced within several studies in relation to homework completion in CBT for hoarding, found to be a key predictor of treatment outcome (Worden et al., 2014).

Ayers et al. (2019) completed a secondary analysis of two earlier studies to explore attrition and treatment response in hoarding. High baseline levels of clutter and reported denial were predictive of an individual dropping out of treatment ($t = -2.79$ and $t = -2.80$ respectively, both $p = .006$). As previously mentioned, the authors applied Prochaska and DiClemente's Transtheoretical Stages of Change model (1984) and reported that good response was predicted by individuals being in the 'maintenance' stage as well as demonstrating high levels of readiness to change. The authors suggest that motivational interviewing alongside treatment may increase readiness to change, and that tailoring treatment to an individual's identified stage of change may be beneficial.

Also exploring characteristics within those offered treatment, Medard and Kellett (2014) found that hoarding individuals had higher levels of attachment anxiety and less social support than student and community controls. These relational difficulties may also influence the reported challenges in engaging with support available (Frost et al., 2010).

1.5.3.2 Helpful and Unhelpful Components of Treatments.

Beyond traits or demographics within individuals, research has also attempted to explore the components of treatments or support to establish which are helpful from the perspective of people with hoarding difficulties and those which are less so. In relation to the CBT treatment developed for hoarding Ayers et al. (2012) sought client feedback on the intervention from 12 older adults. They reported finding the therapeutic alliance and exposure work helpful, but that the cognitive techniques

within the intervention and formulation were unhelpful. The authors suggest that a focus upon exposure elements of therapy alongside either altering or reducing techniques aimed at cognitive restructuring may be beneficial.

Rodriguez et al. (2016) explored the acceptability of 11 hoarding treatments through an online survey. Individual CBT, professional organising and self-help books were the options which narrowly met the threshold to be considered acceptable to respondents. Their acceptability was linked to the personalised support offered, accountability promoted and the respondents' beliefs that the treatment would be effective. The authors reported that doubting a treatment's effectiveness, associated distress and a perceived lack of control were linked to respondents considering a treatment option unacceptable. This finding may be particularly pertinent in relation to this research exploring experience and meaning attached to help seeking. The authors highlight clinical implications in that personalisation and promoting an evidence base may improve the acceptability of interventions offered.

Worden et al. (2017) piloted financially incentivised treatment through a system called contingency management. Participants received a monetary reward based on their progress, further to evaluation by an independent individual. The authors report that this approach has previously boosted outcomes in substance misuse treatment, a clinical population commonly reporting high levels of ambivalence. The authors found no overall reduction in clutter when comparing the financial incentivisation plus CBT to a group receiving only CBT, although the incentivised group reported less difficulty in discarding items.

Also exploring manualised CBT treatment, Muroff and Steketee (2018) trialled its delivery via webcam, citing that this may overcome barriers around motivation. Based on clinical judgement, the authors deemed insight levels to be

similar to a comparison group beginning face to face therapy, but the webcam format allowed appointments to be rescheduled with ease and overcame any possible travel barriers. Contrastingly to findings from the meta-analyses exploring CBT for hoarding (Tolin et al., 2015, Rodgers et al., 2021) there appeared to be less response in relation to difficulties discarding than other domains of hoarding behaviour through the webcam format.

Remote delivery of treatment options is a particularly pertinent area in light of the COVID-19 pandemic, but such formats of therapy may also raise ethical issues around boundaries and privacy, particularly if the participant lives with others. Gibson et al. (2010) further explored ethical considerations when working with those who hoard in the US. They described possible issues in relation to record keeping whilst moving between client homes as well as potential ambiguity in roles, e.g. the clinician being both a therapist and a house guest. These ideas may be particularly relevant when considering the different types of support offered from statutory or voluntary services further in the chapter.

1.6 Help seeking

There is limited literature focusing on those who acknowledge hoarding difficulties and choose to seek help. Such research may allow us to understand more how they vary from others within this clinical population who do not access support.

Robertson et al. (2020) sought to explore the barriers to those who hoard seeking psychological help. They used quantitative measures, and the most frequently cited barriers to accessing treatment were cost (66%), a drive to resolve their difficulties independently (58%) and being unsure of treatment options (42%). The study asked about intent to seek future treatment and the average score was 2.96

(SD = 3.12) on a scale of 1 being ‘not at all likely’ and 10 being ‘extremely likely’. Finally, in relation to treatment preferences participants indicated a preference for individual face to face treatment (41.3%), followed by a low intensity remote treatment (30.4%).

However, the online convenience sample would have had to demonstrate insight, acknowledge their hoarding to be problematic and display a level of motivation to volunteer to participate. This suggests that they may not be representative of those who hoard more generally. Yet interestingly, 28% of the sample also selected ‘I don’t believe this is an issue that requires psychological intervention’ as a barrier, suggesting some did struggle to acknowledge hoarding behaviours.

In 2016, Bratiotis et al. explored the requests for information received by a hoarding research project in Massachusetts during a three-and-a-half-year period. The majority of requests were from friends, family members or clinicians supporting an individual who hoards. Only 30% of the requests came from individuals themselves who identified as hoarders; of those 44% were seeking general information, 34% contacted to seek help or treatment, and 7% were contacting in relation to a housing or legal crisis. The relatively small number of self-referrals is interesting, and the authors suggested that the general nature of these requests may indicate that people are unsure of what to ask for. In an exploration of the lived experience of those who report hoarding behaviours in Singapore, Subramaniam et al. (2020) also identified help seeking as a theme. However, the full paper provides little further detail on this theme with no interview quotes offered. To consider possible influences, literature around help seeking in presentations which may be considered psychologically similar to hoarding will be considered next.

1.6.1 *OCD*

Hoarding has been believed to be related to OCD for a long time, therefore it was considered relevant to begin exploring help seeking in relation to this presentation and consider any possible applicability to hoarding. Challenges in discarding items appear to link to rumination on the possible consequences of actions (Kellett et al. 2010), like the possible perceived consequences of not performing ritualistic behaviours in OCD. Both OCD and hoarding behaviours have a significant impact upon individuals and the environment around them. In relation to help seeking in OCD, Simonds and Thorpe (2003) suggest that wider attitudes towards behaviour dimensions (in this study washing, checking and harming) including their social acceptability, may influence an individual seeking help. Applying this to hoarding it may be that if some behaviours (e.g. difficulty discarding) are subject to different attitudes from external sources than other behaviour subtypes (such as compulsive acquisition) there may be varying influences upon deciding to seek help.

Studies have also explored barriers to help seeking in OCD, and Marques et al. (2010) reported from online survey results that barriers included practical and financial barriers, as well as stigma, shame and the individual's perceptions of treatment availability. Garcia–Soriano et al. (2014) reviewed the literature and also found shame to be a barrier to help seeking in OCD. They suggested that greater insight and severity of symptoms was associated with those who sought help. Barriers around shame and perceptions of treatment as being unsatisfactory may also be applicable to hoarding.

Murphy and Perera-Delcourt (2014) explored the lived experience of OCD and found a theme around both loving and hating the condition. This may be

applicable to hoarding in explaining the reported wish to change then subsequent disengagement from treatment of some individuals (Ayers et al., 2019).

1.6.2 *Eating disorders*

This ambivalence around both the problem and treatment can also seen in people with eating disorders. Eating disorder literature may relevant due to the similarity to hoarding around challenges in relation to insight, and the presentation also being a behavioural response to distress. The dialectical struggle of feelings towards anorexia was explored in Williams and Reid's 2010 study on ambivalence. They noted conflicts as to whether the condition was viewed as positive or negative by the individual, whether they felt it to be a means of control or controlling of them, and whether they wished to recover or maintain life with anorexia. The study found barriers to accessing treatment for anorexia were low self-efficacy and perceived limitations in treatments available, echoing suggestions raised by the OCD literature. In a study of anorexia recovery weblogs, Smethurst and Kuss (2018) found themes including public perception (including social ideals), time and the need for patience, as well as the personification of the condition (particularly it having a 'voice') as barriers to recovery. The perceptions of others may be linked to the attitudes towards behaviours noted in OCD, and likely applies to hoarding presentations given the shame often associated with the condition.

An overview of the literature on eating disorders and OCD suggests themes influencing help seeking including ambivalence or insight, ideas of control, perceptions of support available and wider perceptions of others. Additionally, many of these conditions are associated with high levels of shame for the individual. The literature on hoarding highlighted similar themes, suggesting that these problems are not unique to hoarding.

1.7 Summary of the literature

Hoarding behaviours have a significant impact both on the individual and the system around them. Whilst much of the literature explores hoarding behaviours in relation to the wider family, community and public services around the individual, there is a dearth in the literature exploring the experiences of the hoarding individual. A possible reason for this may be the widely reported challenges around insight and motivation. This is despite an established model and evidence base for a CBT treatment for the presentation, although treatment research has also outlined high rates of attrition and non-response to therapy interventions.

Within the literature on help seeking and acceptability of interventions there appears to be a developing theme of non-statutory support being favourable. Help seeking literature in similar presentations also highlights issues around ambivalence, a perceived need for control, shame as a barrier and the influence of wider social attitudes towards the behaviours. These final points link to an idea that some aspects of hoarding may be socially constructed, for example in a consumerist culture excessive shopping would likely be deemed to be more socially acceptable than living in squalid, cluttered conditions. The literature on treatment and the reported difficulties seeking help also raises a question around who should make the decision as to when somebody has too many possessions.

1.7.1 *Why is this study important?*

Despite being a relatively new independent diagnosis, hoarding behaviours have been documented for some time within research literature as well as the wider media (Discovery Studios, 2010; Screaming Flea Productions, 2009). Though difficult to establish true prevalence it appears that hoarding occurs across populations to varying degrees. The significant impact of this presentation has been

outlined, and those who experience these complex and debilitating difficulties seem to struggle to engage with a range of services and agencies.

1.7.2 *Aims and Research Question*

The British Psychological Society's Division of Clinical Psychology summarised the evidence base in their 2015 guidelines, but recommend further research be undertaken into the phenomenon, particularly in relation to improving engagement with services. This thesis seeks to explore:

What are the experiences of those seeking help for hoarding?

Understanding the lived experience of those who choose to access support for hoarding and the meaning they have attached to their experiences may enlighten us as to any psychological changes or influences in acknowledging their hoarding as problematic. The project will explore when or how the individual became motivated to change their behaviour, or their decision to seek help. Themes identified relating to barriers or levers in accessing support may aid services in understanding and promoting motivation amongst others with hoarding difficulties. As outlined above, a small number of papers have explored the subjective experiences of hoarding individuals, but this would be the first study exploring the experiences of individuals specifically on their choice to seek support.

2. Method

This chapter will outline the background of the study design, project planning, including other approaches considered and a rationale for the method selected. The details of the project design will be described, including sampling, eligibility criteria, recruitment strategies, data collection and data analysis.

2.1 Procedure

Semi structured interviews were conducted to capture each individual's experiences of seeking help. The topic guide which was used is appended (Appendix B). Data was analysed using Interpretative Phenomenological Analysis.

2.2 Setting

Recruitment was from charity and support organisations for people who hoard across the UK. Initially it was intended that face-to-face interviews would be offered at a location of the participants' choice, however, shortly before data collection the COVID-19 pandemic began, and government restrictions necessitated that remote interviewing be adopted. Participants were offered either telephone interviews or video interviews via an online platform such as Zoom.

2.3 Design

One online video interview and seven telephone interviews were undertaken with an opportunistic sample of individuals who identified as seeking help in relation to hoarding behaviours. The audio content of interviews was recorded on an encrypted device before being transcribed for analysis.

2.4 Participants

8 individuals who identified as seeking support in relation to their hoarding behaviour participated. This sample size was selected based on guidance within Smith et al. (2009).

2.5 Eligibility criteria

Adults over the age of 18 who identified as seeking support for hoarding behaviours were eligible to take part in the project. Participants were required to have an adequate written and spoken level of English to provide informed consent and be able to engage in the interview. As outlined within the previous chapter, hoarding difficulties commonly occur alongside other conditions therefore here were no exclusion criteria relating to co-morbidity.

2.6 Recruitment

Recruitment materials were advertised on the Hoarding UK charity website (Hoarding UK, 2022b) and on Twitter (see recruitment advert, Appendix C). Additionally, contact was initiated with facilitators of ten support groups. Due to public health restrictions as a result of the COVID-19 pandemic it was not possible to meet with facilitators or attend support group meetings, and some groups were not running at that time. Contact was initially made with support groups across the Yorkshire region, however as it became apparent that restrictions were unlikely to ease quickly to allow face to face interactions, recruitment was widened to promote remote participation for those accessing support across England and Wales.

Where contact was successful and facilitators advised that the support group remained active, a verbal overview of the project and it's aims were given via telephone. This was followed up by providing recruitment materials (see Appendix

C) via email with the request that information be forwarded to attendees who may be interested in participating. Potential participants who made contact with the author were provided with the participant information sheet detailing further information (see Appendix D), then a second contact was scheduled to allow a cooling off period and an opportunity to ask any questions before consent was taken.

2.7 Ethical considerations

2.7.1 *Informed consent*

Participants were invited to ask any questions about the study and provided with a participant information sheet. They confirmed their informed verbal consent prior to the interview on a separate recording.

2.7.2 *Withdrawal*

Participants were made aware of their right to withdraw verbally and through information materials. They were reminded of this before commencing interviews. It was explained to participants upon completion of their interview that they could contact the researcher and indicate that they wished to withdraw for up to two weeks following the interview. It was advised that beyond this point data analysis may have commenced and it would no longer be possible for their data to be withdrawn. No participants requested to withdraw at any stage of the project.

2.7.3 *Confidentiality*

Participants were informed within the participant information sheet that if there were significant concerns in relation to risk, confidentiality may be broken. This was not necessary during the research.

Participants were asked to select a pseudonym or initials to indicate their contribution to the data in any written reports. The first participant selected to use

initials instead of a full pseudonym, therefore this choice was also offered to subsequent participants.

Audio data for each interview was transcribed either by the researcher, or a university approved transcriber who had signed a confidentiality agreement. During the transcription process all interviews were anonymised.

2.7.4 *Data storage*

Audio recordings were collected on an encrypted device and transferred to the university password protected secure drive as soon as possible, then deleted from the recording device. Due to remote working during the COVID pandemic no physical data was kept, and an electronic document containing confidential information was stored on the university secure drive in a password protected file only accessible to the researcher.

2.7.5 *Risks*

There were no anticipated risks for participants other than the potential that they may become distressed when discussing their behaviours or experiences of support.

As the interviews involved talking about a behaviour which is commonly considered shameful, there was potential for distress arising from the subject matter of the interviews. In addition to being informed of this in advance of data collection via the participant information sheet, participants had the opportunity to discuss any concerns about this with the researcher before the interview. Participants were informed that they could pause or withdraw from the interview at any point and were under no obligation to answer questions they did not want to, although this did not occur during any interviews.

2.8 Service User Involvement

During the initial planning stages, consultation was sought from a Leeds University service user panel. Key concerns considered with the panel were the language and terminology used in relation to hoarding in the project's materials, which could be offensive or upsetting to potential participants. This was prior to materials and recruitment information being drafted, so was discussed verbally. The panel did not have any direct experience of hoarding difficulties, although they did pass on researcher contact details to a person who hoards and who later reviewed the written documents participants would be provided. This individual did not highlight any concerns or recommended changes.

2.9 Analysis

2.9.1 *Interpretative Phenomenological Analysis*

Interview transcripts were explored using an Interpretative Phenomenological Analysis (IPA) approach. IPA encapsulates three key philosophical concepts: phenomenology, hermeneutics and idiography (Smith et al., 2009). Broadly speaking the approach is interested in the study of experiences and how they are interpreted, but on a particular and discrete level as opposed to similarities across a wider scale.

IPA was selected as it is considered that the phenomenological approach was more relevant to the research question than a realist approach. Within the literature many of those who hoard speak of wanting help or support, but the publications on engagement, attrition and motivation suggest that something is making this difficult. It was considered that IPA would be helpful in providing an opportunity for those who are seeking help to make sense of their experiences and the meanings which they have attached to them. The approach also has the potential to consider secondary questions, such as motivation or barriers.

2.9.2 *Alternative Methods*

During the initial research planning process other methods of analysis were considered before deciding upon IPA. A quantitative approach, utilising an online survey for example, would have allowed the capture of data from a wider sample. However, while the literature indicates that help seeking is a problem it remains unclear why, therefore it would have been challenging to formulate a hypothesis to be tested using a survey method. It was considered most appropriate to engage people who hoard in an interview setting, to allow the capture of descriptive information on help seeking which this method would provide. Additionally, rather than establishing results to be generalised, this project aimed to understand how those with hoarding difficulties have made sense of their experiences in seeking help.

Other qualitative analysis approaches were also considered. Thematic analysis (Braun & Clarke, 2006) would have been an alternative qualitative approach to IPA, however given the limited understanding and very personal nature around experiences of help seeking in hoarding, the IPA analytic process of considering both the idiosyncratic themes identified within individual reports, as well as themes within the wider dataset amongst an anticipated small sample, was considered to be particularly pertinent in this project.

IPA was also selected because of its basis in a theoretical framework and focus on phenomenology. IPA acknowledges previous experiences by the researcher and how they have been interpreted – it seemed important to recognise past clinical experience with individuals who hoard and how understandings around this seemed to appropriately fit with a critical realist and contextualist epistemological position in IPA.

To discover participants' experiences of seeking support it was also necessary during the interviews to explore their experiences of hoarding, including their reasons for keeping items, why they hold on to things and associated emotional responses. Whilst this information is not directly relevant to the research question, after discussion within supervision it was determined that this data should be carried through the analysis process as these beliefs and experiences may link to eventual group themes around help seeking.

2.9.3 *Analysis Process*

2.9.3.1 Individual Analysis.

Analysis began on an individual level and was guided by the step-by-step approach described in Smith and Nizza (2022). This recent text also uses updated IPA terminology, which will be utilised throughout.

To begin the process of immersion in the data, each transcript was checked for accuracy whilst listening to the audio recording. Transcripts were re-read and initial reflective notes were diarised, detailing both the content of the interview but also impressions and personal reflections of the researcher.

Hand-written exploratory notes were then made on a paper copy of the transcript, with comments written in the right margin. As per guidance offered by Smith et al. (2009), notes were categorised as either descriptive, linguistic or conceptual comments and written in blue, red and green ink respectively. Linking these exploratory notes, experiential statements for the participant were then noted in the left margin.

Experiential statements were typed and printed, then moved into related clusters until personal experiential themes emerged. As described by Smith and Nizza (2022) some experiential statements were combined if thought to illustrate the

same or closely related events, and others were not incorporated into clusters if unrelated to any other statements and not providing analytic value.

Finally, tables of personal experiential themes were created, detailing the experiential statements identified as contributing to each theme, corresponding quotes and the pages of interview transcript. This process was repeated for each participant.

2.9.3.2 Group Analysis.

Tables of personal experiential themes for each participant were reviewed to consider any similar themes between individuals and whether reorganisation may aid comparison across the group. Alongside this, personal experiential themes for all participants were printed, examined and clustered again. Further to the identification of initial group experiential themes, analysis was refocused upon experiential statements to ensure accuracy and fit.

2.9.3.3 Quality Assurance.

In order to ensure the research remains true to IPA principles, regular workshops held by an experienced IPA researcher were attended during the research planning process. Peer supervision with colleagues was part of this.

Findings being based on a snapshot of a handful of a population, and subject to the interpretation of a researcher based on their own stance, may lead questions around how IPA research can be conducted in a way which ensures quality and validity. Smith et al. (2009) suggest a number of guidelines, including Yardley's four principles (2000). Within this project s*ensitivity to context* is demonstrated through exploration of the existing literature, consideration of ethical issues, choice of approach and sensitivity during interviews, analysis and write up. *Commitment and rigour* are achieved through immersion in relevant literature, careful sample

selection, effective and considerate interviewing, and commitment to the analytic approach such as participation in workshops and supervision. *Transparency and coherence* are evidenced through the clear presentation of data and descriptions of the research and analysis process. It is also apparent through the application of a true IPA approach and the sound fit of identified themes. Finally, this project will demonstrate *impact and importance* both in terms of adding to a limited literature base, as well as the practical, clinical and sociocultural impact of a greater understanding of hoarding disorder.

A key element of quality assurance within this project was the rigour applied to analysis. Two interview transcripts were simultaneously coded by the researcher and one research supervisor to verify agreement in relation to key words and statements within the data. During analysis the research team also met up on multiple occasions to consider and agree emerging themes, ensuring findings remained true to the data.

2.9.3.4 Situation of self within the research.

IPA takes into account the knowledge, experience and epistemological stance of the researcher. It suggests that neutrality cannot be assumed within analysis and posits the importance of reflexivity. As stated by Smith et al. (2009), ongoing awareness and exploration of personal ideas throughout the planning and execution of the research are key.

Reflective discussions were held regularly in supervision sessions, and notes were kept throughout the project. Reflective discussions also occurred during ongoing training and peer supervision. Before the collection of data, I completed and recorded a reflective interview with one of the research supervisors in order to explore my own assumptions and expectations. To maintain the transparency

specified by Elliott et al. (1999) I will summarise my experiences and beliefs prior to data collection below.

I am a white female in my early thirties during the time the research has been conducted. I grew up in a city with little ethnic diversity and come from a working-class background. I am unaware of any significant hoarding tendencies within my extended family, and my interest in the phenomenon started within my previous clinical experience as a student mental health nurse. Whilst working with an inpatient service user who hoarded, I became aware of our very distinct views on her behaviours – I perceived them to be debilitating, she denied there being any issue. It also seemed remarkable to me that this individual presented as intelligent and articulate but could not perceive any difficulties with her hoarding behaviours and denied their impact. Our once positive working relationship ultimately became fractured when I was required to challenge her collecting due to the increasing risk and clinical implications for the ward. To this day I continue to feel sadness when I reflect on the interaction which ruptured our working relationship, despite knowing that in the interests of infection control within a hospital setting I had no other option but to remove perishables which were decomposing within her room.

Additionally, during my nursing training I undertook an elective placement in Uganda, and whilst there became curious about cultural definitions and ideas related to hoarding. The service user I worked with in the hospital would cite keeping things ‘just in case’ or suggest creative uses of the items she kept - I began to consider how a developing country like Uganda seemed to offer a more obvious context for such behaviours. I considered that such an approach would make sense and wondered if the phenomenon was common in developing countries. And yet, within Western cultures particularly, to do this to any extreme was deemed to be a

‘disorder’. This consideration of context and constructs has also been apparent in my reflections around the boundaries of diagnostic criteria; how are they determined and the position of professionals in the implementation of this. Who decides where the ‘line’ between a ‘collection’ and means of tackling poverty crosses over into being a mental health disorder to be diagnosed?

This consideration around cultural constructs and hoarding led to my interest in help-seeking. During my nursing degree I completed a review of the literature around cultural differences in hoarding, and some publications suggested that there may be transcultural variations in the beliefs which underlie hoarding (Subramaniam et al., 2014; Timpano et al., 2015). I began to question if societal values and beliefs around hoarding could influence how someone experiences hoarding behaviours, including whether cultural perception influences whether and how a person seeks help.

I was also aware of varying approaches in response to hoarding. As a mental health professional I experienced the response from statutory services to be fragmented and task-focused, with those who hoard seeming to fall between the gaps of services which didn’t know how to respond to their situation. I had read about specialist hoarding task forces in the US (Bratiotis, 2013) and questioned whether such an approach could be valuable in the UK. I also had a preconception of a significant variation between the different types of UK support available. I experienced statutory services as proposing interventions but not hearing what the hoarding individual was asking for or needed. I expected that support groups and charitable services would provide a valuable space for the person to share their story, but little in the way of practical support.

I anticipated that those likely to make contact and participate in the current study would not be comparatively the most ‘extreme’ presentations. I expected that those requiring multi-agency input from statutory services would not be likely to demonstrate the insight to seek charitable or peer support. Based on my understanding of the literature I assumed that those volunteering to participate would likely be older with longstanding difficulties, due to the probable journey to insight and acknowledgment of the issue. I also expected that they would live alone and have difficulties within their relationships either parallel to or because of their items. Additionally, I suspected that their motivation to access support would be largely external (e.g. encouragement from children/family, pressure from services), but that to be choosing to engage with charitable or peer support would suggest some level of internal motivation. I also had preconceptions that barriers to support would be described around support not being available or not being what the person is looking for.

I further reflected on the expected influence of context upon interview content, namely to COVID pandemic, and anticipated hearing about this within the interviews. Data collection began at the height of lockdown, although some later interviews were conducted during a period when some restrictions were eased. I expected that the context of being at home as ‘safe’ and instances of panic buying and stockpiling items ‘just in case’ would resonate with those with hoarding difficulties. However, I also considered the impact of lockdown if any individuals were already feeling overwhelmed and trapped by their belongings.

When recruitment began, I noticed a sense of surprise at the pace with which individuals were volunteering to participate. In planning the study and during discussions with my supervisors we had anticipated a real struggle to recruit due to

the shame attached to the presentation. This was to the extent that we had discussed changing the focus of the research to capture carers experiences of help-seeking in relation to their loved ones if we were unable to recruit. With reflection I wonder if recruitment would have been more challenging without the protection offered to participants of interviews being remote due to COVID-19 restrictions.

My first interview went well, but the participant was somewhat reflective having spent a lot of time completing his own training in helping others, as well as exploring his experiences within support groups. Whilst he described a level of ambivalence about is hoarding, he acknowledged his difficulties and was thoughtful in a way that I anticipated would not be standard for all participants.

As I was conducting the interviews my preconceptions were also challenged by those who participated but still struggled to acknowledge their hoarding behaviours as problematic. I had anticipated that the research would capture a discrete group of people who hoard 'with insight', and yet during the interviews some explicitly told me they didn't view the behaviour as an issue. I found myself confused as to why they were seeking help, and what had led to them participating in research about getting help for hoarding.

I don't think I changed my interview style significantly as interviews progressed, but I suspect as I became more familiar with the topic guide and confident in my technique the conversations flowed more naturally. I found one interview particularly challenging, as a participant seemed to hope to use the space to reflect on considerable trauma within their life. This was difficult to navigate as I really did not want to seem to be dismissing her experiences. I reflected whether I could have responded differently, perhaps been more directive, but upon listening to

the recording prior to analysis I noticed many attempts to manage this which were largely in vain.

I have considered the possible impact of me being white, female and working class upon my interviews. Except for the single video interview, the only time my race would have been apparent to participants was based on a photograph on the recruitment advert. Nonetheless, race and ethnicity were discussed by a few the participants within their interviews. I wondered how this may have been experienced for them, to explain how this difference impacted upon them and their help-seeking journey. I'm not sure how things might have differed had I shared their ethnic background – perhaps they might have opened up more about their experiences in the context of race, or maybe they would have assumed some shared experiences or understanding which did not need to be further detailed explicitly.

Several female participants described turbulent or abusive relationships with males, therefore I suspect me being female allowed them a sense of safety to open up about their experiences which may not have felt as straightforward with a male interviewer. I'm unsure how my gender might have influenced interviews with male participants, although I suspect ideas around masculinity and mental health might have made it difficult for them to be as open about their experiences had I been a male interviewer.

I have reflected upon my working-class background clinically, and generally believe that my style can help in putting those I work with at ease. I hope this was also the case within my interviews. I anticipate those volunteering to participate in research may have their own preconceptions about the academic they contacted, and I wonder if my accent and approach might not have matched their expectations. I have also reflected upon whether those who described social deprivation may have

found it easier to open up about the topic to a researcher who they might recognise as coming from a working-class background.

Finally, it is also worth considering my age. Whilst the telephone nature of most of the interviews may have led to some ambiguity in relation to how participants perceived this, they again might have made assumptions based on the photograph within the recruitment advert or upon hearing my voice. Only two participants were of a similar age to me, the other six were older. Of the two also in their thirties I noticed quickly warming to one, but the other participant close to my age seemed quite emotionally disconnected so I didn't develop the same rapport. This leads me to suspect age was not the sole influence upon this. Whilst I did not perceive any difficulties interviewing participants who were older than me, I did wonder how they might have regarded me. Perhaps they would have found it easier to open up to someone of a similar age, whom they may perceive to be more like them and possess greater life experience.

Looking back at my preconceptions and what I found, I can reflect that some of the things I anticipated were accurate – the majority of those who participated were older, lived alone and described difficult relationships with those around them as well as barriers to accessing support. I expected those who volunteered to describe comparatively low-level hoarding behaviours, but contrastingly a number of interviews detailed a lot of distress associated with their difficulties and a significant impact upon their daily function. I think another striking difference between my preconceptions and the findings was the expectation that participants would describe external motivators to access support – whilst this was touched upon by some it was not described as a key influence.

2.9.3.5 Final reflections on analysis.

This acknowledgment of my own position influences the hermeneutic circle and double hermeneutics outlined in IPA; that is a researcher making sense of a person making sense of their own experience. IPA does acknowledge that personal experiences of the researcher will influence analysis and interpretation of data.

A further key concept within IPA is that the sample represents one perspective. For instance, in this case the findings represent the perspective of a small group of people seeking help for hoarding behaviours, it will not be representative of a population of people who hoard. This is an accepted limitation of IPA, as researchers are not seeking generalisable findings. Just as this is an accepted shortcoming within this research – accounts provided only the experience of a handful of individuals seeking help for hoarding, therefore do not inform us of the perspective of those who hoard who do not see the behaviour as problematic or do not wish to seek support. Nonetheless, a greater understanding of those who do seek help may be useful in considering the challenges others might face in doing so.

3. Results

Within this chapter I will present the findings. Firstly, I will outline context in relation to the experiences discussed, then provide a pen portrait of each participant. Results from the group analysis will then be described, utilising interview quotes in italic to illustrate the themes identified.

3.1. The context of hoarding

As detailed in the topic guide (Appendix B), in order to build rapport with participants during interview and understand the context of their help seeking it was also necessary to hear about the nature of their hoarding behaviours. This resulted in data detailing each participants' background (including trauma in several cases), their reasons for keeping items and the challenges they face in discarding objects.

In addition to the context of their hoarding difficulties, data also captured the wider societal context. At the time interviews were conducted (between May and August 2020) the UK was in the height of the first wave of the COVID-19 pandemic and 'lockdown' restrictions. Several participants described the impact of these circumstances upon their difficulties and daily life.

These contextual details were coded and analysed as part of the whole data set but were not the focus of the research question, nor did they clearly link to emerging themes. Nonetheless understanding of this backdrop is undoubtedly important, therefore information in relation to each individuals' experiences of their difficulties and the pandemic (if discussed) will be incorporated into the below pen portraits.

3.2. Pen portraits

3.2.1 *JB*

JB was a male in his fifties. He lived alone in rented accommodation. JB spoke of noticing a theme of loss throughout his life, some of which he identified as traumatic. Events included the bereavement of a parent during childhood and, in his adult life, a breakdown in his relationship resulting in separation from his children.

Items collected by JB were linked to his creative hobbies, and he described buying things fuelled by ideas of how they could be used artistically but that he rarely gets around to using the objects bought. He also mentioned initially being "cynical" of panic buying at the onset of lockdown, but that he later became 'swept up' in the phenomenon – *"part of me was like, well, I'm being a bit silly, but then part of me was like, well, you know buy, buy a few months food just in case"*. JB also described that he had hoped to buy a car and make trips to the tip with items to be cleared, but that lockdown had thwarted this.

During the interview JB spoke about how much he enjoys reflection and group work, and that it was during coaching training that he began to share with others his difficulties with hoarding. He described how another member of his coaching group signposted him to a hoarding support group that he had begun to attend within the last couple of years. He also spoke of his wider reading about hoarding throughout our interaction, as well as accessing counselling through his employer to maintain his general mental health.

JB repeatedly stated a strong reluctance to engage with mental health services or any support which may amount to a mental health 'label' on his medical records. He described that as a black male who had emigrated to this country, he

was wary of racial prejudice, and that both mental health and physical disabilities were stigmatised in his home culture.

JB was the first interview I conducted, and his engaging nature made me feel at ease. He offered insight and reflection I had not expected, discussing his difficulties in a straightforward but thoughtful way.

3.2.2 *GD*

GD was a female in her sixties living alone in private rented accommodation. GD spoke of significant trauma and losses throughout her life, and that she kept items for a wide range of reasons. This included a sense that objects were "precious" and held memories, that it would be "dishonourable" to discard possessions she had inherited, and that due to social deprivation she often thought that items could prove useful at a later point.

GD described attempts to access different support throughout her life, including counselling and NHS pathways. She had also considered participating in a TV show. GD described issues or barriers with each of the options. She had been accessing a support group for approximately two years at the time of the interview.

GD described experiencing her own 'personal lockdown' in response to trauma, as well as speaking about the impact of COVID restrictions. She said that "everything is on pause" and detailed having had support from a neighbour previously, but that this had been forced to a halt when restrictions were imposed.

This was my second interview, and I was aware that GD seemed very conscious of the situation, in particular that the interview was being recorded (e.g. frequently clearing her throat, checking her answer was OK, changing names of the people she mentioned). GD was forthcoming and enthusiastic in her approach to participation and had many experiences that she hoped to share in the interview,

which frequently led us away from the planned interview schedule. This interview was the longest and GD spoke quickly. While it was possible to keep up with her account, it was only at the point of transcription and analysis that some of the finer details in GD's experiences were picked up. I noticed feeling guilt upon realising some of the poignant information I had missed during the interview itself.

This was quite a challenging interview and only the second I had completed – in subsequent interviews I was certainly more aware when an interviewee may be moving further away from experiences relevant to the research question. With reflection though I do not feel this changed my interview style, partly as other participants did not seem to drift as far from the question posed, but largely due a personal urge to present as agreeable to participants.

3.2.3 *TC*

TC was the third interview conducted. A male in his thirties, TC lived alone in rented accommodation, having previously lived in supported accommodation. He described difficulties in relation to hoarding behaviours since childhood and said that both of his parents demonstrated hoarding tendencies. TC also reported that he experienced OCD and described difficulties discarding objects based on rituals and ordering.

TC had been accessing a support group for his hoarding for approximately three years. He described having been pushed by his mother to access support for his mental health more than a decade prior to this, and that he had initially resisted support from his GP including medication. He also recalled having begun CBT with a psychologist in the past. TC described a sense that professionals did not 'get' him, including one clinician who he felt couldn't understand how hard it was for him to attend appointments and that he could be late due to his mental health difficulties.

During the interview I noticed I warmed to TC and felt a hope that those around him would support him. When I reflected upon this, I noted his similar age to my own and that his voice and accent frequently reminded me of a family member's voice.

3.2.4 *AN*

AN was the fourth interview conducted and the only participant who opted for a video interview. I was very aware during the interview that my own facial expressions would be visible and may perhaps influence her responses. AN was in her seventies and the only participant who lived with a partner, her husband. They owned their home.

I noticed that I warmed to AN quickly. I reflected this may have been due to her age, that I was able to see her face, or her poignant response when I asked the first question about her motivation to participate and she spoke of it likely being too late for her to overcome her difficulties, but that she wished to help others. At points AN became distressed talking about the impact of her stuff, and I questioned whether the video medium perhaps made it more difficult to explore her emotional responses. She became tearful at one point whilst describing her shame and embarrassment towards her home but acknowledged that public health restrictions at that time meant that others couldn't visit anyway.

AN described that her father and several relatives in her extended family had hoarding tendencies, so she believed the phenomenon to be "genetic". AN spoke of having a professional career which required her to keep confidential documents for several years as evidence, and that having worked from home for part of her life this accounted for some of her stuff. She also described a wider theme of keeping other

items in case they were required in the future too, but that the lockdown restrictions meant that her acquisition at the time of interview was minimal.

In terms of help AN spoke of having repeatedly tried to access support through the NHS but feeling like she 'fell through gaps' between services. She spoke of having fought to access services by escalating complaints or using advocacy support previously, but that at the time the interview took place *"there's no point at the moment, not with Coronavirus. It's going to be a long time before they're going to want to deal with anything."* AN also described having paid for counselling in the past as well as travelling across the country to participate in research and access support groups.

3.2.5 *RO*

A male in his thirties, RO lived alone in rented accommodation. He described keeping items from a young age as he felt that they contained "information" and "precious" memories. He outlined a difficult relationship with his parents, and ongoing struggles with hoarding, OCD and generalised anxiety disorder.

In relation to historic support RO described having "a session" of CBT, and that on another occasion a support worker within mental health services had visited his home and assessed it to be unsafe which he did not agree with. RO also spoke of having been prescribed medication for his mental health, but that he perceived he was given the prescription and then dismissed by services.

RO was accessing a hoarding support group which he believed was through his local NHS trust. He described that as well as attendees sharing their own experiences, the group used resources including videos and images of examples of hoarding.

Throughout the interview RO seemed unable to come to a decision as to whether his hoarding was “a problem”. He repeatedly described that it was others who took issue with his behaviour (mainly his parents and services) and that he did not have a problem. He would then state that services were lacking and unhelpful.

RO was the fifth interview I conducted. At times the interview felt challenging; his conflict as to whether his behaviour was problematic or not led to me feeling very tentative in how to word questions and prompts. I did not feel there were difficulties in establishing an apparent rapport with RO, but I thought his responses lacked emotional depth. RO’s communication was disjointed throughout and at times unclear, with frequent hesitations. He also largely spoke in a way which was noticeably emotionally disengaged from his circumstances.

3.2.6 *DS*

DS was a female in her forties who lived alone in rented accommodation. She was the sixth participant to be interviewed and described a difficult relationship with her parents who often bought her items such as ornaments as a child then implied she was ungrateful when she disclosed she did not want them. DS spoke of keeping items such as newspapers or videos that she intended to read or watch, although she recognised that she often did not. She also described trying to care for her objects and feeling upset if they were to deteriorate or become damaged. DS also mentioned noticing that she tended to ‘stock up’, and that this became problematic again just before lockdown whilst many were panic buying.

She briefly mentioned having sought counselling further to difficult family relationships, and that she had been offered antidepressants for low mood but had declined them. DS described a preference for talking therapies and a belief that her depression was a result of what she described as ‘her circumstances’. She had been

accessing telephone support in relation to her hoarding for approximately two and a half years, and a support group for a year and a half. She said that she had been aware of the group for a year prior to accessing it but was fearful she would be recognised if she attended.

From the start DS's interview flowed easily. Her tone was light and humorous at times, and her story felt easy to follow. DS's voice sounded relatively youthful, and despite being older than me I quickly warmed to her, and it felt like chatting to someone of a similar age. I found DS to be frank and engaging during the interview. She spoke insightfully and seemed to be open about her difficulties around the stuff she kept having 'got on top of her', despite struggling to name her behaviours and referring to 'the h word' on multiple occasions.

3.2.7 *PB*

PB was the seventh interview completed. She was a female in her forties who normally lived in a mortgaged house with her children, but at the time of interview (during lockdown) was staying at her boyfriend's house.

PB provided little information on what she kept and why, other than briefly mentioning sentimental attachment to items her children had created. At the time of the interview PB was awaiting the concluding hearing of a residency dispute with her ex-husband around her children. She had been subject to longstanding social services input about this, and at times her account could focus on her perceptions of agencies in relation to this situation, rather than the research question.

PB described having accessed talking therapies to help with trauma and grief, but that she had avoided seeking support beyond informal family help in relation to her hoarding. She described that support from a specialist organisation for those who hoard had been coordinated by social services once they became

involved, but that the pandemic had impacted upon the support received including delays before remote therapy and a lack of home-based support. PB also spoke of her intent to access peer support groups when COVID restrictions eased.

When conducting the interview with PB I initially feared a difficulty establishing rapport with her after she challenged a term (unrelated to hoarding) which was used during initial questions about demographics. She then also spoke of her reason for participating being because a decluttering supporter suggested it, and she felt indebted to them for their help. However, this did not prove to be an issue and PB's interview was one of the longest conducted. There were some issues with the sound quality of the recording and the telephone line dropping during the interview, and a handful of statements remain unclear despite many attempts to clarify from the recording.

My own circumstances made reflection upon PB's interview particularly interesting; I conducted the interview immediately before taking maternity leave to have my first child, then returned as a new mother when I began analysis of the transcripts including PB's. The sadness I felt around the impact of this situation upon PB's children and her, as a mother, felt particularly poignant.

3.2.8 *VI*

VI was the final interview completed. A female in her sixties, VI lived alone in a property she owned. She described a difficult childhood and extensive trauma and losses throughout her life. VI identified past social deprivation as a significant driver in her relationship with items, as well as other influences such as the behaviours of others including her ex-husband, generational cultural values from her parents and social narratives around consumerism.

VI estimated that she had been intermittently seeking help for her mental health for around thirty years, but never directly for her hoarding. She said that she would not consider taking medication as she did not believe her difficulties were due to a "chemical imbalance", but that she had accessed talking therapies as well as participating in a reality TV programme. VI had seen a recruitment advert for the project on a charity website and made no reference during the interview of accessing a support group.

Unfortunately, this interview proved to be the lowest quality audio recording. I don't feel that this impacted upon the accuracy of transcription, but question whether some of the emotional content may have been lost. VI sounded much younger than her reported age, but she described an isolated existence and moving personal history. Interestingly I do not recall connecting to the emotion of this to a great extent at the time of the interview. When reflecting I wonder if VI's rather matter-of-fact descriptions of distressing situations may have influenced my response. Though on revisiting the recording and transcripts the sadness of VI's situation felt overwhelming at times, and I wondered if her loneliness was more tangible because she hadn't found the companionship of a support group, unlike other participants.

VI described lockdown restrictions further compounding her isolation, *"…you know people, people crossing the street when you went out. Nobody speaking to each other, you know. You can't see anybody's facial expressions 'cause they've got a mask. It alienates everybody…and if you haven't got a family to go back to, if you're alone…"*

3.3 Group Analysis

As per the process described in the previous chapter, group analysis of the transcripts was conducted and themes across the data were synthesised. Group experiential themes and subthemes will be discussed within this section and supported with quotes. Four group experiential themes were identified across the data: **Wrestling with identity, Who can I trust?, Services that don't fit** and **'They just see the hoard, not the person': Overlooking the individual.** Each theme was comprised of four, three, two and three subthemes respectively. A thematic map is provided in Figure 1. Table 1 provides a representation as to which participants contributed to each theme.

Figure 1. Thematic Map

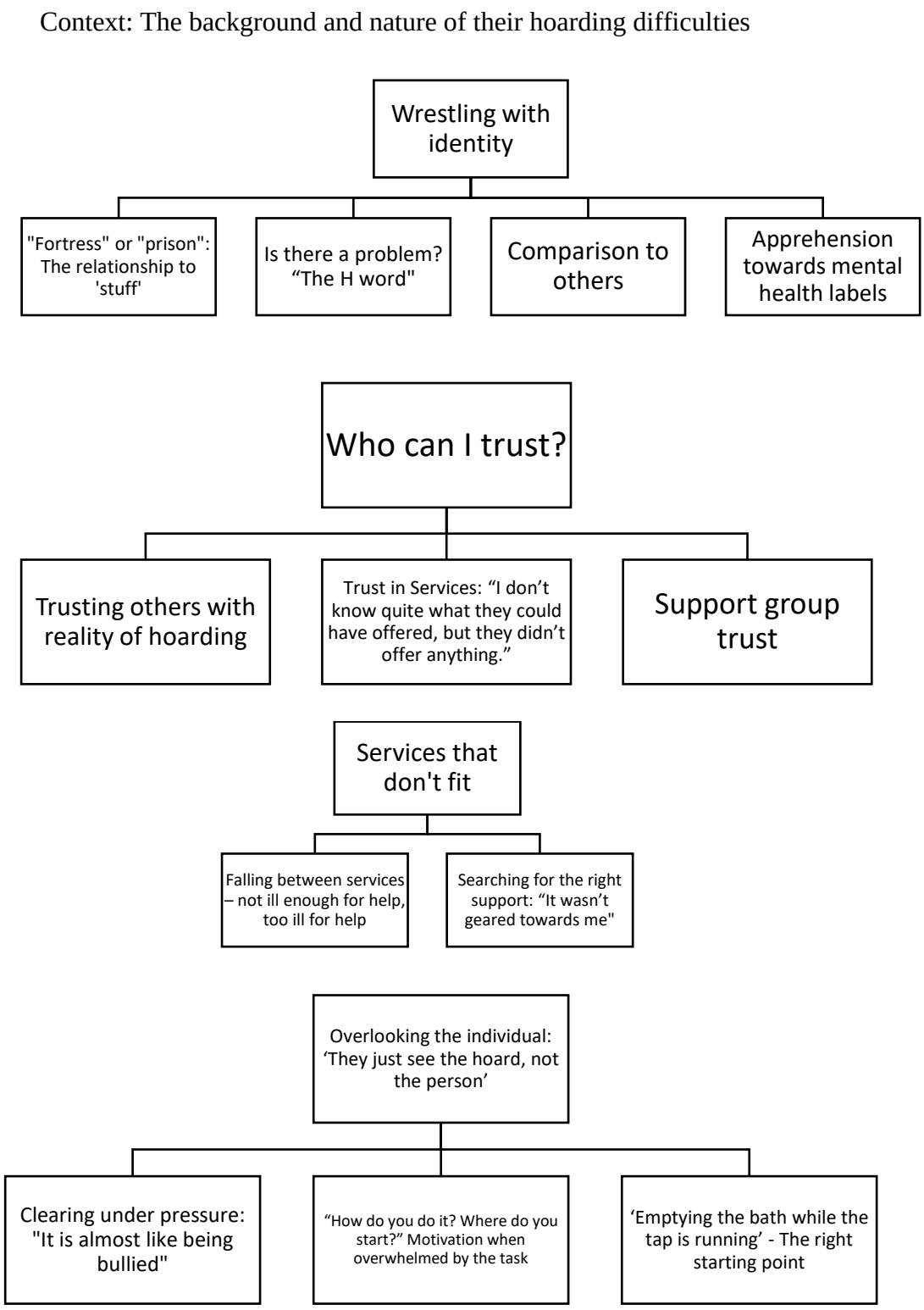


Table 1. Representation of participant's contributions to themes

Group Experiential Theme	Subthemes	JB	GD	TC	AN	RO	DS	PB	VI
Wrestling with identity	"Fortress" or "prison": The relationship to 'stuff'		✓	✓			✓	✓	✓
	Is there a problem? "The H Word"	✓		✓		✓	✓	✓	✓
	Comparison to others		✓	✓		✓	✓	✓	✓
	Apprehension towards mental health labels	✓							✓
Who can I trust?	Trusting others with the reality of hoarding	✓	✓	✓	✓	✓	✓	✓	✓
	Trust in Services: "I don't know quite what they could have offered, but they didn't offer anything."					✓	✓	✓	✓
	Support group trust	✓	✓	✓	✓	✓	✓		
Services that don't fit	Falling between services – not ill enough for help, too ill for help		✓	✓	✓	✓		✓	✓
	Searching for the right support: "It wasn't geared towards me"	✓	✓	✓	✓	✓	✓	✓	✓
Overlooking the individual: 'They just see the hoard, not the person'	Clearing under pressure: "It is almost like being bullied"	✓		✓		✓	✓	✓	✓
	Motivation when overwhelmed by the task: "How do you do it? Where do you start?"	✓	✓		✓		✓	✓	✓
	'Emptying the bath while the tap is running' - The right starting point		✓		✓		✓	✓	

3.3.1 *Wrestling with identity*

This theme described how the participants struggled to define themselves and their hoarding behaviours. Four subthemes were identified:

1. ***"Fortress" or "Prison": The relationship to 'stuff',***
2. ***Is there a problem? "The H word",***
3. ***Comparison to others*** and
4. ***Apprehension towards mental health labels.***

The first two subthemes represented conflicting perspectives in relation to identity. There was a juxtaposition between participants who described their items as protective or restrictive, as well as whether they perceived their behaviours to be problematic or not.

3.3.1.1 "Fortress" or "prison": The relationship to 'stuff'.

This subtheme detailed the conflicting perceptions between participants about their relationship to their possessions. Possessions could be seen to provide a form of safety blanket, the possession of which provided reassurance but, at times, participants reflected on the limitations on their lives they experienced because of the volume of 'stuff' in their homes. The title of the subtheme is based on GD considering whether her items were protective or problematic:

"…this has been my little hoardings of fortresses, for any situation. And now it's become like a little… 'prison's' the wrong word; it just, it feels like a sort of security net…"

TC also suggested a conflict. He described *"…I'm surrounded by stuff again, it's the feeling of safety and security…"* and identified that perhaps he had used items as a physical barrier when he had previously been required to move from his rented property – "*…maybe subconsciously I didn't want to throw it away because if*

I threw it away that meant I had to move out." Contrastingly, TC also detailed a sense of being overwhelmed and trapped by his stuff, particularly in relation to his difficulty discarding.

"I just couldn't throw anything away…I can get a mental block every so often where I-I can't cope with life. Um, I struggle with life, and I get very overwhelmed with life, and I feel quite suicidal."

PB very explicitly detailed the restriction and negative impact her possessions had upon her life – *"I felt trapped. I felt trapped by the house. I felt trapped by the situation. I felt trapped by the stuff. And it all, again, it was another vicious circle, A fed into B, fed into C, just round and round and round. And I couldn't quite see any way out of it."* And yet, even when fantasising about escaping the situation PB described the relationship with her items continuing to be a significant pull *"…it got to the stage where I could've happily just locked the door of my house and walked away. Apart from the fact there was stuff in there I still wanted…"*

VI felt that her hoarding behaviours stemmed from a difficult childhood, *"I think that, that happened because I was removed from my family, family setting and with nothing, nothing at all where I think that's where it stems from."* She described her collecting being a protective measure against social deprivation, *"I would tend to buy things and bring things in because there was a fear around losing my job and not having any money."* VI was less direct than other participants about feeling 'trapped' by her items, but described possibly being stuck in relation to her behaviour, for example that "*In a funny sort of way, I cling on to it, but it doesn't really matter er, and that doesn't make sense, but that's how it is…"* She also recognised feeling unable to let go of her items despite understanding that they were

no longer required - *"…as I've got older, I don't need, I don't need all that. I don't need the stuff. I don't need it in the same way, but it's hard to get rid of, you know."*

This was less of a conflict for DS, who described being physically blocked in by her possessions *"…um, a lot of things sort of got on top of me and I end up um collecting papers and dropping them almost just inside the door. I ended up blocking the doorway."* She noted that this barrier would have prevented her getting support, *"…if somebody had have come in to try to help me at its worst, there would've been hardly anywhere for them to sit."* DS also described throughout the interview having had her gas cut off for several years and the impact this had upon her ability to function in her home. She felt unable to allow an engineer into her property to fix this and chose to live without heating rather than allow someone in her home– *"…actually just sitting with a woolly hat on really makes a difference, and I've just ended up doing that and wearing a big, thick, fleecy thing; and really layering up and I haven't frozen to death…"* Additionally DS spoke of the social cost of her difficulties, *"Um, I, I've kind of not had relationships because of it, that's another thing."* and there was a sense of her feeling imprisoned, having her life taken by her items, when reflecting *"you only get one life and I would like to get it back before it's too late."*

3.3.1.2 "The H word": is there a problem?

Individuals expressing contradictory positions throughout the interviews was also noted in the second subtheme around identity. This subtheme represented how the participants defined themselves and their behaviour, including whether they perceived themselves to be 'a hoarder' and if they understood their hoarding to be a problem. It also captured that many of the participants who accessed mental health services initially did so for other problems, rather than hoarding.

Seemingly all interviewees must have self-identified with having hoarding difficulties to volunteer to participate in this research, but there were clear differences in how participants used terminology around hoarding. While some could apply the label to others, only three ever referred to themselves as a "hoarder" - interestingly one of the three was RO, who was a key contributor to this theme due to his struggle in relation to whether his behaviour was problematic. Several predominantly described hoarding as a verb; a behaviour they happened to exhibit. Some repeatedly referred to "the hoarding" or their "issues with hoarding", suggesting a sense of distance between themselves and the problem. Whilst others struggled to say the word at all, which led to the title of this subtheme.

Perhaps most noticeably fluctuating around whether his behaviour was problematic or not was RO. For much of the interview he perceived his hoarding to be acceptable, and that it was others who were unable to tolerate it.

"But, for me it wasn't a problem like. For them it was a problem…I always thought "what is the problem?" Like am I making the problems or…for me it was completely normal. There was nothing wrong with hoarding. Or, it's not considered as a problem…For me, it's totally normal."

As the interview progressed, it seemed that occasionally RO would fleetingly consider whether his hoarding was an issue - *"I think hoarding er, (pause) I think with hoarding it became a problem in terms of like er, it wasn't a problem or it became a problem…I don't think er, it came to an extent where y'know I thought to myself I couldn't go on any longer, that er I'd lost my er…mind in terms of er, there was something wrong but I didn't know what was wrong."* He also spoke of feeling like he had not been supported by services, despite his previous assertions suggesting that there was no problem he required help with. "*They haven't helped me because they've*

always said to me there's a problem, but I've always said it isn't a problem. But, then again (silence)."

JB described recognising his situation as problematic but repeatedly suggested that emotionally he felt disconnected from it. *"Oh god! Erm, do you know what, I ought to be a lot, I ought to feel a lot more frustrated than I do, to be honest…erm, or maybe I just become, maybe I've just become numb to…a deeper level of frustration."* There was a sense of JB's ambivalence throughout the interview, illustrated by quotes such as *"…every so often I will think, oh, hell, you know what's going on-I am actually tryin' solve the problem but um, I'm not, I'm not kind of pulling my hair out or anything like that."* On occasions he also seemed to directly contradict himself in relation to whether he experienced his situation as stressful - *"I'm not freaked out. But what does freak me out actually is the thought that, I'm renting this place, and if I was asked to move…"*

Aiding in generating a title for this subtheme, DS acknowledged her difficulties with items but seemingly was unable to say the word 'hoarding' throughout the interview *"…because I didn't want to say the 'h' word, I've said, 'I've got in a real pickle'…and I've, I've got myself in a mess, like literally."* Like several other participants, DS had accessed mental health support but was not able to name her struggle with hoarding - *"…but because I'm so scared, I've, I've not specifically asked for one-on-one proper counselling through my doctor specifically to address the 'h' word."* DS did suggest that she had almost hinted about the true extent of her difficulties to clinicians *"…but I did mention a bit to my doctor that I was depressed, and my house was a bit cluttered."*

Like DS, within PB's interview she spoke of accessing *"grief counselling"* during which she alluded to her hoarding difficulties – *"And I do remember sort of*

saying that I had, that I had, that I had boxes of stuff and I didn't want to live like that, you know I had some boxes we hadn't sorted out from when we moved." PB also spoke of being aware of her hoarding behaviours, but not feeling able to make the initial contact with a specialist hoarding organisation and ask for support *"...I had seen something about [organisation] but I hadn't got round to calling it. And I don't really know, does one phone up and self-refer and say, 'Help. Hello, I need your help?'"*

VI similarly outlined that she had repeatedly accessed support but had never focussed on her hoarding behaviours. *"Well, I didn't ask for help, I haven't actually gone down the route of asking for help for hoarding. I've gone down, you know the addressing other issues, other problems."* VI did not elaborate as to whether this support was from statutory mental health services or other organisations.

TC was one of several participants who spoke of parents who had hoarding tendencies. He described a difficulty recognising his hoarding as problematic, because a cluttered environment was all he had ever known. He recalled having been resistive of mental health support generally when intervention was initiated by his mother as a teenager – *"I'd be kicking and screaming basically! But I basically gave in to and accepted the help."* TC was attending a hoarding support group, but stated that initially accessing this support was not motivated by any drive to tackle his hoarding *"It was more about um, cause I'd suffer with really bad depression and been reclusive for a long time…so that was actually just about getting out again and socialising and getting back into company…"*

3.3.1.3 Comparison to others.

Within the interviews there was also a sense of some participants trying to make sense of their own identity by comparing themselves to other people; friends, family members or individuals they meet in support groups.

When describing her ultimate aims DS described striving for something which could be considered 'normal', *"I don't want to have a problem, this problem. I um, I wanna beat this and I wanna be normal again…"*. Interestingly though, DS's progress in clearing her home had led her to question whether she was a 'typical' hoarder as she reported that she didn't feel attached to every item, drawing comparisons between herself and other people who hoard - *"…this is when I actually question whether I was a conventional one because, you know you hear about some people that are attached to every little thing but actually I've heard of quite a few people who weren't."*

DS also spoke of measuring her own difficulties against those of others at a support group she attended and not wanting her hoarding to escalate;

"…and I don't want to be, (how can I put it without sounding bad); I don't wanna be as bad as. . . some people are with theirs, and if that's bad then, I don't think that's bad. I mean it's like someone going to diet club and there's someone there that's 50 stone and-and most people there are like going 'well I don't want to be that person. I don't want, I don't wanna be as bad' and when you realise how people can get worse um, if you don't tackle it and um, I don't wanna be…" She also felt her difficulties were more plausible in comparison to others who have larger homes, given her social circumstances - *"I do think it's different, though if somebody says, "Oh, it doesn't matter if you've got 50 rooms or 5. It's the same…" Well no, I think I'm allowed to be more er, judgemental of people that have filled*

loads of rooms and... "but um there's nothing wrong." Hang on a minute! It's much easier to get cluttered if you've got less room, of course it is…"

Like DS, GD described a sense of being reassured by others she perceived to be 'worse' than her at the support group. She noted *"Some, one of them had a lockup to store things in. And I thought 'I'm not at that stage yet…'"* as well as *"But thank goodness I don't have to run and wash my hands for four hours or whatever…I'm not as, I could've developed alongside of hoarding a lot of detrimental things…um invasive thoughts, that sort of thing."*

In addition to comparisons showing how hoarding can increase in severity, comparison also demonstrated progress in treatment. GD also described being inspired by the recovery of others - *"She'd really turned her life around and she was the one that introduced me to this."*

PB was working with a specialist hoarding supporter and felt this professional's comparison of her to others she had worked with had led to an optimistic assessment that PB could succeed – *"I feel that she believes in me. I mean she's got almost two decades worth of experience of working with people. And she's seen cases where intervention hasn't worked and cases where it's been very successful."*

While contemplating whether his hoarding behaviours were 'normal' or problematic, TC seemed to use his friend's actions to try and make sense of this, *"…I mean um, I've got a friend who's a bit of a hoarder. So, she'll go to places like [shop]…she'll go to there and she'll hoard things in her house, and she'll have like stack fulls of toilet roll or water or kitchen roll or um, all sorts of stuff. So, it's, in a way she kind of feels it's a bit normal as well. It, it's a normal way of being so."*

PB reflected upon her understanding of herself and tidiness as part of her personality through comparing herself to her sister, *"But my sister, my youngest sister and I were brought up the same and shared the same bedroom. But she's a neat freak and I've always been messy".* Like PB, VI also compared her tidiness to a family member's but identified a drive to be unlike her mother - *"Well, I think my mum had, she had OCD, definitely, but that sort of it wasn't even recognised so…umm, and I was determined I wasn't going to be like her. So, you know if anything I went from one ideal which was being very tidy and clean, and you know and then I identified that with my mother and then, then sort of went to the other extreme I think, you know…"*

VI also reflected on her upbringing, culture, and generational influences upon her hoarding behaviours, describing that her parents were *"immigrants"* and *"They came here with nothing."* She recalled that coincidentally a professional whom she had been in contact with had a parent of the same nationality as VI's father and understood the cultural context of her identity as someone with hoarding behaviour, *"And she, she was great because she recognised everything that I had said about my dad and her father, so it was like, it was almost like it's a...a national, you know a national thing of-of people of a certain age, you know what I mean."*

RO hoped to see the properties of others with hoarding difficulties in order to compare their home to his own. *"...I'm intrigued to find out like. I'm very keen to find out er, I wanna find out whether, are they gonna be similar to my property, my layout? Like er are their hoar…is their hoarding behaviour or their challenges, or difficulties similar to my difficulties…"* Contrastingly to other participants and the wider literature, RO did not describe shame in relation to his behaviours during the interview. He recalled an occasion when he had asked a peer if he could visit their

home and appeared perplexed as to the person's lack of response, "*…er, one lad I said to him d'ya know, "can I come to your house or your flat to see, or can I just come and visit one day?" and er, he didn't take…he didn't even answer my question."*

3.3.1.4 Apprehension towards mental health labels.

Following on from apprehension around identification and hoarding, some participants described a wish to avoid being 'labelled' as having a mental health issue. This then influenced their options for support seeking. The inter-relationship between race and mental health was also explored by one participant in particular.

JB repeatedly discussed his avoidance of mental health services because of the cultural stigma he carries, *"…so yeah, I, I, probably, yeah, I-I'm probably, yeah, probably carrying this, this idea that, well this idea of 'mad people' and 'crazy people' and, you know in [home country] I think, you know traditionally people with mental health have been treated really badly."*

He described a fear of racial prejudice should he be given a mental health 'label' – *"So, maybe I'm carrying that. Um, and there's also this, this stigma of, of black men er, this kind of like, you know dangerous, mad, crazy, violent black men. So, I'm always kind of aware of that and this label of mental health."* JB also felt at risk of being subject to such prejudices from professionals too, "*Yeah. So that's what stops me; I don't want er 'seeking mental health services' on my record. Cause that could be, cause my fear again is being black, and you know that could be interpreted by all sorts of people with all sorts of er prejudices wherever um, how professional they say they are, you know people have biases."*

Consistent within other subthemes JB has contributed to, there remained a conflict. He admitted having considered the value of a hoarding-specific talking

therapy, before reiterating his wish to avoid statutory mental health services - *"But sometimes I think I wouldn't mind some counselling, actual counselling with the hoarding…but I don't want mental health, I don't want that on my GP label at all."* JB also seemed to acknowledge that he recognised in rejecting identifying as having a mental health difficulty he may be reinforcing wider stigma, *"So, there's a kind of, yeah, that label, of mental health or mental health problem. Doesn't quite sit well with me. I know I'm not helping; I'm not helping with the whole stigma thing."*

VI also described a wish to avoid the stigma of a mental health label, *"I don't particularly want to go down mental health route...I don't..."*. She felt that her options were either a decluttering organisation or mental health services - *"…as all I see is that it's a business model or it's a mental health, go down the mental health route, it's now recognised as a mental illness. Erm...and it, I think the hardest thing is being labelled. I don't wanna be labelled [pause] I think there's a great stigma attached to that."*

3.3.2 *Who can I trust?*

A further theme identified was difficulties in relation to trust in individuals and organisations. Many participants spoke of avoiding sharing the extent of their difficulties – there was a sense of anticipating shame and fearing rejection, with some participants giving examples of when their difficulties had been cited as a reason people had ended relationships. A number felt wary of services or perceived services to be acting not in their best interests. Although some found that they can trust in others, particularly peers at support groups with similar experiences. This theme comprised of three subthemes.

1. ***Trusting others with the reality of hoarding,***
2. ***Trust in services: "I don't know quite what they could have offered, but they didn't offer anything."***
3. ***Support group trust***

3.3.2.1 Trusting others with the reality of hoarding.

This theme encompasses the participants' relational experiences and fear of making themselves vulnerable to others by opening up about their difficulties. It was described by all eight participants.

GD described a sense that those who had had a 'straightforward' life couldn't understand her difficulties, so she isolates herself as a means of protection from their judgement –

"Um, people outside the house who have a life where they've not had difficulties, friends I come across at group meetings, ladies' groups, card making, that sort of thing. Um, if any of them saw my house they would just think I'd come from another planet. Um, so I really shut them out of it, if you know what I mean, don't invite them in for tea and coffee. There's very few people allowed to come in for a cup of tea or coffee."

AN also described trying to prevent friends from seeing the reality of her home, but wondering if those who may have caught a glimpse have discussed what they saw with others, *"...I always keep that door shut but I think one or two of them may have opened that door and seen what it's like and the others haven't whether they've spoken to other people or not, I don't know."* When considering what was so fearful about others seeing her space, AN worried that she may be rejected because of her difficulties *"Umm, that their . . . opinion of me will be, go down . . . some of them might not want anything to do um, with me."*

TC recalled an occasion when his mother had called to advise him that she had tidied his room, "*Well, I panicked cause umm, I panicked because I thought she'd seen the way I was living…so, I was panicking thinking she's gonna see how I'd been living and I'm gonna feel ashamed by that, you know…"* He also reflected on his response to others seeing his space generally - *"er, hu-humiliated, you know. Yeah. Pretty embarrassed, and I sort of felt, yeah, I felt ashamed of myself really, you know."*

The extent of this emotional response to the prospect of others seeing their home was also echoed by DS, who said *"…if somebody came in at its peak, I would've, I literally think I would've tried to fight them or had a heart attack or something really horrific. Um, I would be absolutely mortified if somebody saw it at its worst. Um, I would just feel* ***terrible*** [her emphasis]*."* She considered what might make such circumstances more tolerable should she access help and summarised a hope that upon opening up to a supporter they're *"not going to judge you."*

Similarly, JB described a fear of shame and judgement from others upon seeing his property. He spoke of negative responses from his family in the past (*"they're so critical"*) which caused him to retreat from sharing his situation with others, *"So, that, that does make me step back and like, okay. So, you're, you're being a bit, a bit pushy, a bit judgmental. I'm not going to share anymore…I'm going to go into my shell a little bit."* JB described a powerful emotional response to the prospect of being judged by others - *"Erm, well it's just the um. . . the thought of somebody coming into this flat and just seeing the horrible-what a horrible place. And it's also the fear that I'll get reported for being a fire a-fire hazard…um, so that, that's pretty well, scary and embarrassing…There's kind of fear and a shame."*

Despite ambivalence about his hoarding behaviours (see earlier subthemes) and not explicitly describing shame or fear of judgement, RO did describe being wary

of how others may perceive his home. When asked about his hopes for the future he identified a goal to have a romantic relationship, but he seemed unable to envisage how this could happen -

"Erm, I think I would ideally like er a partner, like er someone I can settle down with. But er, dating is a problem like er, I think to myself (pause) erm the property I live in like, how would I bring her up there? Or d'ya know where would I…how would she feel? Or how would she react?"

Turbulent, fractured or abusive relationships were common across participants. But some of those interviewed detailed the impact these relationships had upon their ability to trust others. This seemed to be particularly pertinent where their hoarding behaviours had been an influence upon a relationship breaking down.

VI described her hoarding behaviours as being referenced as a reason for a family member ending a relationship with her, although she questioned whether this was truly the reason – *"My son er doesn't speak to me because he said until I've got my house straight. That was one of the things that he firmly object…but you know but he never came to the house anyway when I didn't hoard. He never used to come over. So, I just feel it's an excuse partly erm, and of course friends. I don't have, I don't have anybody around to the house. . . but that also fed into the hoarding thing because when I didn't hoard, which was quite a long time, I used to invite people round and nobody would come…you know."* VI felt that her son had other grievances with her, but that her hoarding was used *"as an emotional um . . . as an emotional what's the word, tool, as an emotional tool to try and get me to do something, you know…"*

PB described a sense that her hoarding difficulties had been used against her on several occasions. She noted input from social services as an example *"…unfortunately the children were categorised under 'neglect'; cause I'd neglected*

the house. And they keep talking about the damage that's happened to the children cause of the house…", and also that her difficulties had been cited as a reason those closest to her had left, *"…my, my ex-husband has retrospectively said it's one of the reasons…"*

PB described one interaction with her daughter – *"…my eldest child turned around and said "other people…I know daddy left, but you know other people have got divorced and haven't fallen to pieces. Why did you?" You know like, 'thanks!' …But I-I suppose she verbalised then what I feared my reaction, people's reaction to me would be…"*

PB stated both in relation to her home and other areas *"…it's, it's extremely painful to make myself as open and vulnerable to people…"* She described *"…a feeling of shame and meant that I was keeping private from umm . . . sort of friends and family, you know."* However, she said that despite previous rejections she had begun to ask those closest to her for help – *"So, the revelation happened when I did make myself vulnerable and had my father and a close friend come in to help. And when they didn't reject me it made it easier to sort of, ask for more help."*

PB's experience of having intervention imposed resulted in her having to open up to more people about her difficulties, but she described being surprised by the response, *"So yeah, so, actually a really positive thing has been there's not been, not been one single person in my wider community who's rejected me when I've told them the story or some of the story…and that's been a massive relief honestly."*

3.3.2.2 Trust in Services: "I don't know quite what they could have offered, but they didn't offer anything."

Some participants described a mistrust in services which could offer support, which is detailed within this subtheme. This ranged from worrying that organisations

may judge them or broadly lacking faith in what they could offer, to participants suggesting beliefs that they were being targeted and services were conspiring against them.

PB was subject to social care input in relation to her hoarding difficulties and described negative perceptions of social services specifically. At times her frustrations felt more general, *"...but my experience of um....agencies is rubbish."* and her hopes and expectations of support seemed unclear - *"I don't know quite what they could have offered, but they didn't offer anything. They didn't come-I mean I wouldn't have wanted them to help clear, but they didn't refer me to anybody or anything like that until stuff had already been escalated, and yet they then criticise me for not having moved on enough."* PB described actions seemingly to protect herself in response to these feelings of mistrust, *"... it got to the stage where I wouldn't have a phone call without someone else listening in, because they were saying, changing what they'd said on the call, you know that sort of level."*

PB also reflected on why she may have found it difficult to engage with and trust services - *"...um, they didn't really, I never really felt they got much beyond the 'you've got a problem,' sort of thing, to find out actually what it was and how they could help..."* and *"I never felt like a person with social services. I felt like someone who hoards. If you see the difference."* Others also described elements of different approaches which seemed to overlook the individual, which will be further explored in a later theme 'They just see the hoard, not the person'.

Contrastingly, PB did express trust in non-NHS organisation. In relation to the specialist help PB was receiving, she described being able to trust the professional supporting her as crucial to her progress - *"...Um, you know I don't feel I have to hide*

anything from her, I suppose…cause part of the whole hoarding thing all has been about shame, not the reason I hoarded but the reason couldn't let people in to help."

RO also described a sense that services 'play games', and that he had been left questioning whether he had done something wrong, *"So erm, I think in the back of my mind I think they'll play the blame game with myself that I'm the er…I haven't listened or haven't accessed support, because I've said "what is the problem?" …I think just it feels like … you're annoyed and y'know you feel less hopeful that er d'ya know er, that er, have I done anything wrong? Or have, why I haven't I received the right type of service I needed, and what went wrong?"* He also reported that didn't feel he was heard by services – *"…they don't listen to me…"*

Other participants also touched upon not having faith in services, including VI (*"I've got no confidence in my GP, at all.")* and DS outlining her hope that *"…there are organisations out there that are not gonna judge you and tell you you're just terrible! ...And you know that's what I wanted."*

3.3.2.3 Support group trust.

Amid this struggle to trust others, there did seem to be one situation where many of the participants felt able to trust those around them with their difficulties. Six of the eight participants had accessed a support group in relation to their hoarding. This theme comprises of their experiences of being able to open up to others at these groups.

TC described a sense of belonging when he began to attend the group *"…and being around like-minded people. And it's helped to see that I'm not alone, you know I've got a good group of support er, from me friends as well . . . and. . . yeah, it's definitely changed my life…I couldn't have done without it, that's for sure…otherwise, I'd still be at home. . . depressed and, lonely [chuckles]."* This was echoed by RO, *"I*

know there's a group like er, it's just not me d'ya know who has these difficulties." RO also described how he had been able to build relationships within the group – *"…I've felt comfortable with talking to them and y'know building a rapport. That's where I've struggled for a while."* GD also discussed the value of opening up to others with similar experiences who understand, *"It opened a whole new world up to me cause when you don't share because you're too ashamed, you feel like you're the only person suffering from it."*

AN confirmed the value of this shared understanding, *"Umm, so it's good, good from that point of view to be able to be heard; that somebody understands."* And DS described an example of a peer offering insight which DS felt helped her to understand herself - *"I said to somebody er, a group um, about how I feel [name of shop's] stuff shines more than a lot of shops. Um, and they said "oh that's because um, human beings are designed to like shiny things; that's why we like jewellery". And I'd love more jewellery…"*

JB recalled how he repeatedly used his hoarding as an example within coaching training that he was undertaking, and that eventually a peer signposted him to a support group. He said *"That's when I actually 'stepped out' into like. . . you know into the world, as it were, however private that was. And talking to other people and getting help etcetera, etcetera."*

JB reflected that each time he shared his difficulties and did not feel judged, it provided further evidence to suggest he could open up to others safely;

"So, maybe the process of me sharing and not having somebody say, 'Oh! You dirty hoarder! Blah, blah, blah'…So, I'm kind of opening up a little bit you know more and more.

JB valued space to reflect, but also detailed that he had trust in peers that he would not be criticised - *"…erm, what keeps me coming back to that group is, yeah, it's somewhere that I can go and, and just talk to people who, who'll understand things on another level, that's, no wait. Yeah, basically, it's a non-judgemental group…So, like with work colleagues or with people on the allotment, you know I wouldn't get that, it's not facilitated so, yeah, I wouldn't get that sort of non-judgemental state of space, safe space to...communicate and, and, yeah."*

Although trust was not instant for everyone in the support group; RO had noticed being the only attendee of the support group from his ethnic background, and questioned whether this was accurate in relation to the occurrence of hoarding behaviours within his identified population "*But erm, I seem to be the only one in the group I've observed from a BME community, apart from erm, there's people from other communities but I sometimes think to myself er, y'know er, 'am I the only representative sample in the group or…' I don't see anyone else in my community, or is this a problem, or d'ya know are the other people like myself who are experiencing difficulties?"*

He described initially finding it difficult to talk to other attendees so different in age and background to him, but that with the support of the facilitator he was able to overcome this *"It's very hard like, but I thought to myself I would pull out y'know during the fourth, the third or the fourth session, because er I can't do two-way conversations with these people …So erm, I struggled at first but y'know er, er the coach, he guided us through, and er d'ya know we did a icebreaker and there was a bit of conversation what started as the result of a, d'ya know er putting everyone at ease."*

3.3.3 *Services that don't fit*

In the third theme a number of the participants described finding it difficult to access services, in some cases because they did not fit within thresholds to access services, or because they didn't feel the support on offer was the right fit for them. This theme explores this through the subthemes;

1. **Falling between services – not ill enough for help, too ill for help,** and
2. **Searching for the right support: "It wasn't geared towards me"**

3.3.3.1 Falling between services – not ill enough for help, too ill for help.

A number of the participants described difficulties accessing support, with a subtheme around falling between services becoming apparent. Some described wider barriers to them accessing support available, including because they did not have access to the required technology, for example VI – *"...I don't have a computer. I don't have the internet, everything was online."* But the majority spoke of seeking help but being told that the complexities of hoarding meant they were not able to meet the criteria to access certain services and equally, how the pressure on services had raised the risk threshold for referrals.

AN was the only participant actively seeking support from services specifically in relation to her hoarding, and yet she described this being problematic. *"Umm . . . yeah, so, went, went to the doctor again. Umm, and IAPT when I got in touch with them again they said that I was too, too bad and that I'd be on to the next lot..."* AN then detailed how she was 'not ill enough' for the alternative – *"...he put me forward for more umm, a more intense help but they said I wasn't bad enough. So, so there was, there was nothing, and obviously I was bad enough cause I got a lot worse since."* AN described feeling *"cast aside"* when trying to get help for her hoarding, reflecting that – *"...sometimes it seems you have to be a lot worse to get the*

help. Whereas that seems to be the wrong way round! So, I think the 'stable door after the horse has bolted,' sort of thing…but if they helped people more beforehand, they wouldn't get to as bad a stage as that."

TC also described having recently sought referral back to a specialist mental health team for a review of his medications, but that this was rejected as he was not felt to meet the threshold for the service; *"Um, I'd like to get more support on my medication as well but um that doesn't really happen nowadays because they're not willing to take me on anymore because they don't think I'm serious enough…So, they said, turned me away basically [sighs]."*

Participants reflected that they may not meet clinical thresholds for services, not only because they were not 'ill enough,' but because thresholds were high because of financial and staffing pressures upon services. TC reflected on historic support he had received and concluded that he believed cuts to service provisions would make it difficult to access such help again – "*…I've not had a support worker for a couple of years now. And I know the funding's changed. Things have changed and they've cut back on a lot of funding and the time that support workers can have. So, if I was to get a support worker nowadays or something similar, I think it would be a lot harder."*

GD described having sought referral for support through her GP at around the same time she began to access the group. She recalled "*well, I thought things were going to start rolling then but they didn't, it didn't. And I can't even remember what, why it got stopped for some reason it's their caseload. They-they're under a lot of pressure with perhaps more really seriously affected people."*

PB described a sense that because of her level of function she perceived that she did not 'look ill enough' for support, *"I mean I'm-you'll hear that I'm articulate, and I know my way around stuff…"* and *"I can present in a certain way; I speak well,*

I dress well. People knew that my ex-husband had just left, but you know it's very difficult to say 'no, this is the reality of my life'..."

RO spoke of having applied for financial support as a result of the impact his hoarding behaviours had upon his daily function – "*...with my hoarding difficulties in order for me to, to receive er some assistance and support I was er, not awarded anything because er it wasn't considered as y'know as a illness or y'know a disability I was suffering with..."*

3.3.3.2 Searching for the right support: "It wasn't geared towards me."

All eight participants suggested at some point that the support offered by services did not meet their needs for various reasons. Participants spoke of services being too focused on pharmacological interventions or imposing unrealistic time pressures. Others described struggling to find a model of psychotherapy which suited them, or that they couldn't accept the nature of professional decluttering being a business. Despite participants seemingly being unclear on what support they truly want, this theme also highlights the lengths participants may go to in order to access alternative support outside NHS pathways. This included research participation and reality television shows.

DS spoke of avoiding asking for help as she feared intervention would be forced. This will be detailed further in a later subtheme (Clearing under pressure: "It is almost like being bullied"), but she summarised by saying *"I didn't feel like there was really, the help that I wanted, that was right for me. And um, I think I was just even more desperate, and at the end of my tether."*

TC spoke throughout the interview that his OCD often meant it took him longer to complete tasks. He was wary of support as he understood it to be time-limited; *"the support workers now, you only get, if it's through charity or NHS, you*

only get six months anyway. And so that was another trigger that I had er only six months um. . . you know plan, I only, I only had a six-month deadline, you know."

RO described an impression that what is offered by services does not fit with his need. He felt that options were limited, *"…the mental health services aren't geared enough d'ya know to support me. Or I don't feel that they're sufficient or appropriate enough."* and that there was a focus upon medications *"But erm, then again, er whenever I said to them say about they put me on this medication and other medication, 'ba bye now we'll be seeing you back in about 6 months' time, so that's all they do."*

Others had accessed varying support options before concluding they did not help. GD recalled being rocked by one therapy assessment she felt was too direct, "*But I wasn't prepared for what this woman did to me…when I got into the room, she, she said to me, 'so,' and she just hit me with the most pointed question…Um, but this woman just sort of hit me with this big question. 'So, how, how did all this come about?' Something like that. I can't remember the exact word…"* But later in the interview she reflected on another therapy intervention which she perceived as not being direct enough – *"…I made sure I followed the course, and I took a special appointment, and you got an hour and um, it didn't help at all…so that didn't help at all because um, I-I tried to explain why I just felt, this is one thing I don't want to kind of be judging anybody, certainly not anybody at all but she would ask me loads of things and it was like I just went round in a circle…"* and *"…and I didn't get any advice. I didn't, she'd just ask me to think more deeply."* GD mentioned at times during the interview a hope for more practical support.

VI described that support offered by services fell into two categories, either a decluttering organisation, or mental health services neither of which were acceptable

to her, "…*all I see is that it's a business model or it's a mental health, go down the mental health route, it's now recognised as a mental illness*." She spoke of a hope for a more compassionate approach – *"I'd rather it was somebody who cared about me as an individual and took my needs into consideration. Cause I think that's what tends to happen when it's a job, when it's a business; there's a detachment there."* She also mentioned a possible role for peer support beyond the support group she was accessing; *"…you know business might be better if hoarders help each other out. I don't know. I mean it would be easy for me to go and help somebody than sorting my own stuff out, I think."*

AN described having engaged in CBT but that "…*it wasn't really helpful, wasn't sort of geared towards me…"* She recalled that during her help-seeking journey a professional had completed a course of therapy with her, then advised AN that she would benefit from a different model of therapy which AN was still looking for, *"…you know this psychoanalytic or psychodynamic therapy, would be trying to find out what that is and trying to tackle that."* AN also described that *"because there's nothing else here"* she continues to access an OCD support group. *"So, when I found out about that I did start going to that but most of the time there aren't many hoarders there as it was mainly people with OCD…and I know OCD and hoarding can, can be linked but in my case they're not really; it's really hoarding that's, that's my problem."*

Contrastingly to other participants PB described support that did suit her needs, but this was not from standard statutory services. Her input from social services led to a referral to a funded social enterprise organisation offering specific help for those who hoard. PB reflected on the general value the approach offered – *"So, it's a combination of, of tools that she knows works by experience, um, personal rapport*

and the fact that she's encouraging and can see positivity." PB also felt that the focussed nature of the input was important, *"So um, I think someone like [name] has a much, in some senses a much tighter remit. She's just there for the hoarding. So that's where her focus is, that's where her expertise is."* She also described that the supporter also had links to refer her to other interventions "*She referred me and-but had more specific stuff to do with like with grief through that. So that is hopefully unpicking the underlying issue."*

The final component of this subtheme describes the varied range of options participants had used as a means of accessing support whilst either avoiding or being unable to access statutory services. This included AN who had contributed to several research projects; *"Umm [clears throat] so, every so often I've taken part in more research; been down to [city south west] and umm, done some exercises down there and helped in er [city in north] as well; that's sort of been online like this or doing questionnaires and some more stuff in [city in south] as well. Been to various things in [city in south]…"* JB described accessing occupational counselling and a coaching course as a means of reflecting on his difficulties whilst avoiding mental health services.

Interestingly, a number of the participants had either participated in a reality TV programme in relation to their hoarding, or been in contact with production companies about doing so. VI recalled *"But er, certainly the production company that were involved, there was no, there was no counselling with that or there was no, you know there was no talking therapies. It was, it was, it was entertainment rather than anything really positive."* She offered a warning to others contemplating the idea; *"I think people have to be very careful of reality TV…that it can be nothing and it can also be very damaging…and it, it plays on people's vulnerability."* AN described her

relief at having not gone through with participating *"And I'm so glad we didn't…most of these programmes are very voyeuristic. I know some of them are helpful but some of them are very voyeuristic".* GD described a fear of judgement preventing her from taking part. The fact that from this sample several participants described either considering or accessing television, despite expressing shame and fear of judgement at showing others their homes, illustrates levels of desperation for help and emphasises how limited current support for this group is.

3.3.4 *Overlooking the individual: 'They just see the hoard, not the person'*

The final theme describes the participants' perceptions that support options often focus upon their stuff without considering their personal needs or circumstances. It comprises three subthemes;

1. ***Clearing under pressure: "It is almost like being bullied"***
2. ***Motivation when overwhelmed by the task: "How do you do it? Where do you start?",***
3. ***'Emptying the bath while the tap is running' - The right starting point***

3.3.4.1 Clearing under pressure: "It is almost like being bullied."

Six of the eight participants described a fear or avoidance of support which felt pressuring. RO cited the value of the group being that he wasn't pressured to clear, *"I think the group was ideally better because er, there was no 'action plan'…".*

VI repeated her preference for a more compassionate approach to support for hoarding difficulties - *"...I think my experience of it is almost like being bullied into it, into doing things, for a good reason. But that, that doesn't work as well with me, that being bullied, sort of like, you know there's, that approach doesn't work well with me. What works better is a kindness approach. A gentler approach. A more*

human approach...I haven't found that really." She described being reluctant to have to justify her reasoning for wanting to keep an option to someone offering support; *"...if I don't want to throw something away, that's probably the easiest thing. And I can't, then, then the person who's trying to get me to do that, wants an explanation or why is it important to you, you know and it goes on like that. Rather than just respecting that actually for whatever reason, you know I can't always-you can't-I can't always articulate why...I don't want to."*

DS also spoke of being wary of help which might pressure her to discard items she was reluctant to; *"...other than having a helper or a forced clear out, which I didn't want cause I wanted to separate things, and rescue the good stuff, as it were."* She cited avoiding accessing support because *"...um and I was scared to ask for help because I, I didn't want any forced help."*

A couple of participants reflected upon occasions when they had been pressured to clear by others in positions of power. JB recalled having been ordered to clear his office by a manager at work; *"...I felt there was an unfair pressure on me to, to do something. And that, oh that was embarrassing and shameful and that stopped me sharing and opening up about my hoarding at work..."*

Similarly, PB spoke of being pushed to clear by social services - *"...and I got very negative feedback on this from social services cause they didn't think I was making any headway. I was making shed loads of headway but if you're going through piles of paper and you're having to look at every one, everything, you know it's quite time consuming...in some ways, that was emotionally intense..."*

TC again described that tasks can take him longer to complete than other people, and a sense that he can require tasks to be adapted to suit his pace - *"I suppose in a way like my mental illness can get in the way and make things; like I said that's*

why I tend to work slowly cause I might have weeks where I'm pretty bad, and I have to sort of sit back a bit and just wait for it to pass over in a way… and um, that can be a bit of a barrier.."

3.3.4.2 Motivation when overwhelmed by the task: "How do you do it? Where do you start?"

Participants reflected on approaches to decluttering, their struggles with motivation and knowing where to begin as significant barriers to progress. The sense of participants being overwhelmed by the prospect of clearance was common, but GD's quote generated the title for this subtheme; *"Something like that can take me two days or maybe more. So, that I never seem to get round to clearing up and deciding which clothes have got to go, but anyway where do they go? How do you do it? Where do you start?"* PB echoed this predicament - *"…perhaps I wouldn't have known how to start. I think probably that's always been the big thing…"*

GD spoke of an intention to clear, but that *"… something happened, every time I tried to get help there was a problem...."* Beyond external circumstances which GD felt thwarted her, she also acknowledged an internal struggle - *"Even if I did have the physical and emotional energy to get rid of all the stuff that I should get rid of, I need to get rid of, I've still got to get past that barrier in my head."*

Like GD, JB described a sense that circumstances would often conspire against him, citing an example - *"I spent weeks…I'd done like the kitchen and the bathroom…and then there was the problem with the plumbing. So, basically, all the work, I-I'd put some Lino down; I'd put seashells in. And it was actually quite minimalist in the bathroom…and then the bloody plumber came and ripped up all my [chuckles] work!"* He described coming to a conclusion that his efforts were pointless, and that *"…sometimes I get a little bit superstitious like. . . there's forces against me…You know like, I don't know. So, I kind of gave up and thought oh what the hell."*

VI spoke of dreading the prospect of clearance; *"...you know and then there's the horrible sinking feeling when I come back...you know like today I should be, the plan today was to come out earlier then go home and do some decluttering, throwing away (laughs). But I find I procrastinate, and I'll find excuses not to, you know it's such a horrible job to do, you know it's horrible."* Whilst AN described finding concentrating on the task to be challenging - *"Well, I, I procrastinate a lot...I've got what I would describe as a butterfly mind."*

Whilst DS openly named her challenges in relation to motivation, likening clearance to a physical work out - *"I suppose it's like exercise – you don't think you want to but when you do it or when you've done it - at the end of it anyway, maybe not during - but you know you feel great to have done it...and proud of yourself and you know that you've done a good thing. I mean I still struggle um, thinking 'oh gosh! I've gotta do that thing. I've gotta clear that, and then move that thing. Argh, it's all so hard, it's all so boring.'"* DS did also reflect upon a cycle she had noticed in relation to the influence of her mood, *"[sighs] just that, you know um, being depressed and that. I mean it's not obviously, you know it's quite a serious thing and it's, it's not helped, and then it's a vicious circle because you know it affects motivation..."*

3.3.4.3 'Emptying the bath while the tap is running' - The right starting point

Participants described noticing a tendency of support interventions to focus on the stuff, rather than work with the person or tackle the underlying causes of hoarding behaviours. There was a sense from a few individuals interviewed that rather than clearance, support should initially focus upon what causes the hoarding behaviours, particularly in relation to acquisition.

AN said *"...some of the help seems to be, you know some people think should be tackling the hoard. Well, you know we've been to lots of groups and things and*

need to tackle the underlying cause…first." Her husband's analogy for this generated the title for this subtheme - *"'It's like emptying the-the bath with the tap still running, if stuff's still coming in.'"*

PB also described a sense of those offering support being over-focussed upon the hoarding; *"…um, they didn't really, I never really felt they got much beyond the 'you've got a problem,' sort of thing, to find out actually what it was and how they could help..."* She reiterated AN's sense that *"…it was more about clearing anything that was actually there rather than why it was there, if you see."* Although PB felt that this was to the extent that the ability to see the individual amongst their difficulties was lost - *"they're too busy looking at the thing, not the person, you know."*

Whilst not specifically voicing her view as a critique of help options, DS supported this view that reducing or stopping what is being collected should be prioritised above clearance efforts - *"I mean there's two parts, the the main thing is - which um forgive me if I say anything you're already aware of or state the obvious - but the main thing is you've got to stop acquiring and deal with that as well…the clearing itself is um, secondary."*

When thinking about starting to tackle the underlying causes of hoarding behaviours, two participants reflected upon the importance of timing and readiness to engage with help. PB frequently repeated perceiving that *"genuinely, I do believe that some of the counselling and stuff I've had in the run up to social services involvement actually had helped tremendously."* She recalled *"…my head was actually in a better place, I'd just finished sort of two terms of counselling. And so, when I started having to deal with the stuff … um, I found that, yes, I could actually deal with stuff."* Summarising *"So, my head was more receptive…"*

GD detailed several attempts to access or engage with help during her life but seemed to differentiate instances when she *"...was just too, I was in too much of a hurtful mess..."* to accept what was offered, compared to other occasions *"This time I felt I really needed help."* This didn't appear to be a linear journey to acknowledging needing support though – GD also said this of a separate much more recent attempt to access help, *"I contacted the GP, told her that I needed help. This time I knew I needed help."*, then at another point during the interview contemplated that *"I think I'm approaching that time now where I need both a little bit of physical help, but mostly to just fix it in my head."*

4. Discussion

In this final chapter I will revisit the aims of the project and reflect upon the findings in the context of the wider literature. I will discuss the strengths and limitations of the study, highlight ideas for future research and make clinical recommendations.

4.1 Summary of findings

The aim of this project was to explore the experiences of a group of individuals who had sought help for hoarding difficulties. It was hoped that exploring the meaning attached to their experiences would allow further understanding upon influences which had led to them recognising their hoarding to be problematic. The research also anticipated greater understanding in relation how individuals became motivated to change their behaviours, as well as any barriers identified in accessing help.

Further to analysis of interview transcripts, four themes comprising of four, three, two and three subthemes and were identified. Many of the participants described grappling with issues around identity: were they a ‘hoarder’? Was their stuff protective or restrictive? Was their hoarding as ‘bad’ as others? Could they acknowledge their difficulties given the implications of the presentation now being a diagnosable mental health disorder? For many this conflict continued to be unresolved at the time of interview.

This struggle was further exacerbated by issues with trust. Participants described a background of trauma and turbulent or fractured relationships. Almost all detailed a fear of opening up to others about their hoarding behaviours, some spoke of their hoarding behaviour having previously resulted in rejection. Others

suggested a deep mistrust of statutory services. Shame and a fear of being met with judgement rather than compassion seemed to drive these issues in relation to trust. However, for six participants, meeting with peers in support groups had allowed them to develop positive and trusting relationships.

There was a sense of ill fit between the participants' perceived needs and statutory service interventions. A number of participants described barriers in accessing services, with several describing being told their difficulties were too complex for some services but did not meet the threshold for others. All the participants detailed a sense of searching for the right help, with several deliberately looking outside of statutory services in the hope that it would suit them.

The final theme was also associated with this search for support that 'fits'. Participants described that the interventions offered often focussed on clearing their items, rather than understanding the individual and their difficulties. Several feared that support would be pressuring so opted to avoid it. Others noticed that help focused on clearance seemed pointless if they were still collecting. Participants detailed feeling overwhelmed by the prospect of clearance, and some gave considerable thought to when the 'right' time was to accept help and try to change.

4.2 Wrestling with Identity

Participants within this project struggled to identify whether their behaviours were problematic, supporting Frost et al.'s (2010) and Worden et al.'s (2014) challenges in relation to insight amongst those who hoard. Frost et al. (2010) suggested that some individuals who hoard do identify their behaviour as an issue and seek help, so it is of interest that of the 8 current participants (recruited to a study explicitly exploring help seeking for hoarding), only one had actively sought help specifically for their hoarding behaviours. The majority described accessing

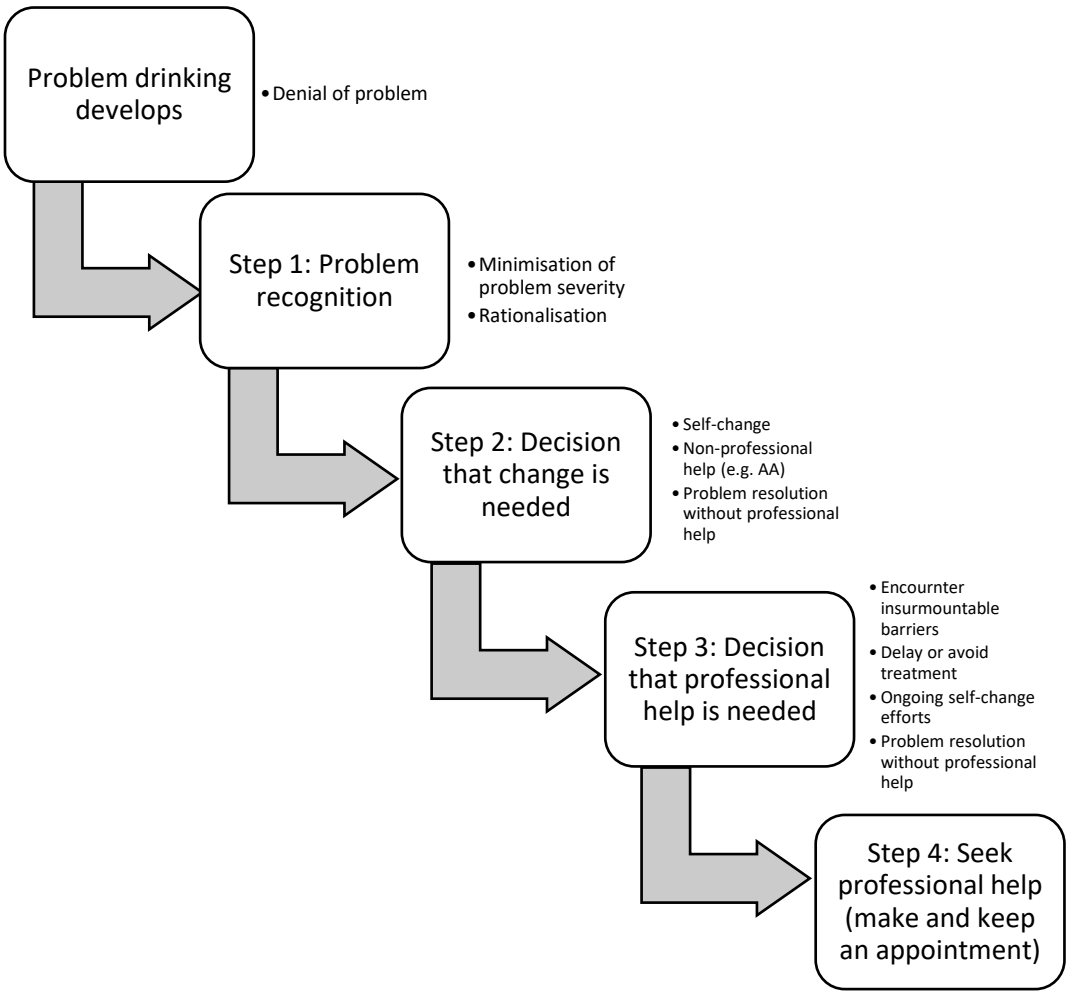
talking therapies or counselling for other mental health issues including trauma, grief, and depression.

As reflected in the first theme, throughout the interviews some participants seemed to move between two very different positions; first denying there was any issue, then shortly afterwards acknowledging their behaviour to be problematic. A similar phenomenon was apparent in the switch between seeing their items as protective then describing them as restrictive. The conflict between collections being a "fortress" or a "prison" resonated with a theme outlined by both Kellett et al. (2010) and Murphy and Perera-Delcourt (2014) and discussed in Chapter 1. In Kellet et al.'s work participants reflected on feelings of physical and psychological entrapment in hoarding. Whereas Murphy and Perera-Delcourt (2014) explored the lived experience of those with OCD and some participants identified that they both loved and hated the condition. Within the current interviews this conflict seemed to go beyond simply liking or disliking the behaviour and its external representation in 'stuff', indeed the participants truly seemed to move between being able to recognise the issue and at other times being unable to accept there was any problem. This phenomenon prompted exploration of an area of literature which had not been considered within the initial review of relevant literature – insight and recognition in addiction.

On many levels the presentation of hoarding behaviours could be easily conceptualised as an addiction to 'stuff.' and some similarities are apparent when considering the help-seeking behaviours for those with alcohol difficulties. Probst et al. (2015) used self-report measures across six European countries to explore the reasons given by primary care patients reaching the clinical threshold for an alcohol use disorder for not accessing treatment. The most frequent reason cited by more

than half of respondents (55.3%) was that they lacked awareness of any problem. The next most common response was in relation to fearing stigma and shame, followed by coming up against barriers (including not trusting the treatment options, or that the help they wished for was not offered). These findings are similar to the reasons given by those interviewed for the current study. Probst et al. (2015) highlighted a theoretical framework produced by Saunders et al. (2006) outlining a stepped treatment-seeking process based on recognition first of the issue, then recognition of the extent of the problem and that wider support is required. Much of steps 1 to 3 within this model, shown in Figure. 2 mirror the experiences as described by the current participants. Participants described minimising the impact of their behaviour or attempts to rationalise their collecting as a response to social deprivation. A number described trying to 'solve the problem themselves' or specifically accessing non-professional help including peer support groups. They described barriers, such as difficulties accessing services as well as their efforts to clear being thwarted by circumstances outside of their control. Additionally, the alternative action of delaying or avoiding treatment seemed to resonate with the theme around help being at the 'right' time. Seemingly none of the participants were at Step 4 at the time of interview in relation to their hoarding behaviours. Some described having successfully accessed mental health services previously, but that the primary focus of this support was not their hoarding.

Figure 2. Saunders et al.'s 2006 model of the treatment seeking process in relation to alcohol use



Note. Alternative decisions and actions detailed alongside each treatment seeking step.

The similarities of this help-seeking model to the experiences described by those who hoard seemed to support the applicability of literature around alcohol use. Additionally, the common nature and social acceptability of alcohol use felt more related than literature around other addictions such as gambling or the use of illegal substances.

In the case of both alcohol misuse and hoarding, to access services it is crucial that an individual recognises the behaviour to be problematic, with the evidence outlined suggesting that in many instances this is not straightforward. It was anticipated that the individuals who volunteered for this research would have reached a fixed position of 'insight' into their presentation, yet this was not reflected in the findings.

A further complexity regarding whether an individual identifies as having hoarding difficulties may be the influence of other mental health issues. The diagnostic criteria within the DSM-V (2013) outlines it to be crucial that hoarding difficulties should not be attributable to any other medical condition, giving examples including obsessions in OCD and decreased energy due to a depressive disorder. Of the sample of eight in this study, two described a comorbid diagnosis of OCD and the influence these difficulties had upon their hoarding, such as a need to order items and ritualistic processes to discard them. Another described reduced energy and motivation because of low mood which exacerbated their hoarding. It is not difficult to see how, amongst a myriad of mental health difficulties, an individual may find it challenging to determine influences upon their behaviours and therefore determine whether this constitutes identifying as a 'hoarder'.

Although it was noteworthy that participants did not identify any discomfort with other mental health diagnoses they had been given - many describing having received diagnoses of depression, anxiety and OCD – but some spoke of actively avoiding mental health services as a means of rejecting being labelled in relation to their hoarding. Huggett et al (2018) sought to explore the experiences of a sample of participants recruited from non-statutory, charitable services. They aimed to understand more about the subjective experience of mental health diagnoses and considered that individuals may access this type of organisation as they anticipated it

would be less focused on labels and the support from peers would not be stigmatising. Though thematic analysis of focus group transcripts, it was noted that participants perceived mental health diagnoses as labels which were associated with stigma. One theme they identified was around a 'hierarchy' in relation to stigma – that there were varying degrees of stigma attached to different diagnoses. This was in relation to both internal stigma and public perception. It may be that the participants interviewed within this study perceived a similar hierarchy; other diagnoses were acceptable, but the stigma attached to being labelled a 'hoarder' would be intolerable.

Beyond diagnostic manuals, it seems clear throughout the literature that individuals who demonstrate hoarding behaviours and those around them often do not share an understanding of the extent of the presentation and whether it is problematic. Whilst this fits sociocultural considerations around 'who's problem is it?' (as defined by society or services) this deeply held difference of opinion can offer context to the fractured relationships and difficulty trusting others as described within the second theme of this research.

4.3 Who can I trust?

When considering insight and identification, Worden et al. (2014) suggested that those who hoard may not receive feedback from others that their behaviours are likely to be considered unacceptable. To some extent the current participants indicated experiences that support this idea, often describing isolated existences and broken relationships. However, whilst participants largely confirmed that their collections were hidden from others, this was not because they lacked insight - in many cases this seemed to be based on an intentional avoidance because they anticipated that their presentation would be met with judgement and shame. This

adds a further layer of complexity to the discussion around insight if they are acknowledging their environment may be perceived to be a problem.

Historic trauma and difficult relationships were consistently mentioned by participants within this study, supporting research which found that those who hoarded reported significantly more traumatic life events that non-clinical controls and participants with OCD but no hoarding tendencies (Landau et al., 2011). The same authors also reported that the severity of hoarding symptoms on multiple measures was positively correlated with the frequency of traumatic life events participants reported. Research has suggested a link between trauma, particularly that involving loss, and the emotional attachment to objects within hoarding presentations (Fontenelle et al., 2021b).

This mistrust in relationships went beyond family and social contacts though, with some participants describing lacking trust in services. This suggests a likely barrier for those who hoard experiencing support or treatment as successful, given the range of literature outlining the importance of alliance in therapeutic interventions. Asay and Lambert (1999) described that much research has confirmed that therapy is effective, and seemingly varying approaches, models and manuals yield comparable results. They suggest that the effectiveness of therapy despite the range in approaches may be because different therapies encompass common factors which support change, including relational factors. The authors outline fundamental values widely accepted to be at the centre of forging a successful therapeutic alliance and highlight research suggesting how the client perceives these factors within the relationship is key, rather than how any objective observer may rate them. They also summarise findings which emphasise the importance of a warm, non-blaming approach. Whilst this may appear obvious, the interviews within this study

suggest that hoarding individuals are very wary of perceived judgement, and the emotional impact for professionals of working with those who hoard has also been reported (Holden et al., 2019). Asay and Lambert (1999) also summarise literature detailing the importance of shared goals within therapy fostering alliance, and yet those who were interviewed for this research described a sense of having been pressured by support, or not understanding or agreeing the focus of therapy. Finally, Asay and Lambert describe that many people experience change within therapy simply due to expectations that it will be beneficial. This factor seemingly does not fit with the experiences of individuals who participated in this research, where some described not having faith in services and all outlined a sense that the support on offer does not fit with their needs.

Whilst being guarded in relation to professionals, those who had accessed a support group described a sense of being able to open up to other members. Research specifically exploring the value of support groups for those who hoard would certainly be beneficial. Based on the challenges described in other themes it could be hypothesised that this support is valued because individuals don't feel pressured or encouraged to change, or that they are seen as people rather than being defined by their items.

There appears to be no literature specifically exploring the role of trust in a mental health support group, however, linking to the previous theme Crabtree et al. (2010) explored the process of identification within a group and whether this influenced stigma, support and self-esteem. They found a complex picture, that group identification could be both positive and negative. Their findings suggested that the shared identity of being part of a stigmatised group offers social support, which in turn offers some protection against stigma and prejudice. This led to an

indirect improvement in self-esteem. However, they also found that group identification itself predicted a direct negative impact upon self-esteem. The authors suggest that this direct negative effect is suppressed by the positive influence of the collective coping strategies mentioned. This complicated picture seems to fit with the experiences described by participants within this project – they spoke of support and acceptance within the group, feeling that they could be understood in contrast to the stigma they faced in wider society, and yet they continued to outline limited motivation or confidence that they may overcome their difficulties. However, it is important to consider that support groups were accessed as a means of recruitment, therefore participants were likely to describe the help they offer as valuable.

4.4 Services not fitting

Even if the barriers in relation to trust could be overcome, participants described a sense that the interventions available did not match with what they felt they needed. Several interviewees spoke of having been offered CBT but finding this did not meet their needs. This is consistent with the evidence in relation to CBT and limited clinically significant change described in Chapter 1 and systematic reviews such as Thompson et al. (2017), although exploration around what those who hoard hope for from this treatment and the barriers to achieving this would be valuable. There is growing research on more novel approaches and interventions based on third-wave therapies. Examples are described below, which seem to offer promising results.

Noting the shortcomings of CBT interventions and the challenges of inconsistent definitions of clinically significant change, David et al. (2022) proposed incorporating concepts from other approaches such as emotional regulation, mentalization and consideration of interpersonal attachment style. The authors

outline the associations those who hoard describe in relation to their objects, as well as emotional reactivity at the prospect of discarding them. They also describe the literature on attachment style in relation to those who hoard, and that objects may become a substitute for interpersonal relationships. Participants' intensity of emotions and descriptions of items replacing relationships for some individuals was noted within the interviews conducted as part of this project, which may indicate the value of including such approaches.

David et al. (2022) also suggested that treatment may be improved if preceded by a harm reduction approach, offering an example of professionals supporting a hoarding individual to resolve safety hazards within the home before accessing therapy. Whilst theoretically this sounds advantageous, given the accounts from participants that they feared judgement and being labelled a 'fire risk' the acceptability of this idea may be questionable.

Compassion focussed therapy (CFT) interventions may offer a non-blaming option to overcome the shame described by those who hoard. Almost all the participants within this project spoke of shame around their behaviour and fearing judgement from others. Chou et al (2020) undertook a pilot CFT intervention and compared this to a second repeated programme of the current standard CBT treatment. Within the CFT intervention an evolutionary model was presented to understand hoarding; emotions and behaviours were attributed to motivational systems, and techniques focused on mindfulness, soothing skills and compassionate responses. They found 72% of the CFT group participants completed all 16 sessions, whilst just 32% of the CBT group completed treatment. CFT participants also rated their treatment higher in terms of acceptability than CBT. The project also suggested a greater treatment response to CFT, and a higher percentage of the sample

achieving clinically significant change versus those who received CBT. Several participants within this project identified social deprivation or trauma as key influences upon their hoarding, suggesting that a model of understanding their difficulties as a response to threat and a means to survive would likely be acceptable to them. It may be more tolerable for those who hoard to consider the external influences upon their difficulties, rather than the cause being a result of them being unable to challenge thoughts or behaviours.

Applying Acceptance and Commitment Therapy (ACT), Ong et al. (2021) outline how psychological inflexibility and associated concepts, such as experiential avoidance and cognitive fusion, might be applied to HD. The approach varies from CBT in encouraging individuals to notice thoughts and consider their responses rather than to challenge thoughts, and to accept emotions rather than to tolerate distress with a view to reduction. This study used a small homogenous sample of six white women, although results did seem to suggest the ACT intervention decreased HD severity, clutter and functional impairment. The study suggested preliminary support for the use of ACT principles when treating those who hoard, but there is a need to explore such interventions in wider samples and using a more robust approach to clearly differentiate process from those targeted with CBT. In relation to participants within this project, it may again be that ACT would be a more acceptable treatment option for them. Framing difficulties in relation to psychological flexibility and supporting someone to notice how they may be fused with their thoughts might feel less judgemental and shaming than suggesting they lack insight or motivation.

Exploring a wide range of treatment options and their perceived acceptability, Rodriguez et al. (2016) asked self-reported hoarding individuals to consider eleven

different hoarding treatments as part of an online survey. Individual CBT, professional organising and self-help books were the options which narrowly met the threshold to be considered acceptable to respondents. Their acceptability was linked to the personalised support offered, accountability promoted and the respondents' beliefs that the treatment would be effective. The authors reported that doubting a treatment's effectiveness, associated distress and a perceived lack of control were linked to respondents considering a treatment option unacceptable. The findings of this project counter these 'acceptable' interventions though – many participants had tried CBT and found it unhelpful, and others also spoke of being averse to professional organisers.

Interestingly though, these acceptable interventions are widely different to each other. This finding was echoed in Robertson et al. (2020), within which authors sought to explore treatment preferences for HD and the treatments indicated as the most popular were polarised – face to face individual high intensity treatments, with the second most acceptable option chosen being remote low intensity interventions. The existing literature seemingly substantiates the experiences of those who participated in this project around being undecided about what might help with their hoarding difficulties.

The findings of Rodriguez et al. (2016) and Robertson et al. (2020), as well as the experiences described within this study, suggest that different individuals seemingly wish for diverse interventions at varying times. The findings of Tinlin et al. (2022) around heterogeneity in hoarding beliefs and presentations may also support this. The authors used Q-methodology to explore varying beliefs in relation to objects and whether these were associated with different comorbidities. Some beliefs were rated to be important by all (e.g. a worry that an item may be needed

later), though four factor profiles were produced in relation to beliefs around objects; objects express identity, objects as a responsibility, items offer stability, objects possess emotions and have attached meaning. These categories were respectively associated with lower to higher rates of distress, depression, and anxiety. This suggests a complex picture around the reasons an individual may hoard and the emotional impact of their beliefs. The authors also found that some individuals fit multiple profiles. They summarise by considering that current models and measures used may not be encompassing the wide range of beliefs attached to hoarding behaviours. This seems pertinent given that if an individual can overcome the barriers identified to access mental health services within the UK, there is little offer of choice or flexibility in relation to interventions provisioned. Descriptions from participants within this study suggest alternative means of gaining support have been sought. These included research participation and television productions, although the latter poses a risk around the exploitation of individuals who hoard for entertainment purposes.

4.5 “They just see the hoard not the person” Overlooking the individual

Participants within this research often reported feeling that person-centred support was lacking. Such an approach being offered may be influenced by the perceptions and experiences of professionals offering intervention. Holden et al. (2019) used a Q-sort method to explore the experiences of public sector professionals who had worked with people who hoard and identified three clusters; those who were therapeutic and client focused, shocked and frustrated workers, and professionals who were pragmatic and task-focused. It was noted that discipline seemed to influence this, with all but one of the mental health clinicians categorised

clustered under the therapeutic group. Nonetheless, the third category of task-focused professionals seemed to have been experienced by a number of participants who described a fear of clearance that felt like "being bullied", and Holden et al. (2019) described this group to be less focused upon the therapeutic relationship when working with those who hoard. This contradicts literature around the importance of common factors and a human approach above treatment models and guidelines in interventions (Asay & Lambert, 1999; Wampold 2015). Additionally, Fontenelle et al. (2021b) suggested that forced decluttering may be experienced as additional trauma by those who hoard.

Participants also described a sense that the interventions offered by services did not suit them because the service responses often focused on the possessions, rather than the individual. Interestingly, Chou et al. (2020) sought participant feedback on their CFT treatment and one of the themes was that the CFT was acceptable as it was less focused on clutter. Although this doesn't support Rodrigues et al.'s (2016) finding around the acceptability of professional organising, an intervention solely focussed on the clutter. As mentioned above, those who hoard seemingly want varying types of help, and individuals might seek differing support options across timepoints. Others also described support starting in the 'right place' - perhaps interventions focused on decluttering are more acceptable after trauma has been processed or acquisition reduced.

Within this theme several participants spoke of challenges in relation to motivation while describing a perception that as an individual they were being overlooked. Worden et al. (2014) mention the importance of not using the terms 'insight' and 'motivation' interchangeably in HD, and the findings of this research in relation to struggling with identity further support this – how can an individual be

motivated to consider changing a behaviour if they truly struggle to see it as problematic?

Participants detailed feeling overwhelmed by the scale of the task to clear their property. This supports Worden et al.'s (2014) that willingness to change may be influenced by a person not having confidence in their ability because of the vast scale of the task or the distress experienced during previous attempts to discard items. Postlethwaite et al. (2020) clustered individuals who hoard based on a Q-sort task and reported individuals describing feeling overwhelmed.

Exploring literature around motivational interviewing and avoiding individuals becoming overwhelmed, Miller and Rollnick (2012) suggest strategies such as 'agenda mapping' to manage this. For participants within this study who described feeling that interventions didn't start in the 'right place' (namely tackling acquisition before beginning to clear), this idea of working with people to support them to identify small goals that they wish to focus on first would likely be favourable.

Some participants spoke of previous attempts to break clearance down into smaller targets which felt more achievable, but others described ongoing significant difficulties around motivation. This could be linked to wider issues including comorbid low mood, and Smith (2012) proposed an interesting model. He suggested that whilst some approaches suggest motivation is a loss of desire which is distinct from and doesn't affect beliefs, it may be that depression interferes with perception to influence motivation. Rather a than a desire to act on a belief that a situation could be changed simply diminishing, he suggests that low mood may interact with beliefs and perceptions causing tasks to be appraised differently or assessed as being incredibly difficult when compared to how a non-depressed person would view a

situation. He also describes physiological characteristics of depression which may also interfere with motivation. Depression is often also experienced by those who hoard and based on this view it may be that those who hoard truly experience their situation as completely overwhelming, rather than their reporting of lacking motivation simply being that a desire to change their circumstances has waned. If this is the case it could be that interventions rated as acceptable such as a professional organiser might be helpful where a person is unable to overcome depression and be motivated to clear, although this idea may oppose Frost et al.'s (2010) descriptions of defensiveness as discussed in Chapter 1, likely due to attachment to items.

Traditionally a thesis would consider chronology and the participants hopes moving forward in summary, but for this group there seemed to be little hope or anticipation of moving forward. As outlined in Chapter 1, Tolin et al. (2010) suggested that those who hoard often remain in the 'precontemplative' stage of Prochaska and DiClemente's 1984 Transtheoretical Stages of Change Model. The findings of this project would support that – many interviewees struggled to acknowledge hoarding behaviours as problematic, suggesting little intent to change any behaviour. Of those who demonstrated identifying a problem, this was often followed by citing barriers to change such as lacking motivation, not trusting services or support available not being suitable. The descriptions of traumatic backgrounds, feeling let down and seemingly being stuck with no escape from their situation dominated the findings. But literature suggests that there may be approaches which could offer hope. Perhaps with recognition and clinical guidelines noting the crossovers between hoarding and alcohol addiction, a compassionate approach to support, and flexible personalised interventions, individuals who hoard may feel more able to access services and achieve better outcomes.

4.6 Strengths and limitations

This project recruited the anticipated number of participants, and their gender, age and ethnicity were varied without purposive sampling. Despite the context of the COVID-19 pandemic it was possible to conduct 8 in-depth semi-structured interviews which provided a wealth of detailed qualitative data suitable for the chosen method of analysis. Telephone interviewing (with one video interview) may well have supported recruitment as it is less invasive of an individual's space than face-to-face interviewing.

A further strength of this research was involvement of the wider research team to ensure the validity of findings. Two of the eight interview transcripts were coded by a research supervisor for comparison. Key words and statements noted were shown to match coding by the lead researcher. Upon generation of personal experiential themes for each participant, thematic tables were second-checked by research supervisors to ensure that they remained true to the data. Group experiential themes and subthemes (with supporting quotes) were also synthesised by the lead researcher before being considered with the supervisory team.

The findings of this project suggest that the help seeking journey for those who hoard is often complex and far from linear. Unfortunately, it was not practical to explore this in depth with each individual who participated, establishing precisely when they first sought help, who from, how this was experienced, and so on for each instance of support seeking. Nonetheless, capturing the depth of such a timeline would likely add further context and detail to findings.

To respond to the recruitment advert the participants in this study needed to self-identify as engaged in hoarding behaviours, demonstrating some insight and display a level of motivation to volunteer to participate. This suggests that they may

not be entirely representative of those who hoard more generally. However, their ambivalence in identifying as having a problem with hoarding despite having volunteered for the research illustrates the complexity of the topic of insight.

A further limitation was that demographic information did not capture participants' ethnicities, and yet three of the eight participants spoke about the influence of race and culture upon their hoarding. Cultural influences upon hoarding also remain an interesting area of expanding research (Timpano et al., 2015; Subramaniam et al., 2020).

It was not possible to assess or confirm the hoarding status of participants, so their difficulties were entirely self-reported. The use of photographs or the requirement of a home visit to interview were considered as a means of triangulation during the early planning stages of the research, but it was decided that this would likely have a negative impact upon recruitment.

Finally, although some participants responded to advertising online, a key source of recruitment was through support groups. Participants actively accessing this support are understandably much more liable to identify this means of help as beneficial. Had recruitment been through a mental health service for example, analysis may have yielded alternative findings.

4.7 Further research

The aim of this project was to explore the experiences of those who recognised that their hoarding was problematic and had sought help, and yet the findings suggest that there may not be a point of realisation which results in a fixed position of being 'insightful'. The impression that individuals seem to struggle to maintain a sense of identification in relation to their hoarding behaviours is

fascinating, and the interchanging position in relation to insight warrants further exploration. Some individuals described that they had gained understanding of their behaviours through others; lived experiences of comprehension and identification through comparison or peer support would be another interesting area of further study.

Further research exploring hoarding in the context of ethnicity, race and culture would be advantageous, as a number of participants within this study touched upon their experiences. Equally, the literature around any influence of social context and economic status remains unclear and would benefit from further attention. Regarding the current context, publications investigating any effect of the COVID-19 pandemic upon hoarding are beginning to emerge (Fontenelle et al., 2022a). but the possible impact of this global event should be considered further.

In relation to treatment and intervention, there appears to be no research upon whether motivational interviewing approaches may have a role within supporting those who hoard. Participants within this project also often described feeling that they had received poor support from services. It would be useful to gain an understanding of the impact this might have upon them, for example do those with a negative view of service support choose to disengage or become disillusioned. Given the diversity of interventions researched and varying levels of reported acceptability, further exploration around the role of the therapeutic relationship in delivering treatments would be advantageous. Based on the findings around trust, could it be that, as outlined by Wampold (2015), the common factors across therapies (e.g. alliance, expectations and empathy) are key in working with individuals who hoard? In some areas social enterprises appear to be taking this therapeutic, person-centred approach and providing positive testimonials (Clouds

End, 2021). More empirical analysis and evaluation of their interventions and impact would be valuable.

Finally, despite a range of literature detailing shame attached to hoarding presentations and those who participated describing this, several of those interviewed had either considered, liaised with, or taken part in a reality television production. This is challenging to make sense of alongside the significant fear of judgement the same participants outlined, and further examination of not just the rationale for participation but also the impact afterwards would be beneficial.

4.8 Clinical Implications

Results from this project support wider literature suggesting common comorbidities alongside hoarding include depression and OCD (Wheaton & Van Meter, 2014). The findings in relation to struggling with identity suggest that there are likely individuals presenting to mental health services whilst simultaneously struggling with hoarding difficulties. They may not recognise the behaviours as problematic or be minimising the extent of them. Equally, as described by some participants, those accessing support may offer clinicians ‘clues’ such as mentioning their house being cluttered or having things in boxes. As such, there may be a value in disseminating the potential for this to clinicians through specific training, who could then be alert to possible hints suggesting hoarding behaviours may be either the true difficulty an individual is struggling to express or a concurrent issue.

Nonetheless, even if a clinician does identify an individual accessing health services and presenting with hoarding behaviours, there are currently no defined treatment pathways specific to the condition. As mentioned within Chapter 1, hoarding presentations are briefly mentioned as a possible complexity within OCD treatment guidelines (NICE, 2005), but the findings suggest that some people with

such difficulties may be struggling to access mental health services. Given the similarities in the recognition of, challenges around motivation, and fear of stigma associated with both hoarding and alcohol use disorders, it may be valuable to formulate clinical guidance for hoarding based on existing recommendations around supporting those who misuse alcohol.

NICE guidelines for alcohol use disorders advise motivational interviewing as part of a comprehensive assessment, with the aim of increasing insight and willingness to change (NICE, 2011). The possible applicability of such approaches to increase motivation have been outlined within this chapter, and as suggested may also help to manage expectations and goals given that participants described the prospect of behaviour change for those who hoard to be overwhelming.

Agreed and shared goals are also key in establishing an effective therapeutic alliance, and there is no shortage of literature supporting the value of relational factors in outcomes. Services should be promoting clinicians investing time to foster a compassionate and trusting relationship, experienced by the individual who hoards as being free from blame or judgement. Within alcohol misuse guidelines (NICE, 2011) the importance of building a trusting, empathetic and non-judgmental relationship is explicit, likely a recognition of barriers identified within the literature to accessing treatment. The same guidelines also mention family interventions given the wider impact of the presentation. This also echoes literature around hoarding, and it may be helpful for additional interventions to support those around a person who hoards.

As the evidence base for alternative treatments expands it may be well-timed to offer help beyond the commonly utilised CBT approach; the literature suggesting models and approaches yielding similar results has been outlined. The effectiveness of CBT remains limited (Tolin et al., 2015) and participants suggested that they did

not find CBT to be helpful. There was a sense from participants that they were unclear what support they wanted, but that the current options available did not fit. The only exception was often a peer support group. Whilst the impact recruitment may have had on this preference has been noted, the acceptance and safety from judgement the group offered seemed key to its acceptability. Perhaps there may be a role to incorporate co-production with experts by experience in the planning and provision of support, as this involvement may offer a lever to overcome the fear of judgement, shame and wider mistrust of others which those who hoard describe.

It is impossible to overlook the wider context of pressures upon statutory services when considering clinical recommendations based on the findings of this research. Acknowledging service limitations, it is unlikely that services can provision flexible approaches with no time constraints. This bleak outlook may well parallel the experiences of those who participated in this study, but recommendations have been outlined for an ideal world.

4.9 Conclusion

This study has explored the lived experiences of people who identify as having hoarding behaviours for which they are seeking help. Hoarding is a relatively new clinical diagnosis, with the literature around it growing, though suggesting clear challenges in relation to insight and motivation.

The project aimed to learn more about how individuals came to see their behaviour as problematic, what influenced or motivated them to seek help, and any barriers they may have faced in accessing support.

Eight participants were interviewed, seven on the telephone and one via videocall, and IPA analysis was conducted upon interview transcripts. Four group

experiential themes were identified which provided an insight into participants' experiences of help-seeking; Wrestling with identity, Who can I trust?, Services that don't fit, and Overlooking the individual: 'They just see the hoard, not the person'.

The findings depicted complexity around the recognition of hoarding behaviours and that 'insight' was not a fixed destination, as many individuals continued to move between seeing their behaviour as problematic or protective. Participants struggled to trust other individuals and services, but many had found that they had been able to open up in peer support groups. Those who were interviewed suggested that those who hoard do not fit within clinical thresholds for services, and that support interventions which were available were often not felt to be acceptable. This was seemingly often because the treatment focused on the clutter, and the individual felt overlooked.

This study calls for further research into increasing insight and motivation within hoarding presentations. Additionally, further exploration of compassion-focused interventions and the influence of human factors, including therapeutic alliance, when supporting the group would be valuable.

Many accounts offered within this project were deeply moving and marked by a sense of inertia. This study suggests that those who hoard may be seeking help for other mental health difficulties whilst struggling to acknowledge the true problem. Should an individual present to services and hoarding is identified to be an issue, their readiness to change should be considered before intervening. Professionals should strive to create a compassionate bond, building trust and not apportioning blame. Shared goals should be agreed and identified as a focus for therapy, but where possible support should be flexible and with as few time pressures as practicable. Fluctuating insight and motivation, as well as a fear of

shame and judgement appear to be significant barriers for those who hoard in seeking help. Co-production and peer support may offer a valuable tool in overcoming this.

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Appendix A: Terms and databases used for literature search

A comprehensive search of the literature was undertaken using PsycInfo, Medline and Web of Science databases. A title search was undertaken and results were checked for potential relevance, including review of the abstract if of potential interest.

Search terms used:

"hoard*" or "clutter*" or "collect*"

AND

"help*" or "support*" or "assist*" or "treat*" or "manag*" or "counsel*" or "program*" or "therap*"

PsycInfo search on 10th January 2020 yielded 842 results.

PsycInfo search on 4th July 2022 (limiting results to publications since 2020) yielded 129 results.

Medline search on 13th January 2020 yielded 1993 results.

Medline search on 6th July 2022 (limiting results to publications since 2020) yielded 516 results.

Web of Science search in January 2020 yielded 6708 results.

Web of Science search on (limiting results to publications since 2020) yielded 1328 results.

Appendix B: Topic Guide

The participant's preferred terms (e.g. "clutter", "collecting", "stuff", whether they use the words "hoarding/hoarder") will be established early within the interview and the researcher will then adopt the participants' self-defined terms within questions.

Topics are detailed in bold, example questions highlighted in speech marks.

Researcher introduce self

Obtain basic demographic information

Recruitment Method:

General location (e.g. county):

Age (or age range if preferred):

Gender:

Other demographic data will be obtained during interview once rapport has been established: Living situation e.g. alone, with partner. Housing type, e.g. rented, own, social housing.

- Initial question seeking the individual's narrative.

"What led to you participating in this research?"

"Can you tell me a bit about your (preferred term for hoarding) [experiences/journey]?"

"What sort of things do you find yourself keeping?" "Do you have a sense of why you keep those things?"

- **Perceptions of hoarding**

"What's it like for you when you get something new?"

"How does it make you feel when you think about making space/[their term]/clearing?"

"When you look at your home what do you feel?"

- Attitudes of others

"Is there anyone else this effects?" "In what way does it affect them?"

"Who is around/important to you?"

"You mentioned earlier about [person], can you tell me a little bit more about that?"

- Recognising hoarding as a problem

"Can you tell me about the first time you sought support for [preferred term for hoarding]?" [may be multiple attempts to seek support between first and this current one]

"When did you first make contact with the organisation/group we met through?"

"How did that come about?"

"So, thinking about when you first sought help; what changed for you, what was the trigger/what prompted you to?"

- Motivation; internal and external

"What do you get from the support?"

"Have you previously sought help for any similar difficulties?"

- **Perceptions of support**

"Have you had any contact with GP/social services/housing/mental health?" "How was that?" "How does this support compare to other times you have asked for help [for this or something else]?"

- **Barriers to seeking support**

Picked up within content. "Did anything make it harder to seek help?"

If necessary: "I'm getting a sense there were some problems when you saw [organisation/service] can you tell me a bit more about that?"

- **Facilitators to seeking support**

"Was there anything about [organisation] that you liked/felt helped?"

If positive interaction with support "What kept you coming back to [support organisation]?"

- **Perceived ability to change**

"Are things different since seeking support? Since you got in touch with [organisation]?" "What has made the difference? / What has got in the way?"

"How would you like things to be in the future?" "How do you think you can get there?"

"What support do you see yourself needing in the future?"

Closing comments

"Is there anything else you wanted to tell me about your experiences?"

Check additional demographic information has been collected.

Living with:

Accommodation Status (e.g. Social Housing, Private Landlord, Owned Home):

Other mental health issues:

Thank for participant for their time and comments. Should they wish to get in touch remind participant that they have been provided with researchers' contact details. Remind them that a summary of findings will be sent to them if they have expressed an interest.

Appendix C: Recruitment Advert

Seeking support for hoarding difficulties

Hello, I'm Megan. I'm doing a research project on when and why people get help for hoarding. I would like to interview people online to understand how services could best help. It would be really great if you would read this information and consider taking part. You would also receive a £20 voucher as thank you for your time. My details are at the end if you have any questions.

Why am I doing this research?

I am interested in this topic because I have worked with people whose hoarding became a problem for them. I would like to interview people who have looked for or used support to overcome this.

What would participation involve?
If you express an interest in taking part, I will arrange a brief telephone chat with you to give you further details and (if you want) arrange an interview appointment.

How long will it take?
Interview lengths may vary but are expected to take approximately one hour.

Where will it take place?
Interviews can take place at your preferred location. Interviews may be carried out online, at your home if you are comfortable with this, or alternatively at a suitably private space such as a room booked at a local university.

How can you find out more information?
If you think you may be interested in taking part, or would like to discuss this project further, please contact me via email: ummbea@leeds.ac.uk

Appendix D: Participant Information Sheet

Faculty of Medicine and Health

UNIVERSITY OF LEEDS

Participant Information Sheet

Seeking support for hoarding difficulties

Hello, I'm Megan. I'm doing a research project on when and why people get help for hoarding. I would like to interview people to understand how services could best help. It would be really great if you would read this information sheet and consider taking part. You would also receive a £20 voucher as thank you for your time. My details are at the end if you have any questions.

Why am I doing this research?

I am interested in this topic because I have worked with people whose hoarding became a problem for them. I would like to interview people who have looked for or used support to overcome this.

What is the purpose of the project?

Many who hoard do not wish to seek help or find it difficult to access support. This study aims to help us better understand how people access support.

Why have I been chosen?

I am hoping to talk to you because you have been in touch with an organisation or group that provides help for hoarding.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form when we do the interview. If we do the interview on the phone or online you will be asked for verbal consent. You can withdraw from the study at any time until two weeks after the interview. This is when the information you have provided will be analysed. If you wish to withdraw you do not have to give a reason.

What do I have to do?

You will have the opportunity to chat to me face to face, online or via telephone. I will tell you more about the project and answer any questions you may have. As we are unable to provide translation services it is important that you are able to speak English well enough to participate in the interview.

If you decide to take part, I will discuss with you when you may be available to chat in more depth about your experiences, and agree a date and time. This interview can be conducted at home or wherever you feel comfortable.

Taking part involves just one interview about your experiences, which would normally last about an hour. Questions would be broad and interested in your experiences of support. The interview will be recorded.

If we meet face to face, I will travel to your local area to meet with you. Expenses cannot be reimbursed, however you will receive a £20 voucher to thank you for your contribution.

Will I be recorded, and how will the recording be used?

The interview will be recorded in a password-protected format. As soon as the recording has been uploaded (onto a secure computer drive) the recording will be erased.

The content of the interview will then be typed up and any identifiable information will be removed. Information collected during the interviews will then be analysed to help understand what it's like to seek help for hoarding.

When I write up the research, I will use quotes from people I have interviewed, but these will be anonymous.

What are the possible disadvantages and risks of taking part?

There are no anticipated risks in relation to taking part in this project. Some people might find it difficult at times to talk about their experiences - that's ok. We can take our time and stop if you need to. If I am very worried about you or anybody else, I will discuss with you what may be best to do next. This might include speaking to your GP or another professional who can help.

What are the possible benefits of taking part?

I don't think that there are any direct benefits from taking part in this study, but I think people might like to share their experience. Hopefully, if I can understand more about what helps people access support then I can influence services.

Use, dissemination and storage of research data

All information will be securely stored in line with the University of Leeds Research Data Management guidance. You will also be provided with a copy of the Research Participant Privacy Notice which contains more information on how the University uses research data. Findings will be written up for submission of a Doctoral thesis, and may be published in a research journal. Whilst individual quotes from interviews may be used, no identifiable information in relation to any person will be published.

What will happen to my personal information?

Identifiable information will be securely stored in a separate location to interview data. Information provided within interviews will be anonymised so that you are not identifiable. Personal information and interview transcripts will not be shared with anyone outside of the research team. All participant details and interview data will be kept secure and destroyed 3 years after the research is completed.

The research findings may be published and quotes used, but your personal details will not be printed.

What will happen to the results of the research project?

At the interview I will ask you if you want to know the results, and if you say yes, I'll keep your details and send you a summary of what I found.

Who is organising/ funding the research?

This project has been funded as part of a Doctorate in Clinical Psychology qualification by the University of Leeds. Ethical approval for this project has been sought from the School of Medicine Research Ethics Committee (application reference number MREC 19-050).

Contact for further information

Meg Beadle
Telephone: 07935 264542
Email: ummbea@leeds.ac.uk

Requests for further information, concerns or complaints can be directed to:
Dr Ciara Masterson
Telephone: 0113 343 2712
Email: C.Masterson@leeds.ac.uk

Thank you for taking the time to read this information. You will be provided with a copy of this information sheet to keep.

Appendix E: Confirmation of ethical approval

Rachel De Souza [Medicine]

on behalf of

Medicine and Health Univ Ethics Review

To:

Megan Beadle

Cc:

Ciara Masterson;

Amy Russell [LIHS];

Medicine and Health Univ Ethics Review

Wed 18/03/2020 12:58

Dear Megan

MREC 19-050 - Seeking support for hoarding difficulties

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) Committee and on behalf of the Chairs, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://leeds365.sharepoint.com/sites/ResearchandInnovationService/SitePages/Amendments.aspx or contact the Research Ethics Administrator for further information (FMHUniEthics@leeds.ac.uk) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes

Rachel

On behalf of Dr Naomi Quinton and Dr Anthony Howard, co-Chairs, SoMREC

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Rachel de Souza, Lead Research Ethics & Governance Administrator, The Secretariat, Room 9.29, Level 9, Worsley Building, Clarendon Way, University of Leeds, LS2 9NL, Tel: 0113 3431642, r.e.desouza@leeds.ac.uk
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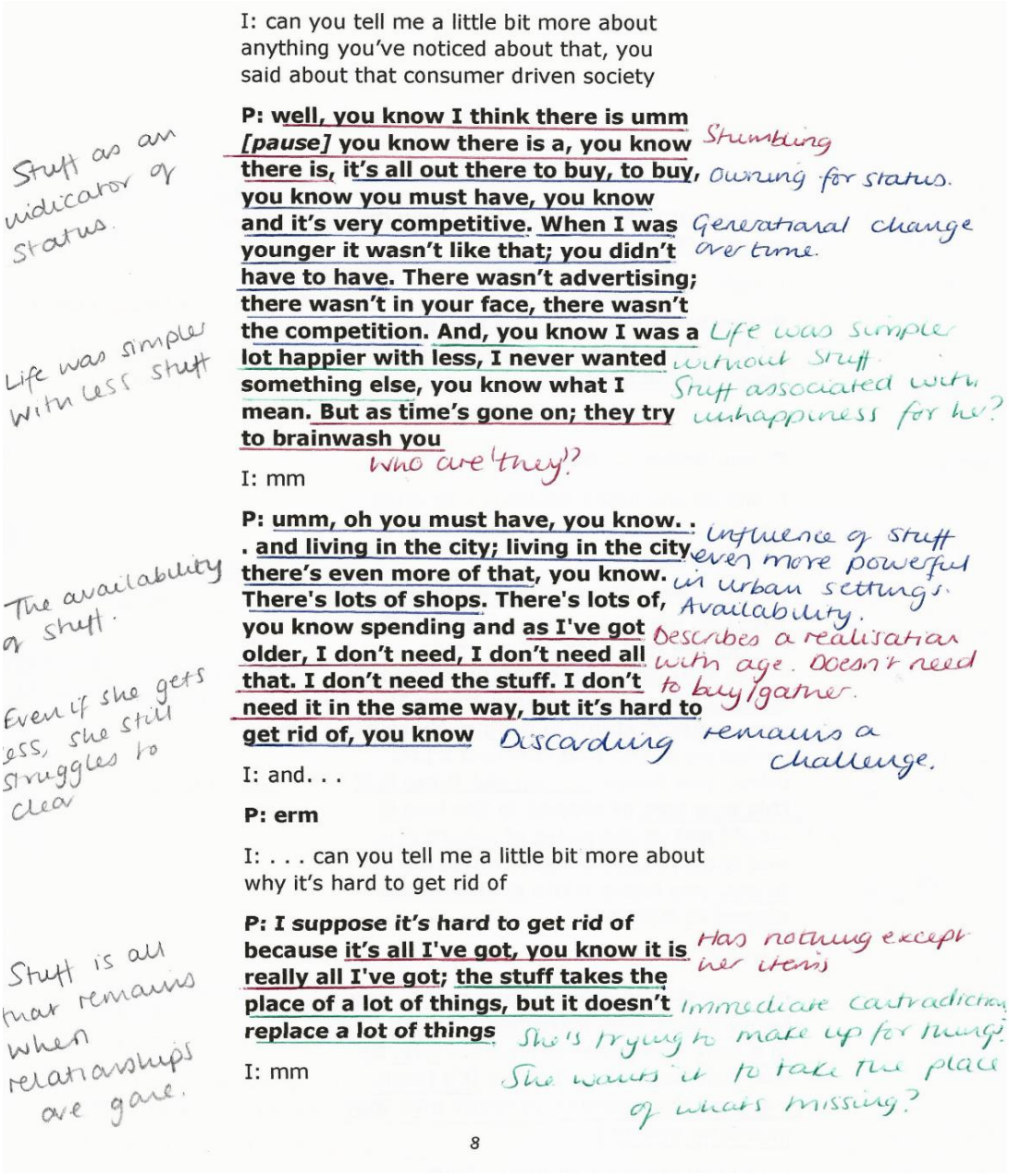
Appendix F: Example of initial notes on a transcript



I: can you tell me a little bit more about anything you've noticed about that, you said about that consumer driven society

P: well, you know I think there is umm *[pause]* you know there is a, you know there is, it's all out there to buy, to buy, you know you must have, you know and it's very competitive. When I was younger it wasn't like that; you didn't have to have. There wasn't advertising; there wasn't in your face, there wasn't the competition. And, you know I was a lot happier with less, I never wanted something else, you know what I mean. But as time's gone on; they try to brainwash you

I: mm

P: umm, oh you must have, you know. . . and living in the city; living in the city there's even more of that, you know. There's lots of shops. There's lots of, you know spending and as I've got older, I don't need, I don't need all that. I don't need the stuff. I don't need it in the same way, but it's hard to get rid of, you know

I: and. . .

P: erm

I: . . . can you tell me a little bit more about why it's hard to get rid of

P: I suppose it's hard to get rid of because it's all I've got, you know it is really all I've got; the stuff takes the place of a lot of things, but it doesn't replace a lot of things

I: mm

Stuff as an indicator of status.

Life was simpler with less stuff

The availability of stuff.

Even if she gets less, she still struggles to clear

Stuff is all that remains when relationships are gone.

Stumbling

Owning for status.

Generational change over time.

Life was simpler without stuff.

Stuff associated with unhappiness for her?

Who are 'they'?

Influence of stuff even more powerful in urban settings.

Availability.

Describes a realisation with age. Doesn't need to buy/garner.

Discarding remains a challenge.

Has nothing except her items

Immediate contradiction

She's trying to make up for things?

She wants it to take the place of what's missing?

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Appendix G: Example of a personal experiential theme collated to table

Theme 11. Struggling to acknowledge hoarding as the key issue when seeking help

Experiential Statement	Page	Quote
Struggles to acknowledge the term	20	"And, and yeah, so, I, I definitely had a 'h' word house."
	49	"…because I didn't want to say the 'h' word, I've said, 'I've got in a real pickle'…and I've, I've got myself in a mess, like literally."
Sought help for low mood rather than clutter	34	"However, um, and they er, referenced that they were for er, for people with depression issues. And again, I was too scared to specifically mention um, the 'h' word."
'Mentioning' the issue to those who could help		"…but I did mention a bit to my doctor that I was depressed, and my house was a bit cluttered. I've mentioned to my housing association um, explaining why they um, I didn't want my gas put back on for, because they would have to come in um…"
Downplays the problem because she is ashamed to admit it's full extent	35	"I've said to them that "oh there's some stuff in the way." Um, and I would be ashamed to say the, that it's that bad…"
Fearful of accessing support for hoarding specifically	36	"…but because I'm so scared, I've, I've not specifically asked for one-on-one proper counselling through my doctor specifically to address the 'h' word."