NHS Mental Healthcare Staff Experiences of Working with Service-Users Displaying Hoarding Behaviours – A Thematic Analysis

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Abstract

Background: Hoarding Disorder (HD) became its own clinical entity in 2013 and, since then, it has gained more research attention. Evidence suggests that professionals responding to the complex needs of service-users displaying hoarding behaviour lack relevant expertise and highlight hoarding as notoriously difficult to treat. Multi-agency approaches are becoming increasingly popular in the management of hoarding; however, little is known about the treatment of hoarding in UK-based National Health Service (NHS) mental healthcare services.

Aim: The aim of the current study was to qualitatively explore NHS mental healthcare staff experiences of working with adult service-users across the lifespan displaying hoarding behaviours. This was to gain a greater understanding of the condition, and to explore how staff respond to the needs of service-users within the context of the NHS.

Method: Fifteen mental healthcare staff were recruited from six NHS Trusts in England. Semi-structured interviews were conducted, and the six steps of Reflexive Thematic Analysis were followed.

Results: Five themes and fifteen subthemes were identified: (1) How staff understand hoarding behaviour: "The stuff is rarely the issue"; (2) Staff frustrations, challenges and systemic constraints; (3) Treatment approaches for hoarding; (4) Updating practice: Seeing hoarding as a diagnosis; (5) Service-users' experiences of help.

Conclusion: The results of this study highlight how mental healthcare staff attempt to understand hoarding by considering the numerous contributing factors associated with its onset and maintenance. There was ambiguity amongst staff regarding appropriate treatment for this population; however, adopting multi-agency approaches was seen to support service-users' needs effectively. Staff reflect on the complexities of undertaking this work and consider the impact this has upon service-users and accessing help. Difficulties relating to

staff role, service constraints and the lack of staff training are explored. Clinical and policy implications, including the development of best practice guidelines are discussed. Recommendations for future research are proposed.

Table of Contents

Chapter One: Introduction

1.1 Chapter Summary

This chapter provides the introductory context for the present study, which explores NHS mental healthcare staff experiences of working with service-users displaying hoarding behaviours. This chapter discusses the history of hoarding and the development of what is now known as hoarding disorder (HD), how it is defined and its prevalence. The various types of hoarding will be discussed and the impact hoarding can have on the individual, their relatives and the communities they live in, will be explored. The findings of a systematic literature review investigating the lived experiences of individuals who display hoarding behaviours will be presented. Following this, the chapter will consider the differing practices of working with hoarding individuals in different countries, as well as the current practice in the United Kingdom (UK) within the National Health Service (NHS) mental healthcare system. The research aims of the current study will then be addressed.

1.2 Hoarding Behaviour

1.2.1 History of Hoarding Behaviour

'*Hoard*', according to the Online Etymology Dictionary (2025), has roots in the old English word '*hord'*, which was described as a "treasure, valuable stock or store, an accumulation of something for preservation of future use". In 2025, the Merriam-Webster Dictionary defines '*hoard*' as "to collect and often hide away a supply of: to accumulate".

Hoarding as a concept has evolved throughout history, dating back to prehistoric times when hunter-gatherers hid supplies and necessities to stay alive. As civilisation developed, hoarding was apparent across various time periods including that of the ancient Greeks, the Romans, the Vikings, the Renaissance period and emerged into 18th and 19th Century literature (Penzel, 2014). This literature presented stories of 'hoarders' and 'misers',

who were often portrayed as monsters of squalor and misanthropy, which readers in this era found entertaining.

From there, social theorists and behavioural scientists began to consider the causes of hoarding and explored behaviours such as consumerism and accumulation of material possessions (Penzel, 2014). In William James' work, *The Principles of Psychology* (1893), hoarding was seen as instinctual and a character trait of 'misers'. He considered hoarding behaviour as a mental illness or type of derangement which, up until this time point, was not previously the case. The phenomena of hoarding continued to be explored through the lens of psychoanalytic theories in the twentieth century by Sigmund Freud. In his 1908 paper *Character and Anal Eroticism*, the 'anal character' was described as having three peculiarities: orderliness, obstinacy and parsimony, which "may appear in the exaggerated form of avarice" (p.294), known as extreme greed for wealth or material gain. This description of parsimony was likely one of the earliest depictions of what would later be termed 'hoarding' (Stumpf et al., 2018). Fromm (1947) added that people who acquire possessions are doing so to relate to the world around them, and that collecting provided a sense of security. The 'anal character' type endured for many years and created the foundation of the classification of Obsessive-Compulsive Personality Disorder (OCPD) in the second edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM; APA, 1968) published in 1968 (Penzel, 2014).

Prior to the 1990s, speculative work was published regarding hoarding as a phenomenon, but largely this was not based on empirical evidence. Throughout the 1990s, hoarding gained wider systematic research attention and was defined and medicalised during this decade (Shaeffer, 2017). Up until the 4th revised edition of the DSM, published in 2000, hoarding was classified as a symptom of OCPD and indirectly associated with Obsessive-Compulsive Disorder (OCD;APA, 2000).

Notorious cases of individuals living in cluttered squalor, such as the Collyer Brothers (Moran, 2016) and Edmund Zygfryd Trebus (The Telegraph, 2002 cited in Penzel, 2014), brought hoarding behaviour into the public view, and stories of extreme hoarding have been present in the media and news since. Television programmes such as '*Hoarders*' in 2009 (IMDb, 2009) and '*Hoarders: Buried Alive*' in 2010 (IMDb, 2010), and more recently '*Sort Your Life Out*' in 2021 (BBC, 2021), programmes of which can be described as "transforming homes…by life-changing decluttering" (BBC, 2021), have brought more public awareness to hoarding behaviour.

1.2.2 Definitions of Hoarding

In the 2013 publication of the DSM-5 (APA, 2013), HD became its own diagnosis and was categorised as distinct from OCD (please refer to Appendix A for the DSM-5 criteria for HD). It is now classified under Obsessive-Compulsive and Related Disorders (OCRDs) and is acknowledged to emerge independently of any other condition (Albert et al., 2015). Frost & Hartl's (1996) operationalised definition of hoarding is still widely used and formed the basis of the DSM-5 criteria (Snowdon et al., 2012). It defines hoarding as "(a) the acquisition of, and difficulty discarding, large numbers of possessions that appear to be useless or of limited value; (b) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and (c) significant distress of functional impairment caused by the hoarding" (p. 341). The National Health Service England (NHS, 2022) defines a person with HD as "someone who acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter. The items can be of little or no monetary value".

The current chapter will use the terms 'hoarding behaviour' and 'hoarding disorder' (HD) interchangeably to capture the experiences of people living with hoarding. The researcher acknowledges that the addition of HD as a diagnostic entity is recent, and still

somewhat controversial, therefore many people presenting with hoarding symptoms do not have a formal diagnosis. Much of the literature presented throughout uses 'HD'; therefore, this terminology will be referred to for ease. However, the researcher has decided to use 'hoarding behaviour' to inform the current research question. This is to be inclusive of those individuals with, and without a formal diagnosis, and to investigate the broad experiences of working with hoarding-related difficulties.

It is important to consider that having cluttered living spaces and acquiring items to excess is not always pathognomonic of HD (Stumpf et al., 2018). HD can only be diagnosed if the causation of hoarding is not attributable to other physical and mental health conditions (e.g., brain tumour, cerebrovascular disease, Prada-Willi syndrome, OCD, depression and schizophrenia; Stumpf et al., 2018). The main differential diagnoses of HD are: 'Normative Collecting', which is recognised as the habit of acquiring items of a specific type (e.g., coins, stamps), commonly known as 'collecting' (Nordsletten et al., 2013); and 'Organic Accumulation' (or 'Diogenes Syndrome' or 'Severe Domestic Squalor'), a condition characterised by "extreme self-neglect of environment, health, and hygiene, excessive hoarding, squalor, social withdrawal, and distinct lack of concern or shame regarding one's living condition" (Proctor & Rahman, 2021 p. 1). In cases where hoarding is secondary to organic pathology (e.g. brain damage, or dementia) then HD should not be diagnosed (Stumpf et al., 2018). Please refer to Appendix B for differences between HD and Organic Accumulation.

The historical association between OCD and hoarding was not without reason, as a proportion of people with OCD (around 53%) were found to show hoarding symptoms (Lochner et al., 2005); however, only a small percentage of these people (around 5%) presented with hoarding as the most prominent clinical feature (Albert et al., 2015). Differences that exist between OCD presentations with hoarding symptoms and distinct HD

are that, in HD, thoughts are generally not experienced as intrusive, distressing and repetitive. The thoughts are linked to pleasure and reward, as opposed to traditional obsessive-thoughts, which can be distressing (Albert et al., 2015). In HD, symptoms are perceived to be ego-syntonic, which contrasts with obsessions and compulsions that are generally regarded as ego-dystonic (Stumpf et al., 2018). Another distinguishing feature is that, in HD, distress occurs with excessive clutter, compared to OCD-driven hoarding, where distress is attributable to the intrusive nature of the condition (Fontenelle & Grant, 2014). Crucially, the reasons for acquiring and accumulating are different in HD and OCD-driven hoarding. For people with HD, they fear that items might be needed in the future, they have intrinsic value and/or they have a strong emotional attachment to possessions. Whereas in OCD, accumulating items aims to reduce or alleviate obsessions (Fontenelle & Grant, 2014). Therefore, hoarding should only be viewed as a symptom of OCD when distress is related to the obsessional thoughts, compulsions and resulting hoarding behaviour (Albert et al., 2015). There is also evidence that hoarding and OCD are comorbid independent conditions and can co-exist (Mataix-Cols, 2014).

1.2.3 Types of Hoarding

1.2.3.1 Inanimate Objects. Cluttered living spaces, in the form of inanimate objects is the typical indicator of hoarding, and this presentation is therefore required for a diagnosis of HD (Mataix-Cols et al., 2014). Types of items accumulated vary across individuals. However, virtually everything imaginable can be saved; examples include paper, newspapers, clothes, books, empty bottles, toys, and photos (Frost et al., 2011; Mulligan-Rabbitt et al., 2022). Evidence has also found that unusual, and at times unsanitary, items are hoarded, including faeces and urine. However, this presentation is often linked to OCD-driven hoarding and squalor, rather than a distinct HD presentation (Pertusa et al., 2008; Proctor & Rahman, 2021).

1.2.3.2 Animal Hoarding. Patronek (1999) state that for animal hoarding "collecting a large number of animals becomes a concern when the number overwhelms the ability of the hoarder to provide acceptable care" (p. 82). It can be seen as a variant of object hoarding and the most hoarded animals include dogs, cats, birds and farm animals (Patronek, 1999). Individuals who hoard animals display similar distress to those who hoard objects when required to give them up, even in cases where animals are sick, dying or sometimes already dead (Frost et al., 2011). Despite similarities between object and animal hoarding, Patronek and Nathanson (2009) highlight conceptual differences, namely the distress experienced when discarding animals, witnessing their suffering, and emotional attachment to animals, is likely to be profoundly different compared with possessions.

1.2.3.3 Data Hoarding. The phenomena of digital or data hoarding has gained research attention and is defined as "the accumulation of digital files to the point of loss of perspective, which eventually results in stress and disorganisation" (van Bennekom et al., 2015, p.1). Data clutter is not only problematic for organisations, with large cost implications (McKellar et al., 2020), but also for individuals with problems associated with poor productivity and compounded feelings of stress and anxiety (Sweeten et al., 2018). Reasons for keeping data include the possibility of needing files in the future and that data holds an emotional value. Sweeten et al., (2018) highlight that virtual possessions, such as photograph or music files, have become an important aspect of the user's extended self; therefore, data is seen as sentimental.

1.2.4 Prevalence of Hoarding

Studies exploring prevalence rates of HD indicate variability across populations. In European countries, where more reliable data exists, the prevalence is around 2.5% of the population (Postlewaite et al., 2019). Levels in the community could be higher, at around 4% of the population (Samuels et al., 2008). It is largely supported in the literature that hoarding

appears to be a chronic progressive disorder, with little known about its trajectory across the lifespan (Cath et al., 2017). Prevalence estimates are typically lower in studies of children and adolescents, than for adults or older adults (Mataix-Cols et al., 2008; Ivanov, 2021), despite there being an indication that symptoms begin in adolescence (Carnevale, 2021). However, in clinical samples, it has been found that hoarding severity increases with age (Grisham et al., 2005), meaning that HD is most prevalent in the older adult population due to the progression of symptoms across the life-span (Roane et al., 2018). Despite the seemingly high prevalence of HD in the population, McGrath et al., (2024) highlight that there are currently no treatment guidelines from the National Institute for Health and Care Excellence (NICE; 2005), with hoarding only mentioned as a possible complexity of OCD.

1.2.5 Theories of Hoarding

This section aims to present the most commonly considered theories and models that help to understand hoarding behaviour. The cognitive behavioural model, genetic components, developmental factors (including trauma experiences and attachment) and social and cultural influences will be explored.

1.2.5.1 Cognitive Behavioural Theory (CBT). The cognitive behavioural framework of hoarding originally proposed by Frost and Hartl (1996) and later expanded upon by Steketee and Frost (2003), is the most widely researched theory to help with understanding how hoarding behaviour is maintained and reinforced. The model proposes that the core hoarding symptoms (excessive acquisition, difficulty discarding items and clutter) result from problems in three areas: (i) emotional attachment to, and beliefs about, possessions; (ii) maladaptive emotional responses and behavioural patterns; and (iii) information processing.

1.2.5.1.1 Emotional Attachment to, and Beliefs about, Possessions. Cognitive factors that appear to drive attachment to possessions is one of the most thoroughly researched areas of the CBT model (Wheaton, 2016). The Saving Cognitions Inventory (SCI; Steketee et al.,

2003) was devised to assess four hoarding-related cognition domains linked to the CBT model. These are: beliefs related to emotional attachment to possessions (e.g. 'losing this possession is like losing a friend'); responsibility of possessions (e.g. 'throwing this away means wasting a valuable opportunity'); memory concerns (e.g. 'if I put this in a filing system I will forget about it completely'); and control of possessions (e.g. 'I like to maintain sole control over my things'). Evidence suggests that people with HD score higher on the SCI compared to healthy controls and other clinical groups (Wheaton et al., 2013). These cognitions are considered to play a causal role in leading individuals to: excessively acquire possessions (attachment), be unable to organise clutter (memory support) and have difficulty discarding (responsibility of possessions; Kyrios et al., 2014 cited in Wheaton, 2016).

1.2.5.1.2 Maladaptive Emotional Responses and Behavioural Patterns. When people who hoard are confronted with the possibility of discarding possessions, they experience overwhelming emotions including anxiety, sadness and guilt. To suppress or relieve these feelings, individuals will keep their possessions; therefore, hoarding-related cognitions evoke strong emotional reactions that drive maladaptive behaviours (Wheaton, 2016). Avoidance of behaviours relating to discarding or organisation leads to a temporary decrease in distress through principles of negative reinforcement; however, this process maintains hoarding behaviour (Wheaton, 2016). Furthermore, principles of positive reinforcement are observed when acquiring possessions, with positive emotions present, which leads to an increase in keeping and acquiring items (Kim et al., 2003 cited in Steketee & Frost, 2003).

1.2.5.1.3 Information Processing. Cognitive domains, including attention, memory and executive functioning (specifically areas relating to planning, categorising and decision-making), have been suggested to relate to hoarding symptomatology, but this remains a complex area of enquiry (Wheaton et al., 2016; Kyrios et al., 2018). Woody et al., (2014)

found that participants with clinical levels of hoarding, compared to healthy controls and clinical controls, had replicable performance deficits in planning and problem-solving decisions, visuospatial learning and memory, sustained attention and working memory, and organisation. Hoarding and links to Attention Deficit Hyperactivity Disorder (ADHD) are explored below in 'co-presenting difficulties'.

1.2.5.2 Genetics. Hirschtritt & Mathews (2014) present findings across a range of studies suggesting that hoarding has a strong genetic component. These studies included case-based family research, where hoarding is more common in first-degree relatives from the person initially displaying hoarding, known as a 'proband', compared to people without the hoarding trait. Furthermore, multiplex studies identified that hoarding is heritable and twin and non-twin studies demonstrated a strong sibling concordance to hoarding, along with a unique genetic contribution (Hirschtritt & Mathews (2014). Specific genes that predispose an individual to hoarding have not been consistently reported (Roane et al., 2017 cited in Stumpf et al., 2018) and a full exploration of genetic studies is beyond the scope of this study.

1.2.5.3 Developmental Factors, Trauma and Attachment. Research suggests that early developmental factors, such as trauma, are linked to the expression of hoarding behaviour. Cromer et al., (2007) found that hoarding individuals, compared to people with OCD, were significantly more likely to report at least one traumatic life event (TLE). Furthermore, participants who met the criteria for hoarding and who had experienced TLEs had higher hoarding symptom severity than hoarders who had not experienced trauma. Landau et al., (2011) corroborate this finding and reveal that the total number of TLEs correlated significantly with hoarding severity levels. Sanchez et al., (2023) also note that HD participants reported more experiences of early life stress (ELS) compared with non-clinical controls. The most impactful reported ELS events that contributed to individuals' relationships with material possessions included having a scarcity of support from family or

peers that was perceived to be long lasting in duration (e.g. chronic family illness or feeling ostracised). They explain that participants relied on their possessions instead of relationships.

The literature speculates potential links between hoarding participants and experiences of material deprivation (Frost & Gross, 1993), which could support the idea that objects have a compensatory function associated with attachment and motivation to hoard (Steketee et al., 2003). However, such studies have failed to find a significant association between hoarding severity and material deprivation (Landau et al., 2011 cited in Kyrios et al., 2018).

In line with the CBT model of hoarding behaviour, individuals have a strong emotional attachment to possessions, which could be due to the tendency to locate human-like characteristics in objects, known as 'anthropomorphism' (Frost & Hartl, 1996). Objects are seen to be a part of identity, with some people expressing feelings of responsibility to items (Orr et al., 2019) and being 'worried' about objects e.g. worrying that items feel lonely or unloved (Timpano & Shaw, 2013; Neave et al., 2015). The model establishes that objects are a source of comfort, security and safety (Kyrios et al., 2018). Furthermore, Yap & Grisham (2021) note the use of possessions in psychodynamic and attachment theories, demonstrating that when social connection is unsuccessful, people seek to meet this need via compensation, perhaps using objects as substitutes. They also highlight relational ambivalence and insecurity towards possessions amongst individuals who hoard. Although possessions provide comfort, individuals report a lack of control over their items, and this lack of control, coupled with discarding, evokes negative emotions. In paradox, hoarding also causes relational conflict with family, neighbours and friends, ultimately creating more social isolation and loneliness. Mathes et al., (2020) propose that individuals who hoard have dysfunctional relationships with both people and possessions. Yap & Grisham (2021) equate this to an insecure object attachment, which can be characterised by "fear of losing items, a

need to be close to possessions, and a feeling of vulnerability when separated from belongings" (p78). Objects therefore do not meet the person's relational needs, but instead become a source of anxiety. However, more research is required to expand on findings related to hoarding and interpersonal relationships (Mathes et al., 2020).

1.2.5.4 Social and Cultural Influences. Rather than viewing hoarding as located within an individual, it can also be explored within the wider social and cultural context. Exploring social inequalities including class, gender, sexuality, ethnicity, religion or disability is one way of doing so. Samuels et al., (2008) identified that hoarding is more common in the unemployed, those from less wealthy backgrounds, in men and widows. Samuels et al., (2008) also suggest that parental psychiatric symptoms are associated with hoarding and could contribute to increased adverse life experiences, such as material deprivation, and therefore resulting in the risk category of having less wealth. Hoarding has been associated with functional impairment, namely difficulties with home management tasks due to a lack of living space (Frost et al., 2000). Exploration into links between hoarding and disability is more limited. However, Nutely et al., (2022) found that, for hoarding individuals, disability was seen independently of comorbid medical or psychiatric diagnoses across domains of mobility, self-care, and impaired cognitive and social functioning.

Although less is known about cultural differences in hoarding populations, societal values, particularly in western cultures, are shaped by consumerism, which promotes material possessions equating to the illusion of happiness and success (Deivanayagam, 2023). Psychological factors underpinning consumerism include a fear of scarcity and a quest for validation through material possessions (Yuen et al., 2022). Deivanayagam (2023) argue that society places undue influence on acquisition of possessions, with individuals becoming trapped in a cycle of discontentment and desiring for more.

Orr et al., (2019) highlights how the diagnostic definition of HD in the DSM-5 (APA, 2013) might exclude relevant cultural factors. Their participants referred to everyday discourses embedded within their social context as informing their hoarding behaviour, including "getting a fair price for what one wants… waste not want not" (Orr et al., 2019, p.274). Therefore, the DSM-5 diagnostic label can disregard the agency individuals show when attributing their own meaning to their behaviour. They conclude that exploration into the complex landscape behind HD is necessary and that reductionist understandings can lose sight of the sociocultural context. Fernandez De la Cruz et al., (2016) suggest that hoarding behaviours are severely under-researched in non-western cultures and a call for transcultural perspectives is required to make meaningful assumptions about HD across culture and ethnicity.

1.2.6 Co-Presenting Difficulties

1.2.6.1 Anxiety Disorders. Children with clinical characteristics of hoarding also demonstrate higher rates of anxiety, panic, poorer attention span and insight, suggesting a pattern of behavioural and emotional dysregulation early in life (Hamblin et al., 2015). Findings suggest that in adulthood, individuals with HD report greater deficits in emotional regulation, specifically struggling in areas of emotional clarity, regulation of behaviour when distressed, acceptance of emotional responses and ability to implement strategies, than control participants (Frost et al., 2012). There is also a high comorbidity between HD, Generalised Anxiety Disorder (GAD; Frost et al., 2000) and social phobia in individuals with clinically significant hoarding (Samuels et al., 2002). Interestingly, Samuels et al., (2008) highlight a strong association between alcohol dependence and hoarding, corroborated by Wheaton et al., (2008), which was initially suspected to interfere with the process of discarding and organising possessions. However, Raines et al., (2017) have since found no significant association between difficulty discarding and alcohol consumption.

1.2.6.2 Autism Spectrum Disorders. Hoarding difficulties have been shown to be associated with Autism Spectrum Disorders (ASD; Storch et al., 2016); however, it is unclear if ASD and HD share similar phenomenological features, or if they are comorbid conditions. In ASD, restricted and repetitive patterns of behaviour, interests or activities (RRBIs) and its sub-categories are a core feature of the condition (Shuster et al., 2014). Hoarding may be seen to fall under the sub-category of behavioural expression of restricted interests (Mayes, 2018), with hoarding behaviour manifesting as collecting, which would form a part of "special" interests. However, the DSM-5 (APA, 2013), states that if hoarding behaviours are better explained by a diagnosis of autism, then a diagnosis of HD should not supersede ASD, without consideration for whether these conditions can comorbidly exist. Other features of ASD, which relate to HD, include the emotional attachment to objects, social isolation and executive-functioning difficulties (Goldfarb et al., 2021). A final consideration is whether hoarding behaviour in ASD is seen as ego-dystonic, which is the case for OCD presentations, or ego-syntonic, which can be seen for hoarding, and for people with ASD (Baren-Cohen, 1989 cited in BPS, 2015). Therefore, further research is required into hoarding behaviours that occur in ASD presentations to draw meaningful conclusions.

1.2.6.3 Attention Deficit Hyperactivity Disorder (ADHD). ADHD has been linked with HD samples (Frost et al., 2011). Studies have reported higher levels of ADHD symptoms amongst hoarding participants, including self-reported inattention and distractibility (Grisham et al., 2010). Interestingly, Tolin and Villavicencio (2011) highlight that this relationship is suspected to be specific to inattention, and not hyperactivity. Frost et al., (1996) explain that indecisiveness is a core feature of hoarding and that responding inflexibly, for instance continuing to acquire despite the already disproportionate number of possessions, could demonstrate impaired self-regulation and motivation (Grisham & Barlow, 2005).

1.2.6.4 Intellectual Disabilities. Research surrounding the association between HD and intellectual disabilities (ID) is limited, with some evidence to suggest that salient hoarding behaviours in children with ID were relatively common and not associated with OCD or autism (Testa et al., 2011). Furthermore, hoarding has only been associated with one phenotype of ID, known as Prada-Willi Syndrome (PWS; Clarke et al., 2002). PWS is associated with the insatiable need for food and sometimes the consumption of non-food substances; thus, hoarding behaviour can present in the form of acquiring food and non-food (Storch et al., 2011). Hoarding behaviour in PWS can be seen as ego-dystonic, which is noteworthy as this is seen in OCD-driven hoarding, and results in distress for the individual (Dykens et al., 1996). Other than the links between hoarding and PWS, the British Psychological Society (BPS; 2024) suggest that instances of hoarding in ID should be regarded as idiopathic.

1.2.7 Implications of Hoarding

This section explores the implications of hoarding, specifically looking at the impact hoarding has on the individual, their family and communities.

1.2.7.1 Impact on the Individual. Hoarding behaviour has been described as a debilitating condition (Saxena et al., 2011), with severe cases resulting in infestations, fires, falls and an inability to carry out daily living tasks (Steketee & Frost, 2003). Findings suggest that hoarding populations have poorer overall functioning than non-hoarding OCD patients, with higher rates of anxiety (Saxena et al., 2002) and poorer psychosocial functioning than those who do not hoard (Samuels et al., 2008). Furthermore, hoarding individuals reported lower levels of quality of life in domains of safety, referring to crime victimisation and lack of protection in their community, and their living circumstances, compared with non-hoarding OCD clients (Saxena et al., 2011). Due to the history of hoarding being categorised under OCD, a number of historical studies explored outcomes using non-hoarding OCD

populations as control groups, therefore some caution should be exercised when interpreting findings. Despite this, studies acknowledged the shift towards HD becoming its own diagnostic entity, with a suggestion that hoarding clients had a unique behavioural profile and set of symptoms, compared with OCD populations (Saxena et al., 2002).

Due to hoarding symptom severity generally increasing with age, there are poor outcomes associated with elderly populations who hoard (Samuels et al., 2008), with hoarding behaviours becoming more chronic and persistent (Carnevale, 2021). Roane et al's., (2018) literature search of HD in ageing patients revealed challenges associated with unsafe living conditions, social isolation, psychiatric and medical co-morbidities, as well as cognitive impairment. Therefore, numerous implications for hoarding populations are apparent across the lifespan.

1.2.7.2 Impact on Family. Research has demonstrated the negative impact hoarding can have on family members, including a detriment to their physical and mental wellbeing (Büscher et al., 2014). Büscher et al's (2014) literature review revealed families were under huge pressure to provide support to their loved one, when often they received little support themselves.

Nix and Dozier (2023) investigated the generational impact of household clutter and found that parental clutter was a predictor for self-reported hoarding in adult children of hoarders. Their psychosocial functioning was reported to be lower, suggesting increased levels of anxiety and depression. Neziroglu et al., (2020) categorised the impact of parental hoarding on adult offspring into three overarching themes: psychological, relational, and social. The psychological theme referred to the emotional impact on the adult child, relational focussed on the parent-offspring relationship, and the social theme explored experiences of isolation and adult children's attempts to access services. Park et al., (2014) found that as parental hoarding increased, family dysfunction increased, and growing clutter was a source

of conflict between family members. Despite the largely negative outcomes reported, Rees et al., (2018) highlighted psychological strengths adult offspring of hoarding individuals reflected on, including the development of awareness, acceptance and tolerance, representing resilience within this population.

Nonetheless, this research emphasises that family members, particularly adult children of hoarders, are vulnerable and therefore require specific support and psychological interventions Neziroglu et al., (2020). Wilbram et al., (2008) also highlight that carers and family members lack formal and informal support networks for both themselves, and when trying to seek help for their family member.

1.2.7.3 Impact on Community. Hoarding behaviour can have significant economic and social costs within the community (Neave et al., 2017), as well as acting as a public health threat (Frost et al., 2000). Housing providers and emergency services are heavily relied upon due to properties having significant safety issues, including fire hazards and the potential for infestations (Luu et al., 2018). The impact of hoarding also requires support from physical and mental health providers (Drury et al., 2014), and unemployment and disability benefits (Neave et al., 2017).

Despite the high economic and social burden hoarding presents to the community, it is suggested that the person with HD is unable to acknowledge the severity of the problem (Bratiotis et al., 2019). Frost et al., (2012) propose that some individuals with HD appear to have ‘anosognosia’, which refers to “the lack of awareness of the existence of an illness or its consequences” (p.229). Therefore, they are unlikely to seek treatment from health professionals and services, and only access support once a crisis point is reached. Robertson et al., (2020) corroborate this finding, noting people with hoarding behaviour are less likely to present for psychological treatment specifically designed to target HD and can have poor treatment compliance.

Due to the complexity of HD and widespread implications for the person and the system surrounding them, it appears crucial to explore individuals' perspectives of living with hoarding behaviour. Therefore, a systematic literature review presented below aims to address this. The literature review will be followed by an exploration into NHS mental healthcare staff perspectives of working with hoarding via the current study, to better inform care and treatment pathways. For instance, there are no specific NICE treatment guidelines for working with hoarding difficulties in the UK (French et al., 2022; McGrath et al., 2024; BPS, 2024) and therefore there is uncertainty about what approaches and protocols are most effective, with individuals often reporting poor outcomes and barriers to treatment (McGrath et al., 2024). This is compounded by professionals' expressing a poorer working alliance and feelings of frustration when supporting this client group (Tolin et al., 2012). By gaining an understanding of the experiences of living with hoarding, and subsequently experiences of working with hoarding via the current study, the research hopes to discover more about barriers to effective work.

1.3 Literature Review

The lived experiences of individuals who display hoarding behaviours: A thematic synthesis.

1.3.1 Introduction

Considering the growing body of valuable research evidence into understanding the field of hoarding behaviour presented throughout the chapter, a literature review was conducted to seek to understand hoarding behaviour from the perspective of the individual. The researcher hoped to gather an in-depth understanding by obtaining individuals' voices and experiences of hoarding, which will aid the development of the overarching research aim, outlined at the end of the chapter.

1.3.1.1 Objective. The aim of the literature review was to meaningfully synthesise the research base surrounding the lived experiences of individuals who display hoarding

behaviour; there is currently no systematic review to date that has explored this enquiry. The research question was:

What are the lived experiences of individuals who display hoarding behaviours?

1.3.2 Methods

The International Prospective Register of Systematic Reviews (PROSPERO; National Institute for Health and Care Research) was searched in August 2024, which confirmed that no previous or ongoing reviews have addressed this research question. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009) were followed for this review.

1.3.2.1 Search Strategy. An electronic search was conducted in August 2024 using EBSCOhost to simultaneously search APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE Ultimate. PubMed and Web of Science were also searched. This involved searching for published journal articles using an 'Abstract' search. No limiters were placed on the search.

The search terms used, consisted of keywords for hoarding in combination with terms related to individuals' experiences.

1. hoard* or hoarding disorder or compulsive* hoard* or compulsive* acquir* or hoarding behaviour* or excessive* acquir*
2. service-user* or patient* or client* or person* or individual*
3. lived experience* or experience* or perspective* or living with
4. interview* or qualitative*
5. #1 AND #2 AND #3 AND #4

1.3.2.2 Inclusion and Exclusion Criteria. Studies were included if:

a) They had a qualitative methodology;

b) They were peer-reviewed;
c) They were from the perspective of an individual who hoards or displays hoarding behaviours; and
d) The aim of the article was to explore perspectives and lived experiences of people who hoard.

Studies were excluded if:

a) They had a quantitative methodology;
b) They were not peer-reviewed;
c) They focussed on other mental health presentations, such as OCD; or
d) They did not explore experiences of hoarding from the perspective of the individual who hoards (e.g. from a family member perspective).

1.3.2.3 Screening procedure. Following a detailed search of article titles and abstracts via the databases, nine articles were identified for inclusion (Kellett et al., 2010; Orr et al., 2019; Ryninks et al., 2019; Subramaniam, 2020; Schou et al., 2020; Mulligan-Rabbitt et al., 2023; Ruby-Granger et al., 2023; Sanchez et al., 2023; McGrath et al., 2024). The reference lists were examined and a citation search of the nine included peer-reviewed articles was conducted, and one further study was identified for inclusion (Brien et al., 2018). Therefore, 10 articles were included for synthesis. Figure 1 illustrates the study selection process for synthesis.

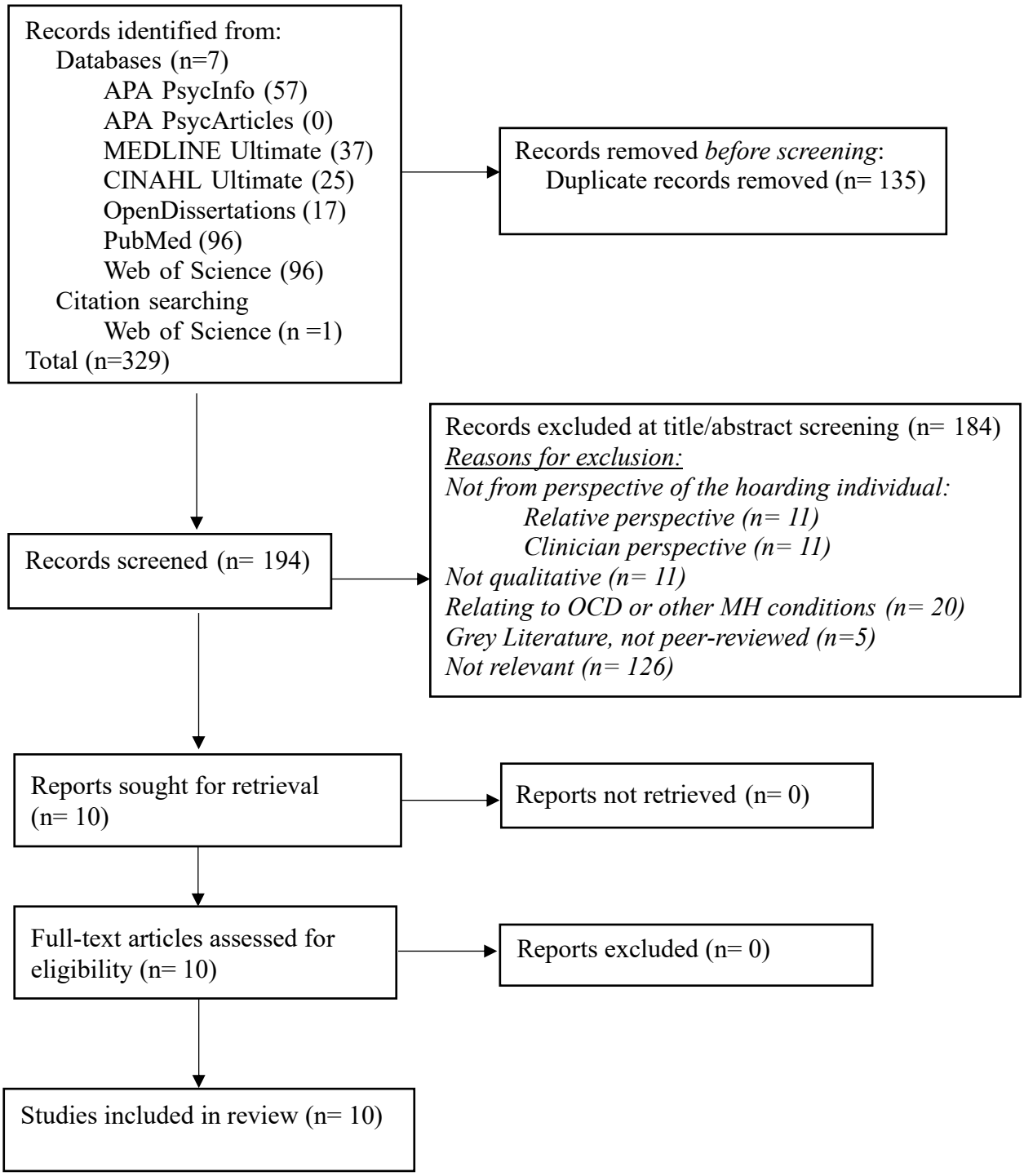
All of the included articles were from the perspective of individuals displaying hoarding behaviours with a predominant qualitative focus. However, one study (Sanchez et al., 2023) utilised a mixed methods approach, but only the qualitative findings were analysed for this review. Furthermore, Ryninks et al.'s, (2019) methodology explored experiences of both people who hoard and volunteers providing support. Only the findings pertaining to the experiences of individuals who hoard were included for synthesis. Finally, Schou et al.,

(2020) examined the meaning of hoarding for individuals with a diagnosis of schizophrenia spectrum disorder and associated psychopathology. The decision was made to include this study to portray the wide-ranging experiences of hoarding in different populations and to contribute to the aims of the wider study.

Despite there being five relevant non-peer reviewed dissertations available, the decision was made to include only peer-reviewed articles for the purposes of this synthesis. The reason for excluding grey literature is because the topic of hoarding is becoming a popularised area for research and media attention, and a lot of information written has not been peer-reviewed or subject to sufficient scientific rigour (Conn et al., 2003; Bratiotis et al., 2021). Furthermore, the content of the available grey literature may not have been appropriate. For example, one study focussed on the philosophical concept of hermeneutics to understand hoarding (Doss, 2017), while another used an occupational lens focussing on the management of daily occupations in a cluttered environment (Millanta, 2017), therefore communicating a less psychologically informed view of individuals' experiences. Therefore, the ten peer-reviewed articles would likely inform the research question adequately, while sustaining high-quality research for synthesis. A full critical appraisal was conducted and outlined in the section below.

Figure 1

Study Selection Process for Synthesis using the PRISMA 2020 Flow Diagram for New Systematic Reviews (Page et al., 2021).



1.3.2.4 Quality Assessment of included studies. The Critical Appraisal Skills Programme (CASP) checklist tool for qualitative research (2018) was used in this systematic literature review to explore the strengths and limitations of each study. Critically appraising research is paramount when synthesising studies within the healthcare sector to ensure that reliable conclusions are being drawn (Thomas & Harden, 2008; Long & Godfrey, 2004).

The CASP checklist (2018) encompasses exploration into areas of study context, data collection and analysis, which are central to the qualitative paradigm (Long & Godfrey 2004). It uses three areas of questioning: are the results of the study valid, what are the results and will the results help locally (CASP, 2018). The CASP tool is the most commonly used checklist for quality appraisal in healthcare-related qualitative evidence synthesis and is a good transparency measure of research practice and reporting standards (Long et al., 2020). There is no scoring system other than 'yes', 'no', and 'can't tell', therefore researcher discretion is required when completing the checklist. Please refer to Table 1.

All included studies provided a clear statement of aims and the use of qualitative methodology was justified and appropriate. For each study, the research designs were appropriate and clearly discussed within the methodology. For the majority of studies, the recruitment strategies were explained, with one study utilising service-user panels for support with reviewing recruitment materials (McGrath et al., 2024). However, for one study, which examined the meaning of hoarding for patients with schizophrenia spectrum disorders (Schou et al., 2020), the recruitment strategy was questioned by the researcher. The study involved searching for patients diagnosed with schizophrenia who showed signs of hoarding, which they defined as 'having a large amount of possessions', rather than participants having a confirmed HD diagnosis or recruiting using a validated hoarding scale.

Data collection across studies was deemed appropriate, with all studies conducting interviews with participants. For example, wherever possible, interviews were held in

participants' homes, except for Mulligan-Rabbitt et al., (2023) and McGrath et al., (2024), which were held online due to the Covid-19 pandemic restrictions. Ruby-Granger et al., (2023) conducted two phases of interviews, which enhanced data collection and the analysis processes. Data analysis across studies was also considered sufficiently rigorous. In Brien et al (2018), data analysis considered both conscious and unconscious material, while findings in Sanchez et al., (2023) utilised member checking with participants to ensure their analysis was reflective of participant experiences.

Half of the included studies explored the researcher-participant relationship (Kellett et al., 2010, Brien et al., 2018 Ryninks et al., 2019, Mulligan-Rabbitt et al., 2023, and McGrath et al., 2024); however, the other half did not demonstrate this reflexivity in their research process. Similarly, only half of the included studies commented on ethical issues within the article itself; however, all studies included a statement of ethics at the end. Please refer to Table 1 for specific study details.

All studies had a clear statement of their findings within their discussion sections and all studies were considered valuable to the research field. Every article discussed the implications of the research, its limitations and recommendations for future work. Full quality appraisal details can be found in Table 1.

Table 1

Quality Assessment of Included Studies (CASP)

Author	Clear statement of aims	Qualitative methodology appropriate?	Research design appropriate for aims?	Recruitment strategy appropriate?	Data collection appropriate?	Researcher-participant relationship considered?	Ethical issues considered?	Data analysis rigorous?	Clear statement of findings?	Is the research valuable to the field?
Kellett et al., (2010)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Implications, limitations, future research discussed
Brien et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Implications, limitations, future research discussed
Orr et al., (2019)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Implications, limitations, future research discussed
Ryninks et al., (2019)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Implications, limitations, future research discussed
Subramaniam et al., (2020)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Implications, limitations, future research discussed

Schou et al., (2020)	Yes	Yes	Yes	Can't tell	Yes	No	No	Yes	Yes	Implications, limitations, future research discussed
Mulligan-Rabbitt et al., (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Implications, limitations and future research discussed
Ruby-Granger et al., (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Implications, limitations and future research discussed
Sanchez et al., (2023)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Implications, limitations, future research discussed
McGrath et al., (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Implications, limitations and future research discussed

1.3.2.5 Data Synthesis. Methods of synthesising and reviewing qualitative research are still emerging and are subject to debate (Thomas & Harden, 2008). Noblit and Hare (1988) were the first to conceptualise the process of synthesising qualitative research and coined the methodology 'meta-ethnography'. Drawing from this original work, newer methods have developed which, like meta-ethnography, critically 'go beyond' the primary data of an individual study and synthesise multiple study findings. Syntheses of this kind are "integrations that are more than the sum of parts, in that they offer novel interpretations of findings. These interpretations will not be found in any one research report but, are inferences derived from taking all of the reports in a sample as a whole" (Thorne et al., 2004, p.1358).

Thematic synthesis is yet another way to synthesise qualitative research. The context for the development of this methodology stems from public health and promotion in the UK, where questions regarding the appropriateness and acceptability of health interventions were being questioned (Thomas & Harden, 2008). Research from the perspective and experience of those with a particular health issue receiving the intervention came into focus. In line with this, the current review seeks to gain an understanding into the experiences of people with hoarding behaviour; therefore, a thematic synthesis framework was used to integrate and synthesise the findings of the ten included studies (Thomas & Harden, 2008).

Thematic synthesis involves three stages; the first is the coding of text 'line-by-line', which according to Thomas & Harden (2008) requires extraction of primary data from all text labelled as 'results' and 'findings' in the included articles. This includes any statement of findings set out in the abstract and participant verbatim quotes. The ten articles were read twice by the researcher to aid familiarity with the dataset. An inductive orientation to coding was adopted, whereby the researcher aimed to capture meaning by 'giving voice' to participants' experiences (Braun & Clark, 2022). Initial codes began as semantic; however, after some familiarisation with the data, there was a shift along the continuum to latent

coding (Braun & Clak, 2022). NViVO 14 software was used to support the researcher with translating concepts from one study to the next (Britten et al., 2002), through the process of coding and the creation of themes. Stage two involved following the principles of thematic analysis, where codes were generated into descriptive themes. The final stage of the thematic synthesis required developing analytical themes by using the descriptive themes established in stage two to go beyond the data to identify key messages.

1.3.3 Results

For each of the ten articles, study characteristics and contextual information was gathered. Please refer to Table 2.

Table 2

Study Details and Contextual Information

Author	Purpose	Sample Size	Data Collection	Method of Analysis	Setting	Themes
Kellett et al., (2010)	Explored experiences of people who hoard & how they make sense of their hoarding behaviour	11	Interviews	IPA	UK	(1) Childhood factors; (2) Relationship to hoarded items; (3) Cognitive and behavioural avoidance of discard; (4) Impact of hoarding on self, others and home environment
Brien et al., (2018)	Exploration of emotional underpinnings and meanings of compulsive hoarding	5	Interviews	Psychoanalytic interview	UK / Ireland	(1) In two minds; (2) Covered-up shame; (3) Meaningless carrying-on
Orr et al., (2019)	Explored individuals' experiences of personal and cultural factors that shape their hoarding	10	Interviews	1.Framework method 2.Thematic analysis	England	(1) Notions of value and waste; (2) Connections with sociality, relationships and/or loss; (3) Physical constraints; (4) Mental health
Ryninks et al., (2019)	Experiences of receiving and providing help in the context of HD	4	Interviews	IPA	UK	(1) Relationship between client and volunteer; (2) Live life again; (3) Challenges; (4) Supporting volunteers
Subramaniam et al., (2020)	Investigated the lived experience of hoarding and impact on significant others	12	Interviews	Thematic Analysis	Singapore	(1) Types of hoarded items; (2) Sources of hoarded items, (3) Ways of storing/arranging hoarded items; (4) Help-seeking/treatment contact; (5) Reasons for hoarding; (6) Experiences with decluttering; (7) Impact upon family; (8) Community and self; (9) Restricting hoarding behaviours and insight

Schou et al., (2020)	Examined the meaning of hoarding for patients with schizophrenia spectrum disorders and associated psychopathology that might motivate hoarding	13	Interviews	Thematic Analysis	Denmark	(1) The time of onset of hoarding; (2) The meaning of hoarding and associated psychopathology; (3) The presence of insight in hoarding; and (4) Problematic issues about discarding.
Mulligan-Rabbitt et al., (2023)	Investigated the experiences of people who hoard and their relationship to their hoarded material	14	Interviews	1. Moment-by-moment analysis 2. Psychoanalytic research interview	UK	(1) "It's not yours. It's mine"; (2) "Keeping within the walls"; (3) "Sorting through"
Ruby-Granger et al., (2023)	To understand the development of hoarding from a qualitative perspective	14	Interviews	Constructivist Grounded Theory	UK	(1) Struggling to manage and (2) Trying to overcome hoarding. Subcategories include: managing possessions, managing life, resisting temptation, accessing formal and informal support, building a life beyond the hoard.
Sanchez et al., (2023)	Exploration into the role of early life stress in HD	12	Interviews	Thematic Analysis	USA	(1) Emotional scarcity in family; (2) Emotional scarcity in peers
McGrath et al., (2024)	Exploration into the experiences of people with hoarding behaviour and who are seeking support	8	Interviews	IPA	UK	(1) Wrestling with Identity; (2) Who can I trust?; (3) Services don't fit; (4) Being overlooked: 'they're too busy looking at the thing, not the person'.

Note. 'IPA': Interpretative Phenomenological Analysis

Six themes and two subthemes were created from the data synthesis process, which contain descriptive and analytical components. The themes are presented in Table 3.

Table 3

The Main Themes and Subthemes of the Thematic Synthesis

Main Themes	Subthemes
Adverse Life Experiences	Attachment and Fusion Attempts to Make Meaning
Relationships to Possessions	
Challenges of Discarding	
Perceived Stigma	
Experiences of Help Seeking and Trust	
Moving Beyond Hoarding	

1.3.3.1 Adverse Life Experiences. Many studies explored the development of participants' hoarding behaviour and the onset was often related to adverse life experiences, with one study highlighting that hoarding behaviours typically emerged during childhood (Kellett et al., 2010). Unprocessed past experiences was a recurring concept arising in participant accounts, with reports of childhood abuse, including sexual and physical abuse, and having possessions destroyed. Participants expressed an inability to show emotion during these experiences, with some participants recalling that other family members' emotions were ‘paramount’ to their own (Kellet et al., 2010). Sanchez et al., (2023) highlight that the most salient adverse life experiences were ones that elicited a scarcity of emotional support from

family. Brien et al., (2018) acknowledged that the failure to process these experiences was evident across accounts, with participants recalling painstaking detail of past conversations, with what appeared to be memory fragments stockpiled in the mind, with no clear organisation.

Other significant events included sustained bullying and rejection from peers, resulting in isolation with an urge for connection to others; therefore, participants sought items as a way of facilitating relationships (Sanchez et al., 2023). Experiences of loss were also commonplace in study findings with suggestions that early loss, perhaps of a loved one or of a beloved possession, might motivate people to take comfort in possessions and "hold onto everything" due to fear of experiencing more loss (Mulligan-Rabbitt et al. 2022 p.126).

Studies spoke of the potential damage within the parent-child relationship and a resulting hoarding disposition. Brien et al., (2018) posit that shame was disguised as guilt in childhood experiences, with participants feeling unable to meet their parents' expectations despite the perceived parental investment. Participants recount how owning items did not always make them "mine", with memories of parents deciding they no longer needed such possessions (Mulligan-Rabbitt et al., 2022). Schou et al., (2020) highlighted that hoarding has become a strategy for coping with an imbalance within one's self, perhaps due to adverse life events.

1.3.3.2 Relationships to Possessions. This theme encompasses how people relate to their possessions and it is split into two sub-themes.

1.3.3.2.1 Attachment and Fusion. Many studies placed emphasis on the emotional attachment participants had towards their possessions. For instance, people stated that hoarding objects provided companionship (Subramaniam et al., 2019), protection and a feeling of safety (Sanchez et al., 2023), comfort (Mulligan-Rabbitt et al., 2022) and a way of retreating from the outside world (Kellett et al., 2010). Similar to how a young child might

perceive the role of a caregiver in meeting their emotional needs, one participant likened the thought of losing their hoard to feeling as though they would be vulnerable and "break into small pieces without them" (Schou et al., 2020, p114).

A common thread amongst studies was the act of anthropomorphising objects, which suggested a fusion between the person and their hoarded items (Kellett et al., 2010; Ruby-Granger et al., 2023). Cognitive examples of attributing human characteristics to objects included assigning them feelings and personalities (Ruby-Granger et al., 2023), for example believing that items might be lonely if left on a shelf (Kellett et al., 2010). There was also a suggestion that keeping objects enabled a life force and that participants did not want to "kill" objects (Ruby-Granger et al., 2023). Items also represented a form of love and intimacy due to holding memories, perhaps of lost loved ones handling such objects (Ruby-Granger et al., 2023). Some participants compared discarding objects to getting rid of family or children (Ruby-Granger et al., 2023), while Orr et al., (2019) reported on how owners have a responsibility for their items, which continues even once they had finished getting direct use.

Furthermore, studies highlighted strong feelings of ownership in acquiring what is theirs or "mine". Studies reported on the instinct-like urge to claim what was theirs due to past experiences of not always feeling like they had ownership of their possessions (Mulligan-Rabbitt et al., 2022). For others, keeping possessions gave them a sense of immorality and that disposal might feel like "discarding part of the self" (Ruby-Granger et al., 202,3 p1286).

1.3.3.2.2 Attempts to Make Meaning. Across studies, participants attempted to make meaning and rationalise their hoarding behaviour. For some, this included focussing on the value of hoarding and that by keeping objects, this would likely serve a future purpose (Mulligan-Rabbitt et al., 2022), be a way of overcoming future uncertainties (Schou et al., 2020) and protect them both physically and emotionally (Sanchez et al., 2023). Subramanian

et al., (2019) refer to the Risk Minimisation Theory (McKinnon et al., 1985) when relating to their findings, which suggests that hoarding might serve a future use if the objects become expensive or unavailable, therefore objects are seen to provide utility.

Hoarding items was also considered as self-expression, with accounts of their possessions providing participants with an inner silence, a place of calm and a sense of richness and love (Schou et al., 2020). For others, hoarding symbolised hope and that one day the meaning of the hoard will be evident (Mulligan-Rabbitt et al., 2022).

1.3.3.3 Challenges of Discarding. Study findings revealed a sense of conflict arising in participants when speaking about their hoard or when confronted with discarding possessions. Contradictory experiences were highlighted by McGrath et al., (2024), who used the analogy of either a 'fortress' or a 'prison' to represent how possessions provided safety but also led participants to feel trapped (p.5). Other findings displayed the internal conflict felt when wanting to move on, but also feeling ill-equipped to cope when items were discarded (Mulligan-Rabbitt et al., 2022). This dialect was apparent in other accounts where individuals wanted to make change but there appeared to be minimal effort to do so (Mulligan-Rabbitt et al., 2022), and similarly wanting perfect order in the home, but the other extreme of living in chaos prevailed (Kellett et al., 2010). Others felt 'trapped' by the 'stuff' and their situation and wanted to walk away; however, they acknowledged there were still items they wanted to keep (McGrath et al., 2024, p.5).

Most studies reported on the negative emotions associated with discarding possessions, including profound anxiety, anger, discomfort, distress and ambivalence or rumination about the possibility of needing items in the future (Schou et al., 2020; Subramaniam et al., 2019). Furthermore, decision-making and the finality of committing to a decision also led to anxiety, and ultimately increased acquiring (Ruby-Granger et al., 2023).

1.3.3.4 Perceived Stigma. Findings revealed that often participants felt stigmatised by society and neighbours, as they would lack understanding (Subramanian et al., 2019). In Kellett et al., (2010), one participant felt that their hoard would shock and horrify people, subsequently leaving them feeling alienated. Similarly, studies reflected on how hoarding behaviour can be seen as a barrier to accessing the outside world, both physically and mentally, and that acquiring had the unanticipated consequence of keeping others out (Mulligan-Rabbitt et al., 2022; Orr et al., 2019). Tensions and breakdown of family relationships was also acknowledged as a result of the hoarding (Orr et al., 2019), often due to family asking them to de-clutter or to stop acquiring (Subramanian et al., 2019).

1.3.3.5 Experiences of Help Seeking and Trust. Two UK based studies focussed on experiences of seeking support for hoarding (Ryinks et al., 2019; McGrath et al., 2024), while other studies explored help-seeking in their findings. Some participants felt scared to disclose their struggle with hoarding due to fears of what an intervention might entail or being reported as a fire hazard (McGrath et al., 2024). Conversely, other participants had been looking for help for a long time (Brien et al., 2018). In McGrath et al., (2024), participants reported actively avoiding mental health services or confiding in health professionals due to lacking faith and confidence in what could be offered, feeling that services don't listen and being told they do not fit service thresholds, therefore feeling 'cast aside' (p.7). Furthermore, participants reflected on the unrealistic time pressures services offer, which contributed to not seeking support. A thread amongst findings was a mistrust of services due to feeling judged and the focus of help being on clearing out, rather than facing the underlying causes of the hoarding (McGrath et al., 2024).

Studies revealed the impact of language surrounding hoarding and the importance of terminology. In McGrath et al., (2024), one participant referred to hoarding as the 'h' word and feeling shame to disclose their difficulties, while others referred to themselves as

'collectors' (Orr et al., 2019). There was a sense across accounts that participants did not want to feel vulnerable by opening up, due to their past experiences of criticism and rejection (McGrath et al., 2024). Hoarding was often used as a verb in accounts, as a way of externalising a behaviour they happened to engage in. This could help create distance between themselves and the problem (McGrath et al., 2024). Hoarding conversely was seen as a positive act for some, with a sense of joy, comfort, pride and satisfaction (Mulligan-Rabbitt et al., 2022).

Despite largely negative experiences with health services, several studies reflected on the positive benefits of attending support groups. Participants felt a sense of reassurance and normalisation of their behaviour (Orr et al., 2019), despite support groups often not being local (Ruby-Granger et al., 2023). Ryninks et al., (2019) also highlighted how participants valued volunteer support due to its informal, flexible and less time-restricted nature. Others had also sought support by taking part in research and featuring on reality television programmes (McGrath et al., 2024).

1.3.3.6 Moving Beyond Hoarding. Some studies spoke about life beyond hoarding and the journey towards change. One participant expressed feeling liberated to learn that hoarding could be a mental illness (Orr et al., 2019) and having volunteer support made a huge psychological difference by regaining self-respect, confidence, and purpose in life (Ryninks et al., 2019). To achieve change, participants felt that support should involve working with someone who has familiarity with hoarding and the ability to build up trust and rapport (McGrath et al., 2024). McGrath et al., (2024) also acknowledges the impact of being around others who hoard and witnessing their progress, and how this motivated and inspired change and recovery. A thread amongst narratives was that to move on from hoarding, a shift in identity was required, including attempts to restore or build a new sense of self, where new values and habits were adopted (Ruby-Granger et al., 2023). An adjustment to a post-

hoarding life was required to navigate the “struggle to manage” and resisting temptation to acquire (Ruby-Granger et al., 2023).

1.3.4 Discussion

The current literature review has collated the lived experiences of people who hoard and six themes emerged from the findings, which aimed to encompass their broad experiences. Individuals described the context surrounding the onset of their hoarding behaviour and specifically made links to adverse life experiences. They highlighted the nature of their relationship towards their possessions and described an emotional attachment and fusion to their hoarded items, through processes such as anthropomorphising objects. It was also apparent across accounts that individuals attempted to make meaning and rationalise their hoarding behaviour, which included considering the future use of an item. A further finding highlighted individuals’ feelings of conflict related to their possessions and at the prospect of discarding, with some reporting how they wanted to move on, but simultaneously feeling ill-equipped to cope. Feeling stigmatised by others was identified as a common experience for individuals, resulting in feelings of alienation and a breakdown of relationships. When considering individuals' experiences of seeking help, they largely reported a mistrust of services, which contributed to a fear of disclosing their difficulties. The focus of help should consider the underlying causes of hoarding, rather than clearing out of possessions. Finally, for those individuals who are no longer engaging in hoarding behaviour, they reported a shift in identity and highlighted the importance of working with someone who has a familiarity with hoarding, which enabled trust to achieve change.

Whilst the literature review highlighted many similarities across experiences of living with hoarding difficulties, there are several limitations to be discussed. The first is the included studies often recruited participants that were ‘self-identified hoarders’ suggesting that methodologies lacked sufficient screening of participants. This is a concern because

participants might not have met the established clinical and theoretical definition of hoarding, which could have been confirmed using screening tools such as established hoarding measures and clinical interviews (Kellett et al., 2010). However, due to the issues relating to disclosure of hoarding difficulties (McGrath et al., 2024) and the high levels of concealment hoarding presents (Kellett et al., 2010), it is believed most studies took the appropriate steps to recruit as effectively as possible, for instance recruiting from charities and hoarding networks.

Furthermore, the studies reviewed were from several different countries including the USA, Denmark, Singapore and the UK. Therefore, despite the similarities between participant accounts across countries, individuals' hoarding behaviours and their experiences will likely be affected by their social and cultural context (Fernández De la Cruz et al., 2016), which has not been taken into account in this review. The current study will be focussed on UK-based findings; therefore, the results of this review are to be used with caution. Furthermore, to have increased the quality of this review, a second, independent CASP rater should have been used to appraise the studies.

Despite the current review attempting to ensure methodological rigour by excluding grey literature, this can also be seen as a limitation, as the search could be seen as too narrow and limit the inclusion of available and relevant evidence, thus threatening validity (Moher et al., 2000 in Conn et al., 2003). However, this limitation is often associated with quantitative studies, where publication bias, which involves only publishing statistically significant results, has been apparent (Conn et al., 2003). Therefore, this could be less of a concern in qualitative analysis, where findings are not subject to significance thresholds.

Even with the limitations presented, the review is the first to systematically explore the experiences of people living with hoarding behaviours. It is hoped that the rich findings, which have been collated into themes, accurately capture the wide-ranging and varied

perspectives individuals with hoarding behaviours experience. Further research is required to corroborate the review findings and to build upon the growing body of evidence into understanding individuals' lived experiences of hoarding behaviour. This would help to reduce the negative impact on the individual, their family and community. Furthermore, by continuing to explore individual experiences, this can go hand-in-hand with research conducted into professional experiences of working with hoarding, representing a collaborative multi-dimensional approach.

The review identified that for individuals seeking help, they were mistrustful of services and struggled to disclose their difficulties. Individuals that did seek help felt that services did not listen and they were being judged for their behaviour and experienced feeling ‘cast aside’. Currently, no research has investigated NHS mental healthcare experiences of working with service-users displaying hoarding behaviours, thus leading into the current treatment of HD and the rationale for the current research.

1.4 Current Practice in the Treatment of Hoarding Disorder

Literature highlights that HD is notoriously difficult to treat and staff working with hoarding patients rate service-users as having worse insight into their condition than non-hoarding OCD patients, which results in increased intervention-interfering behaviours and reduced adherence to treatment (Tolin et al., 2012). Due to the complexity hoarding poses to the individual, their family and the community, a wrap-around community response with an emphasis on coordination of care has been highlighted as necessary (Bratiotis et al., 2011).

Countries including Canada, USA, Singapore, and Australia have adopted popular approaches, including community taskforces and case management, to respond to difficulties associated with hoarding (Bratiotis, 2013). These approaches are often coordinated by social service staff to support vulnerable populations, who might require longer intervention time and an opportunity to develop rapport with professionals (Bratiotis et al., 2019). Taskforces

aim to coordinate hoarding services across providers, conceptualise hoarding from multiple perspectives and allow for sharing of information, ideas and support (Bratiotis, 2013). Crucially, Bratiotis et al., (2019) in Canada, highlight the importance of professional diversity to address the issues that arise from hoarding in the community (e.g. housing, fire, and health services) and how interventions are best delivered collaboratively amongst professionals with different knowledge and skillsets. Further research is required to explore which elements of taskforces are effective and achieve positive outcomes for hoarding clients.

Although, this approach appears beneficial to support hoarding populations, there are several barriers. The first barrier highlights the importance of agencies arriving at a shared understanding of hoarding to develop a unified approach to treatment. A lack of clarity amongst colleagues was uncovered by Koenig and colleagues (2013) in the USA, who stressed the need for increased knowledge in this area. Furthermore, Bratiotis and Woody (2020) reflect that amongst mental healthcare staff, very few clinicians viewed hoarding as a multi-agency concern. Secondly, when translating taskforce principles to the UK, they are incredibly resource intensive. This would be challenging to implement in the NHS and other health and social care systems, which are largely publicly owned, resource deficient and under-funded, compared to the countries listed above (Haighton et al., 2023).Therefore, the principles of taskforces can be useful but may not fully equate to the UK system.

In the UK, Haighton et al., (2023) conducted focus groups with key stakeholders from an existing hoarding research group, who were involved in supporting hoarding populations. These included representatives from English universities, local authorities, housing organisations, emergency services, social care and NHS mental health services. By consensus, organisations were largely focussed on decluttering, eviction and legal action to resolve hoarding in their communities, despite the notion that these approaches were extremely traumatic for hoarding individuals. Housing stakeholders felt that without

identifying the root cause of the hoarding, people will return for support, ultimately resulting in them being passed around between services. Engagement with mental health services was deemed difficult due to restrictive referral pathways, meaning that multi-agency, collaborative working was challenging. Stakeholders worked together to suggest that a 'psychology led multi-agency model' for people living with hoarding behaviour would be most beneficial and therefore therapeutically driven. This is corroborated by Caiazza et al., (2018) who propose such a model for use in the UK, with a suggestion that hoarding-related concerns could be addressed by specialist 'hoarding-specific teams', where the multi-agency treatment plan is led by psychological intervention. However, acceptability of such approaches is yet to be explored, with a lack of consistency and universality of processes across agencies (Caiazza et al., 2018).

Bratiotis et al., (2019) highlighted that few mental health providers have the relevant expertise to provide treatment for hoarding (Bratiotis et al., 2019) and due to funding limitations, mental health services are not available to provide support (Koenig et al., 2013). Multiple professional disciplines play a role in supporting the practical, physical, and mental health needs of a person who is hoarding. However, there is limited research into the specific role and experiences of mental health staff and services working with HD in the UK. Furthermore, the limited studies that do explore staff experiences are usually focussed on those who work with older adult hoarders (Ayers et al., 2015) or are based outside of the UK (Haighton et al., 2023).

One recent UK-based mixed-methods study collated the experiences of mental health professionals working with older adults with HD and identified that mental health staff had limited skills and knowledge about HD (Tinlin, 2022). The findings revealed further complexities of working with hoarding, including added considerations with assessment,

formulation, treatment, the therapeutic relationship, and multi-agency working. The study was limited by using an online survey platform, due to Covid-19 restrictions.

A further UK-based study conducted a two-phase mixed methods design, focusing on the multi-faceted nature of inter-agency working with people with HD (French et al., 2022). Phase one looked at quantitative levels of change across professionals' understanding and confidence of working with HD following participation in a hoarding conference, which incorporated training and cognitive behavioural ideas. A qualitative content analysis then investigated professionals' perceptions of improvements that could be made to service-provision. They found that for professionals who attended the multi-agency conference, there were improvements across levels of confidence and understanding when treating hoarding. This indicates the beneficial effect multi-disciplinary training can have on supporting professionals' confidence and understanding of hoarding. Phase two highlighted a range of suggestions for how to improve services from the perspective of hoarding individuals. These included improving understanding of hoarding, improving resources, and improving multi-agency working. The study concludes that further research should focus on how multi-disciplinary working may be of benefit to people with hoarding problems.

Finally, McGrath et al., (2024), a study included within the literature review presented above, found that individuals with HD experienced barriers to accessing NHS support, including falling between a 'gap' of service-provision, by either being too complex or not meeting other service-thresholds. They reported a 'poor-fit'- between their perceived needs and what support or interventions were available via the NHS. While for others, the ambivalence felt towards change was intertwined with trusting professionals and overwhelm at the prospect of discarding. The authors highlight how exploring the role of the therapeutic relationship with hoarding populations in delivering treatment would be beneficial to improve service engagement.

1.5 NHS Mental Healthcare Staff

Within the NHS, the role of mental healthcare staff is vast and varied. NHS England (2025) describes mental health practitioners as providing integrated models of primary and community mental healthcare to support children, adults and older adults with severe mental illnesses to live well in their communities. Evidence suggests that following the Covid-19 pandemic, there have been sharp increases in symptoms of anxiety and depression within the general population, compared to pre-pandemic levels (Daly & Robinson, 2021), and NHS staff are under competing pressures to respond to the national growing mental health need (NHS England, 2025). Therefore, the current context of the NHS is resource-deficient, with difficulties associated with funding and workforce shortages (Jefferies et al., 2024). The National Centre for Social Research's British Social Attitudes 2023 survey describes the NHS as being in a continual state of crisis since the Covid-19 pandemic, with overall public satisfaction of the service falling to 24% in 2023 (Jefferies et al., 2024).

NHS mental healthcare staff typically form multi-disciplinary teams (MDT), which aim to bring together healthcare professionals from various fields to support care planning and provide care for patients (Bháird et al., 2016). Staff that would generally support the needs of service-users with hoarding behaviour include Mental Health Nurses, who tend to the biopsychosocial needs of individuals experiencing mental health challenges (Gournay, 2021 cited in McShane et al., 2024) and to provide out-reach, case management, education and advocacy to the hoarding population (Fleury et al., 2012). Additionally, Social Workers support the environmental and health-related risks associated with hoarding (McGuire et al., 2013). Occupational Therapists (OTs) are interested in 'a person's health and wellbeing through engagement in meaningful and purposeful occupations' (Clarke, 2019, p. 6). They consider hoarding to have a detrimental effect on an individual's wellbeing, as the home is no longer serving its intended use, therefore hoarding acts as an occupational restriction (Clarke,

2019). Clinical Psychologists and Psychological Therapists provide evidence-based practice for hoarding behaviour using assessment, formulation, intervention, and evaluation. Their role is to also support MDT colleagues by providing training, supervision and consultation (BPS, 2024). Other professional disciplines, including psychiatry, are also involved in the care of service-users presenting with hoarding behaviours by providing treatment, including diagnostic assessment and medical evaluation (Millen et al., 2017).

1.6 Rationale for Current Study

Following from Tinlin's (2022), French et al.'s, (2022) and McGrath et al.'s, (2024) valuable work and suggestions for future research, the purpose of the current thesis is to qualitatively explore the experiences of NHS mental healthcare staff working with service-users displaying hoarding behaviour and HD. The term 'service-user' will be used throughout to represent individuals living with hoarding behaviour who have accessed NHS mental health services. The use of this term will be explored further in chapter two.

The study will attempt to build upon previous work and address methodological limitations, including the past use of survey data and lack of individual interview data (Tinlin, 2022). The study will aim to explore mental healthcare staff experiences of working with adult service-users across the lifespan and not just with the older adult population. It is hoped that the findings will aid greater understanding of hoarding, equip staff and increase their confidence to treat and respond to the needs of those living with HD effectively. This intends to inform NHS service provision to support the needs of service-users, and reduce the potential barriers to accessing help via NHS services, as outlined by McGrath et al., (2024). Implications will also be considered to inform UK service-development, policy and practice.

Chapter Two: Methods

2.1 Chapter Summary

This chapter will outline the methodological process conducted throughout the research, with justification for the qualitative paradigm. Ontological and epistemological positioning will be explored, with support for the critical realist stance. The researcher's positionality is presented and is later reflected on in chapters three and four. The recruitment procedure is outlined, with data collection occurring between September 2023 and September 2024. Reflexive thematic analysis was used to analyse the fifteen semi-structured interviews following Braun & Clarke's (2022) six steps. Ethical considerations and plans for dissemination are then discussed.

2.2 Justification for Qualitative Methodology

In psychological research, quantitative methods have been the predominant choice of methodology, with reliance on experimental and correlational techniques to test theory (Gelo et al., 2008) with research aiming to understand the relationship between prescribed concepts (Marshall & Rossman, 1999). In recent years, qualitative methods 'regained their foothold' within psychological research, challenging the (post)positivist empirical research design and practice, which previously dominated (Braun & Clark, 2013, p.7). Qualitative methods are concerned with the interpretation of personal and subjective experiences (Carter & Little, 2007) and aim to generate knowledge grounded in human experience (Sandelowski, 2004).

The current study utilised a qualitative methodology, which aligned with the overall study aim of investigating the experiences of NHS mental healthcare staff who work with hoarding behaviour. Gathering participants' perspectives and meanings allowed for a rich and deep understanding of hoarding through the lens of mental healthcare staff (Braun & Clark, 2013).

2.3 Philosophical Paradigm

The sections below will aim to outline the philosophical paradigm the research is grounded in. Within the current qualitative research methodology, it is important for the researcher to be transparent in how they understand reality, as this will strengthen the rigour of the research (Willig, 2013). Howell (2013) posit that ascertaining the ontological and epistemological positions is crucial to confirm that the research methods being used, align with the philosophical foundation.

2.3.1 Ontology

Ontology refers to "the branch of philosophy which deals with the nature and structure of reality" (Guarino et al., 2009, p.1), which more simply states that "ontology is about what it is that we think we can know" (Braun & Clarke, 2022, p.166). It is important for researchers in social sciences to acknowledge their ontological and epistemological positioning, as this provides their understanding of 'reality' (Guba & Lincoln, 1982), and influences research methodology (Guba & Lincoln, 1994). Ontological positions are on a continuum, with realism at one end, asserting that there is an observable reality, which can be accessed via objective research (House, 1991; Braun & Clarke, 2013). Relativism, at the other end, proposes that there is no singular reality, rather multiple socially constructed realities exist (Fletcher, 1996; Braun & Clarke, 2013).

Central on this continuum is the critical realist stance, which sits between realism and relativism and combines the notions of both positions. It understands that "the world is theory-laden, but not theory-determined" and it "does not deny that there is a real social world we can attempt to understand or access through philosophy and social science" (Fletcher, 2017, p182). Critical realists acknowledge that the truth exists, but this is context dependent and shaped by human experience (Braun & Clark, 2022).

2.3.2 Epistemology

Epistemological positioning, closely linked with ontology, is concerned with the theory of knowledge, namely "how, and what, can we know?" (Willig, 2013, p.4). It aids the process of knowledge conceptualisation by understanding what reality is (Grix, 2018) and it broadly aligns with the ontological positions discussed (Braun & Clarke, 2022). A realist ontology offers a (post)positivist epistemological framework, where reality exists independently of human efforts to know and understand it (Burr, 1998). Here, a researcher's role is to collect the data; however, they do not influence knowledge production (Willig, 2013). A relativist ontology closely aligns with the multiple constructionism epistemological positions, which aim to produce, rather than reveal knowledge (Braun & Clarke, 2022). Constructionism would argue that there is no one truth and knowledge is formed by how we come to understand it (Braun & Clarke, 2013).

2.3.3 Research Paradigm

The philosophical orientation of the researcher, inclusive of their beliefs and values, combined with ontological and epistemological positions informs the present research paradigm (Braun & Clarke, 2013). A critical realist position has been utilised for the current study as it provides a scientific alternative to both (post)positivism and constructionism but incorporates methodological aspects of both ontology and epistemology in its approach (Fletcher, 2017). Critical realism is not linked to a specific methodology (Fletcher, 2017) and it "does not advocate for an absolutist epistemological position" (Farasoo, 2024, p.123). This is due the ongoing philosophical debate that views critical realism as attempting to avoid the epistemic fallacy that reduces ontological questions to epistemology (Albert et al., 2020).

Therefore, critical realism aligns with the research question and the understanding of hoarding behaviour the researcher wishes to achieve. For instance, hoarding behaviour is a 'true reality' that exists within NHS mental health systems, but mental health staff will all

hold differing meanings about this presentation. Therefore, the critical realist stance allows for different subjective interpretations about hoarding behaviour, which are derived from multiple social contexts and backgrounds.

2.4 Design

Ethical approval was obtained by the University of Essex and the Health Research Authority (HRA) and the details are outlined below in 'procedure'. Individual semi-structured interviews were conducted between the researcher and participant due to their suitability in gaining insight into experiences of working with hoarding behaviour, which aligned with the current research question (Braun & Clark, 2013). Reflexive thematic analysis was the chosen method for data analysis, and critical realism aligns closely with its assumptions (Braun & Clarke, 2022). It highlights that a reflexive researcher is fundamental to this approach, with the researcher offering transparency throughout the analytic process and reporting of the study (Braun & Clarke, 2019). The researcher has therefore positioned themselves as a 'questioning researcher' situated within the research process to ensure reflexivity (Braun & Clarke, 2022, p.5). The researcher was able to reflect on their dual role as a student researcher and as a NHS mental health professional, which was particularly important due to the research aim. This is explored further in the researcher's position statement below.

2.5 Researcher Position Statement

In line with a critical realist stance and with the application of reflexive thematic analysis in the current study, it is essential that the researcher reflects on their own positioning within the research. Reflexive thematic analysis values "a subjective, situated, aware and questioning researcher" who can critically reflect on their role in research practice and process (Braun & Clarke, 2022, p.5). The researcher adhered to keeping a reflexive diary

throughout the duration of the research process, which is presented here, and in chapters three and four. Writing the diary continually required the researcher to ask questions of their assumptions and biases, in the hope of achieving a nuanced and transparent account of the reflexive thematic analysis process. Please see diary reflections below.

I am a 29-year-old white British female and a trainee clinical psychologist working in NHS mental health services in the UK. Before my clinical training, I completed an undergraduate degree in psychology and a master's degree in clinical psychology and mental health. Both experiences were the starting point of my journey into psychology and my first exposures to research. My undergraduate and master's degree research projects were both quantitatively driven, with little option to complete qualitative research. The curriculum was dominated by quantitative approaches and 'the scientific method' was at the core of my learning. Since working within the NHS, I have gained more 'real world' experience and I can see the value of investigating the fluid relationship between people and their context, which aligns more to me as a clinician and a researcher.

Prior to my clinical training, I worked as an Assistant Psychologist where I could see my academic learning in practice. While working in a community mental health team (CMHT), with varying mental health presentations, I had some indirect exposure to service-users' presenting with hoarding behaviour. These referrals were rare; however, I was intrigued about how the staff and service would respond to their needs and provide meaningful treatment. During this time, I worked more closely with individuals who had a diagnosis of Borderline Personality Disorder (BPD). I thoroughly enjoyed this work and I was well supported through clinical supervision and the MDT. Despite my positive experiences, this presentation evoked difficult emotions within colleagues and staff found the condition difficult to treat. I witnessed staff endure burnout due to competing pressures in the NHS and feeling ill-equipped to respond to service-users' needs.

When I first considered researching HD and started my early reading, I was drawn to my previous career experiences of working with BPD presentations, and how there were similarities between both presentations. Namely, they are both difficult to treat, they evoke difficult emotions amongst those providing care and are highly stigmatised by the public. These connections sparked my interest and motivated me to pursue this topic area to improve the evidence-base and ultimately help service-users with this presentation.

For full transparency, I have not directly worked with anyone or know anyone personally who presents with hoarding behaviour. Therefore, I view myself as an 'outsider' into the world of hoarding. However, I recognise that I am an employed NHS mental health professional who has worked in over eight mental health services. Therefore, I also view myself as an 'insider' into the culture and structures of NHS mental health services (Gallais, 2008).

As stated in chapter one, the term 'service-user' will be used to represent individuals living with hoarding behaviour who have accessed mental health services. I acknowledge that language, involving labelling groups of people, can be contentious; however, there is little agreement in the UK about how best to describe people accessing healthcare (Beresford, 2005). The term 'service-user' is what I am familiar with in my clinical work, and it has been in use for around 25 years. Despite its shortcomings, it can be seen to unify groups in solidarity (Beresford, 2005). Therefore, the term 'service-user' has been used.

Throughout the research process, I have reflected on my biases, assumptions, and judgements about hoarding presentations and my experience of being an NHS mental health professional. I hope this positionality statement has given a sense of transparency of how I have approached this research.

2.6 Procedure

2.6.1 Recruitment Procedure

Initial ethical approval was obtained by the HRA for four NHS mental health trusts in the Southeast of England on 30th August 2023 with the approval number 23/HRA/3378 (please see Appendix C for certification). Furthermore, the University of Essex Ethics Sub Committee 2 also approved the study on 1st September 2023 (please refer to Appendix D). An ethical amendment was submitted to extend recruitment to two further NHS trusts, one in the Southeast of England and one in the North of England. This was approved by the HRA on 10th June 2024 (Appendix E) and by the University of Essex Ethics Sub Committee 1 on 5th August 2024 (Appendix F). Therefore, a total of six NHS mental health trusts were approved for recruitment, which took place between September 2023 and September 2024.

The sampling method used to recruit participants was largely purposive to enable a selection of participants who were most appropriate for the study (Gill, 2020). A snowball sampling technique was also utilised when appropriate. The researcher intentionally approached NHS mental healthcare staff for participation due to their knowledge and experience of working with service-user(s) with hoarding behaviour. Once participants were identified, they were asked if they could highlight other staff who had worked with someone with hoarding behaviour. If appropriate, they would also be approached for participation, which enabled further selection.

At the time of the project, the researcher was employed by and had professional links with one of the participating NHS mental health trusts. Therefore, at the start of recruitment, the researcher attended an Older Adult CMHT meeting to advertise the study; four participants were recruited from this service. Full participant service-related recruitment details are outlined in Table 4 in chapter three.

Recruitment continued via the Research and Development (R&D) departments, within the six participating NHS trusts, emailing out the research advert to their adult and/or older adult CMHTs (please see Appendix G for the research advert). R&D departments also posted the advert onto their Trust intranet pages to gain the attention of all their employed mental healthcare staff. One Trust R&D department, at the researcher's request, uploaded the advert onto a private staff Facebook page. Links were made with the NHS trust in the north of England via the charity *Hoarding Helping Hoarders*. The charity coordinator put the researcher in contact with an NHS mental health trust to support with recruitment, which followed the same processes as other trusts, once the ethical amendment was authorised. The advert had the researcher's contact details attached and staff were encouraged to make contact via email if they were interested in participating or required further information. Eleven participants were recruited from NHS trusts in the southeast of England, and four participants were recruited from the north of England trust.

The email sent out to mental health teams and the trust intranet bulletin with the project advert, had a brief checklist of questions pertaining to the hoarding symptoms present within the service-user(s) they have worked with. The questions were based on Frost & Hartl's (1996) definition of hoarding, and staff needed to have considered these and found that they applied to the service-user(s) they had worked with before agreeing to participate in the research. These questions then served as a preliminary screening tool. The questions were: (a) does the person excessively acquire possessions and fail to get rid of them?; (b) are living spaces cluttered to the point that daily living is impacted?; and (c) does the person experience distress at the thought of discarding possessions?

2.6.1.1 Inclusion Criteria. Participants were included if they were a clinical NHS mental healthcare staff member who worked in a participating NHS mental health trust, either in the southeast or north of England. Staff taking part must have worked with at least one

adult or older-adult service-user (age 18+), while they were employed in their current or previous NHS service, who engaged with hoarding behaviour. Staff must have considered the service-user(s) in relation to the screening tool questions outlined in the advert, and the criteria needed to have been satisfied to proceed with the interview. Participants were required to speak English, however if a staff member who did not speak English communicated a request to engage with the study, then an interpreter would have been sought, however this did not occur. Participants must have been willing to engage and provided informed consent.

2.6.1.2 Exclusion Criteria. Participants were excluded if they were not employees of the participating NHS mental healthcare trusts at the time of taking part. Participants were excluded if they had not worked with at least one service-user who presented with hoarding behaviour and if the service-users did not meet the screening tool questions included in the advert. Furthermore, staff could not take part if they were not in a clinical role; admin and other non-clinical roles were excluded as it would be unlikely for them to work in a therapeutic capacity with hoarding service-users. Clinical staff experiences from a range of disciplines were prioritised in line with the study aim. Participants wishing to share their experiences of working with service-user(s) with hoarding behaviour under the age of 18 were also excluded.

2.6.2 Research Procedure

Once the staff members expressed an interest to the researcher to participate in the study, the researcher confirmed that the screening tool questions were sufficiently satisfied, and the inclusion and exclusion criteria were met. Informed consent was then obtained from each participant, please see Appendix H. Furthermore, a participant information sheet was also provided (Appendix I). The researcher offered the opportunity to participating staff

members to view the interview schedule ahead of the interview to prepare (Appendix J). If participants requested this, then the schedule was also sent.

Individual semi-structured interviews were chosen as the method of data collection. This was to ensure that rich and detailed data was collected about staff members' individual experiences and perspectives on hoarding behaviour. It also enabled researcher control to ensure that useful data emerged (Braun & Clarke, 2013). Other methods of data collection, including focus groups were considered, however focus groups would not allow for in-depth follow-up of individuals' experiences, and can easily become 'off-topic' (Braun & Clarke, 2013). Therefore, conducting interviews was deemed more appropriate to meet the research aim.

Once informed consent was obtained, an individual meeting was set up at a time convenient to the staff member, which was organised in an initial exchange via email between the researcher and participant. Participants who worked for the five NHS Trusts in the southeast of England, local to the researcher, were asked their preference of where they wanted the interview to take place, namely in-person or online via video-call technology. All participants opted for their interview to take place remotely, specifically using Microsoft Teams (MS Teams). All interviews were recorded using video-call recording technology with the consent of the participant. The transcripts followed an orthographic style, where the spoken words of participants, and other non-semantic observations, including pauses, tone of voice, and volume were recorded (Braun & Clarke, 2013). The researcher also took written notes to aid with reflexivity and the analysis process.

At the start of the interview, the researcher confirmed with the participant if they were in a confidential appropriate space. Informed consent and debrief procedures were reiterated. During the interview, which was made clear in the participant information sheet, participant demographics were clarified, these were the participant's name, age, sex, ethnicity, job role,

and their specific experiences of working with service-user(s) with hoarding behaviour. Participants were asked not to name the service-user(s) they have worked with, and if necessary, they were asked to use pseudonyms to protect service-user confidentiality. Service-user confidentiality was upheld by all participating staff.

At the end of the interview, the researcher provided an opportunity for the participant to add any further details to their account, to ask questions, give feedback on the interview process, and they were thanked for their time in completing the interview. Interviews lasted for no longer than one hour, or they were ceased earlier due to interview schedules being completed and data saturation achieved. All interviews lasted between 45 minutes and 1 hour.

2.7 Participants

Fifteen NHS mental healthcare staff took part in the study, with 13 self-identified cis-women and 2 cis-men. Participant ages ranged from 29 to 67, with a mean age of 48 years old. Thirteen of the participating staff were white British, one person identified as white Other, and another staff member was black African. They were recruited from a range of mental health services including adult and/or older adult CMHTs, dementia and frailty services, adult psychosis services etc. They either: received an email with the research advert, viewed the advert on their Trust intranet page, were contacted through researcher connections, or heard about the study via word of mouth from other participating NHS mental healthcare staff. They had worked with between 1 and 15+ number of service-user(s) with hoarding behaviour. There were six mental health nurses, four occupational therapists, one clinical psychologist, one psychological therapist, two social workers, and two staff members with dual job roles, who participated in the research. Three further staff members expressed an interest in taking part; however, they did not respond to communication following the initial response from the researcher, therefore interviews were not arranged.

Please see Table 4 in chapter three for participant demographic information and a full description of participant characteristics.

Across interviews, participating staff discussed thirty service-users, with 13 females and 17 males, with an age range of 35-87 years old and a mean age of 61 years old. Please refer to Table 5 in chapter three for full service-user demographic information.

Due to the qualitative nature of the research, no formal sample size calculation was used for participating staff members. Braun and Clark (2022) discuss the difficulty in determining the right sample size, which captures richness, depth and complexity. Therefore, participant recruitment was based upon the degree to which 'information power' was achieved, which is described as information richness within the data set (Malterud et al., 2016 cited in Braun & Clark, 2022, p.28). The researcher suspected that to gather enough information for the subjective experiences of staff to be meaningfully captured, then 12-18 NHS mental healthcare staff would aim to be recruited. Braun and Clarke (2013) recommend that for a professional doctorate thesis using reflexive thematic analysis, which is classified as a 'medium project', 10-20 interviews would be suitable. Participants did not receive any payment or incentive for participating in the research.

2.8 Data Collection

Semi-structured interviews were selected to gather rich and detailed information through in-depth discussions with NHS mental healthcare staff regarding their experiences of working with service-user(s) with hoarding behaviour. Interviews enabled individual experiences and perspectives to be sought, while having an element of researcher control to produce useful data in this under-researched field (Braun & Clarke, 2013). In line with qualitative methodology, questions were open-ended to encourage participants to give detailed responses (Braun & Clarke, 2013). Despite having a prepared interview schedule, the researcher did not rigidly adhere to the question wording and was flexible in their approach.

It was important to give participants an opportunity to discuss ideas that the researcher had not anticipated to ensure responsiveness to their developing account (Braun & Clarke, 2013).

After the initial demographic questions regarding the staff member, there were a set of questions relating to the service-user(s) they had worked with, or were currently working with. These included the service-user(s)' demographics, reason for referral, and previous past support they might have received. If participating staff had worked with more than three service-users with hoarding behaviour, the researcher asked them to only discuss and provide demographic information of the three most salient cases, and to then discuss their experiences more generally throughout the interview. This was to ensure that interviews still kept a focus on staff experiences and to make sure the allocated time was not exceeded. Please see Table 5 in chapter three for full service-user demographic information.

Once this information was obtained, ten interview questions were asked. Example questions include "*what were your personal reactions to the hoarding behaviour?*", "*how confident as a mental health professional were you to work with and support someone with hoarding behaviour?*", and "*what are/were some of the barriers to working with someone with hoarding behaviour?*" For each question, prompts were available to the researcher to ensure an in-depth response from the participant. Please refer to Appendix J for the full interview guide.

At the end of the interview schedule, there was an opportunity for staff members to add anything to their interview that might have been missed and to ask questions. Participants were also offered time to debrief with the researcher, or to be signposted to sources of support if they felt this was necessary, however no participants required this.

2.9 Data Analysis

The qualitative interview data exploring NHS staff experiences of working with hoarding behaviour was analysed using reflexive thematic analysis. In line with the research

aims, reflexive thematic analysis can be used to understand the shared experiences and perspectives of participants and it uses these subjective experiences as the main source of data. The analysis followed Braun & Clarke's (2022) six steps of reflexive thematic analysis: (1) data familiarisation; (2) coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining, defining, and naming themes; and (6) writing the report.

Reflexive thematic analysis requires researcher subjectivity, which involves the researcher regularly reflecting on their own biases, assumptions, expectations and choices throughout the research process (Finlay & Gough, 2003). A reflexive researcher can be seen as a resource when completing analysis, because being a thoughtful, knowing practitioner, who actively involves themselves with the research, are all fundamental components to high quality reflexive thematic analysis (Braun & Clarke, 2022). Knowledge in reflexive research can be seen as being situated in, and shaped by, practices of knowledge production, including the practices of the researcher (Braun & Clarke, 2022). Therefore, the discipline and knowledge within which the researcher is situated is an integral part of the analysis process. Nowell et al., (2017, p.2) describe this as "the researcher becomes the instrument of analysis".

For the researcher to adopt reflexive practices throughout the analysis process, they initially reflected on and set out their positionality, which is outlined earlier in this chapter. The researcher also kept a reflexive journal throughout the research process and at every stage during the analysis to revisit, reflect on, and engage with meaning making.

The first step of analysis involved the researcher familiarising themselves with the data. The researcher personally transcribed 15 interviews from the video-call technology recordings, and became familiar with the data by actively writing, reading and re-reading each interview account, which resulted in a process of immersion. During this initial step, the researcher also wrote brief notes following each interview transcription about analytic ideas

and insights in relation to individual accounts and the dataset as a whole. At the point of transcription, each participant was allocated a pseudonym to keep the research and analysis anonymous.

In step two, the researcher worked systematically through the dataset identifying preliminary codes within the data that appeared relevant, interesting or meaningful to the research question (Braun & Clarke, 2022). NVivo 14 software was used to facilitate this process where codes were attached to segments of the data, and this was conducted broadly to eliminate the possibility of discarding useful data (Appendix K). Semantic codes capturing explicitly expressed meaning, and latent codes focussing on deeper, more implicit meaning, were included. In line with Braun & Clarke's (2022) guidance, coding was conducted twice to ensure rigour and to capture diverse meaning (Braun & Clarke, 2021; Braun & Clarke, 2022). During the first run, the researcher coded systematically down the data set, and on the second run the researcher started in the middle of the data set and worked 'backwards' and then went back to the middle and worked down. This was to ensure disruption to a familiar flow and to reduce order effects.

In step three, the researcher began generating initial themes. Braun and Clarke (2022, p. 35) emphasise that theme development is an "active process, whereby themes are constructed by the researcher, based around the data, the research questions, and the researcher's knowledge and insights". Themes can be defined as capturing more broad and shared meanings within the data, compared to codes, which generally capture a specific or certain meaning. Once coding was complete, the researcher made the decision to conduct analysis manually by hand, rather than electronically. Electronic codes were printed out and cut into individual strips to help the researcher explore clustered patterning across the data set, please refer to Appendix L for a visual map of theme generation. Multi-faceted ideas and concepts were captured, which contributed to the overarching themes. An extract of the

researcher's reflexive diary is provided below, which highlights the decision to use manual analysis.

> *Using NVivo software was hugely useful to help me assign codes to my data; particularly with the amount of data I had (15 transcripts). This process allowed me to systematically work through the data and to keep track of my codes and the transcript(s) they corresponded to. When I was faced with the task of developing the themes, I felt overwhelmed with the amount of codes I had created; therefore, I knew it would be important for me to do this by hand. I needed to be able to see all of the codes, and not scroll through a screen, to capture the essence of the data. I decided to print each code so that I could physically move them, which aided the process of seeing my themes come to life.*

Step four involved developing and reviewing the overarching themes constructed in step three. The researcher began by re-engaging with the coded data extracts and the entire dataset, which meant the initial clustering of themes could be reviewed. While holding the research question in mind, the researcher was able to reflect on whether the themes captured a core point with multi-facets in the data (Braun & Clarke, 2022). This step started the process of refining, defining, separating and discarding initial overarching themes and sub-themes to ensure they represented the codes meaningfully.

The fifth step required further development of the themes by naming and defining them. This process enabled the researcher to define the focus and lay out the boundaries of each theme, while capturing the rich essence of the data (Braun & Clarke, 2013).

The sixth and final step involved writing a coherent report, which represented the data. A diverse range of interview extracts with staff members were selected to illustrate accounts of the arguments being made in the analysis, and are presented in chapter three.

Overall, the reflexive thematic analysis was inductively driven, as the codes and themes were informed by the data the participants provided, rather than using a pre-existing framework, or theory-driven approach to the data (Braun & Clarke, 2013).

2.10 Ethical Considerations

The study obtained full ethical approval from the HRA and the University of Essex, as outlined earlier. Ethical issues that were considered throughout the research process included, participant consent, confidentiality, conflict of interests and power, risk to the researcher, security of data and quality assurance.

2.10.1 Participant Consent

Prior to interview, participants completed signed consent forms, which outlined the purpose of the study and related ethical considerations. These included explicitly informing the participant that due to the qualitative nature of the study, gathering fully informed consent can be difficult due to the unknown direction of the discussions. It was unlikely that the topics discussed would be particularly sensitive to the participants, however some sensitive areas that could have arisen included self-disclosure by staff members about their own and/or family members' hoarding behaviour. It was also considered that discussing the physical and mental health needs of someone who is hoarding might also be distressing for participants. To compensate for these issues, participants were offered the opportunity to view the interview schedule ahead of the interview to prepare, or to communicate to the researcher they did not wish to answer certain questions. Furthermore, staff had the opportunity to debrief with the researcher at the end of the interview, or be signposted to relevant information and support if necessary; however, no participants required this.

Due to participants being NHS mental healthcare staff, it was considered whether participants might have recently taken part in research. If they had, further time out of their clinical work might have been seen a burden or an inconvenience. This was explored with

participants at the point of recruitment. However, the researcher acknowledged that if staff had already taken part in recent research, then they would be unlikely to express an interest in the study.

2.10.2 Confidentiality

In the Participant Information Sheet, it was outlined that participant identifiable information, including the participant's name, age, sex, job title, and ethnicity would be collected. However, this information was removed at the point of data transcription, and a pseudonym allocated, therefore no identifiable information was reported in the write-up of the study. Direct quotations were used to help elaborate and demonstrate key themes that emerged from the data; however, all personal identifiable information was removed. Quotations were only used for the purposes of reinforcing results appropriate to the study, which kept participant information rich and authentic. Participants were also asked to protect the confidentiality of the service-user(s) they have worked with during the research process, and if necessary, asked to use a pseudonym.

2.10.3 Conflict of Interests and Power

In the current study, it was unlikely that the interests of the researcher would conflict with their duty as a healthcare professional, as the participating mental health staff were aware of appropriate routes of support. However, participants were offered the opportunity to debrief with the researcher following the interview, or they were signposted to relevant information and support if necessary.

The researcher carefully considered being in a position of interviewing someone they knew personally through professional relationships. When this occurred, this was discussed transparently with the participant before the interview took place, reminding them that they did not have to answer questions they do not feel comfortable answering and that they had the right to withdraw at any time. Braun and Clarke (2013) emphasise that it is perfectly

acceptable to interview someone the researcher knows personally, such as a work colleague, however it is important to consider that the relationship then becomes a 'dual relationship'. It was therefore crucial for the researcher not to use pre-existing relationships to pressurise staff to take part or disclose information in the interview, they were sensitive about their position and reflective of this throughout the recruitment process.

The researcher also considered the inherent power imbalance between a researcher and participant, due to the researcher trying to represent the voices and experiences of all participants. The research aimed to be inclusive of all willing NHS mental healthcare staff who wanted to engage, and the researcher considered this power reflexively throughout the recruitment, interview, and data analysis processes.

2.10.4 Risk to the Researcher

Risks to the researcher were minimal as interviews were held with NHS mental healthcare staff members, rather than service-users. Potential risks included participants disclosing distressing content about service-users, themselves, or their families. However, the researcher is a trainee clinical psychologist who is used to working in emotive environments and who was able to meet regularly with their supervising researcher to discuss their wellbeing.

Lone working risks were also limited as the researcher conducted all interviews online via video-call technology during working hours. If the researcher required support following an interview, then they would contact the supervising researcher. The researcher did not experience any psychological distress conducting the interviews.

2.10.5 Storage and Security of Data

Personal identifiable information of participants was stored on the consent forms and a database. This data included their name, job role, age, sex, ethnicity, and their NHS staff

email address. The consent forms and database were stored electronically on password-protected files on either a secure NHS Trust Laptop or University of Essex drive. Only the researcher and supervising researcher had access to these files.

Interviews were recorded via video-call technology, specifically MS Teams. These files were password-protected and appropriate access controls were in place, with only the researcher and supervising researcher having access. At the point of transcribing the audio-recordings, all personal identifiable information was removed and a pseudonym was allocated to each participant. Furthermore, when staff members discussed service-user(s) they had worked with, they were asked to use a pseudonym, which was also used for transcription purposes. Once transcription was complete, the audio-files were safely deleted.

At the end of the study, the data will be stored safely on a University of Essex computer for up to three years to enable the opportunity for publication.

2.10.6 Quality Assurance

Guba (1981) outlines four criteria qualitative researchers should consider to ensure high quality and trustworthy research. These criteria were thoughtfully embedded throughout the research design, analysis and writing up of the study to enhance the rigour of the findings. The criteria, and how the researcher approached each item, are outlined below.

1. ‘Credibility’ assesses whether the data is representative of participant views, and if the findings are plausible and trustworthy (Hannes, 2011; Stenfors et al., 2020).The researcher has justified the use of their chosen methodology and application of reflexive thematic analysis in the sections above. Stenfors et al., (2020) highlight that key markers for assessing the credibility of a study are the selection criteria used and whether the sample size is linked to the methodology. Due to the use of purposive sampling, which specifically recruited NHS mental healthcare staff with experience of

working with hoarding behaviour, 'insight and in-depth understanding' were generated (Patton, 2002, p.230 cited in Braun and Clarke, 2013). Furthermore, the recommended participant numbers adhered to Braun & Clarke's (2013) guidelines for professional doctorate theses' using reflexive thematic analysis, as outlined above in 'participants'.

2. 'Transferability' refers to how the study findings may be transferred to another setting or context (Stenfors et al., 2020). The researcher, provided as much detail as possible about the context within which the participants were recruited from, and how this shaped the findings, while maintaining confidentiality.

3. 'Dependability' ensures that the process of research is clearly documented, logical and traceable (Hannes, 2011). The researcher adhered to this by providing a clear write-up of the research process. They also kept a reflexive diary, which presented their positionality to aid transparency.

4. 'Confirmability' is the link between the data and the findings (Stenfors et al., 2020). The researcher used triangulation by seeking multiple NHS staff discipline perspectives (e.g. nursing, social work), to represent a comprehensive understanding of working with hoarding behaviour (Patton, 1999; Guba, 1981). The researcher, on the majority of occasions, presented quotations from at least two sources to support a claim in the findings (Guba, 1981). Furthermore, the researcher practised reflexivity by exploring their introspections and predispositions in relation to the data (Shenton, 2004). This is important as codes and themes are 'weaker or stronger' depending on the reflexivity of the researcher, and their engagement with the data (Braun & Clarke, 2022).

2.11 Dissemination

Due to the importance of disseminating research findings, and in line with ethical guidance, the research will be appropriately written up in a doctoral thesis. Following this, the researcher hopes to publish the results. Academic journals that will be considered for publication include the *Journal of Obsessive-Compulsive and Related Disorders*, the *Journal of Anxiety Disorders* or the *Journal of Clinical Psychology.* Similarly, it might be useful to consider publishing summarised findings within the *BPS Clinical Psychology Forum*. Conferences that can be considered include the *National Hoarding Conference* hosted by Hoarding UK and the *International Conference of Behavioural Addictions*. The researcher will also consider presenting the results at the University of Essex Staff-Student Research Conference 2025. Arrangements for these submissions will be made in due course.

Once published, it will be important to inform the participants of the findings, which will be in the form of accessible information sheets highlighting the key findings and conclusions of the study. If participants wish to read the full written-up study, then this will be made available to them. The aim of disseminating the findings is to create greater understanding and knowledge around hoarding behaviour, and to better equip staff by increasing their confidence to treat hoarding behaviour effectively, and thus adapt service provision at a local level, dependent on the findings.

Furthermore, the published findings should be shared with people who are living with hoarding behaviour and their communities. There are charities and forums, including *Hoarding UK* and *Hoarders Helping Hoarders*, designed to support the needs of people with hoarding behaviour. The researcher visited these webpages and forums, and unfortunately they observed a frustration regarding research within these communities. . Individuals with hoarding behaviour who had previously participated in research would rarely receive feedback or dissemination from the researcher’s findings. This is understandably frustrating;

therefore, the researcher will ask permission from the community to share relevant study findings, if appropriate.

Chapter Three: Results

3.1 Chapter Overview

This chapter will present the results of the current study. The demographic information of participating staff and the service-users they discussed will be provided. The chapter will then outline the five main themes and fifteen subthemes that emerged from the data. Verbatim quotes are used to support theme interpretations. Reflective notes, including observations made by the author throughout the interview, analysis and write-up process, informed by their reflexive diary will be shared at the end of the chapter.

3.2 Demographics

3.2.1 Participant Demographics

Fifteen NHS mental healthcare staff participated in the study, and their demographic information is presented in Table 4. Every attempt was made to keep participant information anonymous; therefore, only relevant details are presented.

Table 4

NHS Mental Healthcare Staff Participant Demographic Information

Participant	Age	Gender	Ethnicity	Job Role	Number of service-users*	Client Group & Service Context
Eleanor	53	F	White British	Mental Health Nurse	1	Older Adult, Dementia & Frailty service
Ruth	45	F	Black African	Mental Health Nurse	2	Older Adult, Dementia & Frailty service
Maeve	56	F	White British	Psychological Therapist	3	Adult, Addiction & IAPT services
Alice	43	F	White British	Mental Health Nurse	1	Adult, CMHT
Raymond	35	M	White Other	Social Worker	7	Adult, CMHT
Velma	49	F	White British	Mental Health Nurse / EMDR Therapist	1	Adult, CMHT
William	55	M	White British	Social Worker	2+	Adult, CMHT
Dakota	41	F	White British	Occupational Therapist	2	Adult, Inpatient
Nora	38	F	White British	Mental Health Nurse	3	Older Adult, Dementia & Frailty and Crisis services
Olivia	29	F	White British	Social Worker / CBT Therapist	4	Adult, CMHT & Psychosis Services
Grace	51	F	White British	Occupational Therapist	1	Adult, Psychosis Services
Freya	67	F	White British	Mental Health Nurse	4	Adult, CMHT
Juliet	53	F	White British	Consultant Clinical Psychologist	8-10	Adult & Older Adult CMHT
Chloe	54	F	White British	Occupational Therapist	15+	Adult & Older Adult, CMHT & Primary Care
Valerie	51	F	White British	Occupational Therapist	2	Adult, CMHT

Note. “*” number of service-users staff worked with displaying hoarding behaviour, "IAPT" Improving Access to Psychological Therapies, "CMHT" Community Mental Health Team, "EMDR" Eye Movement Desensitisation Reprocessing, “CBT” Cognitive Behavioural Therapy

3.2.2 Service-User Demographics

Participating staff discussed thirty service-users in the interviews. As previously outlined in chapter two, the demographics were recorded for up to three service-users per participating staff member and these were the most salient cases to the staff member. All service-users were under the care of mental health services; however, none had received a formal diagnosis of HD. Therefore, their comorbid mental health presentations were reported. To protect service-user anonymity, only the physical health presentations considered relevant to hoarding were included. Please note, there is missing service-user demographic data due to staff not being able to provide certain information. Please refer to Table 5 for full details.

Table 5

Service-User Demographic Information Reported by Participating Staff

	Current Age	Age at Onset*	Gender	Ethnicity	Client Group & Service Context	Referral & Mental Health Presentation*	Physical Health Status*	Descriptions of Items Collected*
Eleanor								
SU 1	87	-	M	White British	Older Adult, Dementia & Frailty	Memory assessment	Poor, frailty	Newspapers, food cartons, blister packs of medication
Ruth								
SU 2	74	-	F	White British	Older Adult, Dementia & Frailty	Concerns regarding dementia presentation	-	"Everything", food packaging, books
SU 3	72	-	M	White British	Older Adult, Dementia & Frailty	Concerns regarding dementia presentation	Poor, frailty (Care Home)	-
Maeve								
SU 4	71	-	M	White British	Adult, IAPT	Self-referral for low mood	-	Newspapers, paper, "no order to home"
SU 5	68	-	F	White British	Adult, IAPT	GP referred	-	Paper, newspapers, cat litter, collecting items from of skips, "no order"
SU 6	44	-	M	Black Caribbean	Adult, Addiction	Seeking addiction support	-	Gifts for children, "stuff", "no order"
Alice								
SU 7	72	55	M	White British	Adult, CMHT	Paramedics referred-delirium and memory concerns	-	Papers, newspapers, books, video tapes

Raymond								
SU 8	60	-	M	White British	Adult, CMHT	Already under care of service. Schizophrenia diagnosis.	-	Empty food packaging stacked "all over the house", boxes, old computers
SU 9	58	-	F	White British	Adult, CMHT	Already under service	-	Newspapers, personal items
SU 10	62	-	F	White British	Adult, CMHT	Already under care of service. Schizophrenia diagnosis	-	Wrapping and packaging, "belongings everywhere"
Velma								
SU 11	51	45	M	White British	Adult, CMHT	Already under care of service, PTSD and EUPD traits	Long-term health condition	"Rubbish", bottles, cans, appliances e.g. irons
William								
SU 12	61	-	M	White British	Adult, CMHT	Already under care of service. Schizophrenia diagnosis	Partially sighted	Ornaments, furniture, food packets, litter
SU 13	62	-	M	White British	Adult, CMHT	Already under care of service. Bipolar diagnosis	-	"Stuff", paperwork, "rubbish", ornaments
Dakota								
SU 14	62	47	F	White British	Adult, Inpatient	Mental health deterioration. Schizoaffective disorder diagnosis	-	Infestations under hoard, "rubbish", furniture, belongings, clothes, towels
SU 15	59	-	M	White British	Adult, Inpatient	Mental health deterioration. Bipolar diagnosis	Stroke, poor mobility	Books and paper

Nora								
SU 16	84	64	M	White British	Older Adult, Dementia & Frailty and Crisis	Mental health deterioration. Experiencing delusions and paranoia	-	"Clutter", books, vinyl records, ornaments, food (e.g. peelings)
SU 17	73	-	F	Indian	Older Adult, Dementia & Frailty and Crisis	GP referred. Experiencing delusions	Poor, frailty	Dried flowers, plants
SU 18	75	-	M	White British	Older Adult, Dementia & Frailty and Crisis	Memory assessment	Poor, frailty	"Clutter", books, possessions, tissues, paper
Olivia								
SU 19	45	-	F	White British	Adult, CMHT & Psychosis	Already under care of service. Experiencing delusion.	Carbon Monoxide poisoning	"Clutter", floor to ceiling of stuff
SU 20	46	-	F	White British	Adult, CMHT & Psychosis	Mental health deterioration. Experiencing paranoia	-	"Clutter", her children's stuff
SU 21	40	-	M	White British	Adult, CMHT & Psychosis	Carer support for low mood & anxiety	-	
Grace								
SU 22	36	-	M	White European	Adult, Psychosis	Mental health deterioration. Psychotic symptoms	-	Newspapers, books, rubbish bags full of waste, cups of liquid
Freya								
SU 23	68	28	F	White British	Adult, CMHT	Already under care of service. Paranoid Schizophrenia diagnosis	-	"Stuff", baby & children’s stuff, empty bottles, shoes and clothes

Juliet								
SU 24	57	-	M	White British	Adult, CMHT	-	-	Piles of things including books
SU 25	60	-	F	White-British	Adult, CMHT	-	-	Rotten food, children's clothes, furniture, incontinence products
Chloe								
SU 26	35	-	F	White British	Adult, Primary Care	-	-	"Extreme", impossible to access certain rooms
SU 27	70	-	F	White British	Older Adult, CMHT	-	-	"Extreme", impossible to access certain rooms
SU 28	58	-	M	White British	Adult, CMHT	Already under care of service	Long-term health condition	Books, CDs, DVDs, piled everywhere and up the stairs
Valerie								
SU 29	67	-	M	White British	Adult, CMHT	Mental health deterioration. Experiencing psychotic symptoms	Long-term health condition	Books, "rubbish", cardboard boxes, bags, jigsaws
SU 30	48	-	F	White British	Adult, CMHT	Mental health deterioration. Experiencing psychotic symptoms	-	Bags, post, clothes, "mess"

Note. “*” if known, "SU" Service-user, , "CMHT" Community Mental Health Team, "PTSD" Posttraumatic stress disorder, "EUPD" Emotionally unstable personality disorder, "IAPT" Improving access to psychological therapies initiative

3.3 Thematic Analysis

The analysis identified five themes and fifteen subthemes from participant interviews, please refer to Table 6. All themes created were from the perspective of participating staff members and to reiterate, no service-users displaying hoarding behaviours were interviewed. Although each theme aimed to be distinct for the purposes of presenting the findings succinctly, there are areas in which they overlap, particularly across subthemes within an overarching theme. Please see Appendix M for a Refined Thematic Map.

Table 6

Overall Themes and Subthemes

Main Theme	Sub-Theme
How Staff Understand Hoarding Behaviour: "The Stuff is Rarely the Issue"	The Onset of Hoarding
	Maintenance of Hoarding
	Ways of Understanding Hoarding
Staff Frustrations, Challenges and Systemic Constraints	Staff Expectations
	Challenges Faced by Staff
	"We're Dealing with People": Service Constraints
Treatment Approaches for Hoarding	Ambiguity Regarding Treatment
	Useful Ways of Working
	Multi-Agency Working: A Move Towards Specialist Services?
Updating Practice: Seeing Hoarding as a Diagnosis	Staff Role, Responsibility and Feeling Dissatisfied
	The Importance of Risk
	"Going it Alone": The Necessity for Training and Increased Awareness
Service-users' Experiences of Help	Stigma and its Impact
	The Journey of Accessing Help
	Facilitators of Helpful Support

3.4 Theme One: How Staff Understand Hoarding Behaviour: "The Stuff is rarely the Issue"

This theme captures how staff understand and make sense of service-user(s) hoarding behaviour throughout their clinical work. Three subthemes were created: *The Onset of Hoarding*, *Maintenance of Hoarding*, and *Ways of Understanding Hoarding.*

3.4.1 The Onset of Hoarding

Participants highlighted their perceptions of what led service-users to begin hoarding, which aided their understanding of the person and their behaviour. For many service-users discussed, hoarding was explored as co-existing with a significant mental health condition. Staff reported several reasons for the onset of hoarding, including service-users' experiencing loss or grief, traumatic life experiences, and having comorbidities including neurodiversity. Staff identified that hoarding behaviour often acted as a way of coping with these experiences.

Across accounts, there was often a reason why the hoarding had started, however these reasons were difficult to uncover if the service-user did not openly volunteer this information, therefore the onset was sometimes unknown by staff. Freya and Chloe helpfully demonstrate this process.

> *We all know there's a reason why this [hoarding] has started…you can't get to the root of it…I went back to look at her old notes to try and fathom it out myself. Where did this come from? What was that about? And that might make working with her a bit easier and maybe talking about some of those things. (Freya)*

> *If we don't address the root cause, we're only addressing the stuff…and the stuff is very rarely the issue, it's just a consequence of everything else. (Chloe)*

Several participants reflected that hoarding behaviour started when a person's mental health deteriorated, sometimes in the form of a breakdown or a response to a difficult life experience. Valerie noticed, prior to a service-user's mental health breakdown, they were able to maintain jobs and relationships, while Velma acknowledged that poor mental health and loss was a catalyst for hoarding.

> *She had a professional career…So, it [hoarding] wasn't always the way until she had the breakdown…But then after the breakdown the place where she was with her mental health? Yes, everything broke down…those life skills, ability to leave the house, contact with other people, including friends - people dropped off, dropped away out of her life. (Valerie)*

> *He's quite complex. He would have come to the service with definite abuse of alcohol, causing mental health…behaviours, but also underneath…is a lot of childhood abuse…the hoarding didn't start until his mother passed…that was about five years ago, so he hasn't hoarded all his life. (Velma)*

Staff commonly reported that service-users, with, and without significant mental health conditions, had often experienced loss. These losses were described as difficult to process and resulted in difficulty discarding possessions. Alice discussed an older-adult, and identified that the loss of his mum was a catalyst for keeping possessions. Valerie also discussed her work with 'Fred' (pseudonym), and highlights how loss and grief in various forms contributed to why he began hoarding.

> *He lived with his mum and then she passed away…because they lived in the same house…he started to hang on to stuff and didn't want to throw anything away… even in the kitchen there was empty bottles and stuff…he was like 'that's my recycling, I'll throw it away eventually'…he holds onto it for as long as possible…after his mum had passed*

away, he was in this house, on his own and… I personally think maybe he felt lonely, and the loss of his mum hit him hard enough that he didn't want to get rid of anything. (Alice)

There's a lot to be said about there being grief or loss...I think that's kind of key to it [hoarding]…He lost a lot, he's lost his life, basically his career, relationships…his health, his mental health, for years and years and years … there's all that loss…It's [hoarding] definitely…something about loss and grief…I think yeah, it's a big part of it [hoarding]. (Valerie)

Along with experiences of loss, staff reported that service-users had often been through traumatic life experiences, which led to the acquiring of possessions. Olivia helpfully reflects on a service-user's experience of trauma. Gaining this context allowed Olivia to have a better understanding of the hoarding behaviour. Chloe also discusses how trauma has played a role in the acquiring of possessions.

She'd had quite a lot of trauma…and she'd had, about 20 years prior, an experience of carbon monoxide poisoning, and it left her quite physically sort of disabled. She could kind of move and walk, but very slowly…that…significantly affected her functioning…her father, not that long after, had moved into her house and when he died, she then struggled to get rid of all his stuff…She went to the effort of explaining to me…why the stuff was there, where it had come from and I…got to know a bit of her previous trauma and life experiences that had made her how she was the way she was…she was able to…give me that bit of context that helped me…understand how she'd got to where she was. (Olivia)

With him…it's complex trauma from when he was, you know, he was raped as an adolescent, and I think it's his way of coping to have things around him, he feels safer. (Chloe)

Participants reported a number of mental health presentations that led service-users to enter services, which are outlined in Table 5. For almost every service-user discussed, none of their referrals were directly for support with hoarding as a mental health diagnosis. Most referrals were for support with other comorbid diagnoses and presentations e.g. schizophrenia, depression, bipolar. Raymond, a social worker in an adult CMHT queries HD as a diagnosis and posits that when another mental health diagnosis is present, hoarding is just a symptom. Ruth also suggests that hoarding behaviour is due to attachment with possessions, which is likely due to experiences of loss, which she does not consider to be a mental health issue.

> *It's [hoarding] usually a trauma response, and when it's not a trauma response, it's some other mental health condition manifesting or it's a situation they [service-user] can't cope with. It's generally one of those that I've noticed…you just treat it like that's what's happening and the hoarding is just like the symptom, instead of a disorder in its own right… I wouldn't call it a hoarding disorder, it's always a symptom of something else. (Raymond)*

> *These people [service-users] are trying to sort of soothe, or feel, or have a sense of belonging or longing, or there is attachment, they need to have these items…but then I don't think we should just class them all as having mental health issues. I think it might just be sometimes loss. (Ruth)*

Several staff noted that service-users often displayed neurodiversity, including autism spectrum disorder (ASD) presentations. For service-users, ASD often went undiagnosed, and staff reflected on the impact this may have had on the individual and the subsequent onset of their hoarding behaviour. Nora demonstrates this, and Juliet reflects on how hoarding might act as a way of creating distance from other people.

His sister suspected whether he had autism…when he was younger, he was a loner, black and white thinking, and had routine. If the routine went off it would put him off kilter. He was struggling more and more at work, they let him go, and when he could not maintain his independent routine, that's when his home environment became unmanageable...he just didn't seem to be able to function as he should and in came all of those books and studying. (Nora)

I do wonder if there's more people on the spectrum that may struggle with this type of difficulty [hoarding]. So, for example with this person, we've [mental health team] been talking about the possibility of ASD, hoarding/collecting, and OCD. So, I think for them there's a bit of a link with all three… I do wonder, then, whether the function of it [hoarding] is very much around keeping people at arm's length…social anxiety and awkwardness is lost then, because you can keep people at arm's length. (Juliet)

Due to the complex presentations and difficult life experiences service-users have endured, many of the participating staff reflected on how hoarded possessions can become a way of coping. Freya and Grace consider how acquiring and subsequently keeping items provided comfort and safety.

She goes to the charity shops and buys bags of stuff that can include, baby stuff, children's stuff. She told me…she's bought a Barbie doll to take to bed to cuddle. (Freya)

It's probably to do with attachment…he had clearly a very traumatic childhood…he's very estranged from his family, he has no one, really. He's very lonely…he needs to just keep things as a way of making himself feel safe…he gets very anxious about throwing things away, so that's sort of like trying to kind of manage that feeling of anxiety…I do think it's kind of to do with his experiences of being…pushed away and abandoned and 'thrown

away' potentially by his family. So, it's this…can't let go of stuff helps him feel safe. (Grace)

Finally, in combination with service-users' mental health presentations and life experiences, hoarding could have started due to having limited life skills. Maeve identifies that for service-users who had not been shown how to do things by their parents, perhaps due to limited exposure to media, or due to spending time in mental health institutions, their living skills were neglected. Velma also links a service-user's grief and the lack of coping with being unable to manage, which led to the start of hoarding.

We assume… that people know how to do it, and unless you've actually been shown, might be told …Bearing in mind they're [service-users] not living normal lives, they haven't had a life where perhaps they've been watching a film, TV, or reading or picking up [skills] in other ways, and certainly with the younger gentleman he'd lived a lifestyle which was chaotic…"where am I going to get my next meal from?"…drinking with groups of people who had similar problems. So not picking up anything from your peer network either. And the older gentleman never had friends, and neither did the lady from what I could tell, because I think she was institutionalised. (Maeve)

When Mum died, he just says…he just got all these papers sent through, whether they were to do with probation or to do with mental health, or his mum's estate. He just goes 'I just couldn't deal with it, I just put them all in piles and then piles started building up'…'I just couldn't look at it'…'I didn't know where to start'…'It just got out of control'. He doesn't say if it was a comfort or not, he just said he couldn't cope with looking at it. (Velma)

3.4.2 Maintenance of Hoarding

Across interviews, staff tried to understand why service-users continued to engage in hoarding behaviour, often with little motivation to make changes. This sub-theme makes links to how service-users' feel attached to their possessions, how hoarding behaviour aligns with their values, and that a variety of emotions were evoked when considering discarding and acquiring possessions.

In continuation from the previous subtheme, which indicated that hoarding behaviour acts as a way of coping, this subtheme suggests that service-users form emotional attachments to their possessions. Items have memories attached to them; therefore, they struggle to discard. Chloe and Dakota illustrate this from their experience.

> *The first room we decided to tackle was the bathroom because we thought that might be the safest in terms of emotional attachment to stuff, and I think we sensed really early on, that we were going to have severe difficulties when we would open a draw and there would be 30 different shampoos and she could justify an emotional attachment or a rationale to keep all of them. (Chloe)*

> *It was more the impossibility of trying to work out what was the most important, so for him it's all important and everything's got a memory attached to it [possessions]. (Dakota)*

It became apparent that staff perceived what service-users' valued had links to why they continued to hoard. For instance, keeping possessions acted as a way of being helpful to other people, Juliet reflected upon one service-user's experience. Olivia also considered how keeping possessions acted as a way of showing loved ones they cared.

> *Their formulation was very much around wanting to pass on helpful things to people, so…would therefore collect the newspapers to read them and, 'oh that sounds interesting,*

I can pass that on to such and such' or 'I might want to know that down the line, so I'll keep it', but literally have piles and piles of newspapers everywhere…The other bit of hoarding was all around craft stuff because she wanted to make stuff to sell it at charity events, which again kind of fits with that wanting to do things for the people, but then would kind of collect all this stuff and of course never do anything with it. (Juliet)

Her flat had a lot of sadness because a lot of it was her children's stuff that she'd lost contact with when they were quite young. So stuff when they were babies, children, they're now…adults and she's got all this children's stuff that she really couldn't let go of, because she's really worried that one day, when they get back in touch, they would say… 'you didn't love us' and she would say, 'well, I kept all your stuff for all this time'…that's why she was struggling to let go of it….I think it just symbolised…that period in her life, so she hadn't got rid of any of that stuff. (Olivia)

Staff acknowledged the range of emotions present within service-users when discussing acquiring and discarding of possessions. Distressing emotions including anxiety and aggression were evoked when staff explored their experiences of discarding. Ruth outlines the feelings an older adult with dementia experienced when their family removed items from their home. Whereas Juliet explores a service-user's feelings about the prospect of removing items from her home.

She then opened up and gave me the story about how she became aggressive with the family…they just walked in and said 'oh, there's so much stuff here' and they just started taking stuff out. She wasn't asked any questions. (Ruth)

I asked them [service-user] about if I came to your house with a bag bin bag and I was stood next to you and said, 'could you put some things in the bag?' She was like 'no, I can feel it in my belly, it's really anxiety provoking, I couldn't possibly do that.' (Juliet)

Feelings of joy and contentment were also reported when service-users described their possessions, and how acquiring made them feel. Ruth and Maeve give helpful examples from service-users they have worked with.

I began to understand that there must be some form of therapeutic relationship with these items…something about these items or the process of gathering them, or being able to see them, gives them the sense of…feeling very content. (Ruth)

The books are his joy...they are the most important thing in his life…as far as he's concerned, it's his house…it's like this is his comfort thing. This is the place he would retreat to from a young age…his books are his love… some kind of...sense of comfort or love. (Maeve)

Conflicting feelings regarding discarding were also reported by staff. Some service-users recognised that they wanted their situation and living circumstances to be different, but had difficulty implementing a strategy or progressing towards discarding. Eleanor and Chloe highlight these experiences.

I was thinking yes we are getting there and then two weeks later, it was just full of newspapers again …he really did want to try and do something about it and then he'd get to a certain point…then stop again…when we started to…interact with him really well, he really did try and start to do it. So it's as if he knew it wasn't a usual behaviour. But then he would…get to a stage where he would then just stop and regress. (Eleanor)

I know she's found that [discarding] really difficult because she hasn't let go of those things, even though she felt that she should. And …although she consented at the time, she might say, 'well, I was forced into it, you made me get rid of all that stuff that I needed'...a lot of clients will just describe it [hoarding] as a temporary issue and often will have a prepared reason as to why it's going on. (Chloe)

3.4.3 Ways of Understanding Hoarding

The final subtheme summarises the ways staff have tried to make sense of hoarding behaviour. Some staff likened hoarding to that of addiction presentations, which they had seen in their previous clinical work. While some staff considered how service-users' insight also played a role.

William identifies that one service-user displayed addiction behaviour in the past, and Maeve explores how individuals' with hoarding often want to make changes, but find it difficult, in a similar way to those with addiction behaviours.

He used to smoke, and he stopped smoking…used to drink, doesn't drink anymore, and he used to gamble a lot, but he doesn't do that anymore either. So his thing was purchasing…it was a real value to him that there's an outlet for him to buy these things really. (William)

They know perhaps they want to stop, they want to…they have every intention, like addictions, 'tomorrow I will do this', that doesn't come…I could see the parallels in the addiction cycle…and part of me felt quite hopeful about that because with a substance…you've got something that's really hard to work against…cocaine or an alcohol addiction. Whereas with hoarding, I think in my mind I was feeling like, oh, well, it's a behaviour so surely…behaviours developed, so they can change, right. (Maeve)

Insight, and whether service-users' viewed hoarding as a problem, was also considered a way of understating hoarding behaviour. Nora explained that for older-adult service-users accessing crisis services, it is unlikely they will view hoarding as a difficulty. Juliet also acknowledged that individuals who appear more entrenched in their hoarding behaviour, lacked insight that it was a problem.

> *My guys [service-users], they don't think there's anything wrong with it [hoarding], but then we have to remember, I'm working with people experiencing an acute, severe deterioration in their mental health. So it might be different for other teams. (Nora)*

> *I do find it really challenging because… I think it's more of a problem for everybody else and I think it can become so entrenched that they [service-users] don't see it…I think why would you walk over things every day or squeeze down corridors in your house to get past? But they…become oblivious to it and it becomes their normality. (Juliet)*

3.5 Theme Two: Staff frustrations, Challenges and Systemic Constraints

The difficulties and frustrations faced by staff working with service-users' with hoarding behaviour are captured within this theme. There are three subthemes, which explore staff expectations of working with this presentation, the challenges faced by staff, including barriers to their work, and finally service constraints, namely the boundaries set by the wider organisation.

3.5.1 Staff Expectations

Within this subtheme, staff expectations, biases and judgements, working with hoarding individuals are explored. Staff collectively felt that hoarding was notoriously difficult to treat, and progress was rare or took a long time. Maeve and Nora explore this.

In those cases…there hasn't been…the 'Stacey Solomon' end [organised living]. I'm hoping maybe they got that at the end…but that recognition that it is going to be highly unlikely…as a single sole therapist working with that sort of problem…you have to manage your own expectations about what you're going to be able to achieve and that it's not all your responsibility…You have a 50-50 relationship with the client and they're there to pull their weight and you're there to support them, and that recognition that it might take a few goes, perhaps. (Maeve)

It's really hard because seeing how they are when it's that ingrained… it's like years of therapy and support, if they're willing to work with it. (Nora)

Staff reflected on their own biases and judgements and how they managed these when working with hoarding behaviours. Important aspects of their work, which aided practice and created progress with service-users were considered. Olivia helpfully describes her experience of working therapeutically with a service-user. She was able to manage her own judgements by considering cleanliness as being subjective. Grace considers how judgements made by staff can be detrimental, and that being respectful is crucial.

You're always mindful about the judgements that you're making about people's lives and the way that they live and I think that comes very much into hoarding….like ideas of cleanliness, tidiness, it's all bit subjective…so working out where that line is and just being mindful of your own judgement and what you're putting on someone else. (Olivia)

I instinctively think I thought, ok, you've got to kind of be really delicate and you've got to be respectful and all of those things, as you would really in anybody's environment because…we can all be quite judgmental, but you have to like park that in these situations. (Grace)

3.5.2 Challenges Faced by Staff

Challenges staff faced working with hoarding service-users included the home environment, staff emotions, and service-users' motivation to make changes. One common experience reported by mental healthcare staff was that service-users' home environments were challenging to complete their therapeutic work, Olivia and Chloe give further details.

> *Just stuff cluttered from floor to ceiling…she had a tiny little walkway into her sitting room and she'd sit on a spot on the sofa and there was absolutely nowhere for you to sit as a staff member. So, most of the time, I actually just sat on the floor in this little walkway. That was how we kind of how we did our appointments. (Olivia)*

> *I find it [service-user homes] can feel overwhelming for the professional as well. It can initially prohibit interventions taking place because there's nowhere to complete the intervention if you want to do some work with someone within the home. (Chloe)*

Staff reflected on the emotions they felt while conducting visits at service-users' homes, and how this affected them. Valerie and Alice share their personal experiences.

> *That was really difficult because…I feel a bit funny standing up for a long period of time and I sometimes have anxiety as well…The house was very hot, very stuffy, I felt like there was no air and nowhere to sit, and I found it quite difficult with my anxiety. (Valerie)*

> *I felt quite claustrophobic because there was stuff floor to ceiling and there was no windows open, there was no air…I remember it being quite hot and quite stuffy…it just felt very close and very claustrophobic. (Alice)*

Another challenge, reported by staff, was that service-users often had very little motivation to make changes, which was a barrier to them engaging in support. William and Freya described service-users feeling content and comfortable with their living arrangements.

> *He was self-neglecting personal care. No kitchen facilities, no bathroom, no hot water, broken toilet…dodgy electricity. He's quite happy. (William)*

> *She's never complained about the hoarding or the state of the rooms…they're comfortable in the way they're living. (Freya)*

Even in situations where a service-user might like the idea of living differently, they struggled to implement change, Maeve describes this below.

> *We explored what it might be like to maybe live in a place where he had better accommodation, where he might be looked after in some way, and he seemed to quite like that idea but he had no ability to be able to bring it forward…When it actually, push came to shove, he would much prefer to stay with everything he knows…that's the hard bar, trying to gently coax somebody to make a change, after a lifelong way of living in a particular way, so hard. (Maeve)*

3.5.3 "We're Dealing with People": Service Constraints

This final subtheme explores the service constraints mental healthcare staff faced working with hoarding behaviour. Staff experiences of feeling undervalued and lacking time to support service-users' needs effectively are unpacked. Wider systemic concerns are explored, including the varying service provision for hoarding across teams.

William captures his frustrations with NHS service constraints and reports feeling undervalued in his approach to engaging a service-user. Alice also reflects on pressures she has received in her role while supporting a hoarding service-user.

Quite often you don't get much closure or appreciation for what you've been trying to achieve with somebody, mainly criticism of how long it's taken. I've just had somebody say to me…'why did this take 100 days this assessment?' I said, 'well, you're dealing with a person who's hard to engage with.' (William)

'He's had his medication review, he's stable, he's not a risk, that's it, step back. He's had a few sessions with a support worker, we now need to discharge back to GP'…We could have done so much more with this gentleman, if we'd have had the chance…it's very time focused, it's very specific…It's very much bang, bang, bang, bang. Whereas we're dealing with people…they're human beings… I think with him, if I'd have been able to work with him a bit longer…we might have been able to clear the place a bit quicker, got him to understand his behaviours, maybe do a little bit of CBT just to help with the thought processes around stuff. Just to make life a bit easier, but I wasn't able to do that unfortunately. (Alice)

Staff in care coordinator roles struggled to meet the needs of people presenting with hoarding due to service-imposed barriers, including their high caseloads and lack of time. Chloe, an Occupational Therapist, and William a Social Worker, both working as care coordinators in adult CMHTs demonstrate this.

Time is the biggest problem at service level because we tend to have big caseloads, you tend to plan visits to last an hour, you can't do anything in an hour. You really need to spend days and days and days with someone consistently, not like 'I'll come and see you for a day here'…the next time I'm going to get a free whole day will be in two months' time, that's not going to work. You need to have that kind of consistent approach with time. (Chloe)

Just appreciating that this is going to take time and he's [service-user] not on my time scale…there is part of you that thinks I need to be showing that we're making progress [to the service managers], but also very conscious of not jeopardising what we've established and making sure that basically each time I've seen him, it's following on from the last time. (William)

Staff demonstrated that compared to CMHTs, those in more specialist services have a different service-provision. Olivia explains that her ability to work with a hoarding service-user was more flexible in a first episode psychosis team, and Eleanor echoes this while working in an older adult service.

If you're relying on someone to help you go through [items], it needs to be someone that you trust and that you obviously feel understands and will help you make good decisions, and also understands how difficult that is, and I think we had that with her…We did spend a lot of hours doing that [helping her go through items], which if she was in a CMHT, she wouldn't have had that. So she was kind of lucky that she was with us in the first episode team where we had more time. (Olivia)

No, I didn't, no [feel constrained by the service]. I could go and see him on a regular basis, whenever. I got a good link in with a social worker and then eventually with the district nurses and the GP surgery. (Eleanor)

3.6 Theme Three: Treatment Approaches for Hoarding

Theme three represents staff experiences of treatment approaches. The interviews highlighted ambiguity around the best way to support service-users with hoarding presentations, and staff revealed ways of working that they perceived to be unhelpful. Staff

then illustrate useful ways of working with hoarding presentations, including a consideration for adopting multi-agency working and finding creative ways to support service-users.

3.6.1 Ambiguity Regarding Treatment

This subtheme captures how staff often lacked clarity regarding the best treatment approach to work with hoarding and comorbid mental health presentations. Some of the approaches that have previously been used are also discussed. Velma and Olivia, provide a sense of enormity at the task of tackling treatment for hoarding.

> *I don't feel I have anywhere near the right skills to even unpick this [hoarding]. You could end up down…1000 avenues, but would it be the right one to help him? Or is the hoarding, is it just a behaviour? Does he, we just need to think of some grief counselling and actually coming to terms with his mother passing, and would the hoarding then go? I don't know. (Velma)*

> *There's also so much other stuff that you're trying to figure out and sort out, which then kind of takes a lot of your focus so yeah, you do less of a targeted intervention because you just kind of mush it in with a bit of everything that you're doing. (Olivia)*

Staff proposed that there are two ways of approaching treatment options for hoarding, the emotional and practical ways of working with service-users. However, different disciplines felt more or less confident in implementing these. Velma, a Mental Health Nurse and EMDR therapist found implementing practical support to be incredibly daunting. Grace, an Occupational Therapist echoes Velma's experience and felt there was an absence of support for staff to seek guidance on practical help in mental health services. Whereas, William, an experienced Social Worker who is well versed in the Care Act Assessment application process and liaison with emergency services, felt that he needed support from Psychology colleagues to gain a greater understanding about a service-user's behaviour.

I come from one nursing side, but even the therapist side, I think sort of links together with the nursing side. I'm more equipped to do the emotional support and absolutely have zero skills in the practical support. In fact, to the point of being absolutely 'oh, my God what do I do? Where do I go?' (Velma)

Having to go through care package applications and…get a deep clean sorted out…it can feel a bit like jumping through hoops and there's not really a place in the mental health team that you can go… Just the practical stuff… that is probably what I would say is a barrier. (Grace)

When I first met him, I referred him for psychology; I thought I can't get to the bottom of this. I need help and he needs help to try and explore this. (William)

3.6.2 Useful Ways of Working

Within this subtheme, staff discussed the useful ways they have worked with, and would like to continue working with hoarding service-users and the wider systems supporting them. These include providing both practical and emotional support, and gaining an understanding about service-users' presentations. Staff suggested that a CBT approach would be beneficial, and they highlighted the importance of finding what motivates service-users to want to make changes. The subtheme ends by considering some of the creative ways staff have considered working with hoarding.

Leading on from the previous subtheme, staff felt that to achieve effective support, a combination of practical and emotional help is the best approach. Velma and Valerie demonstrate this.

What would be nice is…a sort of pathway…'this is what you do practically, and this is what you do for the emotional side'…it should be documented, one piece of A4 that says

'you need to submit a safeguarding, and you need to write to social care and yes, you're going to get it back, so then you're going to have to fill in these forms to go to panel'. Yeah, the practical bit. But then on top of that, you're going to need to…'put it forward to psychology for maybe some support'. Yeah…actually fully mapped out, not just the practical side, but also the emotional side. (Velma)

It's catering for what their needs are, and quite often they need to do something before they can get to that point where they can tackle it…I think it was very much that she was having the therapy alongside it [clearing support]…and that in itself enabled her to then…deal with…the physical stuff she was hoarding, she was going through the processing, mental processing, and then she was able to do the physical, 'ok what's this and where does it go?' (Valerie)

Ruth and Alice speak about their experiences of how important it was to gain an understanding of service-users' presentations, which was common across participant interviews.

It will be helpful in the end to get psychology, because I think for all these people the talking therapy is quite important because…if you engage them…they would be able to give you a bit more, and actually share the concerns and the anxieties, and unless you know what the anxieties are, you can never treat it. (Ruth)

The formulation would have helped because I wonder if there was maybe social anxiety in there, what else was hiding? (Alice)

The interviews highlighted how these treatment options can be explored with service-users to achieve the best outcome. Velma and Alice explored how a CBT approach, specifically consideration of thought patterns, might be useful to consider with hoarding.

A CBT approach to hoarding would be…'what is the instinct of why do I need that? And what am I going to do, and how does it make me feel and how to break that cycle?' Because actually we can do all the hoarding bits and all the practical bits, but actually have we broken the behaviour…the ultimate question is, is he going to go back to it…which of course we don't know...So, I do think it would be nice to have…even just if it was like a 12-week thing of CBT, but it was aimed at hoarding and it just targets, 'what's this? Why do we need to buy 5 irons?' I know they're bargains, but appreciating that there may be different avenues of thought, it's not just stuff. 'Why do I need new stuff? Why do I not get rid of my own stuff? And why do I need other people's old stuff?' They're all very different things, thought patterns. (Velma)

It's all that very well clearing stuff. But we need to change the cognitive behaviours, otherwise it's just going to keep happening, isn't it? It's happened before they cleared it out… it happened again and I'm like it's just going to keep going round in a circle if we don't change something. (Alice)

Interviews explored the importance of finding what motivates service-users to engage with services and treatment, and ultimately make progress towards change. Juliet and Valerie reflect on the importance of supporting service-users to find incentive for things to be different.

It's notoriously challenging and tricky to work with people with hoarding because… unless you can find a carrot to dangle that's going to motivate them through therapy, 'so if you weren't doing these things, what would you be doing with your time?'…unless you can find that incentive… She's aware that she's got a problem, she wants to make inroads into it. She doesn't want to leave her property for somebody else to clear…so that her sons don't

have to face that kind of enormous task at some point, and there's something quite humbling about that…here's somebody who struggled with this, but they really want to make a difference… That's what I was saying around trying to find the carrot for her, we've got the carrot…let's crack on. But you can't always find the carrot. (Juliet)

She's telling me about what she's done on her own… 'I've done it this way and what do you think of that? I've managed to clear.' And again, it was for her friends coming, she needed to clear the spare room to have somewhere where they could sleep, so she did that and she did that on her own. (Valerie)

Staff suggested creative ways of working with hoarding presentations, which perhaps are not being routinely implemented in mental health services. Nora is Mental Health Nurse with experience of working with older adults with dementia. She was curious about whether assisted technology would help to keep service-users safe while living at home.

I think it [hoarding] is just like working with people with dementia in that if you want to keep them at home, like turning off the ovens and things like that... especially for the older adults, an assisted technology route, like what technologies can you put in place to make it a bit safer? Because we obviously have care alarms…and where you could put like these plugs in a bath, so the bath would never fill up too much with water. So, if there are things along those lines, like something gets too hot, nope [turns off], or something's on it [oven], it's not even going to turn on. (Nora)

Valerie considered whether reasonable adjustments could be applied to service-provision for service-users displaying hoarding behaviours, and particularly for service-users with comorbid autism presentations.

Coercion doesn't work [into discarding]…you have to take his needs into account… and it's going to take a lot longer than perhaps our systems can cater for…We need to put that reasonable adjustment in place because these are his needs…neurodivergent needs.… We're not approaching it [hoarding] right, we need to be person-centred…and we need to give those reasonable adjustments. …He needs to meander…and he…goes down rabbit holes quite often. And when I think, with a lot of the professionals…they very much want to go in and then bam, bam bam, 'this is what we need to do and this is what we're going to do and you have to comply with that' and he is totally not compatible with how he needs to do things. (Valerie)

In theme one, staff members discussed the reasons why service-users started hoarding, which Maeve suggested was potentially due to limited life skills. Here, Maeve discussed how using a 'limited reparenting' approach might be beneficial to service-users who have difficulty completing day-to-day tasks. She explored this in relation to what she perceives to be a specialist hoarding team, which will be discussed further in the next theme.

Lots of disconnections within his own family life and from a young age, so never perhaps been taught to clean a toilet, to make a meal, just your basic…I would like somebody to come in and say, 'here's how we cook a meal, here's what we do when we want to go shopping'. I guess limited reparenting isn't it what they call it in schema work, limited reparenting…So, you've got someone that will help clear…somebody that can do that kind of slowly, so it's not rushed, you're talking about things as you're going on. (Maeve)

3.6.3 Multi-Agency Working: A Move Towards Specialist Services?

Some staff were aware of a move towards multi-agency working to support the needs of hoarding service-users, which Juliet, a Consultant Clinical Psychologist outlines below.

Freya, an experienced Mental Health Nurse also reflected on the shift towards multi-agency working, while Velma shared how much she values her relationships with MDT colleagues.

> *There's been so much around the complexity of it [hoarding] and needing to link up with other agencies in terms of the guidance that's out there…fire brigade, social services, councils…they reckon…the best approach is to have that kind of multi-agency kind of involvement. …A lot more came online about needing to…link into other agencies and work together. …That's going to need to be much more thought about seriously because it still tends to be a bit piece meal, on a case-by-case basis. (Juliet)*

> *When people were first referred into services years ago….it was more on the medication, getting them more stable so they didn't have hospital admissions…years ago, community staff had such big caseloads…they didn't have the time to then spend to look at what's going on…Now when people are coming into services, attitudes have changed, that if somebody's presenting and is hoarding, newly hoarding, new to services…I think people take more time now to look into what's that about, and we've got the clinical team psychologists, we're all in the same building…So, we've got different people we can go to. 'This is happening, what can we do about this?' (Freya)*

> *I am very, very fortunate to have such an MDT around me. I don't know how I'd do it on my own because I wouldn't have a clue. (Velma)*

The creation and implementation of a specialist hoarding service was considered one way of supporting service-users' needs effectively. Dakota helpfully illustrates the importance of team working. Maeve, in continuation from her suggestion of the limited reparenting approach outlined in the previous subtheme, and her coining of a specialist hoarding team as

a ‘dream team’ in the first theme, also demonstrates this. Despite Dakota’s hopes of specialist services becoming a reality within NHS services, she acknowledged it is unlikely to occur.

> *If there was a team that was going to help…it's having that time…it’s so time heavy, going and spending that time with somebody and trying to sort through things…how do you get more help to…get more time?… But in terms of the practical stuff of like we've got to try and sort through this, but to have the time to do that is, it's so difficult… if you had a team where that was their role, then that would be helpful. (Dakota)*

> *In my ‘dream team’…let's get a limited parent… so you've got maybe a different person each day and then you all gather on a Friday and chat about it, ‘how's it all gone?’... There hasn’t been an area where we get the ‘Stacey Solomon’ end [organised living]…but that recognition that this [change] is going to be highly unlikely as you're going in, unless you've got your ‘dream team’, of course, and you might have a bit more leverage to get there…without a ‘dream team’ behind you, you're not going to get an awful lot of shift…It's a lovely idea, isn't it? I know it's never gonna happen. (Maeve)*

3.7 Theme Four: Updating Practice: Seeing Hoarding as a Diagnosis

This theme highlights staff experiences of viewing hoarding as a mental health diagnosis, and explores key areas of enquiry to update practice accordingly. The three subthemes that will be discussed are *Staff Role, Responsibility and Feeling Dissatisfied*, *The Importance of Risk* and *“Going it Alone”: The Necessity for Training and Increased Awareness.*

3.7.1 Staff Role, Responsibility and Feeling Dissatisfied

This subtheme aims to capture the essence of how staff view their work with hoarding behaviours with explicit links made to their job role and satisfaction at work. Valerie and Raymond give insights into the uncertainty they feel within their role, and Raymond reflects

on how the guidance provided by the service changed regularly, which would make his role difficult.

> *While she was engaging with the psychologist, I wasn't sure what my role was with her, and I actually upset her once because I was thinking of taking a step back while she was doing that work, until she was at a place where she felt ready to deal with the house, and I didn't realise that she was capable of doing both at the same simultaneously. (Valerie)*

> *Sometimes there was a bit of uncertainty about who does what…different agencies need to talk to each other more and be much more on the ball about 'well, what's the agreement for? Who funds this, who funds that? Who do I need to speak to, to move this on?' … Sometimes even the people in our team wouldn't always know, and it would change on the go and then you have to do it differently, or again, so that could be the tricky bit. (Raymond)*

Staff reported going above and beyond in their role to support service-users. Olivia and Valerie report on their experiences of supporting service-users, which demonstrate how they have gone beyond their role as mental health professionals.

> *Me and the support worker ended up getting our marigolds [washing-up gloves] on and trying to clean her kitchen, just so that when she came back [from hospital] it was that little bit better and nicer for her to be in…we actually ended up getting her a house move and as part of that…she obviously had to let a lot go. …Again, we spent hours practically going through stuff, taking bags of rubbish out, getting things sorted.' (Olivia)*

> *His bin had burst in the kitchen and he can't bend down to pick it all up. So I was kind of there on the floor…and I was really glad that the gloves on that day. (Valerie)*

At times, staff felt sad and dissatisfied when service-users struggled to engage with support. Sometimes they showed an initial willingness to make changes, but then soon reverted to engaging in hoarding behaviours, leaving staff feeling deflated. Eleanor and Dakota demonstrate these feelings.

> *I was thinking yes, we are getting there and then two weeks later, it was just full of newspapers again, it's just…I don't want to sound patronising, I felt very sad because it was like he really did want to try and do something about it and then he'd get to a certain point and yeah, then stop again. (Eleanor)*

> *It's difficult if somebody doesn't want to engage with you or is engaging very superficially and you know that actually they're not going to do any of these things or listen really. So yeah, that could be hard, and…really sad. (Dakota)*

While for other staff, when progress was made, they often felt a sense of achievement to be a part of service-users' journeys and to witness their success with treatment.

> *I went to see him…to close [the work]….Working with him was really quite emotional…it's quite emotional…meeting with him, and the place is unrecognisable. So, the housing association have been able to get in and do all their repairs as well, that were outstanding. …And also a sense of achievement, just to see him…how happy he was. When I'd seen him that day when I was closing him…it was just so wonderful to see a result for him…he was genuinely happy, yeah, grateful for the support. (William)*

> *He had attempted to agree to a decluttering, but he never agreed in the past, and he only agreed towards the very end of me working with him the second time, which was really rewarding because I came to say goodbye when he had the decluttering company there…and the place was completely different. …He went from not even letting us see him*

at home at all, to actually, showing us it while it was being cleaned…that was brilliant. (Raymond)

3.7.2 The Importance of Risk

Across all of the interviews, risk regarding service-users' physical and mental health was discussed, as well as the clinical risk held by staff members. This subtheme highlights the various elements of risk that need to be considered and reflects the complexity of managing these risk issues. Risk was sometimes difficult to disentangle between risk associated with the person's comorbid mental health presentation, and risk due to the hoarding behaviour. Nora and Dakota helpfully explain how delusional thinking and a mental health deterioration can exacerbate the risk of hoarding in regards to fire and self-neglect, via poor food hygiene, in service-user homes.

She was referred in from GP highly concerned. Diarrhoea due to out-of-date mouldy food, delusional thinking that there was someone up in her loft. But…she wouldn't fully disclose what she was hearing or seeing, she had no insight into her mental health. All we could get from her was that 'nope food was ok to eat in any state, no matter if it smelt.' (Nora)

The fear of fire was huge…she used to hang clothes like all over the place and then there'd just be a candle underneath it.…Where she's been unwell, there was melted cassettes in the oven…I'm not saying this was to do with the hoarding, but there would be like buckets of water with like lots of just different objects and rotting things in there. …Health hazard wise, she was quite shocking and worrying from that point of view, and, like the fridge, everything was just liquefied…It's like, so bad, and yeah, just the worry. (Dakota)

Other risks to service-users included the potential for burglary, fires, and emergency services having difficulty accessing their homes, Alice explains. Olivia discusses how one

service-user might have breached their council accommodation tenancy, which had links to their mental health presentation, including paranoia.

> *I've never seen it that bad…the stuff's packed so tightly against the window, it cracked the window. It was quite frightening because that makes him vulnerable because anyone could have broken in, and also the fire risk, all that paper. …Fire Brigades can do a risk assessment and fit fire alarms in the community and I asked him to do a risk assessment, but…he refused to let them in the front door…and obviously if you're unwell and they [paramedics] need to get a stretcher in, they never would have done it. (Alice)*

> *She's obviously in Council accommodation, she was really paranoid…so whenever they tried to come in and do stuff, it was always really challenging. There was always that worry you have when people are…in Council accommodation about whether they're in breach of their tenancy, and trying to navigate those kinds of issues. (Olivia)*

An important element when considering risk is how staff felt about managing this level of complexity in service-users' presentations. Dakota, an Occupational Therapist reflected on how she felt coercive when discussing risk with a service-user who was an inpatient on a psychiatric ward and wanted to go home.

> *She did agree that some of it was dangerous…but she would always downplay everything…'you're making a fuss of nothing, it's fine. All right, I'll take the washing down, put the candle away.'…But otherwise, it was 'this is a big fuss over nothing'. 'But I want to go home, so I have to agree'. It's that feeling, yeah. (Dakota)*

For Velma, she felt powerless to the risk associated with hoarding presentations, and when asked by the researcher if she felt vulnerable as a professional in relation to risk, she answered, yes.

It's quite a powerless position to be in when you actually think of the risk and the fact that safeguarding are now telling us 'you must do all this if you hear of hoarding', which means they're taking it quite seriously. ...I think yes…the risk is so out of everyone's control, including his. It's just an innocent fire risk, where in a normal home…it might be a small fire, but because there is so much stuff, it all goes [up in flames] and it is then uncontainable. (Velma)

3.7.3 "Going it Alone": The Necessity for Training and Increased Awareness

Across all interviews, staff communicated that there has been a lack of training and awareness about hoarding in their work. This subtheme explores the impact minimal training has had on staff. Considerations and ideas for what would be helpful to aid practice are outlined. Alice reflected on having little guidance and feeling alone when trying to manage service-users' needs. Nora also shares her lack of training experience and her hopes for more training.

It kind of feels like you're just going it alone…no one's actually said 'oh this is what happens, or this is available [for hoarding]' ...but you've got the powers that be [mental health services], 'this needs to be complete' [safeguarding referral]…And you're like, yeah, but I don't know how…it's all still quite a new process and…there's no support. (Alice)

Although they've decided to put it [hoarding] under mental health, they've given us no training about it. So, yes, we can look at the mental health and the symptoms, for right, is this mood related? Can we treat that? Is it psychosis?...We don't have the resources, the training or probably even the staffing to help for those years of support with the hoarding. So, I think it's quite difficult, how do you manage that in mental health? (Nora)

Staff shared that any available training tended to be out of date, or not extensive enough for them to feel equipped in their role of supporting service-users' needs.

I did my own reading because I was quite interested... There was a module that we did on hoarding in relation to OCD, where they look at the meanings of the objects… But…it certainly wasn't extensive. (Maeve)

I wouldn't say it was super extensive. There is some neglect training…I've not heard of anything extensive...It has come up…partially in training and sometimes you just get resources shared to you…So, it does come up. I think it could stand to come up more. We could stand to just have…'hoarding training'. (Raymond)

Ideas to aid practice where shared by staff, including considerations for their training needs, an increase in resources, a raised awareness about hoarding behaviour, ways of accessing support, and a call for more guidance. Grace shares ideas for what she would find helpful in training, including ideas to prevent further acquiring of possessions.

We need to understand things and not impose ourselves on them [service-users] and understand whether there are any dangers…I wonder if you are trying to go in there and clear somebody's house and make it all tidy, actually how is that going to be helpful? Is that going to be really detrimental and are you actually going to push that person into even more hoarding because they're feeling so out of control? Potentially…so, I think for us as professionals having an understanding around what psychologically hoarding is about…or do we even know?...Then that will hopefully help with how we… approach it in a sensitive way that isn't going to just reinforce the behaviours. (Grace)

In addition to this, staff wanted an increase of resources and guidance that could be shared amongst staff and service-users. Chloe, an experienced clinician who has worked with over 15 service-users displaying hoarding behaviours, believes that having workbook-style therapeutic support and an increase of guidelines about the best approach to work with hoarding would be helpful. Grace hopes to gain more understanding about treating hoarding.

> *A lot of our clients like material to work through, and a lot of our clinicians do as well. So we often use workbooks around anxiety management…workbooks around emotional regulation. And I think particularly with hoarding where so many clinicians, just feel absolutely lost, maybe some guidelines…how to start a piece of work, how to introduce things to people, would be really helpful. It may already be available...people aren't sure whether you're best to look at a whole system approach or you're best just to tackle a corner of one room...some guidance for staff around that and some resources that a staff member could use with a service user would be really helpful. (Chloe)*

> *Having a sense of whether there are any specific kind of do's and don'ts, what you shouldn't do, or what you should do…and if there is anything that we need to be more mindful of. (Grace)*

Alice highlights the importance of joint working by sharing resources and knowledge across services, which would help increase communication and understanding regarding service-users.

> *If you've got all of those together [fire brigade, social care], to just share what they know, and what's available, would be really helpful, because otherwise it's a bit of a wild goose chase. You go on the internet and it's like you're down the rabbit hole…Or you go, 'oh, that looks really good [resource], oh, it's not in this area.' And you're…back to square*

one… I think it would just open that communication a bit better… Sometimes I'll say to them [other services], 'oh, I found this online, that's really helpful'. Just sharing that stuff would be really good. (Alice)

Finally, staff urged for increased understanding around hoarding and its complexity. Ruth shared that until professionals can understand the reason for service-users' hoarding behaviour, it is difficult to meet their needs effectively. Valerie is hopeful for more research in the field, while William calls for raised awareness and the need for follow-up once service-users have been under mental health services.

I think until we as professionals can understand the reason for the diagnosis, what the reason is for the hoarding, and what it represents, we would never be able to engage with them [service-users] in a manner that meets their need and allows us to make change that would be beneficial. (Ruth)

Definitely, there needs to be more research…there needs to be more understanding and then there needs to be more training around it because…it's complicated, it's complex. (Valerie)

Training's always good…raising awareness of…the time scales that people need… don't go in and do a Care Act Assessment, identify all these issues and then not follow it up… it's not enough to do a plan. It needs either, you to follow it up or get somebody else allocated, a care coordinator…but to pretend that it's enough to do the plan and just leave them with it, it's not. I just don't think that's helpful at all to the person, all those people keep coming back [into mental health services]. (William)

3.8 Theme Five: Service-Users' Experiences of Help

The final theme shares staff perspectives of service-users accessing support. It explores the stigma faced by service-users, at a service and societal level, with queries around whether 'hoarding' is a helpful label and the impact of these debates. The theme then captures service-users' journeys to accessing support, and their perceptions of staff and mental health services. Potential facilitators of support are considered, with a focus on building trust and rapport in therapeutic relationships.

3.8.1 Stigma and its Impact

Service-users' experiences of stigma, from the perspective of staff, are presented. The subtheme illustrates the complexity of labelling the behaviour as 'hoarding' due to fear and judgement service-users' experience. Alongside this, staff biases and their personal reactions to hoarding behaviour are explored. All of which lead into the impact stigma has on service-users and their difficulty disclosing hoarding.

> *He doesn't even see it as hoarding…he says 'don't call me that [hoarder], it's a derogatory name'…But…it is derogatory, he just loves his books. (Valerie)*

> *I've picked up somebody…who, interestingly, has been referred for hoarding but refuses to call it hoarding. We've had to agree on 'collecting'. (Juliet)*

Staff reported that other agencies, including emergency services, lacked understanding about hoarding behaviour, which led to further judgement being placed on the service-user. Alice and Juliet share their views.

> *He [service-user] felt the paramedics came in and judged him straight away and obviously, because they raised the safeguarding about him not being safe, he felt like*

they'd gone in and just judged him on his lifestyle choice and not actually found out about him and who he was. I think that kind of upset him a little bit. (Alice)

I don't think that there's enough understanding within the other agencies to take such a compassionate normalising non-judging kind of approach…there's a bit of… 'this person's a nuisance because they're creating…mess and rats and it's becoming a problem', without really understanding how or why that person might have become involved in that situation in the first place. (Juliet)

Staff reflected on the biases held within their wider MDTs, and they considered how these biases influenced staff willingness to work with hoarding presentations.

I was shadowing [another clinician]… and he gave me like a lot of warning… 'right, we're going to need to take gloves, we've got to take an apron because…this place is going to be a lot to deal with'… So I'm like, oh my goodness, what's going on here? So, even before meeting the guy [service-user], there's this…bias stuff going on….which would be enough to put a lot of people off, I think. (Valerie)

It's not a very glamorous thing [hoarding] is it? People [staff] aren't really interested in it because it isn't very glamorous. (Chloe)

Maeve and Chloe discuss how the stigma service-users face, leads to fear and perceived judgement about their behaviour, which can act as a barrier to seeking support from professionals.

They [service-users], very much hold professionals at bay and that's about the shame… it's also about fear, 'if you're going to take my stuff, actually I don't want you to know about it, because I can deal with this in my own time.' But they don't…so there's a fear of

letting people in, there's a fear of change, there's the shame, the guilt, fear of the unknown… that shame kicks in, doesn't it? 'I don't want people to know and it's pointless going forward anyway because there's nothing there that can help me.'...There's probably lots of people out there that don't present [at services], and they don't present because…'there's nothing anybody can do about it.' (Maeve)

There's a lot of shame and embarrassment and then initially this sense of hope that you might be able to help them work with something, and then as that progresses, I feel like there's often a lot of fear around change. That means that productive work can be really difficult and…the time it takes to do a productive piece of work. (Chloe)

This fear of judgement can also affect upon service-users' experiences of disclosing their hoarding to professionals, and ultimately keep the behaviour secret. Velma and Juliet share their experiences.

I think it is a very secretive behaviour…a lot of people are very ashamed of it because it's not really publicised that there's lots of people who do this, and they do it for a variety of reasons. I don't think there's enough education about it…the level of shame behind it is huge, absolutely massive. …He's very embarrassed and ashamed by what's happened but can't stop it…I worked with him, that took me a good…nine months before… he actually brought it to the table, we could talk about it...What makes it even worse is because hoarding is not even in the public eye or seen as a problem it's sort of on the side peripheral…like safeguarding…are we waiting for a disaster to happen before everyone goes crazy about it? (Velma)

I think hoarding is probably much more prevalent out there than we think it is and… there's still a lot of stigma around it, a lot of negativity. I think people are very scared to

come forward about maybe the extent of what's going on for them at home. Probably because they're quite worried about 'well, would I be forced to get rid of things?'…It's taken a long time for people to disclose… the extent of what they've been doing. (Juliet)

3.8.2 The Journey of Accessing Help

As seen in the previous subtheme, disclosing hoarding behaviour can be an incredibly daunting and fearful task. This subtheme is a continuation of the previous one, it explores service-users' experiences of accessing services, the previous support and help they have had, and how they might view staff providing help. Alice and Chloe helpfully outline service-users' experiences of going unnoticed by mental health services.

He'd never been under mental health services. He hadn't been known to anybody really, until obviously this safeguarding referral was made, and then suddenly social care become involved and…we did as well… It's quite sad really, he slipped under the radar. (Alice)

People go under the radar because when they do meet professionals outside of the home environment, they can often be very well kempt, and they can appear that they've got their act together. (Chloe)

Staff reported an overall lack of previous mental health support for hoarding service-users. There were informal avenues of help that were utilised, including family and community networks. This support was often in the form of assisting with decluttering or helping with practical tasks, such as food shopping. William and Dakota demonstrate this. In Dakota's account, she recalls that a service-user was known to services, due to their mental health presentation, but not because of their hoarding behaviour.

Not that I know of [received any previous support for hoarding], apart from informal support …the family was trying to do what they can to help him keep on top of it and, encouraging him or whatever. (William)

She was well known [to mental health services] and I think the hoarding had got worse over the years. So there have been times when she had been on the ward and people from her church had helped to clear the house…that had happened a couple of times…over the years.…By the time I saw it, it was obviously way too much for anybody from the church to be able to handle…I think it had been getting worse as time had gone on. (Dakota)

Staff were mindful of how service-users perceived support they received from staff. Ruth and Grace share their insights into how they felt service-users viewed them, and the importance of considering the inherent power dynamics in their relationship.

> *I was quite clear that there was concern around the amount of things, items in the property, but she clearly said to me 'if you're here because of the property, then you had better leave because you're not taking anything out'…Sometimes the fact that we come as professionals, that has a lot of impact on that relationship, because they see us in our uniforms coming in telling them what to do. (Ruth)*

> *We were new to him, so we were trying to engage him, and we didn't want to offend him and for him to then disengage from us if we…went in there and started clearing… probably from his perspective it could seem quite critical and quite damning really…So, we needed to be really mindful about how to kind of balance that. (Grace)*

3.8.3 Facilitators of Helpful Support

The final subtheme presents staff perceptions of what facilitates helpful support. It places emphasis on the therapeutic relationship, why it is important, and the challenges

encountered with building rapport. It ends by noting final reflections regarding ways to meaningfully engage service-users and to elicit fewer judgements. Unanimously staff felt that developing rapport and a trusting relationship with service-users was crucial. Eleanor demonstrates how building trust aided a service-user to accept help, and was therefore at less risk. While Olivia reflected that for some service-users who felt mistrustful of services, building rapport was essential for progress to occur.

> *He started to understand why we were trying to put these things into place for him. To start with it was like, 'no, no, no, no'…He'd be up in bed in the middle of the day, so we couldn't get in, so we'd be worried about him…I think it took about four months for him to agree for a key safe, which he did. As our trusting relationship built up, he was more amenable to accept other people coming in. (Eleanor)*

> *They were quite resistant to new people coming in, [they had] really bad experiences with the mental health system, very guarded, very mistrustful…I had to really work to build that relationship, gain trust. Once I had, by the end of the work they were so incredibly grateful and had felt that we had…done a lot and gone above and beyond, me and my colleagues. (Olivia)*

Challenges to building rapport were identified by staff, which included service-users potentially feeling judged for their behaviour, and appearing irritable as a way of keeping staff away. Juliet and Olivia share their experiences.

> *It's been really hard to build up that rapport because I think people have felt…that maybe you're going to be very critical or you're not going to understand…We know it can be hard whatever reason people are bringing to therapy to make a rapport, and trust is really*

important. But it seems much more safe for this kind of client group…they're very worried about being judged. (Juliet)

She could be quite…irritable with you, and she definitely made me work very hard to build that rapport. So, it was…difficult at times in the early stages. (Olivia)

Staff identified ways of building rapport and facilitating support, which included sharing an appreciation for service-users' possessions. Ruth and Valerie helpfully discuss this for two service-users' who share a love and 'collection' of books.

I began to look into the books and read about the recipes and talk about the recipes, she just calmed a lot down. So, I think…engaging with them within the context of the hoarding, and making, and sharing that appreciation for what they have been able to collect, does enable us get to know them a lot better and maybe with time they might like setting stuff go. (Ruth)

I let him lead on that [sorting together] because these are his precious things in his home. These are his precious items…He appreciates that I listen, even though I don't really know much about what he's talking about, but I still give him validation…and I ask questions…I think he really appreciates that, because he doesn't get that from a lot of other people. (Valerie)

Staff provided other observations of how their relationship with the service-user had improved, and rapport was established. William highlighted that sharing humour with a service-user was a good way of engaging the person. Grace also demonstrates the importance of holding a service-user in mind, which has helped with their engagement with the staff member.

This guy had a great sense of humour, so that's one of the things we used to use with each other all the time… I'd say things like 'don't take this away, I mean it'…and he'd just laugh at that, and he would come back with something at me…that was really important, just that human element and…humour was a big part of it. (William)

He came along a few times to the social group and he stopped going to that, but he likes to be invited, and he sent me a text a few weeks ago actually, which was really sweet and he said 'no, I'm not going to come, but please, can you keep inviting me because it shows that people care.'(Grace)

Staff reflected on what elicited fewer negative judgements regarding hoarding behaviour. Juliet believed being genuinely curious puts service-users at ease. While Ruth shares the importance of fostering a non-judgemental stance. Finally, Olivia emphasises that service-users should be empowered by staff to identify what is most important to them.

There's that sense of well, it's just like any other psychological difficulty…Once you can go in, with that genuine curiousness and start to unpick things, it's just a way of being interested in putting people at ease…normalising stuff and saying, 'crikey, given what you've been through, might that be a function of what this is.' (Juliet)

The non-judgmental approach is key…because…people who are hoarding, the first thing they think is 'you're just coming for the hoarding'…not them. So I don't think they think anyone cares about them…having that non-judgmental approach in any way, just make it open to them that you are there to care. (Ruth)

Empowering people to make their own decisions, so working with, not doing for, which I guess is sort of similar to…therapy, as well in terms of…equipping people with the skills

and empowering them to…make their own decisions and take their own actions, and figure out what's important to them. (Olivia)

3.9 Researcher Reflections

The interview process was a novel experience for me, as I had not conducted interviews of this length and depth before. I was mindful about how my natural position as a clinician and therapist would interact with my role as a researcher. I noticed at times, that I wanted to 'therapize' the staff I was interviewing by offering them validation and reassurance for the content they were bringing. I reflected on this, and although these techniques were sometimes relevant, I was able to move towards a position of curiosity and openness as a researcher, and I began to ask more follow-up and clarifying style questions as the interviews progressed. My therapeutic skills of active listening and summarising were still valid to the interview process, and I believe they aided the rapport I built quickly with participating staff.

When I reflected on the interviews, I noticed a range of emotions within myself. The first included a sense of overwhelm with the amount of information provided by participating staff regarding the service-users they had worked with. Staff interestingly also reported overwhelm, for both themselves and their service-users. My feelings were shortly followed by helplessness because of the difficulties staff faced when trying to support service-users therapeutically and navigating complex systemic constraints. My feelings of overwhelm were mirrored during the coding stage of my analysis, where I felt a sense of enormity at the number of codes created from the data. Upon reflection, I considered the parallel process occurring with staff feeling overwhelmed by the 'stuff' service-users had acquired, and how I had replicated service-users' experience of acquiring within my analysis. I explored this in my research supervision, which was a useful way to disentangle my own feelings from that of the participants and their perception of service-users' experiences.

I noticed feeling intrigued about service-users' hoarded items and the condition of their home environment. Gathering this information was certainly relevant to my research question, however in the initial interviews, I had spent up to half of the allocated interview time discussing the service-users, and only leaving a small proportion of the interview for exploring staff experiences of working with hoarding behaviour. It should be noted these discussions were not completely distinct. I was mindful, particularly as the interviews progressed, to not get too caught up in the experience of the service-user, and to spend most of the interview exploring staff experiences of working with hoarding presentations. Therefore, as the interviews developed, and the data was becoming more saturated, interviews naturally became less about the details of each service-user and more broadly about staff experiences. Therefore, service-user demographic data is missing in Table 5, which perhaps reflected my move towards exploring staff experiences and my development as an interviewer.

My final reflection includes the process of choosing and allocating pseudonyms to participating staff. I found this challenging as I wanted to honour the anonymity of each staff member without losing the essence of who each person is and their valuable contributions to the research. On my various Google searches about '*how to allocate pseudonyms to research participants*', I came across a paper, which named my feelings of uncomfortability around name allocation. Lahman et al., (2023) enabled me to consider allocation as a way of increasing my reflexivity as a researcher, which, in line with my methodology, ensured transparency. Therefore, I decided to choose gender matched names to allocate to each participant. These represented 'care-takers' or 'care-providers' due to the nature of each staff member's chosen career of providing mental healthcare within the NHS. The key traits listed when searching for these names included that of compassion, protection, responsibility and guidance. For me, allocating pseudonyms in this way felt like a more comfortable fit, and the

traits aligned with the image I wanted to conjure. Furthermore, I made the decision not to allocate service-users with a pseudonym during the write-up, as the interviews were kept deliberately anonymous, which felt appropriate.

3.10 Chapter Summary

Overall, the results of the current study highlighted various ways NHS mental healthcare staff have worked with service-users displaying hoarding behaviour. Namely, staff have sought to understand hoarding by considering its onset, maintenance and the application of psychological models to aid this process. Staff discussed barriers they faced conducting the work and challenges posed by the wider service and NHS structures they are practicing within. There was ambiguity about how to treat hoarding, with a focus on moving towards multi-agency working. The results indicate that HD is becoming increasingly accepted as a mental health diagnosis; however, risk issues, minimal training and a lack of best practice guidelines, are crucial issues that were raised by most staff. Finally, service-users generally do not present at mental health services specifically for hoarding, it is a secretive disorder and therefore difficult to disclose. Staff considered how the therapeutic relationship and a non-judgemental stance facilitated support and engagement. There are a number of similarities between the findings and the literature presented within chapter one.

Chapter Four: Discussion

4.1 Chapter Summary

This chapter will summarise the results of the current study by discussing each of the five themes and their relevance to the evidence-base. Strengths and limitations of the study will be explored, followed by the clinical and policy implications these findings suggest. Recommendations for future research are highlighted. The chapter will end with the researcher's reflections and concluding statements.

4.2 Theme One: How Staff Understand Hoarding Behaviour: "The Stuff is rarely the Issue"

Within the subtheme '*The Onset of Hoarding*', participants suggested that a 'root cause' had often led to the onset of hoarding behaviour for service-users. This finding aligned with Orr et al., (2019), who interviewed individuals with HD and found that 'an explanation was usually lying behind hoarding' (p. 268), but this 'explanation' varied depending on the person and their context. As discussed in chapter one, there is controversy around the classification of HD as a 'mental disorder' due to concerns around its diagnostic utility. Mataix-Cols and Pertusa (2012) suggested that there should be careful consideration when discriminating between adaptive and maladaptive degrees of hoarding, to not over-pathologise behaviour. The use of the quote "*the stuff is rarely the issue*' as the overarching theme heading was to portray the confusion and uncertainty that staff perceived around whether hoarding is a diagnosis or a symptom of another comorbid mental health presentation. This subtheme therefore described staff perceptions of the many contributing factors that led to the onset of hoarding for service-users.

Experiences of loss, grief and trauma were considered key in the development of hoarding behaviour, which aligned with the literature presented in chapter one. Losses included death of a significant other, which is often accompanied by acquiring possessions.

Psychoanalytic thinking would argue that when individuals lose something, they endeavour to find a substitute. Therefore, they seek proximity with inanimate objects, rather than experiencing the pain of losing transient human relationships (O'Connor, 2014). Furthermore, Chia et al., (2021) considered the importance of both traumatic life events (e.g. perceived or actual threat to life) and stressful life events (e.g. death of a family member or loss of job) in the development of hoarding. Staff observed complex losses, including loss of identity, which could be understood as Complicated Grief (CG). CG is prolonged and traumatic in nature, and Lawrence and Elphinstone (2019) argued that individuals experiencing CG might avoid their negative emotions and seek coping strategies, including hoarding behaviour. The current study corroborates the notion of CG in the development of hoarding; however, staff appeared tentative in this claim, to not over-pathologise experiences of loss and acquiring behaviour.

Neurodiversity, namely ASD, was observed in service-users, which contributed to hoarding. Individuals with autistic traits, compared to neuro-typical populations, have been found to show more hoarding behaviours (Pertusa et al., 2012), which is corroborated by Abouzed et al., (2024) who identified that hoarding is notably more prevalent in individuals with ASD, than the general population. The present findings also suggest that those individuals found managing social situations to be challenging. Staff speculated that engaging in hoarding was deliberate, to keep others away due to social anxiety. Due to limited research directly investigating the link between social anxiety, ASD and hoarding, it is difficult to draw meaningful conclusions. Pertusa et al., (2012) highlighted that social impairment may be a direct consequence of the isolating impact cluttered living spaces have, while Abouzed et al., (2024) revealed that individuals who reported better social skills find it easier to discard possessions. The latter does not directly confirm the current findings, but it does suggest links between social anxiety, ASD and hoarding; however, more research is required.

As discussed in chapter one, the DSM-5 states that if HD is better explained by a diagnosis of ASD, then a diagnosis of HD should not supersede ASD (APA, 2013). The current findings do not dispute this clinical suggestion, but they do offer an observation that ASD is often undiagnosed amongst the hoarding population; therefore, timely appropriate support is not implemented. La Buissonnière-Arizal et al., (2018) examined correlates of hoarding behaviour in children with ASD and comorbid anxiety or OCD symptoms. They found that a third of their sample presented with moderate hoarding levels, indicating the high prevalence of hoarding amongst this population. This has clinical implications, including a call for increased screening for ASD presentations amongst service-users presenting with hoarding behaviour.

For service-users who experienced difficult life experiences, staff observed they had 'limited life skills'. They struggled to cope and subsequently engaged in hoarding. Ong et al., (2015) conducted a systematic literature review exploring functioning and quality of life in hoarding clients and found that clutter was strongly associated with an inability to carry out daily living tasks. However, due to the correlative nature of the study, no conclusion of directionality or causation can be drawn. Ruby-Granger et al's., (2023) qualitative investigation found that traumatic experiences acted as a catalyst for hoarding and when individuals' levels of responsibility increased, they postponed managing possessions. Managing possessions and links to life context were crucial to their findings; however, this connection has not been fully explored in empirical studies, therefore further research into this area is necessary.

In line with the CBT model presented in chapter one (Frost & Hartl, 1996; Steketee & Frost, 2003), the current findings, highlighted within the '*Maintenance of Hoarding*' subtheme, indicated that service-users had strong emotional attachments to their possessions, which contributed to the maintenance of acquiring. The possessions were kept due to the

memories associated with them. This is corroborated by Kellett et al., (2010) who found that for hoarding individuals, objects acted as 'anchors' for positive memories attached to them. Staff in the current study highlighted that service-users gained comfort and safety from their items, which was echoed by Kyrios et al., (2018). Furthermore, staff observed Frost and Hartl's (2006) concept of 'anthropomorphism' in service-users, who located human-like characteristics in possessions (e.g., one service-user took their doll to bed to cuddle), supporting the idea that strong attachments to possessions maintains hoarding.

Furthermore, these findings support the phenomenon that psychological safety is achieved through comfort with a 'transitional object' (Winnicott, 1953). Although transitional objects are often temporary in childhood, for those with insecure-attachment security, they might continue to utilise these objects in adulthood to achieve safety (Stagg & Li, 2018 in Chia et al., 2021). Chia et al., (2021) highlighted an association between an insecure interpersonal attachment style with increased hoarding severity, suggesting that excessive attachment to inanimate objects is a compensatory strategy for a lack of security in relationships (Yap et al., 2020).

Yap and Grisham (2019) emphasised that relationships to possessions are complicated and they are often marked with insecurity and ambivalence. In the current study, negative affect was evoked, including aggression and anxiety, when service-users were faced with the prospect of discarding. Service-users expressed ambivalence about discarding, with a desire for their situation to be different, but they struggled to implement strategies towards change. Yap and Grisham (2019) therefore suggest that relying on objects for connection does not necessarily meet unmet relational needs due to this ambivalence towards objects. Schou et al., (2020) found that individuals expressed love towards their possessions, but also feared they might need them in the future. The Risk Minimisation Theory (McKinnon et al., 1985) highlighted in the literature review in chapter one, would suggest that hoarding possessions

might serve future use and that discarding 'necessary' possessions increases service-user anxiety. Mental health services and staff should consider the complex relationships service-users have towards their possessions and attempt to understand the value and meaning behind possessions.

Within the subtheme '*Ways of Understanding Hoarding',* staff likened hoarding to that of addiction presentations, with an expression that hoarding acted as an outlet. Framing hoarding behaviour in this way enabled a sense of hope and workability amongst staff, in what previously felt quite stuck. This way of conceptualising HD has recently gained attention. One review explored phenomenological, psychological and neurobiological evidence to support HD as a behavioural addiction (Pickering & Norberg, 2023) using the Components Model of Addiction (Griffiths, 2005).

Pickering and Norberg's (2023) model proposes six core components indicative of addictive behaviour. They identify compelling evidence for how symptoms of HD align with three of these components, which are 'salience', 'mood modification', and 'conflict'. 'Salience' represents how activities, such as acquiring and saving in HD, dominate a person's thinking, feelings and behaviour. 'Mood modification' refers to the emotional outcome that motivates individuals to engage in an activity, e.g. experiencing an emotional 'high' following drug taking. In HD, the excessive acquisition of possessions regulates emotions by reducing negative affect and increasing positive emotions (Taylor et al., 2019). 'Conflict' within this model is the 'disagreements within oneself or with others that arise due to excessive and persistent engagement in an activity and the inability to stop the behaviour' (Pickering & Norberg, 2023, p.72). Pickering and Norberg's (2023) review highlighted hoarding individuals have difficulties with social and familial relationships, which aligned with Griffiths' (2005) model; however, there is a lack of evidence that intrapsychic conflict is characteristic of HD, as it is in addictions. Staff in the current study observed an internal

conflict and ambivalence within service-users surrounding their experiences of discarding, which strengthens the evidence that HD aligns with the 'conflict' element of the addiction model. There was limited evidence to suggest that hoarding symptoms mapped onto the other three model components: 'tolerance', 'withdrawal' and 'relapse' (Pickering & Norberg, 2023). The review recommended that future research should focus on whether these components are characteristic of HD; however, it concludes that the Components Model of Addiction provides hope of a feasible way of understanding and treating hoarding, but further research is required (Pickering & Norberg, 2023)

Within this subtheme, and the subtheme '*Challenges Faced by Staff'* outlined in theme two, staff indicated that service-users lacked insight and motivation to make changes, which was a barrier to engagement. Previous work has highlighted the helpful application of the Transtheoretical Stages of Change Model (Prochaska & DiClemente, 1982) to understand hoarding via six stages of change. Tolin et al., (2010) propose that hoarding individuals remain in the first stage of 'precontemplation', which suggests individuals do not intend to take action and will likely refuse treatment. This could indicate that service-users are under-informed about the consequences of their behaviour, have attempted to make changes before but had no success, or are ultimately viewed as unmotivated or not ready for therapy (Prochaska & Velicer, 1997). The processes of change outlined by Prochaska and Velicer (1997), namely 'consciousness raising', which involves increasing awareness of the causes and consequences of a certain behaviour, should be considered by services providing care to hoarding populations.

4.3 Theme Two: Staff Frustrations, Challenges and Systemic Constraints

The sentiments shared within the subtheme *'Staff Expectations'* echoed previous findings indicating that hoarding presentations are notoriously difficult to treat, with a reduced adherence to treatment (Tolin et al., 2012). Staff reported that progress towards

discarding was rare and therapeutic work took a long time. Thompson et al's., (2017) systematic review, which investigated different treatment approaches for hoarding, namely: CBT, pharmacotherapy, cognitive rehabilitation, online support, and family interventions, supports this finding. They found that although most studies reported statistically significant reductions in hoarding symptoms, the reductions were modest, with many individuals remaining in the clinical hoarding range post-treatment. Koenig et al., (2013) further corroborated these findings in a qualitative exploration of MDT professionals' experiences of working with older adult hoarders in the USA, indicating that mental health support for hoarding was a slow process.

Staff in the current study acknowledged their own biases and judgements working with hoarding service-users. To the researcher's knowledge, there is no literature specifically exploring mental health staff biases in relation to hoarding behaviour. However, it is known that individuals with HD are often stigmatised by the public (Mataix-Cols & Fernández de la Cruz, 2018), portrayed by 'semi-mocking narratives' in television programmes (Prosser et al., 2024 p.2). Therefore, it is helpful to draw on Sreeram et al's., (2022) research exploring mental health staff stigma towards individuals with BPD. The stigmatising negative attitudes, emotions and avoidant behaviour towards the illness that mental health professionals exhibited, affected help-seeking and access to treatment for service-users (Sreeram et al., 2022). These concerns are potentially similar to the stigma faced by individuals who hoard, namely that staff find hoarding 'challenging' to deliver care. Further investigation into hoarding-related stigma in staff is required to understand the impact upon service-user engagement and treatment outcomes (Prosser et al., 2024). The impact of stigma upon hoarding individuals will be further discussed in theme five.

Within the subtheme '*Challenges Faced by Staff',* several difficulties were reported. The first included staff having difficulty completing their clinical work in service-users'

homes, with feelings of overwhelm creating barriers to intervention. Tinlin's, (2022) UK-based study exploring mental healthcare staff experiences of working with older adult hoarding service-users corroborates these findings. Clinicians reported a sense of hopelessness when faced with the 'sheer scale of the clutter', with staff trying to contain 'chaos' and finding it 'impossible to know where to start' in service-users' homes (Tinlin, 2022, p.50). Volunteers also encountered challenges, including having difficulty manoeuvring in homes to support with discarding tasks (Ryninks et al., 2019).

The second challenge reported by staff in the current study was the negative physical experiences they encountered conducting home visits to hoarding individuals, including a lack of air in the environment, which compounded claustrophobia and anxiety. Holden et al., (2019) found that for professionals working in hoarded homes, there was an ongoing emotional strain, with reports that these environments are physically and emotionally demanding. They cite Denton et al., (2002), who highlighted that care-workers placed in hazardous homes are at increased risk of poorer mental health and wellbeing. Despite the potentially negative impact on staff working in service-users' homes, staff in the current study did not express a desire to stop this way of working and Koenig et al., (2013) suggested that home-visits can directly address hoarding behaviour and enhance engagement.

The final challenge was the reluctance and lack of motivation service-users expressed towards making change, due to service-users feeling content with their living arrangements, which acted as a barrier for support. Holden et al., (2019) recognised how resistance from service-users to make changes created a sense of hopelessness and overwhelm in staff. McGuire et al., (2013) corroborates the lack of motivation observed by staff in hoarding service-users. Lack of motivation and links to the Transtheoretical Stages of Change Model are explored above in theme one.

Within the subtheme: *"We're Dealing with People": Service Constraints',* staff working with hoarding service-users felt undervalued by the wider service and achievement was not appreciated. Onyett et al., (2011) identified sources of pressure that contributed to stress, burnout and job satisfaction among mental health staff working in CMHTs, including a lack of resources, work overload and issues pertaining to line management and supervision, which could also be present for the staff in the current study.

Although supervision was not directly explored in this study, research indicates that quality clinical supervision is associated with lower levels of stress and increased job satisfaction among mental health professionals (Edwards et al., 2006). Holden et al., (2019) highlighted that for staff working with hoarding, they wanted supervisors to recognise and normalise the emotional labour of this work. Staff in the current study had varying service-provision and constraints, therefore effective supervision and its availability will differ. For professionals to remain compassionate and avoid burnout in their clinical work, "a supportive working environment, appropriate training, and a realistic perspective on the time required to achieve meaningful change" is necessary (Onyett et al., 2011, p.204). Implementation of reflective spaces for staff is also recommended, to consider the impact of their work and to receive effective supervision (Onyett et al., 2011).

4.4 Theme Three: Treatment Approaches for Hoarding

This theme described staff experiences of using treatment approaches for hoarding in mental health services. Staff felt unsure about how to treat hoarding behaviour and reflected a lack of skills to ascertain appropriate avenues of support, hence the subtheme label '*Ambiguity Regarding Treatment'*. Tinlin (2022) reiterated this finding and shared that clinicians had limited knowledge regarding treatment of hoarding and had reduced awareness of best practice guidelines. Therefore, clinicians could not effectively deliver treatment, as they "did not know enough about why people hoard to help reinforce a rationale for them to

start discarding" (Tinlin, 2022, p.49). Staff in the current study communicated that working without a framework to understand and treat hoarding behaviours felt like an enormous task. This notion aligned with Frost et al., (2003), who posited that what is known about HD is that no intervention has consistently been proven effective and successful outcomes are rare. The relevance of this finding is paramount, since staff are operating on outdated principles, resulting in minimal effective outcomes and feelings of hopelessness (Tinlin, 2022).

Staff also considered the impact of service-users' comorbidities, how to disentangle these from hoarding behaviour and how to find the right treatment fit. The current study focussed on exploring staff experiences of working with hoarding behaviour, which mostly coexisted with another mental health problem. Tinlin (2022) reported complexity when assessing for hoarding behaviours, stating there are often comorbidities present.

Staff in the current study proposed two approaches to treatment for hoarding: tackling service-users' emotional needs and their practical needs. Staff likely made this distinction due to their core professional training. For instance, mental health nurses centre on emotional support (Gournay, 2021 cited in McShane, et al., 2024), while social workers focus on practical support (McGuire et al., 2013). This distinction reinforces the lack of clarity regarding treatment within mental health services, due to a lack of integration of approaches. CBT, the most widely used and researched treatment for hoarding behaviour, targets each component of the cognitive-behavioural model: information processing, emotional attachment to possessions, and maladaptive beliefs (David et al., 2021; Steketee & Frost, 2007). It integrates both practical skills, including problem solving, strategies to organise possessions, and exposure tasks (David et al., 2021), and emotional or 'cognitive' skills, including thought challenging and motivational interviewing. Taken together, these techniques have improved self-efficacy and reduced avoidance among hoarding populations (Fernández de la Cruz et al ., 2013 cited in David et al., 2021). Although the efficacy and

adherence to the CBT model was not formally explored within this study, the discussion point is noteworthy for consideration in mental health services. For instance, if a professional with a certain skill-set supports a service-user, then an integrated emotional and practical approach could be difficult to deliver, even when this approach appears the most efficacious way of treating hoarding behaviour (Steketee & Frost, 2003). Staff proposed that clear pathways of care, which fully map out considerations for both practical needs, in the form of safeguarding and social care processes, and emotional needs, such as therapy and engagement, would be beneficial to support their practice.

In the '*Useful Ways of Working'* subtheme, formulation was identified as a helpful tool to aid successful treatment, as it explores individuals' hoarding difficulties and creates a shared understanding amongst staff and service-users. Staff did not name a specific formulation model they used; however, it was alluded to that psychology colleagues conducted this work, which could indicate a further lack of skill integration across disciplines, as discussed in the previous subtheme. Tinlin (2022) found that MDT staff used the 5Ps model (Dudley & Kuyken, 2014) and a needs-based approach (James & Birtles, 2020) to formulate hoarding difficulties. Interestingly, their staff, despite this being indicated as best practice, did not adopt Frost & Hartl's (1996) CBT for HD formulation model. The model aims to formulate hoarding symptoms in a personalised and collaborative way by mapping out "how personal vulnerabilities, thoughts, feelings and behaviours interact to maintain hoarding problems" (Wheaton et al., 2016, p46). Therefore, formulation is a useful way of working with hoarding to increase understanding and aid successful treatment. Please refer to Appendix N for the cognitive-behavioural model of HD symptoms.

To target some of the challenges staff in the current study faced in obtaining effective treatment outcomes, they suggested creative ways of working with hoarding presentations, which may not be routinely used in mental health services. Applying reasonable adjustments,

using Assistive Technology (AT), and utilising a 'limited reparenting' approach, were some of the ideas staff generated and are discussed below.

Reasonable adjustments were deemed appropriate for hoarding service-users presenting with neurodivergence, including ASD. Riaz et al., (2023) indicated that for populations with mental health difficulties, autism and learning disabilities, implementing adjustments including the use of accessible information, giving additional support and allocating more time during appointments, improved wellbeing. In the current study, a lack of time was a barrier for staff to effectively work with service-users, therefore reasonable adjustments, including offering more time for appointments, were considered beneficial to aid successful treatment.

Assistive technology (AT) is a health strategy commonly used in populations who need support with daily living; it refers to 'equipment that is designed to help people with physical or cognitive disabilities carry out daily activities more easily' (Dementia UK, 2025). One of the key aims of AT, which can be applied to supporting hoarding service-users, is to reduce the risk of accidents, injuries and family concerns (Dementia UK, 2025). Examples of AT that could support independent living include: gas safety valves for ovens and hobs to ensure the devices are not left on, and smoke alarms and heat detectors to alert to fire.

A limited reparenting approach, which is a core mechanism of healing used in schema therapy (Young et al., 2003: Andriopoulou, 2021) was also suggested to support completion of day-to-day tasks. Limited reparenting identifies emotional needs often unmet by childhood attachment figures and the therapist endeavours to meet those needs by creating a secure attachment bond with the individual (Andriopoulou, 2021). Staff embodying reparenting qualities, might help to bring about change to hoarding individuals who have experienced traumatic life events. However, the literature is largely focused on supporting the unmet

emotional and attachment needs, and not the completion of practical daily tasks. Therefore, this approach requires further investigation into its efficacy with hoarding groups.

With each suggested creative approach, when treating an ego-syntonic problem, such as hoarding behaviour, it is essential that clinicians operate from the client's frame of reference (Frost et al., 2003) and maintain a person-centred approach (Holden et al., 2019). Staff in the current study highlighted that exploring service-users' motivation, and finding incentive for things to be different, was essential to make changes. A person-centred approach and curiosity was required in the face of hoarding difficulties.

The subtheme '*Multi-Agency Working: A Move Towards Specialist Services?'* highlighted a need for the development of specialist hoarding services. The current findings aligned with Bratiotis et al's., (2011) suggestion that implementing wrap-around community care was essential due to the complexity hoarding poses. Bratiotis and Woody (2020) reviewed hoarding as both a mental health problem, and as a social problem (e.g. risk associated with fire, housing), and found that to achieve successful intervention, expertise from multiple professional disciplines was required. The work of Bratiotis' and colleagues (2011; 2020) was conducted in Canada and their findings are crucial to consider for treatment within the UK. Bratiotis and Woody (2020) recommend treating hoarding by considering the wider system surrounding an individual. Bronfenbrenner's (1992) Ecological Systems Theory views the person within the context of their family (microsystem), neighbourhood and community (mesosystem), and within wider structures including government agencies who implement policies (exosystem). These systems could "identify and implement layers of resources at multiple system levels" (Bratiotis and Woody, 2020, p.5) as a way of targeting hoarding concerns.

Staff in the current study identified that specialist hoarding services, consisting of various professional disciplines, would be most impactful to support the needs of service-

users and implement change. However, cost and time restrictions were highlighted as barriers. Haighton et al., (2023) explored UK-based stakeholder perspectives from a hoarding research group, who corroborated the current findings. Despite stakeholders from different services reiterating the importance of multi-agency approaches as the most cost-effective strategy, they were difficult to implement in practice due to restrictive referral pathways and a lack of support from other services. Furthermore, French et al., (2022) highlighted, in their UK-based study focussing on inter-agency working with individuals with HD, that professionals cited that improvements were achieved when individuals worked more closely with other agencies, had increased funding, resources and training. Finally, Caiazza et al., (2018) proposed a hoarding-specific multi-agency team, which contained specialists from varying professions. They emphasised the psychology-led nature of the teams to aid in the implementation of effective practice and positive treatment outcomes for hoarding service-users, in the context of risk and complexity. This work taken together reinforces the experiences of staff within the current study, and the importance of moving towards specialist hoarding services.

4.5 Theme Four: Updating Practice: Seeing Hoarding as a Diagnosis

This theme captured how staff viewed hoarding as a mental health diagnosis and it described key areas of enquiry to update practice accordingly. Within the subtheme '*Staff Role, Responsibility and Feeling Dissatisfied*', staff expressed uncertainty regarding their role, which resulted in conflicting advice regarding best practice. This uncertainty faced by staff could have been mirrored in their interactions with service-users, potentially impacting on treatment. For instance, in the current study and in Ryninks et al., (2019), staff reported uncertainty working with hoarding service-users and they noticed being kept at 'arm's length'. This resulted in reduced confidence and increased frustration amongst staff (Ryninks et al., 2019), which could have contributed to feelings of dissatisfaction in their role. The

current staff also expressed dissatisfaction when service-users struggled to engage with support, or when they began to make changes but reverted to engaging in the hoarding behaviour.

Acker (2003) found that for mental health staff working with mental illness more generally, role conflict and role ambiguity correlated with emotional exhaustion, which is a key concept of burnout. Role conflict consists of having incompatible demands or expectations when staff work with groups (e.g. agencies) who operate differently, and role ambiguity results from uncertainty about how staff support their service-users (e.g. no clear, planned goals or objectives for their role). Staff in the current study reported 'going above and beyond' their role to support the needs of service-users, undertaking activities such as cleaning, sorting and taking out rubbish. This indicated that staff were stretched beyond their resources, with increased demands, and a lack of clear objectives, putting them under further pressure, which could contribute to dissatisfaction and burnout (Johnson et al., 2018).

Despite these experiences, staff did report a sense of achievement when they witnessed service-users' successes in treatment, which included achieving effective de-cluttering and happiness. Ryninks et al., (2019) similarly found that volunteers, working with hoarding service-users in an informal and flexible way, reported a sense of fulfilment and achievement from their work, indicating that dissatisfaction emerges when staff lack clarity about their role and service-users struggle to make progress.

The risks associated with hoarding behaviour are well known and researched, with severe cases resulting in fires, infestations, falls and an inability to carry out daily tasks (Steketee & Frost, 2003). This was corroborated within the current study in the subtheme '*The Importance of Risk'*. Risks were associated with structural damage to homes, burglary, fire and falls, which resulted in an increased strain on agencies and emergency services. Furthermore, risk issues, namely poor food-hygiene and self-neglectful behaviours, were

difficult to disentangle between what was associated with comorbid mental health presentations and with hoarding behaviour, and whether these were distinct. Although staff did not label service-users as 'living in squalor', the risks, including living in unhygienic conditions, appeared to align with characteristics of 'severe domestic squalor' (Proctor & Rahman, 2021), which is outlined in chapter one. Smith (2001) argued that squalor is a useful behavioural term for an extreme form of compulsive hoarding. It represents a public health hazard and poses a 'grey area' regarding which agency should take responsibility for risk, with disagreements about whether service-users are 'mentally ill, extremely eccentric or plain bloody minded' (Smith, 2001, p.31). Therefore, the management of risk with hoarding behaviour needs to also account for squalor-related risks.

Less research has explored specific mental health staff experiences of risks associated with hoarding presentations, and this study, inadvertently, is likely one of the first to do so. One staff member reflected on their conflictual feelings of aiming to keep the person safe, but felt coercive by doing so because the service-user lacked insight into the risk their behaviours posed. Hoarding research indicates that service-users lack insight into their condition (Tolin et al., 2012), which can result in poor treatment prognosis (Frost et al., 2010). Lack of insight can be considered in three ways: 'anosognosia', known as a lack of awareness of illness or its consequences; 'overvalued ideation', known as fixed and inflexible beliefs; and 'defensiveness', which is the use of denial to resist influence by others (Frost et al., 2010 p.405). It could be helpful for staff to identify which type of insight-related difficulty service-users are experiencing to manage the associated risks. This will aid understanding and ultimately treatment outcomes (Frost et al., 2010).

Staff also reported feeling powerless and vulnerable when faced with risks associated with hoarding. Staff believed that safeguarding concerns were taken seriously, but hoarding-related risk was seen as beyond the control of mental health staff. Owen et al., (2022)

explored adult safeguarding managers' understanding of self-neglect and hoarding and found that hoarding cases were referred onto safeguarding services at the point of crisis, when the risks had escalated. Owen et al., (2022) also stresses that understanding the complicated onset of hoarding for each person requires a fuller risk assessment. These findings emphasise the importance of early identification and timely referrals to appropriate teams.

The subtheme *"Going it Alone": The Necessity for Training and Increased Awareness'* described the lack of hoarding-related training and reduced awareness of the condition amongst staff. This is echoed by Tinlin (2022) who found that from their sample of thirty NHS clinicians, only 13% had ever received hoarding-specific training and 95% reported requiring training to provide good quality care and treatment. The BPS (2024) Division of Clinical Psychology published a perspective on hoarding and they similarly stressed the importance of accessing training and information to inform clinicians' practice.

Despite these recommendations, and hoarding being classified as a mental health condition, staff described 'going it alone' with little support or guidance to reflect this diagnostic update, with available training not being extensive enough for staff to feel equipped in their role. MDT staff in Koenig et al., (2013) reported confusion about whether hoarding was a mental health condition, which could have been due to their limited training. When Koenig et al.'s, (2013) paper was published, HD had only recently been classified as a clinical diagnosis in the DSM-5, therefore the findings are less applicable to current provision. French et al., (2022) recorded professionals' experiences following a hoarding conference, which incorporated training, and found that professionals' confidence and understanding increased significantly, which highlights the effectiveness of upskilling staff via training.

Staff expressed that improving psychological understanding of hoarding was crucial. As discussed in theme three, where Caiazza et al., (2018) proposed a psychology-led multi-

agency hoarding model, they also recommend psychoeducation to services, along with person-centred use of formulation to address underlying psychological issues relating to hoarding. Furthermore, the current staff requested guidelines regarding the best approach to working with hoarding behaviour. As outlined in chapter one, McGrath et al., (2024) highlighted that there are currently no specific NICE treatment guidelines for HD and it is only mentioned as a possible complexity of OCD. These findings emphasise the importance of updating best practice guidelines to better serve hoarding communities and the staff that support them.

Furthermore, staff advocated for workbook-style therapeutic support to treat hoarding in a contained and guided way, rather than feeling out of control or unsure in their approach. McGuire et al., (2013) similarly indicated that their respondents did not have a standardised organisational hoarding protocol to follow, which meant staff struggled to navigate the complexity of hoarding. They concluded that formal training to implement protocols would be beneficial.

4.6 Theme Five: Service-Users' Experiences of Help and Support

The findings from the current study and from the literature review presented in chapter one, reveal how stigma negatively affects service-users. Within the subtheme *'Stigma and its Impact',* staff explored the complexity of labelling service-users as 'hoarders', due to the term being understood as derogatory, and therefore being subject to judgement from others. McGrath et al., (2024) similarly found that 'hoarding' evoked shame in service-users, and the verb acted as a way of externalising the behaviour; thus, creating distance between service-users and the problem. The London Field Trial of HD (Mataix-Cols et al., 2013) found mixed views towards HD as a diagnostic label, and identified that of 29 individuals with HD, 17 did not find it stigmatising, while the other 12 did, with responses including fear that others might misunderstand the label and that it was not socially accepted.

Corrigan et al., (2015) identified three facets of public stigma: 'difference' ('*they are not like me*'), 'disdain' ('*they are bad'*) and 'blame' ('*they are to blame*'), and found that when these prejudicial stereotypes were internalised by individuals with a certain condition, it became a form of self-stigma. Chasson et al., (2018) helpfully applied these facets of public stigma to individuals with HD and found that, overall, HD was associated with negative public perception, with high levels of 'difference' and 'disdain', suggesting these beliefs were internalised as self-stigma. Internalised public stigma has also been linked to reduced treatment-seeking behaviour for individuals with HD (Chasson et al., 2018), as it can elicit 'label avoidance', resulting in individuals not attending clinics where labels are assigned due to fear of prejudice (Corrigan et al., 2015). Staff in the current study also observed stigma acting as a barrier for service-users to access support and to disclose hoarding difficulties.

The subtheme '*The Journey of Accessing Help'* described how service-users often went 'under the radar' of mental health services, which meant they often entered services at the point of crisis, or when safeguarding risk-related referrals were made. In Smith's (2001) psychoanalytic reflections, they concur with this finding, suggesting that the point of referral is likely when living conditions are out of hand. They add that service-users will have experienced years of distress; their views and attitudes may be entrenched, indicating they are less responsive to psychological treatment (Robertson et al., 2020). McGrath et al., (2024) found service-users actively avoided mental health services, as they did not feel listened to and lacked confidence about what could be offered.

Many service-users discussed by staff in the current study had never accessed formal mental health support for hoarding behaviour. However, informal support, including family and community networks, had been utilised, with the aim of de-cluttering and clearance. Although this support initially appeared beneficial, it became increasingly difficult to continue due to the hoarding severity. Family members who support loved ones with

hoarding are at particularly high risk of poor wellbeing (Büscher et al., 2014). Therefore, offering service-users and their families timely access to mental health services is paramount. A pilot study investigated the Family-As-Motivators (FAM) training package for use with hoarding individuals, which is designed to empower family members to address treatment ambivalence in loved ones (Chasson et al., 2014). Despite their small sample, the findings indicated that family members who participated in FAM reported significant improvements in the use of coping strategies and hopefulness, with a reduced negative impact of HD on the family. The findings indicate promising outcomes, which should be considered for use within mental health services.

Staff in the current study noticed that their professional role could appear critical and offensive, particularly working in a time-limited way towards the goal of clearing; therefore, staff were mindful of the power-dynamic between them and service-users. McGrath et al., (2024) punctuate this by identifying that service-users have felt bullied when put under pressure to discard. Ryninks et al., (2019) noted service-users valued the practical and emotional support from volunteers because of its informal, flexible and open-ended nature. They emphasised how volunteers were 'non-professional' in their status and approach, which aided rapport. This informal and open-ended work could be difficult for mental health staff to implement due to service constraints; however, the principles are useful for services to consider when delivering care.

In the final subtheme, '*Facilitators of Helpful Support',* staff unanimously felt that developing rapport and trust was crucial, especially when service-users were previously mistrustful of services. This enabled acceptance of help, progress, and reduced hoarding-related risk. Tinlin (2022) found building trust and a safe relationship with service-users, due to their mistrust of services, was essential for successful intervention. This was achieved through openness and understanding of service-users' loss and attachment histories.

Staff noticed challenges to rapport building, despite this being viewed as one of the most important ways of facilitating support. Service-users presented to staff as irritable, which was considered a strategy to negate judgements towards them. McGrath et al., (2024) corroborates this, stating that service-users had strong emotional reactions at the prospect of judgement. Staff in Koenig et al's., (2013) study found that a barrier to building trust with service-users was having limited time, which Tinlin (2022) concurs by stating that extended periods of time are necessary to build relationships with hoarding service-users.

Rapport was built via staff in the current study using humour to meaningfully engage service-users and through sharing an appreciation of possessions and acknowledging their value. Being genuinely curious and learning service-users' histories facilitated support, which echo the principles staff proposed of developing a shared and thorough psychological formulation with the individual. These findings aligned with principles from mentalisation-based treatment (MBT), which could be appropriate to consider for staff working with hoarding. "A mentalising stance involves an inquisitive, empathic, open-minded and 'not-knowing' approach to mental states, and an ability to consider alternative perspectives" (Welstead et al., 2018, p.102). This approach has been predominantly applied to staff working with BPD populations who exhibit similar difficulties to hoarding populations, including being labelled as 'untreatable', difficulties making progress towards recovery, and experiencing stigma (Warrender, 2015; Robertson et al., 2020). Although MBT has not been explored specifically with staff working with hoarding populations, a skills-based MBT (MBT-S) approach has been deemed effective at improving hope, optimism, empathy and tolerance for risk amongst nurses working with BPD, thus improving therapeutic alliance (Warrender, 2015). The principles of this treatment approach should be considered as helpful ways of facilitating effective support.

4.7 Strengths and Limitations

4.7.1 Sample Size

The sample size is both a strength and limitation within the current study. Recruiting and interviewing 15 participants is a strength, as it aligns with recommended sample size guidance of between 10 and 20 interviews, for a doctoral project using reflexive thematic analysis (Braun & Clarke, 2013). The researcher aimed to capture richness, depth and complexity across accounts, as suggested by Braun and Clarke (2022). Furthermore, the sample size is notable given that NHS professionals volunteered to participate during their working day, while managing the time pressures of their role and responsibilities. However, given that ethical approval was granted for six NHS trusts, this sample size could be seen as a limitation. It can be assumed that the research advert sent out by R&D departments could have reached upwards of 200 staff. Therefore, recruiting only 15 participants could be indicative of limited hoarding-related referrals into services, with few staff having had the required hoarding experience to take part in the research.

Time was also a challenge for staff working in NHS services, which is explored in the *"We're Dealing with People": Service Constraints'* sub-theme. For staff, participating in research may not be a priority, due to the management of their responsibilities and receiving no direct reward. This could indicate that staff have reduced reflective thinking space and effective supervision, as discussed in theme three. Staff shared with the researcher that the interview enabled much needed time to reflect on their clinical cases. NHS staff voices, insights and reflections are crucial to research, and if they are unable to participate due to time constraints, then their voices are being silenced or overlooked.

4.7.2 Participant Demographics

The 15 participants included in the study were from varying professional disciplines. The inclusion of various staff disciplines largely represents how mental health services in the

NHS are structured, e.g. MDTs, and this can increase the study's transferability. Diverse views were obtained and specific professional discipline-based reflections were made. For example, a mental health nurse delivering dementia care notably observed that assistive technology (AT) could be beneficial for hoarding service-users. Therefore, having diversity amongst participants is a strength.

Due to participant ages and the number of service-users they had worked with, it is assumed that staff were experienced clinicians and thus offered rich and in-depth responses. This strengthens the usefulness and reliability of findings, which can be transferred to other services. However, staff were not directly asked how long they had been qualified or worked within their current role. This information should be collated in future research to confidently conclude this suggestion.

Although the experiences of many NHS staff disciplines were included, certain voices, including psychiatry staff, were not. Psychiatrists play a crucial role in the delivery and implementation of mental health services in the UK (Millen et al., 2017) and are likely to have diagnosed and worked with service-users displaying hoarding. Therefore, their inclusion could have offered a valuable differing perspective. This was not an intentional sampling oversight; only certain professions volunteered to take part and psychiatry did not.

Although the sample was diverse in terms of professional discipline, most participating staff members were white British, which is reflective of the population staff were recruited from. This is deemed a limitation due to the lack of racial diversity represented in the sample. In 2023, the NHS Workforce Race Equality Standard identified that nearly 25% of the NHS workforce were from racialised backgrounds. This is particularly important because these staff may hold differing views from their white counterparts, due to their own positionality. Little is known about the prevalence of hoarding behaviour within racialised backgrounds. Therefore, future hoarding-related research would benefit from racially diverse

sampling, in both staff and service-user focussed research, so that differing views can be represented.

4.7.3 Methodology and Transferability

Staff were recruited from a range of mental health services, including adult and older adult CMHTs and other more specialist teams, which is seen as a strength. Furthermore, recruitment was conducted in the southeast and north of England. Taken together, this increases the transferability of study findings and suggests that results are not biased towards one service or one area of England.

Another strength is the researcher's strict adherence to the six stages of Braun & Clarke's (2022) reflexive thematic analysis throughout the study process, which indicates high methodological rigour. The researcher kept a reflective log in each stage of the study process, documenting any biases that emerged, and reflecting upon these. The researcher continued to acknowledge the notion that the "researcher becomes the instrument of analysis" (Nowell et al., 2017, p.2). The semantic and latent approach utilised during analysis further strengthens the findings. The latent interpretations widened the perspective of the data beyond individual experiences (Clarke and Braun, 2018), thus aligning with the critical realist ontological position of conducting explanatory research (Fryer, 2022).

Frost and Hartl's (1996) definition of hoarding was used as a preliminary screening checklist, where staff were asked if the definition aligned with service-users' hoarding symptoms they had worked with. While this was a helpful prompt, staff ultimately used their clinical judgement to confirm hoarding prevalence in service-users. While some staff mentioned using the Clutter-Image-Rating-Scale (Frost et al., 2008) and the associated number, to depict the varying amounts of clutter the person had acquired, the majority of staff did not use any official hoarding screening tools or objective measures in their services. Therefore, hoarding severity could have varied greatly across staff accounts. Lack of

appropriate screening is commonly encountered in clinical practice and research due to the lack of clear conceptualisation of hoarding, and previous classification under OCD (Frost et al., 2012); therefore, it requires further research attention.

A further limitation was the use of retrospective accounts, which was problematic when staff could not recall exact details of their work completed with service-users. This led to some missing service-user information, including the age of onset of hoarding behaviour and its severity, which could have impacted participants' views.

The current study focussed on NHS staff experiences of working with service-users with hoarding behaviour; however, there was no service-user involvement in the development of the methodology. Service-user involvement in health-related research has several benefits, including improvements in information and accessibility of services, and strengthening the therapeutic relationship (Omeni et al., 2014). Both of which are highly relevant for the hoarding population. Despite the lack of active service-user involvement, the researcher aimed to capture the lived experiences and crucial voices of hoarding individuals into the research via the literature review presented in chapter one. Future work should expand upon the limited exploration into perspectives of hoarding individuals accessing mental health services, to improve service-provision and knowledge about hoarding.

Finally, the novelty of the current study is deemed an overall strength. To the researcher's knowledge, this is the only study in the UK investigating this area of enquiry. By exploring NHS mental healthcare staff experiences of working with hoarding behaviour, it has offered insights that have often been overlooked. These experiences highlight implications for the service-user, staff member and for service-delivery initiatives, which will now be explored.

4.8 Implications and Recommendations

4.8.1 Clinical Level

4.8.1.1 Formulation-Driven Support and Accessing Help for Service-Users. This study has highlighted the importance of psychological formulation principles for use with service-users presenting with hoarding behaviour. Formulation aided successful treatment outcomes and created a shared understanding of the difficulties with service-users, the service, and other agencies. The findings indicated that the CBT for HD formulation model (Frost & Hartl's,1996), the 5 Ps model (Dudley & Kuyken, 2014), and a needs-based approach (James & Birtle, 2020), were all appropriate for use with hoarding difficulties. Services, and appropriately trained staff, should apply these models in a person-centred way. Adaptations to usual practice should be considered depending on service-user need. For instance, some staff felt that reasonable adjustments should be made for neurodivergent populations to enhance their engagement. Therefore, a consideration of individual needs is paramount to working with hoarding populations.

Building rapport and trust was essential to working with hoarding service-users, and this generally took more time to achieve, than services permitted. Appreciating the personal value of hoarded possessions, and using humour as a way of engagement, helped to strengthen the relationship. Stigma acted as a barrier to service-users seeking support, with the suggestion from other research that public stigma could become internalised as self-stigma (Chasson et al, 2018; Corrigan et al., 2015), leading to fear and perceived judgement from professionals. Due to the secretive nature and the difficulties faced when disclosing hoarding behaviour, services should ask directly about hoarding-related concerns as part of the mental health assessment process. This might combat disclosure difficulties, by normalising and destigmatising the behaviour, and improve early identification of hoarding. Timely referrals can then be generated, while the therapeutic relationship can be developed.

The suggestions listed should be applied for use with hoarding populations to support engagement with mental health services, as well as informing treatment options and outcomes.

Furthermore, the findings illustrated that service-users required support to find motivation to make changes. Tolin et al., (2010) proposed that hoarding individuals are likely to be in the 'precontemplative' phase of the Transtheoretical Stages-of-Change Model (Prochaska & DiClemente, 1982) and therefore will likely refuse treatment. Prochaska and Velicer (1997) suggest that individuals could be under-informed about the consequences of their behaviour and hence are reluctant to take action. Therefore, staff and services should aim to understand service-users' motivation, provide meaningful psychoeducation and support them to make changes.

4.8.1.2 Multi-Agency Working & Staff Support. Important implications for how staff can feel supported when providing care to hoarding service-users are considered. At a clinical level, staff encountered difficulties acting as the sole professional. They expressed uncertainty regarding their role, being kept at 'arm's length' by service-users, and receiving conflicting advice. They stressed the importance of team working, including being in an MDT and utilising multi-agency connections. The specific skills of each professional discipline were essential to assess, formulate, coordinate, and provide meaningful person-centred interventions to hoarding service-users. Ecological systems theory (Bronfenbrenner, 1992) usefully identified how staff can use their skills across multiple system levels to view the person within their wider context e.g. at individual, family and community levels. Challenges that need to be addressed included agencies moving towards viewing hoarding as a mental health concern and improving communication and collaboration across disciplines and services. Furthermore, referral pathways for appropriate support need to be more accessible to staff to aid transparency across services.

Staff reported vulnerability working with hoarding behaviour and the associated risk concerns, including fire, falls, poor food hygiene and infestations. Research suggested that quality clinical supervision (Edwards et al., 2006) and use of reflective practice spaces (Onyett et al., 2011) increased job satisfaction and lowered burnout among professionals. Supervision was not explicitly explored in this study; however, due to the general lack of understanding about the onset and treatment of hoarding, supervision could be reflective of this and be of low quality. Supervision and reflective practice provision should be reviewed, taking into account the training recommendations outlined in the section below.

4.8.2 Policy Level

4.8.2.1 Access to Training Initiatives. This study, along with other study findings (Tinlin, 2022; French et al., 2022), recommends increased hoarding-related training initiatives. Staff reported a lack of specific hoarding training, which had implications for understanding and treating the disorder. Without training, support and guidance, staff felt as if they were 'going it alone', resulting in feeling ill-equipped. The psychology-led multi-agency model proposed by Caiazza et al., (2018) should be considered for widespread use across mental health services. The model proposes psychoeducation delivery to staff, along with person-centred formulation, while promoting collaborative working with multiple agencies. Furthermore, due to the relatively recent DSM-5 update classifying HD as a diagnosis (APA, 2013), the implementation of training to NHS mental health services nationally is crucial to upskill staff, increase their confidence and improve understanding of hoarding (French et al., 2022).

4.8.2.2 A Call for Action. The current study has identified numerous gaps in service-provision for both service-users seeking support and for NHS mental healthcare staff working with hoarding presentations. Despite the recent increase in research, there has been little

consideration for how theoretical ideas can translate into practice. Staff have made admirable attempts in their roles to understand and treat hoarding behaviour; however, they have overwhelmingly reported that more support and training is required. The BPS (2024) echo this by stating that staff working with hoarding should have access to specific training. To date, there are no clinical NICE guidelines for the care and treatment of service-users with HD presenting in mental health services, despite its classification as a mental health diagnosis (McGrath et al., 2024).

This study recommends bridging the gaps identified by research into clinical practice within mental health services, and for these to be considered at policy level. These include developing best practice guidelines and training initiatives that can be shared amongst mental health providers. Services should provide support, reflective practice and quality supervision, to manage the complexity, difficult emotions and role confusion that is currently present working with hoarding individuals. These recommendations hope to inform and update mental health service provision by creating a shift towards viewing hoarding as a mental health diagnosis. The ultimate aims are for hoarding behaviour to be better understood and for service-users to have increased access to services and improved treatment outcomes.

4.9 Future Research

The current study indicates multiple areas of exploration for future research. The first is to gain an in-depth understanding from the perspective of service-users about their experiences of accessing NHS mental health services and working with staff. McGrath et al., (2024) have begun this area of enquiry; however, they explored experiences of help-seeking more generally, and not directly with NHS mental health services. Due to the classification of HD as a mental health condition, it seems appropriate to conduct research from the perspective of individuals seeking support, to identify barriers to accessing NHS services and target ways of improving these. Furthermore, McGrath et al., (2024) found that individuals

with hoarding behaviour had often received poor support from services and they recommended that further exploration into the role of the therapeutic relationship would be helpful. Staff within this study viewed the therapeutic relationship as crucial to engaging service-users, with some recommendations for how to facilitate this. However, the therapeutic relationship was not explicitly investigated; therefore, future research could explore the therapeutic relationships and facilitators of rapport from service-user perspectives. Due to the complexity and poor treatment outcomes associated with hoarding behaviour, service-users' preferences for treatment should be examined. Robertson et al., (2020) corroborate this and suggest that, by exploring preferences, options to alternative treatment could be discovered.

Secondly, future research should continue to investigate the experiences of NHS mental health staff working with hoarding presentations. Specific exploration into hoarding-related stigma amongst staff should be considered. Biases, judgements and stigmatising attitudes towards mental illness more generally were highlighted, with negative implications for service-users seeking help and accessing treatment (Sreeram et al., 2022).

Furthermore, in acknowledgement of the study limitations, future research should aim to include all professional views, including psychiatry. This will capture crucial staff voices and therefore offer further valuable perspectives. The use of a different methodological approach, namely focus groups could also facilitate inclusion of different perspectives. For example, interviewing MDTs or multi-agency groups could help to ascertain staff and service-user needs from multiple angles.

Finally, future hoarding-related research would benefit from racially diverse sampling across professional and service-user perspectives. At present, little is known about the prevalence of hoarding in racialised backgrounds, which highlights the discrepancies in these groups accessing healthcare and challenges specifically related to disclosing hoarding

behaviour. The current study's sample was not representative of the racially diverse workforce present in NHS services, which contributes to lack of diverse perspectives in research, and ultimately healthcare provision.

4.10 Researcher Reflections

As I reflect on the overall process of completing this research, I am aware of how my own biases have shifted. Prior to, and during the project, I have remained interested in hoarding presentations; however, I acknowledge my own discomfort in how I thought other people viewed these individuals. Before the interviews, I assumed that staff would speak negatively and perhaps use language with connotations of shame and disgust. The reverse in fact occurred, with staff speaking with care, compassion and thoughtfulness regarding the service-users they had worked with. Upon reflection, I now consider that my biases were perpetuated through media representations of hoarding, which can label, stigmatise and dramatize people's experiences.

Negative perspectives that did emerge from interviews were that of frustration due to staff not having enough time, support or training to feel properly equipped to work with hoarding individuals. As a researcher and as a clinician, these reflections resonated with me and I noted the misalignment between the research findings and how this translates into clinical practice, as highlighted in the policy implications above. This study was not the first to highlight the importance of multi-agency working (Bratiotis and Woody, 2020), staff support (Johnson et al., 2018) and training (Tinlin, 2022); however, little progress towards implementing training initiatives, service-level support and national guidance, has occurred. Smith (2001) helpfully reflect on their feelings towards working with hoarding clients and state that "the danger faced…is to quickly launch into doing something, as to do nothing feels unbearable" (p.54), which I believe was a concern present for participating staff, and for me in my dual role as a researcher and clinician undertaking this research.

I have learnt a great deal both professionally and personally during this research. Professionally, I have been able to appreciate the value of applying research skills within a clinical context. My research has highlighted complexities in service-design and treatment implementation for service-users with hoarding presentations, specifically relating to difficulties accessing services and the stigma this group encounters. The research has highlighted values I hope to adopt within my career as a soon to be qualified clinical psychologist. These include implementing staff support, reflective practice, training, team working and multi-agency approaches, as ways to remain compassionate in the face of complex presentations, such as hoarding. Personally, I am honoured to have interviewed staff and heard their unfiltered experiences of their challenging and complex work. I am pleased to have identified key areas of improvement for service-delivery and future research. I believe this research has given voice to an under-researched field and I hope it will contribute to supporting NHS mental healthcare staff working with service-users who hoard and in turn lead to better outcomes for this service-user group.

4.11 Conclusion

To conclude, this study is believed to be the first in the UK to explore NHS mental healthcare staff experiences of working with service-users who display hoarding behaviours. The previous limited existing literature has predominantly explored professionals' experiences of working hoarding behaviour with older adult service-users and using quantitative methodology. Therefore, this study provided original contribution by qualitatively exploring staff experiences of working with adult hoarding service-users across services for adults and older adults. Fifteen participants were recruited from a range of mental health services in England. Reflexive thematic analysis was used and five main themes and fifteen subthemes were found.

The findings highlighted ways staff understood hoarding behaviour, including consideration for the numerous contributing factors associated with its onset and maintenance. Staff identified psychological models to aid their understanding of hoarding, with links made to addiction and stages of change models. There was ambiguity regarding appropriate treatment for hoarding, but adopting multi-agency approaches was viewed as optimal to meet service-users' needs effectively. The findings illustrated the importance of moving towards viewing hoarding as a diagnosis, due to the complexity service-users present with. The findings demonstrated a necessity for training and increased awareness of hoarding amongst professionals. Hoarding was perceived as a stigmatised condition, which resulted in limited access to services. Ways of facilitating support were proposed, including building a trusting therapeutic relationship. The research has generated numerous clinical and policy level implications. Namely, establishing formulation-driven support, adopting multi-agency approaches, increasing staff support and training, and developing best-practice guidelines to equip staff and ultimately support service-users with hoarding presentations. Overall, this research has added novel and important findings to the existing evidence-base.

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Appendices

Appendix A

Diagnostic and Statistical Manual 5 (DSM-5) Criteria for Hoarding Disorder (APA, 2013)

DSM-5 Criteria	Descriptor
Criteria A	Persistent difficulty with discard of objects or possessions, regardless of their actual value.
Criteria B	Difficulties with discard are due to a perceived need to save the possessions and due to the distress created by discard.
Criteria C	Accumulation of clutter that congests living areas and compromises the functioning of the living area.
Criteria D	Presence of clinically significant psychological or emotional distress or impairment to social or work functioning (or any other area).
Criteria E	The hoarding is not attributable to any other medical condition.
Criteria F	The hoarding is not better accounted by the symptoms of another mental health problem

Appendix B

Differences between 'Organic' Accumulation and Hoarding Disorder (Snowdon et al., 2012, cited in Stumpf et al., 2018).

	"Organic" accumulation	**Hoarding Disorder**
Onset	Generally sudden in cases of brain damage. Can be more insidious if secondary to a dementing process	Insidious. Usually starts in childhood/adolescence and has a long natural history
Ability to discard hoarded items	Variable (some people are able to discard their possessions easily or do not care if others discard them, while others are very reluctant)	Inability to discard hoarded items is a core feature of hoarding disorder
Nature of acquiring behaviour	Generally indiscriminate, but can be more selective acquisition of specific items, e.g., umbrellas, or according to their shape/colour) in some cases	Items are always acquired/hoarded according to their perceived intrinsic, practical, or emotional value, but can be more indiscriminate in some cases
Utility of hoarding behaviour	Often purposeless (individuals display little or no interest in the accumulated items) and items seldom used	More purposeful (items are hoarded for specific emotional or practical reasons), although items are often not used
Hoarded items	Any item, including rotten food	Any item, although hoarding of rotten food is rare
Squalor and/or self-neglect	Frequent (especially in cases of dementia)	Thought to be relatively uncommon, although more research is needed
Associated features	Severe personality changes, as well as behaviours commonly attributed to brain dysfunction such as pathological gambling,	No severe personality changes or other behaviours clearly attributable to brain dysfunction. Excessive

	inappropriate sexual behaviour, compulsive shopping leading to financial difficulties, theft, stereotyping, tics, and self-injurious behaviours	acquisition, shopping, and stealing may be present.
Cognitive processes and motivations for hoarding	Hoarding apparently devoid of identifiable cognitive and emotional processes, although more research is needed	a) Information processing deficits: decision making, categorization, organization, and memory difficulties; b) emotional attachment to possessions; c) behavioural avoidance; d) erroneous beliefs about possessions
Insight and help-seeking behaviour	Insight poor or absent. Patients seldom seek help	Insight ranges from good to poor or absent. Initially, hoarding behaviour can be ego-syntonic; it becomes increasingly distressing as clutter increases. Help-seeking is probably related to the degree of insight
Prevalence	Unknown (<1%)	Approximately 2-5%
Genetic	Unknown, but there are anecdotal reports of relatives independently living in squalor	Yes. Hoarding disorder tends to run in families and appears to be moderately heritable

Appendix C

Health Research Authority (HRA) Ethical Approval

Miss Gemma Allen
Trainee Clinical Psychologist
Essex Partnership University Foundation Trust
Professional Doctorate in Clinical Psychology, School of Health and Social Care
University of Essex, Colchester Campus
Wivenhoe
CO4 3SQN/A

Email: approvals@hra.nhs.uk

30 August 2023

Dear Miss Allen

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**NHS mental healthcare staff experiences of working with individuals with hoarding behaviour.**
IRAS project ID:	**327831**
REC reference:	**23/HRA/3378**
Sponsor	**University of Essex**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix D

University of Essex Sub Committee 2 Ethical Approval

University of Essex

01/09/2023

Miss Gemma Allen

Health and Social Care

University of Essex

Dear Gemma,

Ethics Committee Decision

Application: ETH2324-0094

I am pleased to inform you that the research proposal entitled " NHS mental healthcare staff experiences of working with individuals with hoarding behaviour." has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

Dr Aaron Wyllie

(a.wyllie@essex.ac.uk)

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

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Appendix E

Health Research Authority (HRA) Ethical Amendment Confirmation

Subject: IRAS 327831. Amendment
Date: Monday, 10 June 2024 at 15:02:52 British Summer Time
From: no-reply-IRAS
To: Allen, Gemma S

IRAS Project ID: 327831
Sponsor amendment reference: ETH2324-0094

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

Appendix F

University of Essex Sub Committee 1 Ethical Amendment Approval

University of Essex

05/08/2024

Miss Gemma Allen

Health and Social Care

University of Essex

Dear Gemma,

Ethics Committee Decision

Application: ETH2324-1785

I am pleased to inform you that the research proposal entitled " NHS mental healthcare staff experiences of working with individuals with hoarding behaviour." has been reviewed on behalf of the Ethics Sub Committee 1, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance team

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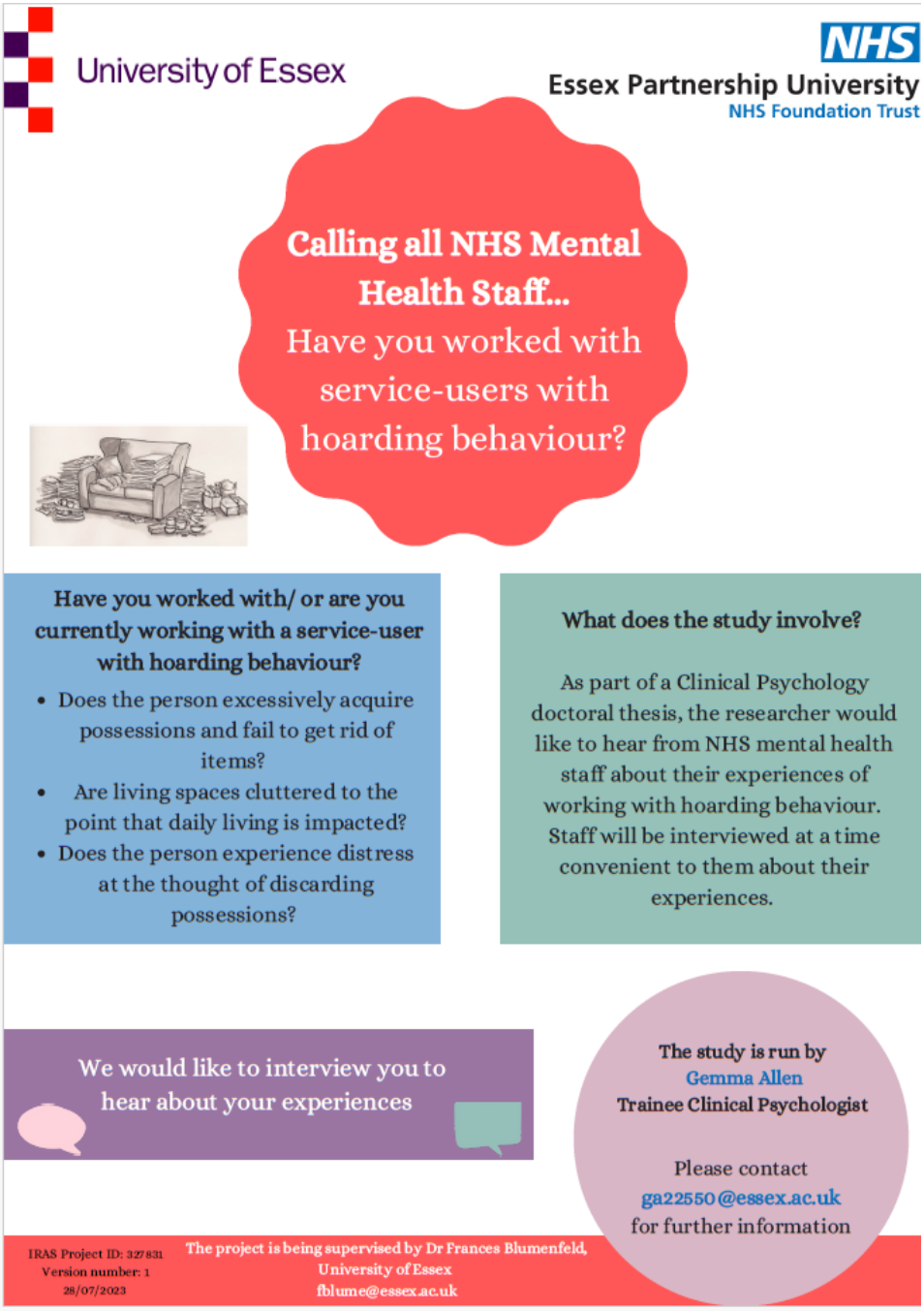
Appendix G

Research Advert



Appendix H

Informed Consent Form

University of Essex

Consent Form

Title of the Project: NHS mental healthcare staff experiences of working with individuals with hoarding behaviour.

Research Team: Gemma Allen

Ethics reference number: 23/HRA/3378

Please initial box

1. **I confirm that I** have read and understand the Information Sheet for the above study to explore NHS mental health staff experiences of working with individuals with hoarding disorder or hoarding behaviours through one-to-one interview. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. 

2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any information collected up to the point of my withdrawal will be kept, however this will be anonymised using a pseudonym. 

3. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. 

4. I understand that my fully anonymised data will be used for a Doctoral thesis, research publications, and scientific conferences. 

5. I understand that the data collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

6. I understand that the researcher might use direct quotes from the interview for the purposes of the write-up. However, these will be kept to a minimum and confidentiality will be ensured with a pseudonym.

7. I agree to take part in the above study.

Participant Name	Date	Participant Signature
_____	_____	_____

Researcher Name	Date	Researcher Signature
_____	_____	_____

1 copy for researcher 1 copy for participant

Consent form (V1)
IRAS Project ID: 327831
28/07/2023

Appendix I

Participant Information Sheet

University of Essex

Participant Information Sheet

Project Title: NHS mental healthcare staff experiences of working with individuals with hoarding behaviour.

Ethics reference number: 23/HRA/3378

My name is Gemma Allen and I am a Trainee Clinical Psychologist at the University of Essex. I am conducting my thesis project and I would like to invite you to participate and share your views. Prof Frances Blumenfeld is supervising the project.

What is the purpose of the study?
I am conducting a study into the experiences of NHS mental health staff who have worked with or who are currently working with adult and/or older adult service users who present with hoarding behaviours or who have hoarding disorder.

Hoarding can be defined as service-users who have persistent difficult getting rid or parting with possessions due to a perceived need to save the items. Attempts made to part with possessions create considerable distress and lead to decisions to save them. The resulting clutter disrupts the ability to use living spaces (American Psychiatric Association, 2013).

The present study is a thesis project being undertaken as part of a Doctorate in Clinical Psychology.

Why have you been invited to participate?

I am inviting you to take part in this study because you are a mental healthcare staff member who has had experience of working with individuals who hoard.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part in this research study. If you do decide to take part, you will be asked to provide signed consent. You are free

to withdraw from the study at any time, without giving a reason, however the information we already have about you will be kept. You do not need to give a reason for withdrawing. Withdrawal will have no impact on your work within the service.

What will happen to me if I take part?

If you agree to participate you will be given a copy of this information sheet and asked to sign a consent form. You will then be asked to take part in a one-to-one, semi-structured interview. These will take place either in person on an NHS Trust site, or by video- call technology such as Microsoft Teams or Zoom. Interviews will take no more than 1 hour. Interviews will be recorded. You will only be interviewed once.

I will ask you a series of questions about your experiences of working with a service-user(s) with hoarding behaviours or hoarding disorder. Some of these questions will also ask about how this work may of affected you whilst working with the service-user(s). If you would like to see some specific examples of the questions I will ask, I can give you some now before you decide to take part. **If you feel uncomfortable with any of the questions you do not have to answer them.** If you want to stop the interview you can do so at any time without giving us any reason. Due to the nature of an interview, the direction of the discussion can be unknown, therefore we reiterate that you can withdraw at any point up until data analysis commences.

What are the possible disadvantages and risks of taking part?

We will be asking you about your experiences of working with a service-user(s) with hoarding behaviour or hoarding disorder. If you become distressed during the interview you can withdraw at any time. There will be time to discuss any concerns you have after the interview with the interviewer. Should you require further support please see the information listed below which can also be found online and on the EPUT intranet.

Here for you:

We would like to remind all staff that everyone has free access to 'Help' (staff counselling and support). Helpline number 0344 257 3960. Alternatively, you can email hereforyou@nhs.net (this is monitored 9am-5pm Monday to Friday).

What are the possible benefits of taking part?

If you take part, you will be helping to expand the research within this small but growing research field. The findings of study will aim to identify recommendations for future service-development and equip staff effectively in working with this client group.

How will we use information about you?

We will need information from you for this research project. This information will include your name, age, sex, profession/job title and ethnicity. The only people who will have access to your personal information are my supervisor and I. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead. We will keep all information about

you safe and secure. An audio recording of the interview will be collected by video-call technology or a dictaphone and the interview will be transcribed by the lead researcher. The transcription will be completely anonymous and names will be removed or a pseudonym will be allocated.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is being used?

You can find out more about how we use your information by asking one of the research team – please send an email to ga22550@essex.ac.uk or Frances Blumenfeld on fblume@essex.ac.uk.

The sponsor's data protection officer can be contacted by emailing dpo@essex.ac.uk

Will my information be kept confidential?

Yes, all information you give us is kept strictly confidential. Only the researcher who interviews you will have access to personal information about you, and no other party will have access to information that is identifiable or can be linked back to you. However, if you tell us something that makes us think either you or someone else is at serious risk of harm, we are obliged to share this information.

When the interview is typed up, all personal details, like specific names of people and places, will be removed making the transcription anonymised. A pseudonym will be used at the point of transcription and to identify your data. Quotations of interviews will also be included in the write-up of the study, however these will be kept to a minimum and confidentiality will be ensured.

All the information about you will be anonymous; no one else will be able to identify you in any publication. All information collected will be securely held at the University of Essex. We will handle your data in compliance with the Data Protection Act 2018. Three years from the end of the study, the information will be deleted from the university computers, and any paper records will be destroyed.

What should I do if I want to take part?

If you would like to take part in the research study, please contact the principal researcher (Gemma Allen) by email. You will then be given a copy of this sheet and be asked to sign a consent form.

What will happen to the results of the research study?

The results of the study will be reported in a Doctoral thesis. They will also published in scientific journals and presented at scientific conferences. You will not be identified in any report or publication.

Who is funding the research?

The study is organised by Gemma Allen, a DClinPsy student at the University of Essex, and is funded by the Essex Partnership University NHS Trust.

Who has reviewed the study?

The study has been reviewed by the research ethics board of the University of Essex and the Health Research Authority (HRA) provide the governance for this project.

Ethics reference number: 23/HRA/3378

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the chief investigator of the project, Gemma Allen, using the contact details below. If are still concerned, you think your complaint has not been addressed to your satisfaction, or you feel that you cannot approach the principal investigator, please contact the supervisor responsible for this project, Dr Frances Blumenfeld (fblume@essex.ac.uk) or the department Director of Research for the School of Health and Social Care Professor, Camille Cronin (Camille.cronin@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (e-mail sarahm@essex.ac.uk). Please include the ethics reference number which can be found at the top of this document.

Name of the Researcher/Research Team Members

Gemma Allen
Email: ga22550@essex.ac.uk
School of Health and Social Care, University of Essex, Colchester Campus
Wivenhoe, CO4 3SQ

Appendix J

Interview Schedule

University of Essex

NHS Mental health staff experiences of working with individuals with hoarding behaviour.

Interview Schedule

Initial and demographic questions of the participating staff member:

- Demographics of staff member – Job title, brief role description, age, ethnicity, gender
- Service context at the time of working with the client with hoarding behaviour/hoarding disorder
- How many service-users have you worked with who have displayed hoarding behaviours or hoarding disorder?

Questions relating to the service-user: *Ask participant to use a pseudonym and to not disclose unnecessary identifiable information.*

- Gender and ethnicity of the service-users
- Were they referred into the service due to their hoarding or were they accessing the service for another reason / co-morbidity?
- Age of the service-user(s) at time of accessing the service?
    - If known, what was the service-users age at the time of onset of symptoms?
- Had the service-user(s) ever received support/intervention for their hoarding behaviour in the past?

Interview Questions:

1. What did you initially observe about the person with hoarding behaviour/hoarding disorder?

    Prompts:

- Social isolation?
- Risk – falls, neglect, physical health, poor hygiene, fire risk, risk to self/others?
- Hopelessness

- Mental health presentation? Depression, anxiety, trauma?

2. What were your personal reactions to the hoarding behaviour?
   Prompts:
   - Condition of the home
   - Emotional response (e.g., frustration, helplessness, anger)
   - Your own safety/ health?

3. What do you think the service-user(s) reasons were for hoarding? Or the cause of their hoarding?
   Prompts:
   - Values linked to saving possessions?
   - Unmet needs?
   - Loss / grief / trauma?
   - Cognitive behavioural model (e.g., information processing deficit etc.)

4. What did the service you were working in offer / provide for the person with hoarding behaviours?
   Prompts
   - Assessment
   - Formulation
   - Intervention (e.g., CBT)
   - Links to local authority
   - Signposting to other services

5. How confident as a mental health professional were you to work with and support someone with hoarding behaviours /hoarding disorder?
   Prompts:
   - Skills, knowledge
   - Support from MDT / supervision
   - Access to training?
   - Ability to assess or provide intervention?

6. What are/were the barriers to working with someone with hoarding behaviour / hoarding disorder?
   Prompts:
   - Client complexity (risk, interpersonal concerns)
   - Comorbidity (mental health, physical health)
   - Multi-agency working? (lack of coordination, differing perspectives?)
   - Service- context (time constraints?)

7. From the perspective of the person with hoarding behaviour, how do you think they found the support from mental health services?
   Prompts:
   - Supported / unsupported?
   - Understanding / lack of understanding?
   - Trust / sense of mistrust from professionals?

- What do you think the service-user felt about you and your role? E.g. Helpful/unhelpful?
- Discharge circumstances?

8. What treatment approach do you think would have been beneficial for the service-user(s)?
   Prompts:
   - Support systems (utilising family, friends, neighbours)
   - Meaningful activity
   - Discarding
   - CBT
   - Monitoring progress

9. How would you describe your therapeutic relationship with the service-user(s) with hoarding behaviour/ hoarding disorder?
   Prompts:
   - Trust
   - Listening
   - Time
   - Engagement

10. Had you as a mental health professional had any training?

11. What were your needs as a professional, what could the service have provided you with?

12. What skills helped you to work with the service-user(s)?

    - Profession specific?
    - Did you feel more/less equipped?

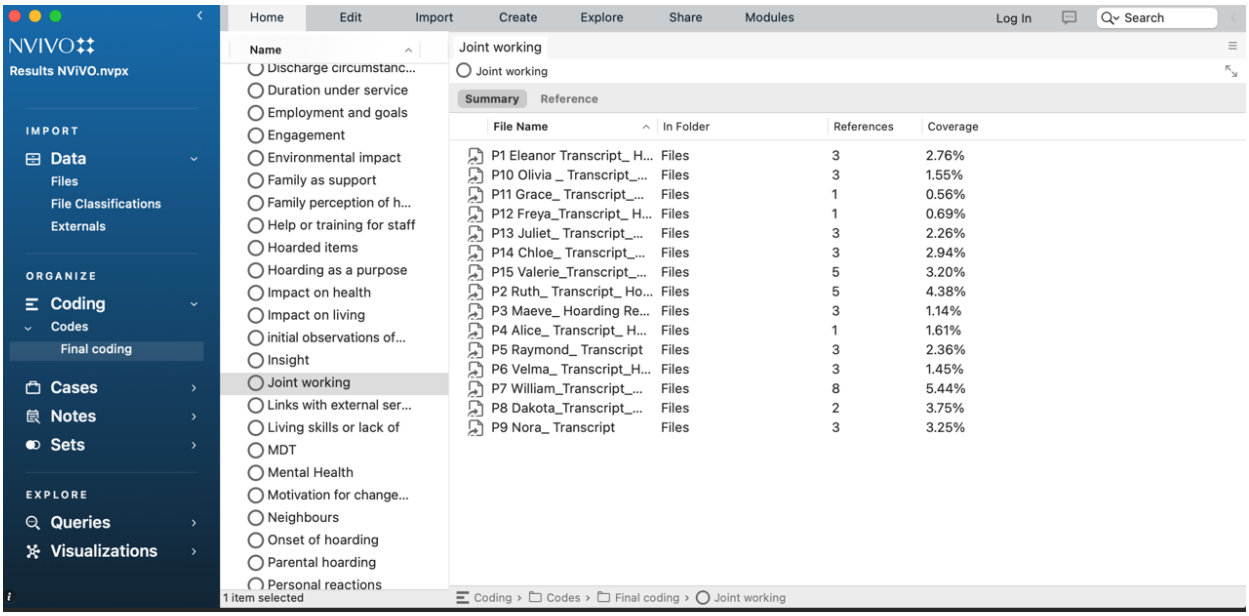
Thank you for your engagement during this interview.

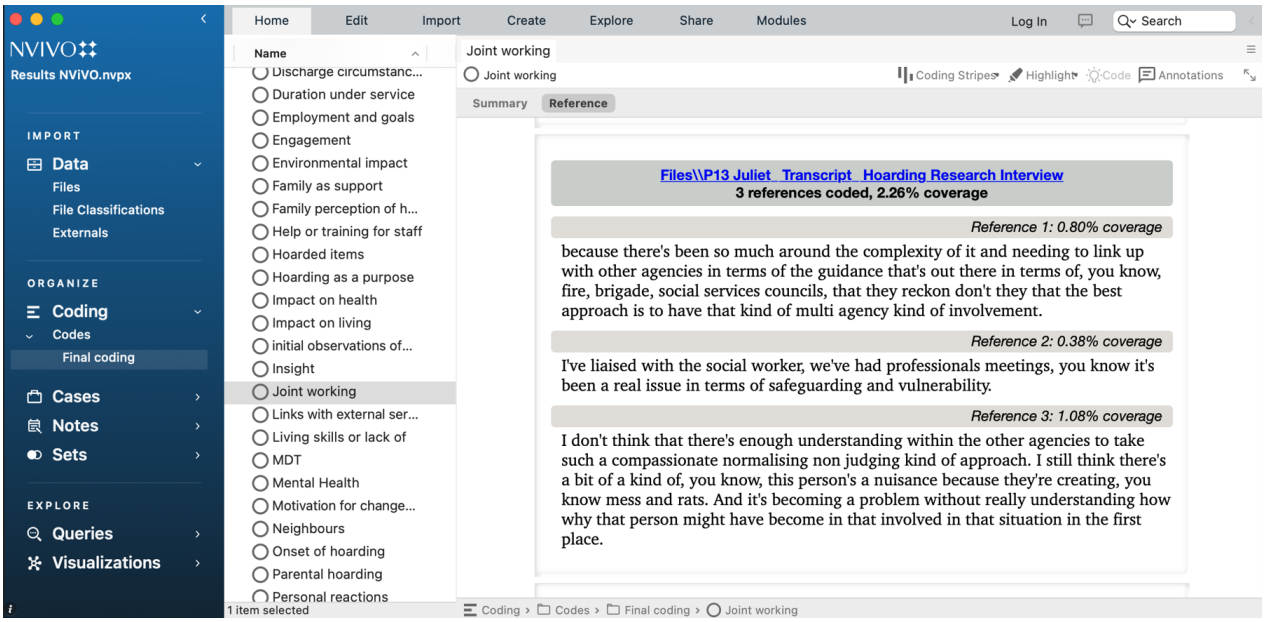
Do you have any questions or anything you would like to add.

If you require any time to debrief or would like access to other services/ sources of support following this interview, then please let me know.

Appendix K

NViVO Software Coding Example



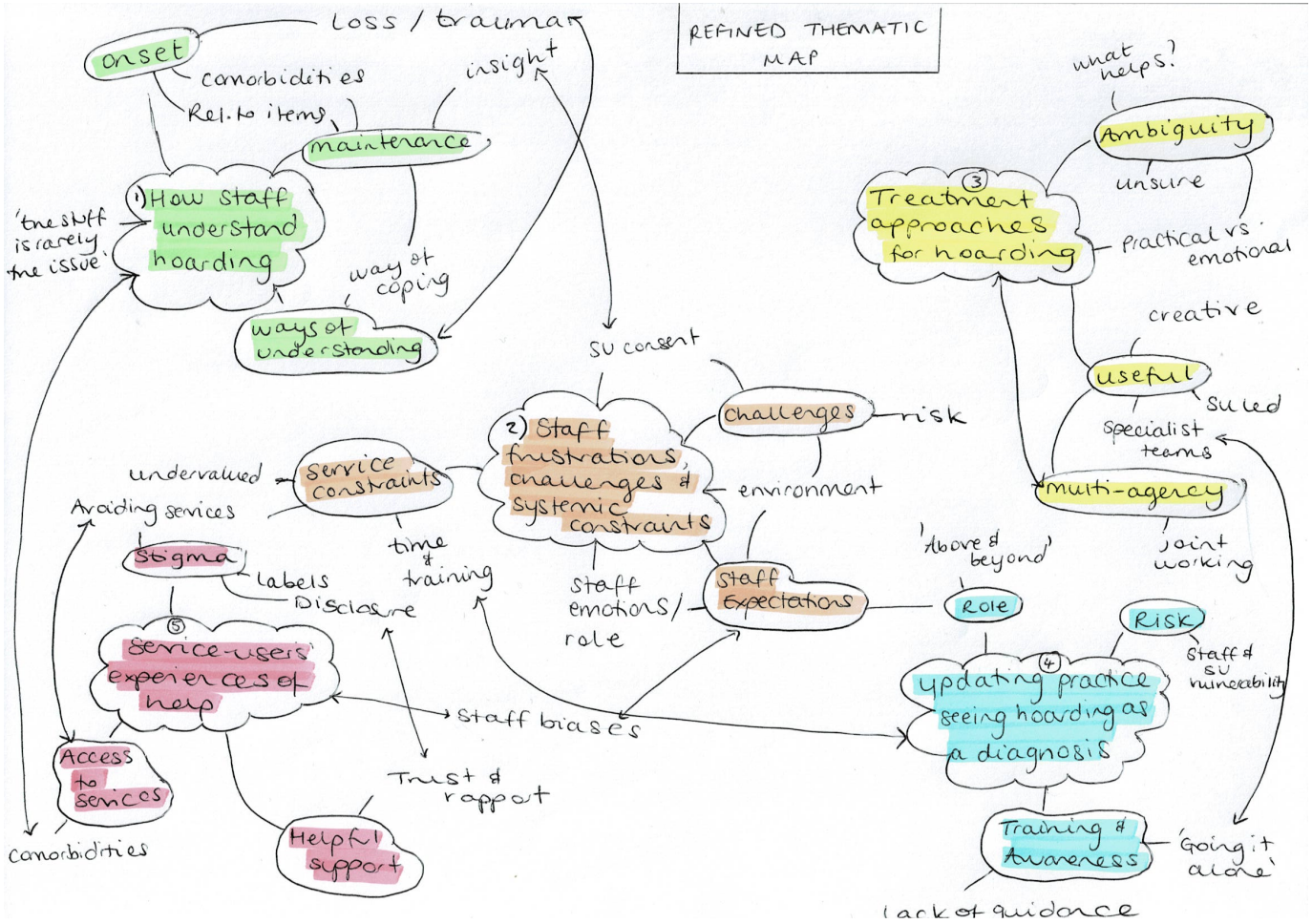


Appendix L

Visual Map of Manual Theme Development

Appendix M

Refined Thematic Map



Appendix N

Cognitive-Behavioural Model of Hoarding Disorder Symptoms, (Frost & Hartl, 1996, Steketee & Frost, 2003, cited in Wheaton et al., 2016)

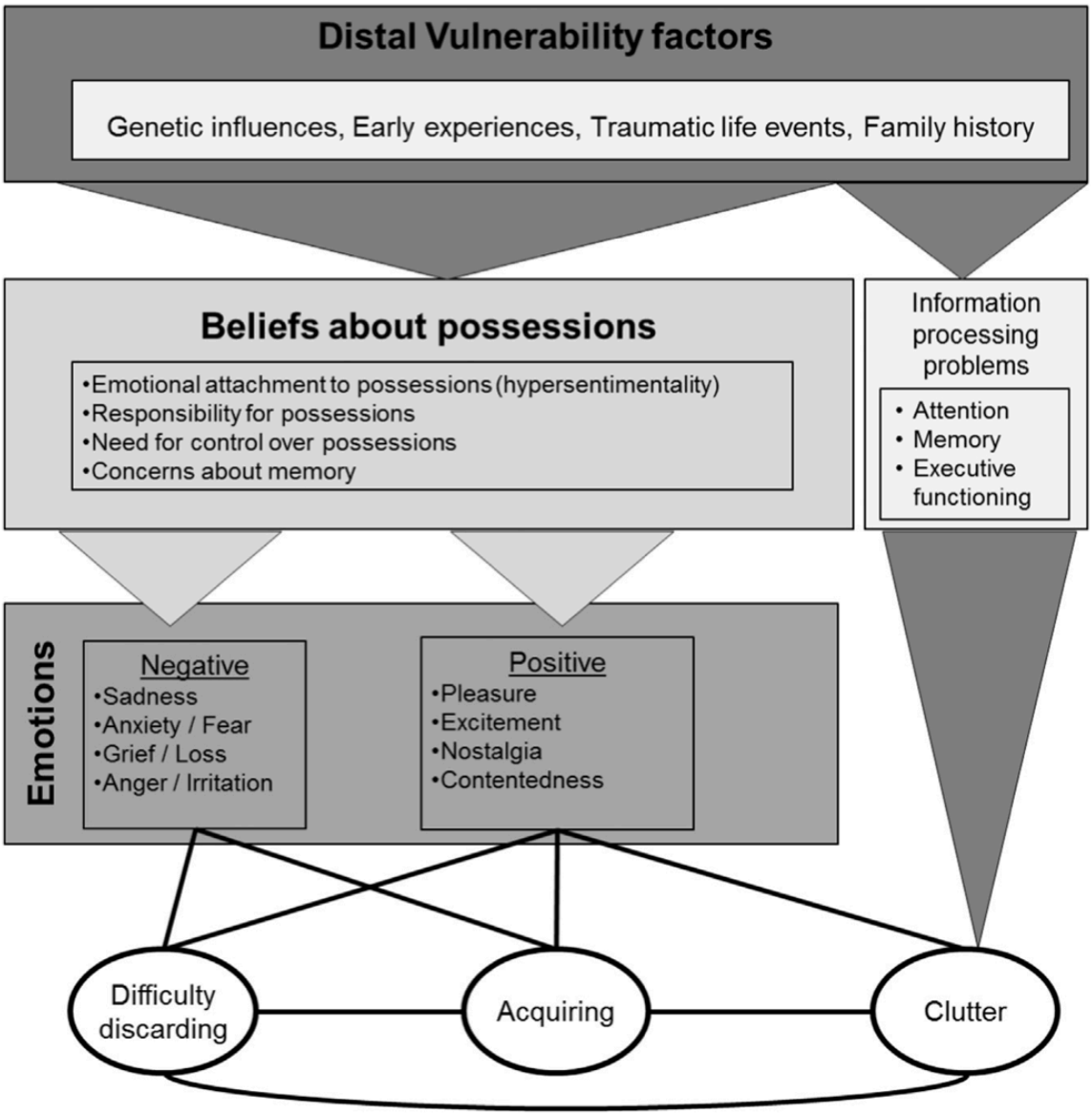


Fig. 1. Cognitive-behavioral model of hoarding disorder symptoms.