Exploring the Wide-Ranging Outcomes of Hoarding Disorder: Understanding the Extent of Its Comorbidity with Other Mental Health Conditions and Its Impact on Childhood Development

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Thesis Portfolio Abstract

Hoarding disorder (HD) is a persistent and disabling mental health condition, associated not only with a considerable negative impact on the affected individual but also with the ability to negatively affect multiple systems around them. The current thesis portfolio aimed to explore, two distinct, yet interconnected aspects of complexity and vulnerability in HD: one at the individual level, focusing on the presentation profile of the condition, and the other within the family system, evaluating its impact on others from a systemic perspective. The systematic review used narrative synthesis to examine mental health (MH) comorbidities in HD, excluding conditions for which the co-occurrence with HD has either already been established or would be expected. The empirical chapter was a study of the childhood experiences of young adults (18-30 years old) who had grown up with a relative who hoarded. Semi-structured interviews were conducted with participants, and these were analysed using reflective thematic analysis. The systematic review suggested that the following MH conditions could co-occur with HD: disorders specifically associated with stress, bipolar and related disorders, personality disorder, eating disorders, disorders due to substance use or addictive behaviours, schizophrenia or other primary psychotic disorders and obsessive-compulsive and related disorders. The qualitative study produced six themes: (1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager; (2) A different type of childhood: on anxiety, fear and stress; (3) My needs: was there ever enough room for me?; (4) Alone with it: on helplessness, feeling alone and the silence of others; (5) Wait, was I ever a child?: on growing up early; (6) Who have I become?. Taken together, these findings enhance the current understanding of HD, providing new insights into how its complexity and vulnerability could manifest at multiple levels.

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CHAPTER 1: Introduction to the Thesis Portfolio

Introduction to the Thesis Portfolio

What is Hoarding Disorder and How Does it Impact Individuals?

Hoarding disorder (HD) is a psychiatric condition that has been defined as the persistent difficulty discarding or parting with any possessions, leading to the excessive accumulation of belongings and severe clutter, causing the congestion of living areas (World Health Organization [WHO], 2019). Additionally, it is characterised by a perceived need to save items and distress associated with discarding them. It is often accompanied by limited or no insight into why the behaviour is problematic (Greenberg, 1987).

HD is a disabling condition, associated with specific and considerable negative effects on the individual's psychosocial, occupational, and family functioning (Ong et al., 2015). Individuals also report lower quality of life as compared to both healthy controls (Tolin et al., 2019) and non-hoarding Obsessive-Compulsive Disorder (OCD) patients (Saxena et al., 2011). The latter distinction is particularly significant, as HD was historically classified as a symptom of OCD rather than a separate mental health condition. Critically, HD symptoms predict disability even when controlling for demographic factors and other comorbid conditions, with the magnitude of the association being comparable to other high-disability burden conditions such as major depressive disorder (MDD), diabetes, and chronic pain (Nutley et al., 2022).

The disorder has a developmental presentation and has been estimated to affect approximately 2.5% of the population, with similar rates for males and females (Postlethwaite et al., 2019). Its symptoms typically emerge during childhood or adolescence with research suggesting that 60% of cases report symptom onset by age 12, increasing to 80% by age 18 (Grisham et al., 2006).

Despite its early onset, HD is frequently undiagnosed and untreated (Morein-Zamir & Ahluwalia, 2023). During the early years, symptoms may remain unnoticed due to external pressures on children to keep living spaces tidy and their relatively limited financial means to accumulate items (Storch et al., 2011). The combination of the individual's attenuated insight and the insidious nature of the disorder means that the excessive accumulation becomes more pronounced over time, while organising and discarding items becomes increasingly challenging (Morein-Zamir & Ahluwalia, 2023). As a result, individuals normally start seeking treatment later in life, between the ages of 50 and 55 (Thew & Salkovskis, 2016), which is when the problematic behaviour has also usually become more severe. Additionally, stigma and shame, even among those with a good insight are common barriers, preventing individuals and their families from seeking help (Prosser et al., 2024).

Advancements and Ongoing Challenges in the Field

Until 2013, HD was classified as a subtype of OCD (Ong et al., 2015). HD has now been recognised as a disorder in its own right in the newest versions of both diagnostic manuals – the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013) and the International Classification of Diseases, Eleventh Revision (ICD-11; WHO, 2019). This distinction has clarified that HD and OCD differ in presentation (Frost et al., 2011; Gordon et al., 2013) and neural underpinnings (Saxena et al., 2004; Tolin et al., 2014), and that the two conditions are not as highly comorbid as once thought (Wheaton & Van Meter, 2014). Furthermore, traditional OCD treatments, such as cognitive-behavioural therapy (CBT) for OCD and psychopharmacological treatment with serotonin reuptake inhibitors, have shown limited efficacy for

patients with hoarding symptoms (Abramowitz et al., 2003; Mataix-Cols et al., 2002).

The classification of HD as a distinct disorder has been a prominent step in the right direction with direct implications for research and treatment. Historically, authors have been using inconsistent, arbitrary definitions of hoarding, unstandardised measures and small samples (Postlethwaite et al., 2019), many of which had been recruited from OCD clinics (Frost et al., 2011). Since its formal classification in 2013 in DSM-5 (APA, 2013), there has been an increase in research on HD, contributing to a more standardised and evidence-based understanding of the disorder (Tolin, 2023). Despite this, compared to other fields, research is still in its infancy, with advancement having being slower than expected, especially in treatment, with multiple gaps in research still existing (Mataix-Cols & Fernández De La Cruz, 2018). Thus, although more high-quality academic papers have been published since HD was recognised as a standalone condition, the field is still very much developing.

There have also been new advancements in the formulation models of the disorder, which have direct impacts on approaches to treatment. Until recently, CBT for HD (Steketee & Frost, 2007; Worden et al., 2017), based on the Frost and Hartl's (1996) CBT model for hoarding, was considered the gold standard approach to therapy. According to Frost and Hartl (1996), HD is related to deficits in information processing, problematic emotional attachments to possessions, behavioural avoidance, and maladaptive beliefs about possessions. The CBT treatment model, therefore, focuses on cognitive restructuring of hoarding-related beliefs, exposure to discarding and non-acquiring, motivational enhancement, and skills training to reduce deficits in executive function, such as problem-solving skills and time management skills (Steketee & Frost, 2007;

Worden et al., 2017). While this approach has demonstrated efficacy in both individual (Steketee & Frost, 2010) and group (Mathews et al., 2018) formats, some evidence has suggested that the rates of achieving clinically significant change are relatively low. For example, a meta-analysis by Tolin et al. (2015) revealed that post-treatment scores in most studies remained closer to the patients' clinical HD range rather than the *normal* range. In response, Tolin (2023), who is one of the pioneers in the field, has recently proposed expanding the original CBT model to a more biopsychosocial conceptualisation of the condition to account for its multiple encompassing features and how its underpinnings can vary between different individuals. More specifically, Tolin (2023) describes several vulnerability factors that can predispose one to HD, including genetics, personality, and environmental factors.

Related to the above, there is also now a wider acknowledgement of the multifaceted nature and complex impact of the condition (Dozier & Ayers, 2017; Gordon et al., 2013; Porter & Hanson, 2022). HD has been recognised as having a significant negative impact on those around the individual who hoards, on multiple systems levels. These include negative outcomes not only for family members and carers (Vorstenbosch et al., 2015; Wilbram et al., 2008) but also for communities; HD is, for example, understood as a community health problem in North America (Frost et al., 2000). Furthermore, there is evidence it poses significant economic and social burden on society due to the generally higher healthcare utilisation and the increased likelihood of affected individuals experiencing financial and housing insecurity (Mathes et al., 2019; Tolin et al., 2008). Finally, the acknowledgment of the condition's complexity has highlighted the need for a coordinated, multiagency approach to care provision, which is now considered best practice (Magos, 2021; Coleman & Latham, 2016).

Aims and Structure of the Current Thesis Portfolio

Consistent with the recent advancements and identified challenges in the field, the current thesis portfolio aims to address two existing gaps in the literature on HD. It examines two aspects of its complexity: one at the individual level, focusing on the presentation profile of the condition, and the other within the family system, evaluating its impact on others from a systemic perspective. First, presented is a systematic review (Chapter 2), exploring mental health comorbidities in HD, excluding conditions for which the co-occurrence with HD has either already been established (i.e., OCD, anxiety-related disorders and depressive disorders) or would be expected (i.e., compulsive buying disorder). This is the first systematic review to examine mental health comorbidities in HD. This is followed by a bridging chapter (Chapter 3) that relates the systematic review to the empirical chapter as a study into another aspect of complexity and vulnerability associated with HD, this time on one of the individual's family members. The empirical chapter (Chapter 4) uses a qualitative methodology to explore the childhood experiences of young adults (18-30 years old) who grew up with a relative who hoarded. Participants' stories were examined through aspects of a systemic model of human development, to capture the effects of the hoarding behaviour on the child's[1] wider context and the child as an active agent in it. The final chapter (Chapter 5) provides a comprehensive discussion and critical evaluation of the thesis portfolio. It includes the main author's reflections on the research process, together with a summary of the findings, an analysis of

[1] The term "child" here is used to refer to participants during their childhood, however, all participants in the study were adults at the time of participation.

the strengths and weaknesses of the thesis portfolio and a discussion of its clinical and research implications.

CHAPTER 2: Systematic Review

Co-occurring Mental Health Conditions in Hoarding Disorder: A Systematic Review Excluding Common Comorbidities

Written as a manuscript for submission to the Journal of Obsessive-Compulsive and Related Disorders (see Appendix A)

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Abstract

Hoarding disorder (HD) is a debilitating mental health condition, also representing a public health concern. Despite its recent recognition as a distinct diagnostic category, it yet remains poorly understood. Comorbidities with other conditions are common and these might, in some cases, explain patients' generally poor treatment outcomes. The present systematic review was the first to explore comorbidities between HD and other mental health (MH) conditions, focusing on conditions for which the link with HD has not already been established or is expected. Four databases: Pubmed Central, PsychINFO, Web of Science and CINAHL Ultimate were searched for relevant peer-reviewed studies published in the last ten years. In total, 11 890 results were screened from which 21 studies met the inclusion criteria. These reported on a total of 1075 individuals with a confirmed HD diagnosis, 307 individuals with significant HD symptoms and 989 individuals for whom symptoms were studied in a continuum. The following MH conditions were identified as comorbid to HD: disorders specifically associated with stress, bipolar and related disorders, personality disorder, eating disorders, disorders due to substance use or addictive behaviours, schizophrenia or other primary psychotic disorders, body dysmorphic disorder, trichotillomania and excoriation disorder. The findings could assist patients and professionals to consider potential co-occurring conditions and their impact on treatment outcomes. The present review has research implications for advancing the knowledge on hoarding disorder with this being the first systematic review on the topic. Future research is warranted to expand the work by using robust, high-powered studies to understand the unique profile of MH comorbidities in HD.

1. Introduction

1.1. Hording Disorder: An Overview

Hoarding disorder (HD) is defined as the persistent accumulation of possessions due to urges to amass belongings, paired with a pronounced difficulty to discard any items (World Health Organization [WHO], 2019). It was only recently recognised as a mental health condition in its own right, rather than a subtype of obsessive-compulsive disorder (OCD), following the publication of the most recent diagnostic manuals, DSM-5 (American Psychiatric Association [APA], 2013) and ICD-11 (WHO, 2019).

Since then , the body of research on HD has been rapidly growing. However, its course, aetiology and presentation are still poorly understood (Tolin, 2023). Despite advancements in therapy, patients' treatment prospects are often suboptimal (Tolin et al., 2015).

1.2. Comorbidity in HD is Common

The WHO acknowledges that one of the developmental characteristics of HD is its frequent association with other mental and physical health conditions. According to the latest clinical descriptions and diagnostic requirements for ICD-11, "individuals with hoarding disorder are more likely to experience co-occurring mental disorders or comorbid medical conditions" (WHO, 2024, p. 324). This is supported by research, with many published papers and reviews providing evidence that HD often co-occurs with at least one mental or physical health condition in both adult and adolescent samples (Frost et al., 2011, 2015; Ivanov et al., 2013; Morein-Zamir & Ahluwalia, 2023; Nordsletten et al., 2013; Nutley et al., 2022; Tolin et al., 2019). For instance, a recent systematic review

investigating coexisting medical conditions in HD found that hoarding was linked to poor physical health across studies (Bates et al., 2021). Hypertension, head injury, arthritis, lung problems and chronic stomach problems were identified as medical conditions that often co-occur with HD.

1.3. Frequently Reported Mental Health Comorbidities in HD

Research suggests that the mental health (MH) conditions that most frequently coexist with HD are depressive and anxiety disorders, as well as OCD (Frost et al., 2009, 2011, 2015; Hall et al., 2013; Mataix-Cols et al., 2013; Samuels et al., 2002; Samuels et al., 2007; Tolin et al., 2008). However, while anxiety and depressive disorders seem to be highly prevalent with HD, the association with OCD appears less robust than previously assumed. According to the findings of both Wheaton and Van Meter's (2014) review on the topic and Frost's seminal paper on comorbidity (Frost et al., 2011), OCD may not be as strongly associated with HD as previously implied. For example, Wheaton and Van Meter (2014) report, "although hoarding has been frequently associated with OCD, only a minority of individuals with HD meet the criteria for comorbid OCD" (p. 84). The latter suggests that likely due to the way HD was conceptualised historically, there has been a disproportionate focus on examining hoarding symptoms in OCD samples and OCD symptoms in hoarding samples. For instance, earlier studies often recruited participants from OCD specialty clinics (Frost et al., 2011), contributing to a bias of how closely associated the two conditions are. Furthermore, even recent reviews might still include studies where HD was assessed with non-standardised measures and according to the old diagnostic criteria (e.g., Brakoulias et al., 2017).

1.4. The Need for a Systematic Review on Mental Health Comorbidities in HD

MH comorbidity is often discussed in empirical and review papers on HD (e.g., Bates et al., 2021; Brakoulias & Milicevic, 2015; Kajitani et al., 2019; Worden & Tolin, 2022). However, it is not uncommon for authors to rely on citing information coming from the same three, now dated sources, of which two are empirical studies (Frost et al., 2011; Hall et al., 2013; Wheaton & Van Meter, 2014). These are Frost et al.'s (2011) empirical research conducted with 217 individuals, 50% of whom were recruited from mental health clinics, followed by Hall et al.'s (2013) study, which was entirely based on self-report measures. There is also the single review by Wheaton and Van Meter (2014), which despite comprehensive, is not a systematic one. Notably, all three sources were published more than a decade ago and reflect the findings of studies where both HD and other MH conditions were assessed using the older diagnostic criteria (APA, 1994; WHO, 1992).

Moreover, some of Wheaton and Van Meter (2014)'s findings are inconclusive, further highlighting the need for a systematic review on the topic. For example, while certain studies suggested that HD is associated with both bipolar disorder I and II, others did not. Complicating this further, the authors noted that bipolar disorder is often listed as an exclusion criterion for participation in HD research, making the rate of their coexistence difficult to determine. Another finding from Wheaton and Van Meter (2014) relates to posttraumatic stress disorder (PTSD), which some studies linked to HD and even to its onset (Landau et al., 2011; Frost et al., 2011). At the same time, PTSD seemed to co-occur with HD at a similar rate as it does with OCD. Based on Wheaton and Van Meter (2014), however, it looks like research at the time had not explored how an OCD

presentation in the two conditions might differ, for example, regarding the contents of the traumatic events.

Finally, a deeper understanding of the mental health comorbidity profile of HD carries implications for clinical practice. Comorbidity has been identified as one of the routes possibly leading to worse treatment outcomes for patients (Wheaton & Van Meter, 2014). The presence of co-occurring conditions can exacerbate core symptoms of HD (Conley et al., 2018), introduce additional barriers to engagement and adherence to therapy (Farquhar & Caiazza, 2020) and lead to the administration of treatment which does not fully target the patient's symptoms (Bloch et al., 2014). This is particularly important as HD is notoriously difficult to treat (Tolin et al., 2015), therefore, understanding the aetiology and presentation of the condition better is essential for an improved patient care and the development of more effective interventions.

1.5. Clarifications on Included and Excluded Conditions in the Present Review

This systematic review did not examine the relationship between HD and OCD, due to this having already been extensively studied in previous research as already mentioned. However, it did include studies exploring comorbidity between HD and other obsessive-compulsive and related disorders (OCRDs), such as body dysmorphic disorder (BDD), trichotillomania (TTM), and excoriation disorder (ExD). These conditions were included because, to date, the existing review literature on their relationship with HD is extremely limited. Previously, only Wheaton and Van Meter (2014) had briefly mentioned BDD in this context, citing findings from Samuels et al. (2007) that suggested that BDD may be more common among women who hoard. By incorporating OCRDs beyond OCD, the current review sought to address this underexplored area.

Moreover, anxiety-related and depressive disorders were excluded from the present review for two key reasons. First, the associations between HD and both anxiety and depression are already well established and frequently cited in the literature (e.g., Frost et al., 2009, 2011, 2015; Hall et al., 2013; Mataix-Cols et al., 2013; Samuels et al., 2002, 2007; Tolin et al., 2008). This was further confirmed in the initial scoping phase of the current review, during which these disorders were consistently identified as commonly co-occurring with HD. Second, as *common mental health conditions*, anxiety-related and depressive disorders affect a substantial proportion of the global population (WHO, 2017) and are also known to frequently co-occur with a range of other psychiatric conditions (Remes et al., 2016; Cuijpers et al., 2023; Roest et al., 2021; Goldstein-Piekarski et al., 2016), making their association with HD unsurprising. Moreover, routine assessment of anxiety- and depressive disorders is standard in psychological research and is, therefore, also commonly included in studies on HD. As such, many existing publications already report on these associations, suggesting that a separate, dedicated review might be better suited to examine the relationship between HD and these conditions.

Compulsive buying disorder was also excluded. This was due to its link with HD being relatively well-established and expected as maladaptive object attachment and difficulties with acquisition behaviours are common in both conditions (Moulding et al., 2021). Additionally, there continues to be a lack of consensus regarding the conceptualisation of compulsive buying as an addictive, impulsive or an obsessive-compulsive disorder (Grant & Chamberlain, 2024). It is not a formally recognised condition in DSM-5 (APA, 2013) and has been included only as an example under the rubric *Other specified impulse control disorders* in ICD-11 (WHO, 2019), introducing ambiguity such as inconsistency

in definitions and measurements, making the interpretation and comparison between studies challenging.

Finally, the present review did not examine the link between HD and neurodevelopmental conditions, given that its focus was on the relationship between HD and other MH conditions. While earlier contributions by Frost et al. (2011) and Wheaton and Van Meter (2014) have discussed the relationship between HD and Attention Deficit Hyperactivity Disorder (ADHD) alongside other mental health disorders, these likely reflect the relative infancy of HD research at the time. The field has developed significantly in the recent years, with a growing number of empirical studies reporting co-occurrence of HD and neurodevelopmental conditions across both adult and child populations (e.g., Hacker et al., 2016; Kajitani et al., 2019; Storch et al., 2016; Worden & Tolin, 2023). In view of the growing body of literature on this topic, the link between HD and neurodevelopmental conditions might also be better explored in a separate, dedicated systematic review on the topic.

1.6. The Present Review

This systematic review aimed to address the above gaps in the literature by providing a synthesis of the recent research on HD in community and outpatient samples to help identify what mental health conditions HD might co-occur with. It included studies published in the last ten years only, to ensure that selected papers reflected the most recent diagnostic conceptualisation of HD according to DSM-5 (APA, 2013) or ICD-11 (WHO, 2019). Additionally, the present work sought to extend the existing literature by examining underexplored MH comorbidities of HD. Therefore, it excluded conditions for which the link with HD has already been well-established (i.e., OCD, anxiety-related disorders and

depressive disorders) or is expected (compulsive buying disorder). The second aim of the review was to shed more light on the prevalence of the identified MH conditions in HD and where possible, how these compare to those in clinical and non-clinical control groups.

The present systematic review was therefore designed to address the following research questions:

What other mental health conditions, apart from OCD, compulsive buying, depressive- and anxiety-related disorders, does HD co-occur with?

What are the prevalence rates in community and outpatient samples for the identified conditions and where possible to determine, how do these compare to clinical and non-clinical groups?

2. Methods

The method and reporting of this review followed the current Preferred Reporting Items for Systematic Reviews and Meta Analyses guidelines (PRISMA; Page et al., 2021). The systematic search protocol was pre-registered in PROSPERO (registration number: CRD42024519966) on the 5th of March 2024.

2.1. Inclusion/exclusion criteria

Only quantitative studies were included in the present review as during the initial scoping phase it was found that qualitative studies typically do not report comorbidity information. Mixed methods studies, where quantitative data could be extracted, were also included. For consistency, the review focused on HD in

working-age adults (18–64)[2] only. This was because research has suggested that typically HD symptoms do not fully emerge before age 18 (Grisham et al., 2006). Furthermore, this decision also helped to avoid confounds with late-onset HD, also referred to as Diogenes syndrome (Clark et al., 1975) which differs in clinical presentation. To be included in the review the studies had to meet the following inclusion criteria:

i. The participants in the study were working age adults, aged 18-64 years.
ii. The sample was drawn from a community or a mental health outpatient population.
iii. HD was conceptualised as a standalone mental health condition and assessed with at least one HD-specific validated tool. This could either be a diagnostic measure according to DSM-5 (APA, 2013) or ICD-11 (WHO, 2019), such as the *Diagnostic Interview for Anxiety, Mood, and Obsessive-Compulsive and Related Neuropsychiatric Disorders* (DIAMOND; Tolin et al., 2018) or a HD-specific screening tool (Savings Inventory-Revised, SI-R; Frost et al., 2004).
iv. Participants' additional mental health condition appeared as a recognised mental health condition in DSM-5 (APA, 2013) or chapter *06 Mental, behavioural or neurodevelopmental disorders* of the ICD-11 (WHO, 2019) or earlier versions of these, excluding OCD, compulsive buying, depressive- and anxiety-related disorders. For clarity, the ICD-11 classification was used to generate the full list of names of all eligible conditions of interest to this review (see Appendix B).

[2] The upper bound of 64 years of age was based on the Office for National Statistics' definition of working age adults (Cabinet Office, 2025). The lower bound of 18 years of age was applied to exclude children and adolescents, ensuring the review focused on adult populations only.

v. Participants' additional mental health condition was assessed either via a validated screening tool (e.g., Posttraumatic Diagnostic Scale, PDS; Foa, 1997) or a diagnostic instrument, according to DSM-5 (APA, 2013) or ICD-11 (WHO, 2019), such as the Structured Clinical Interview for DSM-5 Clinician Version (SCID-5-CV; First et al., 2016) or earlier versions of these.

vi. The study was published in 2014 or any other year thereafter.

Articles were excluded from the review if they met the following criteria:

i. The participants in the study were children or adolescents (aged 0-17 years) or older adults (65+ years).

ii. The sample was drawn from a mental health inpatient population or from the highly specific population of war veterans in the United States[3].

iii. The study was a case study (N = 1), a review study, a conference proceeding, a book chapter or a report.

iv. There was no evidence for the use of a validated measure for identifying HD or the comorbid MH condition(s).

v. Participants' primary diagnosis was OCD/compulsive buying disorder.

vi. The only comorbid mental health condition reported was OCD, compulsive buying, anxiety-related disorder or a depressive disorder according to the ICD-11 classification.

vii. An additional comorbidity with a neurodevelopmental (e.g., autism spectrum disorder) or a neurocognitive condition (e.g., dementia) confounded the findings.

viii. The study was published in 2013 or any other year prior to that.

[3] Several studies investigating HD in US war veterans were published in the period. Given that these were conducted by the same research group (e.g., Ayers et al., 2018) as part of their work for the Veteran Affairs San Diego Healthcare System (VASDHS) and the niche population they studied these papers were considered *too specific* for inclusion in the present systematic review. These were, therefore, excluded in the interest of preserving the generalisability of the findings.

2.2. Search Strategy

A comprehensive search of the literature was conducted using the following databases: Pubmed Central, PsychINFO, Web of Science and CINAHL Ultimate. Searches were conducted for papers published in a peer-reviewed journal in English in the last ten years (January 2014 - 28th of May 2024). The results of all four databases were extracted on the 28th of May 2024 and managed using Endnote software (Clarivate, 2023). The searches of all four databases were then performed between the date of extraction and the 9th of August 2024 when these were fully completed.

The only search term that was submitted in each database was hoard*. This was decided as during the initial scoping search it was noticed that information on mental health comorbidity was routinely reported in quantitative papers on HD, in the Methods section, rather than the title or abstract. This is likely because papers usually explore a different question related to HD (e.g., comparisons of different treatment types; examinations of various aspects of cognitive performance in individuals who hoard) rather than its comorbidity to other conditions (of note, not many papers specifically dedicated to comorbidity in HD were found). Thus, introducing more search terms to the search strategy would have been inappropriate, given the research questions, as it would have resulted in excluding the main source of relevant information for the present review. Therefore, to ensure the search was as robust as possible and that no relevant articles on the topic were missed, only the search term hoard* was used. This resulted in manually screening 11 890 papers (after duplicates were removed; see Figure 1.1). Importantly, during the scoping process it was noticed that *hoarding* is used as a term in other fields (Archaeology, Zoology) and in research related to the Covid-19 pandemic. Hence, many of the extracted

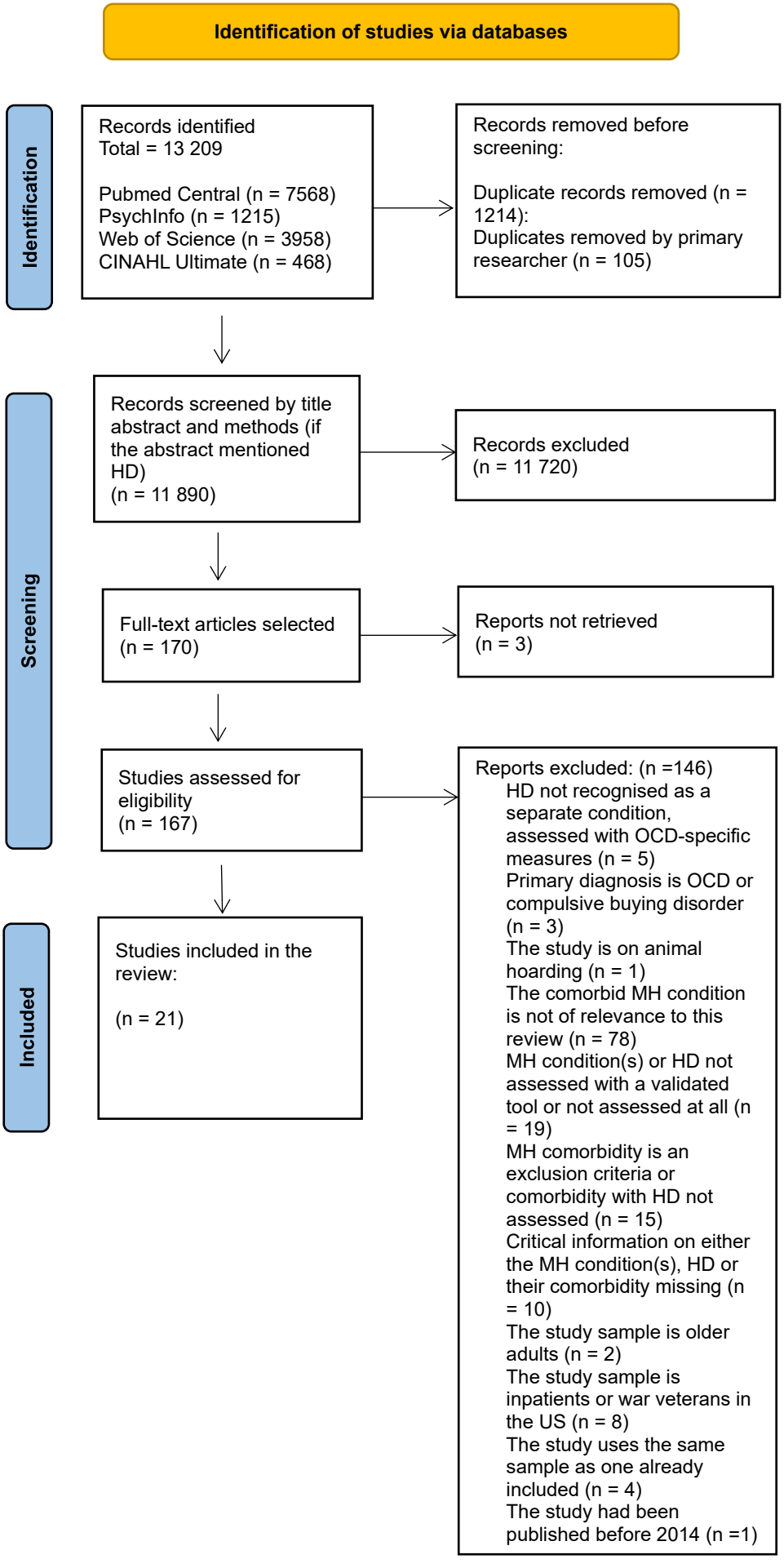
articles were clearly irrelevant to the present review, which made the screening process manageable. Considering the above, all 11 890 records were screened by title and abstract, while papers that mentioned HD in their abstract, were also screened by their methods sections (full text was retrieved for all of these).

A secondary search was then performed on all four databases using the following search strategy: hoard* AND comorbid* OR co-occur* OR cooccur* OR coincide OR coexist OR co-exist OR mental OR condition* OR disorder* OR difficult* OR illness* OR symptom*. This was to ensure that no relevant or very newly published papers had been missed. No new papers that met the inclusion criteria for this review were identified as a result of this additional search.

In total 167 articles, for which full text could be retrieved, were identified in the final stage of the screening process. Fifty percent of these were double screened by an independent reviewer as recommended by best practice in conducting systematic reviews (Institute of Medicine, 2011). The two reviewers disagreed on the inclusion/exclusion of three studies ($\kappa = 0.77$), resulting in substantial reliability of agreement (Landis & Koch, 1977). The discrepancies in opinion were discussed and resolved through a mutual consensus to determine the final list of full-text articles to be included in the review. Following this process twenty-one papers were ultimately retained to be included in the narrative synthesis (see Figure 1.1).

Figure 1.1.

Study Selection Flow Diagram



2.3. Quality Appraisal

The QualSyst Quality Assessment Tool for quantitative studies (Kmet et al., 2004) was used to perform the quality appraisal of the included studies. It consists of 14 criteria for quality where the study could be given a score of 0 (does not meet criteria), 1 (partially meets criteria) or 2 (fully meets criteria). The methodological issues of randomisation and blinding of subjects and investigators were not relevant to the present review, therefore, the selected studies were not evaluated against questions six, seven and eight of the tool and these were removed. Each study was therefore evaluated on 11 possible criteria.

A summary score was calculated by dividing the total sum of scores by the total possible score (excluding items that were not applicable). Each study was then given a categorical quality rating based on their summary score (strong [>0.8], good [0.71–0.79], adequate [0.50–0.70], or limited [<0.50]) as per standard practice in other systematic reviews using the tool (Lee et al., 2008; Maharaj & Harding, 2016; Prosser et al., 2024). The maximum overall score a study could achieve was 1.00. Half of the final list of studies, selected at random, were quality assessed by another rater.

2.4. Data Analysis

The data were analysed with a narrative synthesis following Popay et al. (2006)'s guidance[4]. This included a preliminary synthesis of the results (by using textual description, tabulation and grouping the results according to MH condition category as per ICD-11 [WHO, 2019]; Appendix B), exploring

[4] Please, note that the optional first element of Popay et al. (2006)'s *general framework for narrative synthesis*, to develop a theoretical model based on the findings, was not adhered to in the present review. This was because this refers to developing a *theory of change* model that is more appropriate for reviews examining the effectiveness or the implementation of an intervention which is not the case in the present work.

relationships within and between studies (i.e., by considering moderator variables and overarching theories to explain the overall findings) and ensuring the robustness of the synthesis (i.e., by adopting a quality appraisal of the included studies, involving another reviewer in the study selection phase and critically reflecting on the limitations of the present work in the Discussion). Where studies included analyses outside the remit of this review, only the findings of the relevant research questions have been reported and discussed. All presented comparisons with a control group are only descriptive in nature, with the aim to illustrate the trends and distributions within the samples, and do not represent a statistically significant effect.

This was the first systematic review to explore HD and its comorbidity with other MH conditions, excluding OCD, anxiety-related and depressive disorders, for which this relationship has already been well-established, or conditions for which it is expected (compulsive buying disorder). Therefore, the present work had a broad scope that would have made the use of a meta-analysis problematic. The aim was to provide an overview of the topic by summarising the findings, rather than an estimate of an effect size focusing on HD and a particular MH condition, for example. Thus, a liberal approach was adopted to include as many studies as possible that met the inclusion criteria, allowing for heterogeneity between the studies, making the use of a meta-analysis inappropriate.

A data extraction table was developed by consulting the Cochrane template (Higgins et al., 2024) to ensure it captured all relevant features of the studies, relevant to the review. The following data were extracted from each study retained for analysis: study location, research design, participants

characteristics[5] (age, gender, ethnicity and/or other relevant information about their status where available), sample size, the type of MH condition(s) reported, the HD and MH measures and relevant findings, pertaining to the number of cases and rate of comorbidity observed between HD and the MH conditions of interest. The exclusion criteria have also been reported in the MH condition section for some of the studies as these were of relevance to the review (i.e., if the study excluded for any MH condition(s) of relevance to this review).

3. Results

3.1. Quality Appraisal

In terms of the quality appraisal of the studies, the two raters initially achieved an inter-rater agreement of $\kappa = 0.69$, indicating a substantial reliability of agreement. Consensus between the two raters was reached via a discussion (see Table 1.1 for the final quality rating of all studies).

The actual summary scores for the quality appraisal across studies ranged from 0.59 to the maximum 1.00 ($M = 0.82$, $SD = 0.11$). The quality assessment scores were relatively homogenous, with the majority of studies (n = 14) being rated as *strong*, four as *good* and three as *adequate*. The majority of the studies appropriately described the study aims and objectives, research design, participant characteristics and measures either partially or fully. Almost all studies used appropriate analytic methods (n = 18) and reported the results in sufficient detail (n = 18) to support the conclusions (n = 14). The identified

[5] for the sample of interest only (please, note in the majority of cases this is the HD sample, however, in Novara et al., 2016, for example, these are the two MH groups for which comorbidity with HD was reported).

areas across studies that needed improvement were sampling[6] (e.g., patients being recruited from a single MH clinic), the sample size, the variance estimates and controlling for confounding variables (possibly explained by all studies but one having a non-experimental design).

[6] In relation to Kmet et al. (2004, p.15)'s criteria "to obtain an unbiased sample of the relevant target population or the entire target population of interest".

Table 1.1.

Quality Assessment of the Selected Studies

Study	Aims and Objectives	Appropriate Design	Sampling	Participant Characteristics	Measures	Sample size	Analysis	Estimates of variance	Controlled for confounding	Results	Conclusions	Summary Score	Quality Rating
Archer et al. (2019)	2	2	2	2	2	2	2	2	NA	2	2	1.00	Strong
Chasson et al. (2020)	2	1	1	2	2	1	0	2	0	1	1	0.59	Adequate
Chen et al. (2023)	2	1	1	2	2	2	2	2	1	2	2	0.86	Strong
Chou et al. (2018)	2	1	1	2	1	2	2	0	0	2	1	0.64	Adequate
Grisham et al. (2018)	2	2	1	2	1	1	2	1	1	2	1	0.73	Good
Jaisoorya et al. (2021)	2	2	2	2	2	2	2	2	2	2	2	1.00	Strong
Mathes et al. (2018)	2	1	1	2	2	1	2	2	2	2	2	0.86	Strong
Millen et al. (2020)	2	2	2	2	2	1	2	0	0	2	1	0.73	Good
Morein-Zamir et al. (2014)	2	2	1	1	2	1	2	1	1	2	2	0.77	Good
Norberg et al. (2020)	2	2	1	2	1	1	2	1	2	2	2	0.82	Strong
Nordsletten et al. (2018)	2	2	2	1	2	2	2	2	2	1	2	0.91	Strong
Novara et al. (2016)	2	2	1	2	2	1	2	2	1	2	2	0.86	Strong
O'Connor et al. (2018)	2	2	1	1	2	2	2	2	1	2	2	0.86	Strong
Ouellette et al. (2021)	2	2	1	2	2	1	1	1	2	2	2	0.82	Strong
Raines et al. (2015)	2	1	1	2	2	2	2	2	1	2	2	0.86	Strong
Raines et al. (2014)	2	1	1	2	2	1	2	1	2	2	2	0.82	Strong
Stewart et al. (2020)	2	2	2	2	1	1	2	1	2	2	2	0.86	Strong
Van Roessel et al. (2022)	2	1	1	2	2	2	2	2	2	2	1	0.86	Strong

Vieira et al. (2022)	2	2	1	2	2	2	2	2	2	2	1	0.91	Strong
Weintraub et al. (2018)	2	1	1	1	1	2	2	2	1	2	1	0.73	Good
Woerner et al. (2017)	2	1	1	1	1	2	1	1	1	1	2	0.64	Adequate

Note. 2 = Yes, 1 = Partial, 0 = No, NA = Not applicable. Summary score is calculated as the sum of scores divided by the total possible score (excluding items that are not applicable). This is in line with tool guidance which suggests that "NA" scores should not count negatively towards the quality rating.

3.2. Study Characteristics

Study characteristics are presented in Table 1.2. Sixteen studies employed a cross-sectional design (Archer et al., 2019; Chou et al., 2018; Grisham et al., 2018; Jaisoorya et al., 2021; Mathes et al., 2018; Morein-Zamir et al., 2014; Norberg et al., 2020; Nordsletten et al., 2018; Novara et al., 2016; Ouellette et al., 2021; Raines et al., 2014, 2015; Sordo Vieira et al., 2022; Van Roessel et al., 2022; Weintraub et al., 2018; Woerner et al., 2017), four a before and after design (Chasson et al., 2020; Chen et al., 2023; Millen et al., 2020; O'Connor et al., 2018) and one a mixed cross-sectional and experimental design (Stewart et al., 2020). Four of the studies included both a clinical control and a healthy control group (Grisham et al., 2018; Morein-Zamir et al., 2014; Norberg et al., 2020; Novara et al., 2016), three had a healthy control group[7] only (Jaisoorya et al., 2021; Sordo Vieira et al., 2022; Stewart et al., 2020), one a clinical control group only (Ouellette et al., 2021) while 13 studies had no control group (Archer et al., 2019; Chasson et al., 2020; Chen et al., 2023; Chou et al., 2018; Mathes et al., 2018; Millen et al., 2020; Nordsletten et al., 2018; O'Connor et al., 2018; Raines et al., 2014, 2015; Van Roessel et al., 2022; Weintraub et al., 2018; Woerner et al., 2017). Two of the selected studies were pilot studies (Chen et al., 2023; Millen et al., 2020) and one – an epidemiological study (Sordo Vieira et al., 2022). Fifteen studies included patients with confirmed clinical hoarding, i.e., who met the DSM-5 (APA, 2013) criteria for HD diagnosis (Archer et al., 2019; Chasson et al., 2020; Chen et al., 2023; Chou et al., 2018; Grisham et al., 2018; Millen et al., 2020; Morein-Zamir et al., 2014; Norberg et al., 2020; Nordsletten

[7] The term *healthy control* group has been used throughout the review to indicate ***both*** non-HD community controls taken from the population and specifically matched community control groups, free of any MH conditions.

et al., 2018; O'Connor et al., 2018; Ouellette et al., 2021; Raines et al., 2014; Sordo Vieira et al., 2022; Stewart et al., 2020; Van Roessel et al., 2022). In the remaining six studies (Jaisoorya et al., 2021; Mathes et al., 2018; Novara et al., 2016; Raines et al., 2015; Weintraub et al., 2018; Woerner et al., 2017) hoarding symptoms were assessed with a screening measure.

This resulted in three combined samples, according to how HD was measured and reported in the studies. First, there was a total of 1075 individuals with a confirmed clinical HD diagnosis, with the size of the HD samples ranging from 12 (Chen et al., 2023) to 313 participants (Archer et al., 2019). Additionally, there were 307 individuals with significant HD symptoms, who scored above the clinical cut-off on a HD screening measure (i.e., a significant symptoms sample; SI-R > 41; Tolin et al., 2011 or HRS-I > 11, Tolin et al., 2018). The third combined sample consisted of 989 individuals for whom HD symptoms were studied in a continuum (where participants were still assessed with an HD screening measure, but their symptoms were studied and reported in a continuum). The HD groups consisted of middle-aged adults (range = 40.4 – 60.6 years, *M* = 52.5, *SD* = 7.3), while participants in the other clinical group samples (e.g., ED patients in Novara et al., 2016; *M* age = 20.6 years) and the two community studies which assessed the prevalence of HD symptoms in undergraduate student samples (*M* = 19.0 years in Weintraub et al., 2018 and *M* = 20.6 years in Woerner et al., 2017), were generally younger. The participants in the studies were predominantly female (*M* = 71.0%, *SD* = 12.3%). White ethnicity was overrepresented in the studies (*M* = 70.3%, *SD* = 15.3%, *n* = 15). Finally, the participants in the studies came from a variety of locations: United States (n = 10), United Kingdom (n = 3), Canada (n = 2), Australia (n = 3), Italy (n = 1), Japan (n = 1), Spain (n = 1), India (n = 1), Brazil (n = 1).

Table 1.2.

Study Characteristics and Main Findings

Study authors and year	Location	Study Design	Participant Characteristics (for the sample of interest)	Sample size	Measure of HD	MH condition(s)[1,2]	Measure of MH	N of cases/rate of comorbidity in HD and CC/HC where available
Archer et al. (2019)[3]	United States	Cross-sectional study, no control group	Treatment-seeking individuals who met DSM-5 criteria for HD Mean age = 59.0 years (SD = 11.8) Gender: 74.1% female Ethnicity: White (60.0%), Asian (11.0%), Black (7.0%) Other (21.0%) Mean SI-R score = 65.6 (SD = 11.7)	HD group = 313	SIHD SI-R UHSS CI-R	Bipolar disorder PTSD Alcohol/Substance use disorder	MINI	Bipolar disorder (n = 51, 16.3%) PTSD (n = 37, 11.8%) Alcohol/Substance use disorder (n = 23, 7.3%)
Chasson et al. (2020)	United States	Before and after study, no control group	Non-treatment seeking community adults with diagnosed HD Mean age = 56.7 years (SD = 15.3) Gender: 70.0% female	HD group = 23	SIHD SI-R	Alcohol use disorder Nicotine use disorder PTSD Binge eating disorder	SCID	Alcohol use disorder (n = 3, 13.0%) Nicotine use disorder (n = 1, 4.3%) PTSD (n = 1, 4.3%) Binge eating disorder (n = 1, 4.3%)

			Ethnicity (n = 11 only): White (73.0%), African American (18.0%) American Indian/Alaska Native (9.0%) Mean SI-R = 51.5 (SD = 12.7)			*Participants with current or past psychosis or current mania were excluded.*		
Chen et al. (2023)	Australia	A pilot study, before and after design, no control group	Community adults with a HD diagnosis Mean age = 59.87 years (SD = 12.6) Gender: 75.0% female Ethnicity: White (92.0%), Asian (8.0%) Mean SI-R = 66.8 (SD = 10.3)	HD group = 12	DIAMOND SI-R	Bipolar disorder PTSD *Participants with comorbid psychosis, substance dependence or high risk of self-harm harm/suicide were excluded.*	DIAMOND	Bipolar disorder (n = 1, 8.3%) PTSD (n = 1, 8.3%)
Chou et al. (2018)	United States	Cross-sectional study, no control group	Community adults who met DSM-5 criteria for HD Mean age = 59.9 years (SD = 9.0) Gender: 76.9% female Mean SI-R = 66.0 (SD = 11.7)	HD group = 104	SIHD MINI SI-R	PTSD Substance use disorder Bipolar disorder *Participants with acute suicide risk and/or actively disruptive*	MINI	PTSD (n = 14, 13.5%) Substance use disorder (n = 5, 4.8%) Bipolar disorder (n = 4, 3.9%)

						psychotic symptoms were excluded.		
Grisham et al. (2018)	Australia	Cross-sectional study with a CC and a HC group	Community adults who met DSM-5 criteria for HD, another MH condition (CC) or no MH conditions (HC) <u>HD group</u> Mean age = 40.4 years (SD = 15.6) Gender: 66.7% female Ethnicity: White (50.0%), Asian/South Asian (33.3%) Other (16.7%) Mean SI-R = 59.1 (SD = 12.1)	Total = 72 (HD group = 24 CC group = 22 HC group = 26)	HRS-I SIHD SI-R	Bipolar or cyclothymic disorder PTSD Binge eating disorder Bulimia nervosa Alcohol use disorder Substance use disorder *Participants who were psychotic and/or suicidal were excluded.*	MINI	Bipolar or cyclothymic disorder (n = 5, 20.8%) PTSD (n = 6, 25%) Binge eating disorder (n = 3, 12.5%) Bulimia nervosa (n = 2, 8.3%) Alcohol use disorder (n = 3, 12.5%) Substance use disorder (n = 2, 8.3%)
Jaisoorya et al. (2021)	India	Cross-sectional study with a HC (non-HD group)	Community adults in India, recruited from 71 primary health centres (HD group based on the presence clinically significant symptoms) Mean age = 44.2 years (SD = 11.2) Gender: 68.1% female	Total = 7555 HD group = 69	HRS-I	Alcohol use disorder Nicotine dependence disorder	AUDIT FTND	Alcohol use disorder HD (n = 8, 11.6%) vs HC (n = 108, 1.6%) Nicotine dependence disorder HD (n = 9, 13.1%) vs HC (n = 263, 3.9%)

			Unemployed (58%) Mean HRS-I score NR					
Mathes et al. (2018)	United States	Cross-sectional study, no control group	Community adults who have experienced at least one traumatic event as measured by the Posttraumatic Diagnostic Scale (PDS) Sample recruited as a part of a clinical trial Mean age = 37.3 years (SD = 16.0) Gender: 54.3% female Ethnicity: White (55.4%), African American (31.0%) Asian (1.9%), Other (18.9%) Employed/in education (60.4%) Mean SI-R score = 24.6 (SD = 17.5)	Total = 258 HD group = 51	SI-R	PTSD (interpersonal trauma)	PDS	The relationship between exposure to interpersonal trauma and hoarding symptoms was significantly mediated by aggression F (3, 254) = 15.02, p < .001, 14.07% of the variance explained)
Millen et al. (2020)	United States	A pilot study, before and after design, no control group	Community adults who met DSM-5 criteria for HD and have reported they might be	HD group = 14	SIHD SI-R CI-R	Binge eating disorder	Full psychiatric evaluation, name of the specific measure NR	Binge eating disorder (n = 2, 14.3%),

			evicted due to clutter and/or have received an eviction notice Mean age = 60.6 years (SD = 8.0) Gender: 71.0% female Ethnicity: White (57.0%), African American (35.7%) Hispanic (7.1%), Mean SI-R score = 68.0 (SD = 5.0)			*Participants with risk of suicide were excluded.*		
Morein-Zamir et al. (2014)	United Kingdom	Cross-sectional study with a CC group (OCD+HD) and a HC group	Outpatients in specialist OCD and hoarding clinics, the HD group met the DSM-5 criteria for HD Mean age = 54.0 years (SD = 8.7) Gender: 81.8% female Mean SI-R score = 60.3 (SD = 14.1)	Total = 74 (HD group = 22 CC group = 24 HC group = 28)	Assessed against DSM-5 criteria SI-R	PTSD *Participants with psychosis or excessive drug use were excluded.* *Participants with a neurological disorder, psychosis, head/brain injury or excessive drug* use *were excluded*.	MINI	PTSD HD (n = 1, 4.5%) vs OCD+HD (n = 0, 0%)
Norberg et al. (2020)	Australia	Cross-sectional study with a CC group (another psychological	Community adults and outpatients from psychology clinics (HD group	Total = 71 (HD group = 24	HRS-I SIHD SI-R	PTSD Bipolar disorder Eating disorder	MINI	PTSD (n = 6, 25.0%) Bipolar disorder (n = 5, 20.8%)

		disorder) and a HC group	met the DSM-5 criteria for HD) Mean age = 40.4 years (SD = 15.8) Gender: 66.7% female Ethnicity: White (50.0%), Employed (50%) Mean SI-R score = 54.9 (SD = 8.4)	CC group = 21 HC group = 26)		Substance use disorder *Participants who were psychotic and/or suicidal were excluded.*		Eating disorder (n = 5, 20.8%) Substance use disorder (n = 4, 16.7%)
Nordsletten et al. (2018)	United Kingdom, Spain, Japan and Brazil	International cross-sectional study, no control group	Community adults and outpatients from psychology clinics who met the DSM-5 criteria for HD Mean age = 43.6 – 56.7 years (SD = 11.06 – 13.6) Gender: 40.0% - 55.2% female Married (13.8% - 66.7%) Mean SI-R score = 58.9 – 55.2 (SD = 15.6 – 17.1)	Total = 82 (UK = 29; Spain = 21; Japan = 17; Brazil = 15)	SIHD SI-R HRS-SR CI-R and their translated versions respectively	PTSD Alcohol use disorder Substance use disorder Psychosis Bulimia nervosa	MINI SCID-I	<u>UK</u> PTSD (n = 4, 13.8%) Alcohol use disorder (n = 3, 10.4%) Psychosis (n = 1, 3.5%) <u>Spain</u> Alcohol use disorder (n = 2, 9.5%) Substance use disorder (n = 2, 9.5%) <u>Japan</u> None of these present <u>Brazil</u> PTSD (n = 2, 13.3%)

								Alcohol use disorder (n = 3, 20.0%) Bulimia nervosa (n = 1, 6.7%)
Novara et al. (2016)	Italy	Cross-sectional study with four CC groups (two of these were relevant to this review, ED & PD) and a HC	Clinical populations recruited from disorder-specific outpatient clinics with a formal DSM-4 diagnosis HD group and control group recruited from the community <u>ED</u> Mean age = 20.6 (SD = 4.3) Gender: 100.0% female Duration of the disorder: 4.0 years (SD = 2.8) <u>PD</u> Mean age = 52.2 (SD = 11.5) Gender: 52.9% female Duration of the disorder: 17.7 years (SD = 11.4) Mean SI-R score NR for either group	Total = 124 (ED = 41 PD = 17 HD = 49 HC = 48 and two further groups not of relevance to this review)	SI-R – Italian version	Eating disorder (Bulimia nervosa & Binge eating disorder) Psychotic disorder (Schizophrenia & schizoaffective disorder) *Patients with comorbid personality disorders were not excluded*	Diagnosis according to DSM-4 confirmed by an expert clinician	Eating disorder (Bulimia nervosa & Binge eating disorder; n = 9, 22.5%) Psychotic disorder (Schizophrenia & schizoaffective disorder; n = 1, 5.9%)

O'Connor et al. (2018)	Canada	Before and after design, no control group	Community adults referred by primary mental health facilities who met the DSM-5 criteria for HD Mean age = 53.1 years (SD = 8.9) Gender: 64.7% female Employed (29.5%) Pre-treatment mean SI-R score = 60.6 (SD = 11.1)	HD group = 16	HRS-I SI-R CIR SCI	PTSD Personality disorder *Participants with psychosis and/or suicidal ideation were excluded.*	The scheduled interview for DSM-5 (research version) & The scheduled interview for DSM-4 axis II disorders	PTSD (n = 1, 6.3%) Personality disorder (n = 6, 37.5%)
Ouellette et al. (2021)	Canada	Cross-sectional study with two CC groups (PTSD and an anxiety disorder group)	Community adults, recruited from anxiety and other related-disorders clinics (HD group met the diagnostic criteria for DSM-5) <u>HD group</u> Mean age = 52.5 years (SD = 10.2) Gender: 82.0% female Ethnicity: White (98.0%), Mean SI-R score NR	Total = 150 (HD = 62 PTSD = 32 Anxiety disorder = 56)	A modular semi-structured clinical interview based on DSM-5 the Diagnostic Assessment and Research Tool or A consultation with a psychiatrist to confirm the diagnostic picture SI-R	PTSD	A modular semi-structured clinical interview based on DSM-5 the Diagnostic Assessment and Research Tool or A consultation with a psychiatrist to confirm the diagnostic picture THQ (Criterion A)	PTSD HD (n = 3, 4.8 %) vs anxiety disorder group (n = 5, 8.9 %)

Raines et al. (2015)	United States	Cross-sectional study, no control group	Community adults recruited via Amazon's Mechanical Turk (Mturk) in the US (HD based on the presence clinically significant symptoms) Mean age = 31.9 years (SD = 11.4) Gender: 60.8% female Ethnicity: White (72.2%), African American (15.5%) Asian (8.2%) American Indian (2.0%), Other (2.0%), Mean SI-R score = 53.9 (SD = 10.8)	HD group = 97	SI-R	Binge eating disorder	EDE-Q (the eating concern subscale only)	Increased hoarding severity was significantly associated with symptoms of binge eating (β = .23, t = 2.31, p = .023, sr^2 = .05). The acquisition subscale of the SI-R was significantly associated with binge eating (β = .24, t = 2.32, p = .023, sr^2 = .05), whereas the clutter subscale (β = .17, t = 1.74, p =.09, sr^2 = .03) was not. Difficulties regulating emotions mediated the association between hoarding severity and binge eating (F (3, 92) = 8.58, p < .001, 19% of the variance explained).
Raines et al. (2014)	United States	Cross-sectional study, no control group	Community adults and outpatients from anxiety disorder clinics (HD group met DSM-5 criteria for HD) Mean age = 44.1 years (SD = 16.0)	HD group = 32	SIHD SI-R	PTSD Substance use disorder Eating disorder	MINI	PTSD (n = 6, 18.8%) Substance use disorder (n = 7, 21.9%) Eating disorder (n = 1, 3.1%)

			Gender: 78.0% female Ethnicity: White (59.4%), African American (37.5%), Other (3.1%), Mean SI-R score = 55.8 (SD = 13.3)					
Sordo Vieira et al. (2022)	United States	Epidemiological cross-sectional study, making use of a large participant database (n = 15,978) and a comparison between a smaller HD sample (n = 135) and a HC (non-HD group) (n = 117), where both HD and MH were formally assessed.	Community adults recruited for a larger study (HD group met DSM-5 criteria for HD) <u>HD group</u> Median age = 61.0 years (IQR* 55-67; SD NR) Gender: 77.0% female Ethnicity: White (90.0%), Asian (3.0%) African American (2.2%), Other (2.2%), Mean SI-R score = 59.1 (SD = 10.9)	HD group = 135	SIHD SI-R HRS-SR UCLA Hoarding UHSS	Alcohol use disorder PTSD Binge eating disorder Substance use disorder Bipolar disorder Bulimia nervosa Anorexia nervosa	MINI	Alcohol use disorder HD (n = 27, 20.0%) vs HC (n = 15, 12.8%) PTSD HD (n = 22, 16.3%) vs HC (n = 10, 8.5%) Binge eating disorder HD (n = 19, 14.1%) vs HC (n = 2, 1.7%) Substance use disorder HD (n = 11, 8.1%) vs HC (n = 8, 6.8%) Bipolar disorder HD (n = 9, 6.7%) vs HC (n = 2, 1.7%) Bulimia nervosa HD (n = 4, 3.0%) vs HC (n = 1, 0.9%)

								Anorexia nervosa HD (n = 4, 3.0%) vs HC (n = 1, 0.9%)
Stewart et al. (2020)	United Kingdom	Mixed cross-sectional and experimental design, with a HC group	Community adults recruited for the study (HD group met DSM-5 criteria for HD) Mean age = 57.2 years (SD = 10.9) Gender: 81.5% female Living alone (40.7%) Mean SI-R score = 53.6 (SD = 10.5)	HD group = 27	SIHD SI-R	Binge-eating disorder Anorexia nervosa *Participants with psychosis, bipolar disorder or a current substance dependence were excluded.*	SCID-5-CV	Binge-eating disorder (n = 3, 11.1%) Anorexia nervosa (n = 1, 3.7%)
Van Roessel et al. (2022)	United States	Cross-sectional study, no control group	Treatment-seeking community sample with a formal HD diagnosis. Mean age = 57.0 years (SD = 10.4) Gender: 75.0% female Ethnicity: White (75.0%), Asian (14.0%) African American (4.0%), Other (6.0%), Mean SI-R score = 59.1 (SD = 10.9)	HD group = 71	SCID CIR SI-R SCI	Disorder specifically associated with stress[4] *Participants with a current or history of psychotic disorder, bipolar disorder, current eating disorder, or a current moderate or lifetime severe substance use disorder were excluded.*	SCID	Disorder specifically associated with stress (n = 4, 5.63%)

Weintraub et al. (2018)	United States	Cross-sectional study, no control group	University undergraduate students (sample 1) and community adults recruited via Amazon's Mechanical Turk (Mturk; sample 2) in the US (HD symptoms studied in a continuum) <u>Sample 1</u> Mean age = 19.0 years (SD = 1.1) Gender: 60.0% female Ethnicity: White (71.7%), Hispanic (25.8%) Asian (15.0%) African American (6.7%), Other (6.4%), Mean SI-R score = 18.2 (SD=10.5) <u>Sample 2</u> Mean age = 35.8 years (SD = 11.0) Gender: 56.0% female Ethnicity: White (82.8%), Asian (6.5%) African American (5.5%), Other (2.4%),	Sample 1 = 120 Sample 2 = 291	SI-R	Schizotypal disorder	SPQ	Individuals who fell within the clinical range on the Saving Inventory Revised endorsed significantly greater levels of schizotypal disorder symptoms (sample 1: t (118) = 3.12, p = .002, Cohen's d = 0.57; sample 2: t (289) = 4.40, p < .001, d = 0.89). HD symptoms correlated with odd speech (β = 0.22, p = .01) and magical thinking (β = 0.17, p = .02) in sample 2. Odd speech indirectly predicted hoarding via the distractibility (β indirect = 0.15, p = .001), forgetfulness (β indirect = 0.10, p = .01), and trigger (β indirect = 0.12, p = 0.004) subscales.

			Mean SI-R score = 17.8 (SD = 15.1)					
Woerner et al. (2017)	United States	Cross-sectional study, no control group	Psychology undergraduate university students (HD symptoms studied in a continuum) Mean age = 20.6 years (SD = 4.0) Gender: 79.4% female Family history of HD (n = 25, 4.3%) Mean SI-R score = 16.2 (SD = 12.9)	Sample = 578	SI-R	BDD TTM ExD	DCQ MGH-HPS SPS	Hoarding symptoms were correlated at medium levels with symptoms of BDD; $r = 0.33$, $p < 0.001$), TTM; $r = 0.35$, $p < 0.001$) and ExD; $r = 0.35$, $p < 0.001$)

[1]MH conditions excluding anxiety, depressive disorders, OCD and compulsive buying disorder.
[2]Exclusion criteria have been reported in this column in italics, only when these were of relevance to the review, i.e., if the study excluded for any MH conditions of relevance.
[3]Some of the presented information for Archer et al. (2019) has been extracted from the Supplementary file information.
[4]Referred to as *Trauma- and stressor-related disorder* as per the DSM-5 classification (APA, 2013).
[5]Results associated with these measures have not been reported as they do not fall within the remit of this review.
Note: MH = Mental health, HC = Healthy controls, HD = Hoarding disorder, CC = Clinical controls, SD = Standard deviation, NR – Not reported; PTSD = Post-Traumatic stress disorder, ED = Eating disorder, PD = Psychotic disorder; BDD = Body dysmorphic disorder; TTM = Trichotillomania; ExD = Excoriation disorder; IQR = interquartile range; SIHD = the Structured Interview for Hoarding Disorder (Nordsletten et al., 2018), SI-R = the Saving Inventory-Revised (Frost et al., 2004), UHSS = the UCLA Hoarding Severity Scale (Saxena et al., 2015), CI-R = the Clutter Image Rating (Frost et al., 2008), MINI = Mini International Neuropsychiatric Interview (Sheehan et al., 1998), SCID/SCID-I = Structured Clinical Interview for DSM-5 Disorders Axis I Disorders (First, Williams, Karg & Spitzer, 2016), DIAMOND = the Diagnostic Interview for Anxiety, Mood, and OCD and Related Neuropsychiatric Disorders (Tolin et al., 2018), HRS-I = The Hoarding Rating Scale-Interview (Tolin et al., 2010), PDS = Posttraumatic Diagnostic Scale (Foa, 1997), HRS-SR = the Hoarding Rating Scale–Self Report (Tolin et al., 2010), SCI = Saving Cognitions Inventory (Steketee et al., 2003), , EDE-Q = Eating Disorder Examination Questionnaire (Fairburn & Beglin, 1994), SCID-5-CV = Structured Clinical Interview for DSM-5 Clinician Version (First et al., 2016), SPQ = Schizotypal Personality Questionnaire (Raine, 1991); DCQ = Dysmorphic Concern Questionnaire (Oosthuizen et al., 1998); MGH-HPS = Massachusetts General Hospital Hairpulling Scale (Keuthen et al., 1995); SPS = Skin Picking Scale (Keuthen et al., 2001).

3.3. Primary Findings

The findings of the review have been outlined in Table 1.2.

All 21 studies identified an association between HD and the symptoms of at least one other MH condition of interest to this review. The following MH conditions were reported to co-occur with HD: disorders specifically associated with stress (PTSD), bipolar and related disorders, personality disorder, eating disorders (bulimia, anorexia nervosa and binge eating), disorders due to substance use or addictive behaviours (alcohol/nicotine/substance use disorder, psychotic disorder), schizophrenia or other primary psychotic disorders (schizophrenia, psychosis, schizoaffective and schizotypal disorder), and three OCRDs (BDD, TTM and ExD). Their prevalence in the samples varied depending on condition, ranging from 3.0% (bulimia and anorexia nervosa; Sordo Vieira et al., 2022) to 37.5% (personality disorder; O'Connor et al., 2018). Additionally, regarding the studies that reported effect sizes, these ranged from medium (r = 0.33, for HD and BDD) to large (d = 0.89, for HD and schizotypal disorder, Weintraub et al., 2018).

The findings from the different studies have been grouped together and organised by MH condition group below.

3.3.1. Disorders Specifically Associated with Stress

Thirteen studies reported evidence for comorbidity between HD and PTSD (Archer et al., 2019; Chasson et al., 2020; Chen et al., 2023; Chou et al., 2018; Grisham et al., 2018; Mathes et al., 2018; Morein-Zamir et al., 2014; Norberg et al., 2020; Nordsletten et al., 2018; O'Connor et al., 2018; Ouellette et al., 2021; Raines et al., 2014; Sordo Vieira et al., 2022) and one between HD and the broader category of a disorder specifically associated with stress (Van Roessel et

al., 2022). In the majority of studies (n = 13) the stress-related condition co-occurred in samples of individuals with clinical hoarding, while in one study it was reported in samples with significant HD symptoms (Mathes et al., 2018). For the studies where this was possible to express as a percentage (n = 13), the prevalence rates ranged from 4.3% to 25.0% (*Med* = 13.3%). Additionally, Mathes et al. (2018) found that aggression mediated the relationship between exposure to interpersonal trauma and HD symptoms (F (3, 254) = 15.02, p < .001, 14.07% of the variance explained), while exposure to interpersonal trauma did not significantly mediate the relationship between aggression and hoarding, providing further support for the specificity of the mediator. In the same study increased emotion dysregulation[8] was associated with increased hoarding symptoms, (B = .18, SE = .05, p <.001).

Moreover, in Sordo Viera et al. (2022) PTSD was more prevalent in their HD sample (16.3%), as compared to their healthy control group (8.5%). PTSD was also found to be more prevalent in individuals with HD alone (4.5%) compared to those with comorbid OCD and HD (0.0%; Morein-Zamir et al., 2014). Ouellette et al. (2021) reported a lower rate of PTSD comorbidity in their HD group compared to their anxiety disorder group (4.8 % vs 8.9 %, respectively). Additionally, HD individuals, did not differ in their overall rates of stressful and traumatic life experiences but reported significantly more crime-related events (e.g., robbery and break-ins) when compared to individuals with clinical PTSD and anxiety (F (2,143) = 13.78, p < 0.001, ηp^2 = 0.162; Ouellete et al., 2021). The HD group in this study also endorsed significantly more items as compared to the other clinical groups within the sexual and physical event category for

[8] Emotion dysregulation is defined as difficulties with the ability to understand and differentiate emotions and manage emotional responses (Raines et al, 2015).

both sexual acts against their will, $\chi 2(2) = 15.31$, $p < 0.001$, $\chi 2(2) = 18.63$, $p < 0.001$, and being the subject of a physical assault, $\chi 2(2) = 5.95$, $p = 0.05$.

3.3.2. Bipolar Disorder and Related Disorders

Five studies reported the presence of comorbidity between clinical HD and bipolar disorder in their samples (Archer at al., 2019; Chen et al., 2023; Chou et al., 2018; Norberg et al., 2020; Sordo Vieira et al., 2022) while one study reported such comorbidity without distinguishing between bipolar and cyclothymic disorder (Grisham et al., 2018). The rate of comorbidity ranged from 3.9% to 20.8% across the studies (*Med* = 8.3%). Sordo Vieira et al. (2022) reported a higher rate of comorbidity of bipolar disorder in their HD sample, (6.7%) as compared to their healthy control sample (1.7%).

3.3.3. Personality Disorder

One study provided evidence for comorbidity between clinical HD and personality disorder (O'Connor et al., 2018), with this rate being 37.5%.

3.3.4. Eating Disorders (ED)

Comorbidity between HD and eating disorders (ED) was identified in ten studies in total (Chasson et al., 2020; Grisham et al., 2018; Millen et al., 2020; Norberg et al., 2020; Nordsletten et al., 2018; Novara et al., 2016; Raines et al., 2014, 2015; Sordo Vieira et al., 2022; Stewart et al., 2020). Of these, six studies reported a link between HD and binge eating (Chasson et al., 2020; Grisham et al., 2018; Millen et al., 2020; Raines et al., 2015; Sordo Vieira et al., 2022; Stewart et al., 2020) with the prevalence ranging from 4.3% to 14.3%, (*Med* = 13.3%). The results of Raines et al. (2015), which was the only study in which their HD sample did not have a confirmed diagnosis, also suggested that binge eating was significantly associated with the acquisition subscale of the SIR

(sr^2 = .05) but not with the clutter one (sr^2 = .03). The same study found that difficulties in emotion regulation mediated the association between hoarding severity and binge eating in their sample (F (3, 92) = 8.58, p < .001, 19.0% of the variance explained). Additionally, one study reported evidence that 22.5% of their sample with a diagnosed ED (bulimia nervosa and binge eating disorder taken together) also met the clinical cut-off for significant HD symptoms on the SI-R (Novara et al., 2016). Three studies identified bulimia nervosa in their clinical HD samples (Grisham et al., 2018; Nordsletten et al., 2018; Sordo Vieira et al., 2022) with the rate ranging from 3.0% to 8.3% (*Med* = 6.7%). Two studies identified anorexia nervosa in their clinical HD samples (Sordo Vieira et al., 2022; Stewart et al., 2020) with its rate being 3.0% and 3.7%, respectively. Two studies reported comorbidity between clinical HD and eating disorders without specifying the type of the ED condition (20.8% in Norberg et al., 2020; 3.1% in Raines et al., 2014).

One of the studies that compared these rates of comorbidity to a healthy control sample of a similar enough size, suggested that for all three eating disorders the prevalence rates were higher in their HD sample (binge eating disorder HD 14.1% vs healthy controls 1.7%; bulimia nervosa HD 3.0% vs healthy controls 0.9%; anorexia nervosa HD 3.0% vs healthy controls 0.9%; Sordo Viera et al., 2022).

3.3.5. Disorders Due to Substance Use or Addictive Behaviours

Comorbidity between HD and disorders due to substance use or addictive behaviour*s* was identified in nine studies in total (Archer et al., 2019; Chasson et al., 2020; Chou et al., 2018; Grisham et al., 2018; Jaisoorya et al., 2021; Norberg et al., 2020; Nordsletten et al., 2018; Raines et al., 2014; Sordo Vieira et al., 2022). Of these, four studies reported alcohol use disorder coexisting with

clinical HD (Chasson et al., 2020; Grisham et al., 2018; Nordsletten et al., 2018; Sordo Vieira et al., 2022) ranging from 9.5% to 20.0%, as well as HD, based on the presence of significant HD symptoms (11.6% in Jaisoorya et al., 2021), (*Med* = 12.5%). The rate of co-occurrence between HD and disorder due to nicotine use (Chasson et al., 2020; Jaisoorya et al., 2021) was between 4.3% and 13.1%. Substance use disorder was present in six studies with clinical HD samples (Chou et al., 2018; Grisham et al., 2018; Norberg et al., 2020; Nordsletten et al., 2018; Raines et al., 2014; Sordo Vieira et al., 2022), comorbidity ranging from 4.8% to 21.9%, (*Med* = 8.9%). One study reported the rate of comorbidity between clinical HD and alcohol and substance use taken together (7.3% in Archer et al., 2019).

Two larger sample studies comparing this type of coexisting conditions in HD and healthy controls suggested that the prevalence rates for all of these were higher in their HD groups (alcohol use disorder, Sordo Viera et al., 2022, HD 20.0% vs healthy controls 12.8%; Jaisoorya et al., 2021, HD 11.6% vs healthy controls 1.6%; substance use disorder, Sordo Viera et al., 2022, HD 8.1% vs healthy controls 6.8%; Jaisoorya et al., 2021, nicotine dependence disorder, HD 13.1% vs healthy controls 3.9%).

3.3.6. Schizophrenia or Other Primary Psychotic Disorders

Three studies reported evidence for comorbidity between HD and schizophrenia or other primary psychotic disorders (Nordsletten et al., 2018; Novara et al., 2016; Weintraub et al., 2018). One instance of a psychotic disorder patient (schizophrenia/schizoaffective disorder) who scored beyond the clinical cut-off on the SI-R, was recorded by Novara et al. 2016 (5.9%). Additionally, one UK patient in the clinical HD sample of Nordsletten et al. (2018) also met the diagnostic criteria for psychosis, which was equivalent to a rate of

3.5%. Moreover, in Weintraub et al. (2018)'s sample of university students participants scoring at the clinical range of the SI-R endorsed significantly greater levels of schizotypal symptoms overall (*p*s < 0.002). Furthermore, in one of the samples there was also an association between HD symptoms and odd speech (β = 0.22, p = .01) and magical thinking (β = 0.17, p = .02). . Additionally, cognitive failures[9] mediated the relationship between odd speech and hoarding symptoms (Table 1.2).

3.3.7. Obsessive-Compulsive and Related Disorders

One study reported a medium level association between HD symptoms and three OCRDs. These were BDD (r = 0.33), TTM (r = 0.35) and ExD (r = 0.35) in a sample of university students (Woerner et al., 2017).

4. Discussion

This is the first systematic review to explore mental health comorbidity in HD. It aimed to synthesise the recent research literature on HD in community and outpatient samples to help identify which mental health conditions it might co-occur with, beyond OCD, anxiety-related disorders, depressive disorders and compulsive buying disorder. The second aim of the review was to provide some insight on how the identified rates of comorbidity in HD compare to those in clinical and non-clinical control samples.

4.1. Summary of the Findings

The comorbidity rates between HD and the other MH conditions in the selected studies varied from 3.0% to 37.5%. Notably, disorders specifically associated with stress were the most common, having been identified in 14

[9] These are defined as perceptual, memory or motor lapses that occur in daily life (Weintraub et al., 2018).

studies. Ten papers reported eating disorders in their HD samples; disorders due to substance use or addictive behaviours coexisting with HD were reported in nine. Bipolar and related disorders were identified as a comorbid condition in six studies. Three papers suggested an association between symptoms of psychotic disorder and HD. One study provided evidence for personality disorder coexisting with clinical HD, and another suggested an association between HD symptoms and symptoms of three different OCRDs.

Additionally, four studies also offered information on the comorbidity rate of the same MH condition(s) in healthy (Jaisoorya et al., 2021; Sordo Vieira et al., 2022) and clinical samples (Ouellette et al., 2021; Morein-Zamir et al., 2014). The findings consistently indicated that, compared to healthy controls, HD was associated with a higher prevalence of also presenting with one of the following MH conditions: PTSD, bipolar disorder, binge eating, bulimia and anorexia nervosa, alcohol, substance use or nicotine dependence disorder. As these conditions were also the most frequently reported in the included studies, understanding how the observed rates compare to their base rates in the general population may be informative. Overall, the median rates reported in HD samples for each of these conditions were higher than their prevalence levels globally (e.g., PTSD *Med* = 13.3% vs 3.9% [global rate; Koenen et al., 2018]; bipolar disorder *Med* = 8.3% vs 0.6% [global rate; Merikangas et al., 2011]; bulimia nervosa Med = 6.7% vs 1.0% [global rate; Kessler et al., 2013]). As for the comparisons with clinical samples, the results were more mixed. While PTSD was more prevalent in Ouellette et al. (2021)'s anxiety disorder group, this trend was reversed in Morein-Zamir et al. (2014)'s study where comorbidity with PTSD was observed in their HD group only and not in their OCD with HD group, although this finding was based on a single participant. Importantly, however,

Ouellette et al. (2021)’s study also suggested some qualitative differences between their three clinical samples in terms of the type of traumatic events they had experienced. For example, HD respondents with comorbid PTSD were more likely to endorse crime-related events as compared to individuals, diagnosed with PTSD or anxiety only.

4.2. Potential Mediating Mechanisms

Four of the included studies proposed potential mechanisms that may help explain the observed associations between HD and some of the other MH conditions (Mathes et al., 2018; Ouellette et al., 2021; Raines et al., 2015; Weintraub et al., 2018). It should be noted that due to the cross-sectional design of the studies, no causal inferences or directionality of such relationships can be inferred. The following are, therefore, potential pathways through which the relationship between HD and other MH conditions may occur.

One such mechanism was illustrated by Mathes et al. (2018) who found that aggression mediated the association between exposure to interpersonal trauma and hoarding symptoms. Therefore, it is possible that exposure to interpersonal trauma might increase one’s tendency to have hostile thoughts, experience and express anger, and engage in aggressive behaviour (Mathes et al., 2018). This might then lead to a decreased sense of connection with others and an increased sense of connection to possessions, i.e., maintaining HD behaviours (Mathes et al., 2018). Another potential mechanism, relating interpersonal trauma and HD might be that experiencing events involving a violation of one’s sense of control (e.g., physical or sexual assaults) may also contribute to the development of cognitive distortions, related to control and responsibility over possessions, which are characteristic of HD (Ouellette et al., 2021).

In addition, Raines et al. (2015) identified emotion regulation difficulties as an affective mechanism that might mediate the link between binge eating and increased hoarding symptoms. Individuals might, therefore, be engaging in both types of maladaptive behaviours (e.g., acquiring items and overeating) as strategies to regulate their emotions. Additional support for the significance of emotion dysregulation in HD also comes from Mathes et al. (2018) who found that in their sample, emotion regulation difficulties were significantly associated with hoarding symptoms only, but not with aggression or having experienced trauma. This suggests that in the context of HD, aggression may sometimes reflect a more global difficulty with emotion regulation associated with the disorder.

Finally, Weintraub et al. (2018) found that cognitive failures (i.e., disorganisations in thinking) mediated the relationship between HD and certain schizotypal disorder symptoms in one of their groups, thus, proposing a neurocognitive mechanism for the association. It should be noted that all of the above mechanisms could also present at the same time and interact with one another (Bates et al., 2024), as well as with other factors such as the individual's genetic predispositions and environmental conditions in accordance with the biopsychosocial model of HD (Tolin, 2023).

4.3. Shared Vulnerabilities Across Conditions: The Role of Emotion Regulation

While dysfunction in all of the above mechanisms is well-established in the literature on HD (Frost & Hartl, 1996; Grisham et al., 2010; Barton et al., 2021, Bates et al., 2024), none of these mechanisms is uniquely related to the disorder. This poses the question whether the present findings could be understood from a transdiagnostic perspective that looks at common shared vulnerabilities between conditions (Aldao & Nolen-Hoeksema, 2010; Barlow et

al., 2004; Mansell et al., 2008). For example, emotion dysregulation may exacerbate negative affective states by leading to increased physiological arousal and distress, as well as the use of maladaptive strategies to manage this, such as avoidance and rumination (Aldao et al., 2016). Such difficulties have been implicated as a common construct in the development and maintenance of various types of psychopathology, including anxiety, depression, substance use, eating and borderline personality disorders (Aldao et al., 2010; Sloan et al., 2017), as well as internalising and externalising MH conditions, more broadly (Aldao et al., 2016). One way, therefore, to interpret the present results, is to consider that difficulties with emotion regulation, for instance, might be a central, shared vulnerability across some of the reported conditions. Furthermore, viewing the findings from a developmental psychopathology perspective (Rutter et al., 2006), which posits that symptom expression may remain stable or change over time due to interactions with the individual's biological, psychological, and environmental factors, could help provide further clarity to the results. Within this framework, emotion dysregulation as a common shared vulnerability (Aldao & Nolen-Hoeksema, 2010; Aldao et al., 2010) may contribute to diverse symptom patterns across individuals, which are then shaped by each individual's unique characteristics and experiences, and over time, may lead to multiple forms of psychopathology within the same person (Rutter et al., 2006).

4.4. Comparison with Previous Review Findings (Wheaton & Van Meter, 2014)

Overall, these findings are consistent with Wheaton and Van Meter (2014), although there are also some notable differences. First, similarly to the above review, PTSD does not seem to be a unique comorbidity to HD in terms of its co-occurrence rate (Wheaton and Van Meter, 2014). However, our findings raise

important questions about likely differences in the contents of the stressful experiences between HD and other clinical groups (Ouellette et al., 2021). Second, only one of the included studies reported co-occurrence with personality disorder, which was, however high (37.5% in O'Connor et al., 2018), while Wheaton and Van Meter (2014) had suggested that personality disorders are relatively common in HD. This difference might potentially be due to both sampling (recruitment from MH clinics vs community) and personality disorder being a common exclusion criterion for study participation. Third, discrepant with Wheaton and Van Meter (2014) who had suggested that eating disorders are relatively infrequent in HD, the present review identified an association between HD and eating disorders in nine different samples with the most common eating pathology being binge eating. To note, binge eating was also mentioned in Wheaton and Van Meter (2014) as co-occurring at a higher rate in HD than OCD. Fourth, we identified nine studies that reported an association between disorders due to substance use or addictive behaviours and HD; this result is consistent with the above review which also suggested that this is a relatively common comorbidity in some HD samples. Fifth, similarly to Wheaton and Van Meter (2014) the present review identified one study that provided evidence for coexisting OCRDs and HD. Importantly, these likely co-occur more often than reported due to the researchers' choice in terms of what MH conditions they might choose to screen for. Sixth, Wheaton and Van Meter (2014) did not discuss the association between psychotic disorders and HD. Finally, the present systematic review extends prior work by also providing information on four potential mechanisms that might mediate the observed comorbidities.

4.5. Strengths and Limitations

The present findings should be interpreted in light of their limitations.

First, given the wide range of MH conditions that may be relevant to HD, this review faced a methodological challenge of having to establish clear boundaries for the inclusion and exclusion criteria of empirical papers. As noted in the Introduction, the decision to exclude commonly studied and assumed MH comorbidities with HD, such as OCD, anxiety-, depressive- and compulsive buying disorders, as well as the co-occurrence between HD and neurodevelopmental conditions, was made to enable a more focused investigation of underexamined areas on the topic. As such, the present findings should be interpreted within the context of the specific focus and scope of the work, which, although methodologically justified, may, for example, have led to the omission of interaction effects with more frequently co-occurring conditions.

Second, the list of identified comorbid MH conditions is limited to the type of conditions individual studies chose to assess and exclude participants for, as well as by the type of studies included in the review. As a result, comorbid cases in the HD groups might have been missed in studies focusing on a particular condition rather than using a comprehensive diagnostic measure like the DIAMOND (Tolin et al., 2018). Additionally, it is a standard practice in research to exclude participants from the study if they have an acute/more severe MH conditions or a history of such, some of which were of relevance to the present review, including bipolar, personality disorders and eating disorders. Therefore, such cases are unaccounted for in the present work. A related limitation was that the review included comorbidity data from quantitative studies only. This decision was based on the initial scoping search, during which no qualitative studies on HD, that reported mental health comorbidity information about their participants, were identified. Nonetheless, this exclusion criterion may have resulted in some relevant studies on the topic having been missed, which could

have, in turn, impacted the comprehensiveness of the findings and the overall conclusions. However, a corresponding strength was the adoption of a particularly comprehensive approach to search the literature by screening the Methods sections of all relevant articles, instead of restricting the search with specific search terms. This approach aimed to increase the chance of including as many as possible quantitative studies that reported relevant information to this review. Moreover, findings were only extracted from papers where both HD and MH were assessed with validated measures, thus increasing the construct validity of the review.

A third limitation was the heterogeneity between the studies, making a statistical comparison not possible. Studies differed in terms of research design, sample selection, the presence of a formal diagnosis of HD and/or the MH condition and the measurement tools used. However, hoarding symptoms are dimensional in nature (Timpano et al., 2013), and as such including both studies where the HD group met the criteria for a formal HD diagnosis, and studies where the sample had significant HD symptoms is a strength of the present review. It is also important to note that studies varied in the use of clinical control or healthy control samples and that these were sometimes not matched in terms of size, and at times differed in terms of other characteristics such as age. All of these made comparisons between the included studies difficult, even when they explored the same condition. At the same time, the latter might partly account for the differences in the observed comorbidity rates across samples.

Fourth, many of the studies had a small sample size and used a sampling method that might not be optimal in terms of providing an accurate representation of this population subgroup (Table 1.1 and 1.2). The findings of

this review should be interpreted with these in mind. The latter, however, is representative of the problems related to research on the topic, in general (Mataix-Cols & Fernández de la Cruz, 2018) and papers often having methodological problems (Postlethwaite et al., 2019; Zaboski et al., 2019). Nevertheless, an important strength of the present review is that the included HD samples are very similar in terms of demographic characteristics to what has been reported in recently published systematic reviews on HD (Barton et al., 2021; Bates et al., 2021; Postlethwaite et al., 2019) and the empirical literature in general. For example, the mean age of our combined HD group (*M* = 52.5 years) was very similar to the age of HD participants in research studies as this is when they typically start seeking help (50-55 years in Thew & Salkovskis, 2016).

4.6. Clinical Implications

The findings of the present systematic review provide evidence for the complex clinical profile of the hoarding patient in the community. These might be helpful to patients and family members who may be unaware that HD and other mental health conditions could coexist. This, in turn might positively influence their approach to how they manage the condition and if they try to seek formal support. The findings could also contribute to improving clinical practice by encouraging professionals to consider if additional mental health conditions might be contributing to their patients' difficulties, therefore, warranting more comprehensive mental health assessments to be routinely completed in this patient population, especially for disorders less commonly associated with HD. Such a shift in practice could potentially enhance treatment outcomes by fostering a deeper understanding of the patients' needs and developing more effective treatment plans. In line with Bates et al. (2021), the present results

highlight the need for patient-tailored multiagency working in HD, so professionals can more successfully meet patients' complex needs.

Finally, given that the present review provides a synthesis of the most recent research on the topic, this work has the potential to influence the development of clinical guidelines for the assessment and treatment of HD. For example, currently in the UK no such national guidelines on HD as a separate condition exist. The last most relevant document by the National Institute for Health and Care Excellence (NICE) was published 19 years ago where hoarding was still considered a subtype of OCD (NICE, 2005).

4.7. Research Implications and Directions for Future Research

This chapter presents the first systematic review conducted on the topic. The results could, therefore, be helpful to guide future research as they draw attention to MH conditions for which the link with HD is not well-established and how the prevalence rates for some of these might compare to clinical and non-clinical groups. For instance, in the present review, comorbidity information was primarily drawn from studies on other HD topics, such as comparisons of different treatment types or examinations of various aspects of cognitive performance in individuals who hoard, rather than from studies focusing specifically on MH comorbidity in HD. Future research that directly investigates MH comorbidities in HD as a primary focus could offer valuable insights into the prevalence of conditions that often lead to participant exclusion in empirical studies, such as bipolar disorder, personality disorders, and eating disorders. Furthermore, separate future meta-analyses could examine comorbidity between HD and the MH conditions that were excluded from the present review, as well as explore co-occurring neurodevelopmental disorders with HD. Future work could also compare the prevalence rates of MH comorbidity in different clinical

and non-clinical HD samples. Finally, by identifying potential mechanisms that might underly some of the observed associations with HD, the present review supports the utility of a transdiagnostic framework grounded in developmental psychopathology. With further investigations, this approach may inform future treatment development and clinical practice. Studies could also focus on examining additional factors that might underpin the observed relationships such as gender, socioeconomic status, physical health and other MH correlates.

4.8. Conclusion

This systematic review synthesised the research findings from the past ten years on what MH conditions that might co-occur with HD, beyond OCD, anxiety-, depressive and compulsive buying disorders. It pointed to factors that might mediate some of these relationships and the similarities and differences in comorbidity with other clinical conditions. The findings support the need for more comprehensive assessments and treatments being offered to patients, ideally with a holistic, multidisciplinary approach in mind. It is hoped that these might in turn increase the opportunities to successfully detect and treat additional comorbidities that might otherwise negatively impact on the treatment trajectory of some patients. The present findings could also guide future research to focus on exploring aspects of this topic in a greater detail and with more precision.

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CHAPTER 3: Bridging Chapter

Bridging Chapter

The systematic review chapter highlighted the complex clinical profile of the hoarding patient in the community, identifying that HD can co-occur with a number of other mental health (MH) conditions. These included disorders specifically associated with stress, bipolar and related disorders, personality disorder, eating disorders, disorders due to substance use or addictive behaviours, schizophrenia or other primary psychotic disorders, and obsessive-compulsive and related disorders. Furthermore, the systematic review also suggested that individuals with HD in the present samples were more likely than the general population to meet the diagnostic criteria for or show symptoms of additional mental health conditions. These results align with the well-established finding in the literature that the presence of one type of psychopathology increases the likelihood of developing another (Andrews et al., 2002), a relationship that has also been confirmed across cultures (McGrath et al., 2020).

One influential perspective explaining the frequent co-occurrence of mental health conditions posits that these disorders share underlying vulnerabilities. Instead of being viewed as entirely distinct categories, mental health conditions may be better understood, therefore, as dimensions of psychopathology existing along a continuum of severity (Wright et al., 2013). Simultaneously, research on the social determinants of health has highlighted the interconnectedness between mental and physical health, socioeconomic factors such as income and education, and access to treatment (WHO, 2023; Prince et al., 2007; Starfield, 2007). A disadvantage in one domain often correlates strongly with poorer outcomes in others. For instance, a review of studies in developing countries identified a significant positive association between the prevalence of common mental health conditions and indicators of poverty, including low educational

attainment, limited income, material deprivation, unemployment, and housing instability (Patel & Kleinman, 2003).

Consequently, having a mental health condition like HD can be viewed as a factor that might amplify the individual's general vulnerability across multiple domains. This vulnerability is further compounded when HD co-occurs with additional mental health conditions. Thus, the present systematic review chapter can be seen as a study into one aspect of complexity in HD and the vulnerability associated with it at an individual level.

The empirical chapter in this portfolio (Chapter 4) moves the focus to examine these vulnerabilities at a systems level. Specifically, it explores how the added complexity introduced by having a family member with HD might influence patterns of vulnerability and resilience for children in such households—who, by default, represent one of the most vulnerable groups in this context. This follows from a large body of literature suggesting that parental mental health is one of the primary determinants of the child's mental health and general well-being (Black et al., 2017). Children of parents with mental health difficulties are at an elevated risk of adverse outcomes, such as poorer quality of life (Radicke et al., 2021) and increased rates of psychopathology (Stapp et al., 2020). Additionally, research has demonstrated that the likelihood of offspring developing emotional and behavioural vulnerabilities raises with the number of comorbid conditions their parents suffer from (Watkeys et al., 2023). Notably, HD is linked to various functional impairments, including unemployment (Nordsletten et al., 2013), and its effects can often spread across broader systems surrounding the individual who hoards. For example, the daily exposure to waste and contaminants can pose significant health risks to others in the household (Lacombe & Cossette, 2018).

Taken together, these findings suggest that living with a relative who hoards introduces additional complexities to a child's home environment that extend beyond their relative's mental health condition alone. Therefore, to capture how the problematic hoarding might have interacted with their wider context and contributed to patterns of vulnerability and resilience in such children, the empirical chapter explored the lived experiences of adults, who had grown up with a relative who hoarded, from a systemic perspective.

CHAPTER 4: Empirical Research Paper

Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

Written as a manuscript for submission to the Journal of Obsessive-Compulsive and Related Disorders* (see Appendix A)

Word Count (including references): 14 765

*Where appropriate, material from my ClinPsyD Thesis Proposal has been re-used throughout this Thesis Portfolio.

Abstract

A growing body of evidence suggests that hoarding disorder (HD) can have a negative impact on multiple systems around the individual. Still, little is known about the effects of growing up with a relative who hoards. This research focuses on young adults, paying attention to their wider context, personal characteristics and how their relative's hoarding behaviour might have interacted with these. Semi-structured interviews were conducted with 15 adults who grew up in such an environment. The narratives were analysed using reflexive thematic analysis. Six themes, which followed the child's[10] developmental journey, were identified: (1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager; (2) A different type of childhood: on anxiety, fear and stress; (3) My needs: was there ever enough room for me?; (4) Alone with it: on helplessness, feeling alone and the silence of others; (5) Wait, was I ever a child?: on growing up early; (6) Who have I become?. The findings revealed some of the risks some children might be exposed to as a consequence of growing up with a relative who hoards, their psychological strengths and how nuanced their lived experiences could be depending on the multiple interactions between systems and the person in context. The present study has both clinical and research implications as it is the first to emphasise on the inherent vulnerability of children living in such an environment and to highlight how their experience might differ from that of adults.

[10] Please note that while the term *child* is used throughout this document to refer to the participants in this study during their childhood, all individuals who took part in this research were adults at the time of participation.

1. Introduction

1.1. Definition and General Considerations

Hoarding disorder (HD) is a persistent mental health condition characterised by extreme difficulty parting with possessions leading to the excessive accumulation of items, often resulting in unusable and unsafe living spaces (World Health Organization [WHO], 2019). It affects approximately 2.5% of the population (Postlethwaite et al., 2019) with some evidence suggesting a relatively stable prevalence across cultures (Nordsletten et al., 2018), although importantly, Nordsletten et al. (2018)'s study relied on a relatively small, combined sample, exploring HD in only three cultures. The condition is notoriously difficult to detect and treat for several reasons. First, HD progresses insidiously, with excessive accumulation of objects becoming more noticeable over time, making organising and discarding possessions increasingly challenging (Morein-Zamir & Ahluwalia, 2023). Second, the individual typically has limited or no insight into why their behaviour is problematic (Greenberg, 1987), leading to a general reluctance to cooperate. Third, HD often co-occurs with other mental health disorders (Frost et al., 2011), neurodevelopmental conditions (Storch et al., 2016; Worden & Tolin, 2023), and physical health problems (Bates et al., 2021), further complicating its diagnosis and treatment. Understandably, HD has been reported to be debilitating for individuals, as it is associated with a number of functional impairments, a lower quality of life (Saxena et al., 2011; Tolin et al., 2019) and significant distress for individuals, especially in the context of discarding items (WHO, 2019).

1.2. Impact on Others: The Wider System

A growing body of evidence also suggests that HD also a negative impact on multiple systems around the person who hoards. Considering the wider systems, the disorder is, for instance, associated with economic burden as HD is usually inversely related to income (Nordsletten et al., 2013) and increased health costs (e.g., frequent use of health services; Tolin et al., 2008). Furthermore, HD is recognised as a community health problem in North America (Frost et al., 2000) as it poses various risks of a chemical, physical, biological, and psychological nature, not only to affected individuals and their families but also to neighbours, volunteers, and professionals involved in managing the condition, such as, for example, housing officers (Porter & Hanson, 2022). Some examples include unsanitary conditions in and out of the person's home due to the accumulation of food, animal waste and other contaminants (Lacombe & Cossette, 2018) and the endangerment of others' lives due to an increased risk of fire hazards (Neave et al., 2017).

1.3. Impact on Others: The Family System

Shifting focus to the family system, several studies have highlighted the negative impact that HD can have on the immediate family members. Tolin et al. (2008) studied the familial burden[11] of HD in an online survey with 665 friends and family members of individuals with hoarding difficulties. Their findings suggested high levels of family frustration, hostility and rejection towards the person who hoarded, the latter of which was predicted by the severity of hoarding symptoms and the individual's perceived lack of insight into the behaviour. Moreover, having lived with a person who hoarded during one's

[11] consequences resulting from accepting the hoarding behaviour (Nordsletten et al., 2014).

childhood was associated with elevated rates of distress and rejection towards the person who hoarded, as well as a strained relationship with them (Tolin et al., 2008). Additionally, a quantitative study by Drury et al. (2014) reported that caregivers experienced functional impairments similar to those of the individuals who hoarded and that their emotional well-being was significantly reduced. The familial burden associated with HD was also found to be comparable to the challenges faced by relatives of dementia patients (Drury et al., 2014). Families often get trapped in a cycle of accommodation to the hoarding behaviour where they end up modifying their own behaviour to prevent distress or conflict with the person who hoards (Nordsletten et al., 2014; Vorstenbosch et al., 2015; Wilbram et al., 2008), which then leads to distress and frustration for the family members (Vorstenbosch et al., 2015).

1.4. Impact on Others: Children

Studying the impact that HD has on children is arguably even more important given their ongoing development. Early experiences significantly influence brain development, as neural pathways are shaped by the child's interactions with their environment during critical periods of growth (Shonkoff & Garner, 2012), thus, making children more vulnerable to environmental effects than adults. Despite this, only a handful of studies have examined the impact of HD on children only. In a quantitative investigation Park et al. (2014) analysed what factors mediated the relationship between the person who hoarded and their adult children. Similarly, to Tolin et al. (2008), the authors reported that increased parental hoarding severity and decreased insight were associated with a more strained parent-offspring relationship. Additionally, as parental hoarding severity increased, family dysfunction also increased. Finally, adult offspring were more likely to suffer functional impairments if they were still living with the

person who hoarded and were accommodating their behaviour. Furthermore, in a study with a large sample of undergraduate students, parental clutter and offspring's accommodation were found to significantly predict participants' hoarding symptoms (Nix & Dozier, 2023). Having lived in a highly cluttered environment as a child was associated with respondents' lower psychosocial functioning. To the author's knowledge to date a single qualitative study has examined the impact of growing up with someone who hoarded in more depth, focusing on parental hoarding, in particular (Rees et al., 2018). This sample consisted of seven Australian women aged between 35 and 62 years who lived with at least one parent who hoarded until they were 16 years old. The semi-structured interview focused on the parental hoarding itself (e.g., if the parents looked for help, if they made attempts to alleviate the hoarding), how respondents coped, and on the tangible impacts on the child (e.g., the relationship between the parent and the child, presence of hoarding difficulties in the adult offspring or any other pathology; if it impacted on how participants build relationships now). Four themes emerged following the Interpretive Phenomenological Analysis (IPA) of the data – psychological and emotional outcomes, coping strategies, perceptions of parental hoarding, and impact on relationships. Interviewees expressed resentment and frustration towards their parents, linking their self-esteem difficulties and more limited social interactions, particularly in their childhood and adolescence, to the experience of growing up in a hoarding environment. Many found it difficult to understand the hoarding behaviour and described being frequently in conflict with their parents because of it. Notably, some positive impact of the parental hoarding on offspring was also identified, with some respondents reporting having developed an increased

self-awareness, acceptance, and tolerance of others' difficulties due to their experience.

1.5. Bronfenbrenner's Bioecological Systems Theory

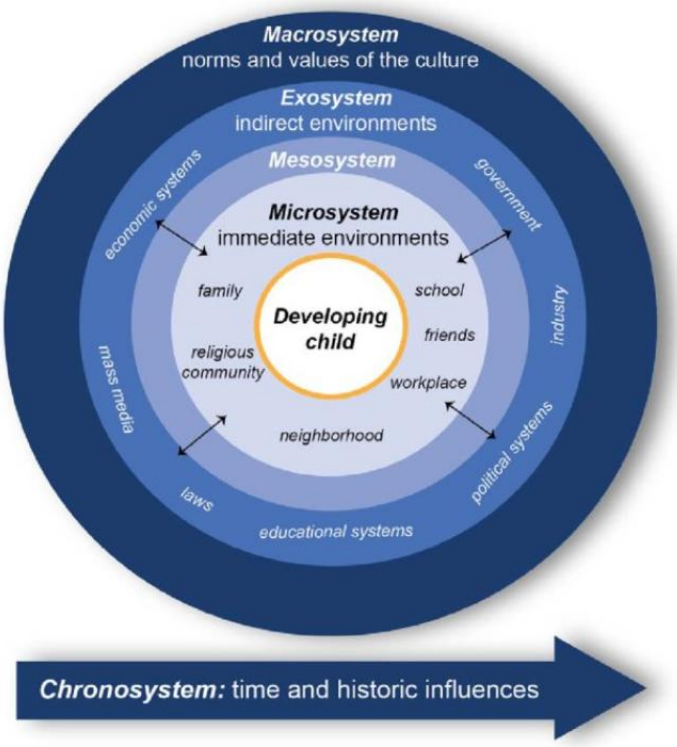
Given the advancements in understanding of HD in the last 25 years, Tolin (2023) has recently proposed a biopsychosocial model to add nuance and better account for its multifaceted nature. At the same time, as described previously, more recently, studies have also evidenced how the hoarding behaviour, more often than not, transcends systems.

One model that might be particularly useful to conceptualise the multi-faceted impact of hoarding on others is Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) which is also one of the most influential and widely cited theories of human development (Weisner, 2008). The model suggests that one's ecological environment is made up of multiple layers (see Figure 2.1), ranging from the individual's immediate context (e.g., their home; *microsystem*) to more distant ones which they might not interact with directly but would still be affected by (e.g., a change in the governing political party; *exosystem*). Furthermore, it incorporates the *mesosystem*, which conceptualises the interactions between different microsystems (e.g., relationships between home and school), and the *macrosystem*, which encompasses the broader values and norms in the individual's culture or subculture (e.g., rules for socially acceptable behaviour). Importantly, Bronfenbrenner's model includes the *chronosystem* (i.e., time in all senses, including historical period), thus acknowledging the temporal aspect of development, recognising that both individual and environmental changes happen over time and influence outcomes. It also introduces *proximal processes* to conceptualise the regular interaction between the individual and their

microsystem (e.g., parent-child, child-friends interactions) as primarily shaping their social, cognitive and emotional development. Additionally, it explicitly acknowledges the role of the *person,* including differences in individuals' inherent dispositions, resources (e.g., skills, knowledge) and capacity to encourage or discourage reactions from others (i.e., *demand characteristics*; Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Finally, this framework puts stress on the dynamic, reciprocal interaction between individuals and their context, postulating that human development is marked by both the *continuity* and *change* of these interactions, as well as the biopsychological characteristics of individuals (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006).

Figure 2.1.

An illustration of Bronfenbrenner's concentric circles from his bioecological systems theory (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Image reproduced from Nicholson and Dominguez-Pareto (2020) with permission



1.6. Current Study: Rationale and Research Question

Taken together, previous research has suggested that problematic hoarding behaviour can have multi-faceted negative impacts on the systems around the hoarding individual. To date, not much is known about how living with a relative who hoards impacts on the developing child, which is particularly important given that children are significantly more susceptible to environmental effects than adults (Shonkoff & Garner, 2012). Previous quantitative studies have focused on the effects of hoarding within the family environment only and on certain aspects of the experience, such as family accommodation and the

parent-child interaction (Tolin et al., 2008; Park et al., 2014; Nix & Dozier, 2023). A single qualitative study (Rees et al., 2018) with a small homogeneous sample of seven Australian women examined the topic in more depth. Importantly, the focus of this study remained primarily on the child's family environment, parental hoarding, offspring's coping mechanisms and the parent-child relationship, with the only other immediate context considered, being the role of friendships. Therefore, no previous research has studied the effects of the hoarding behaviour on the growing child's wider context, while acknowledging the dynamic interaction between systems and the child's personal characteristics.

The present study aimed to breach this gap by qualitatively exploring the childhood experiences of young adults (18-30 years old) who had grown up with a relative who hoarded. The study had two aims. The first one was to explore participants' lived experiences while developing in this environment. The second was to highlight participants' active role in their interactions with their context (e.g., parent-child interactions) and that these would interplay with their individual attributes. Building on Rees et al. (2018), the present study aimed to obtain a rich and nuanced picture of participants' experiences allowing for diversity in the narratives (Braun & Clarke, 2022). To achieve this, the current work did not limit the hoarding individual to being the participant's parent and utilised online recruitment to enable individuals to come from more varied contexts and different cultures.

For context and richness, participants' stories were examined through aspects of Bronfenbrenner's bioecological systems model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006; hereafter referred to as Bronfenbrenner's model throughout for brevity). The reasons for employing this model are twofold. First,

due to its systemic nature, it was deemed suitable to capture the complex cross-systemic effects of HD outlined in the Introduction. Second, it provided an appropriate theoretical framework consistent with the aims of the study to explore participants' experience of having lived with a relative who hoarded while they were also developing (i.e., emphasising the dynamic nature of this process and the importance of proximal processes; Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) and how this experience might have interacted with their individual attributes. Consistent with the novelty of the topic, key elements from the model were selected in accordance with the research aims. The interview questions therefore examined the four key microsystems, namely the person's family environment, school, friends and neighbours, the interactions between these (mesosystem); and the participants' personal characteristics (inherent dispositions, resources and demand characteristics*; the person in context*). Additionally, although not the primary focus of the work, where relevant, the effects from the macrosystem that emerged spontaneously in participants' narratives, have also been reported. Importantly, the model underpinned the present work throughout all stages, from its conception to the final write up. More specifically, it informed the design, development of the interview topic guide, shaped aspects of the data analysis (which was partly theory-driven) and supported the interpretation of the findings.

The present study was, therefore, designed to answer the following research question:

What are the lived experiences of young adults (aged 18-30) who had grown up with a relative who hoarded, and how did these experiences interact with their ecological context and personal attributes, through the lens of selected

elements of Bronfenbrenner's model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006)?

2. Methods

2.1. Design, Research Values and Underlying Theoretical Assumptions

This study adopted a retrospective cross-sectional qualitative design. The principle of overall conceptual coherence was followed to ensure that the study aims, research questions, philosophical and theoretical assumptions and methods were all suitable, and harmoniously fitted together (Braun & Clarke, 2013, 2022). The paragraph below aims to illustrate the attempts to ensure this coherence.

Rooted in Big Q qualitative research[12] (Kidder & Fine, 1987), the study embraced qualitative inquiry not just as a set of techniques but also as a values-driven approach, emphasising researcher subjectivity and the contextual nature of meaning-making (Braun & Clarke, 2013). Aligned with these principles, the primary researcher adopted an experiential orientation as they sought to explore participants' subjective experiences (Byrne, 2022) through semi-structured interviews to generate rich, in-depth data (Patton, 2015). This was guided by a critical realist's stance (Bhaskar, 2008; Maxwell, 2012) which postulates that an objective reality exists (Ontological Realism), while recognising that human practices shape how this is experienced and understood, thereby giving rise to perspectival and contextual truths (Epistemological Relativism; Maxwell, 2012; Contextualism, Braun & Clarke, 2022). In line with Ontological Realism, a

[12] "Big Q qualitative [research] involves the use of techniques of qualitative data generation and analysis within a non-positivist framework informed by qualitative research values" (Braun & Clarke, 2023, p.2), as opposed to "small q qualitative research [which] reflects the use of techniques of qualitative data collection and analysis within a framework of (post)positivism." (Braun & Clarke, 2023, p.1).

theoretical model of human development Bronfenbrenner's model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) was used as a framework to shape the topic guide and inform the analysis and interpretation of the findings, which explored each participant's different, subjective version of reality (Epistemological Relativism[13]). Consistent with the Big Q qualitative values the researcher embraced their own subjectivity in the analytic process as a resource and took extra care to maintain a reflexive standpoint throughout the research process (Braun & Clarke, 2022). They also acknowledged that meaning-making was not objective but rather co-produced between them and the participants (Braun & Clarke, 2022, 2023). Guided by the above, reflexive thematic analysis (rTA; Braun & Clarke, 2019) was chosen as the analytic method as it most closely reflected the study aims, design and the researcher's endorsed assumptions and values. Please, see Appendix C for a more detailed account of the above.

2.2. Quality Assurance

To ensure quality when conducting the present research both Braun and Clarke's (2022) and Yardley's (2000) recommendations on the topic were consulted and kept in mind throughout the research process. Taken together, these emphasise the importance of a deep engagement with the data, sensitivity to context, researcher reflexivity, commitment and rigor, transparency and coherence, as well as impact and significance. To address researcher subjectivity and reflexivity, as suggested by the literature, a reflexive journal was used to document the main researcher's stance, preconceptions and beliefs as they

[13] Although both Contextualism and Epistemological Relativism are used to refer to "different perspectives, interpretations and representations, or possibilities of [a] singular reality" (Braun & Clarke, 2022, p.280), for simplicity we refer to our chosen epistemological orientation as Epistemological Relativism hereafter.

emerged throughout the research process (Lincoln & Guba, 1985; Polit & Beck, 2008; see Appendix C for example excerpts).

2.3. Ethical Approval

The study received ethical approval from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee on the 25th of January 2024 (Application ID: ETH2324-0029; see Appendix D).

2.4. Participants

To minimise the effect of significant historical change on individuals' development, the current study focused exclusively on capturing the experiences of young adults only to ensure that, in Bronfenbrenner's terms (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) they occupied a relatively similar chronosystem. This decision also ensured that participants' lived experiences were relatively recent, in an attempt to minimise the naturally malleable aspect of one's memory, given the retrospective nature of the narratives (Loftus, 1979).

Participants were eligible to take part in the study if they met all of the following: (a) non-hoarding young adults (18 – 30 years old); (b) who identified as having lived with a parent or another relative who hoards/hoarded during their childhood (0 – 17 years); (c) this would have to be for a period of at least three[14] years during which participants had lived with that relative in the same household and had a daily interaction with them; (d) participants had a personal recollection of the experience (i.e., they were not relying on someone else's account); (e) they could still have been living with the person who hoards or

[14] as informed by some models of child development which describe it in stages of three years (Erikson's 1963 psychosocial stages of development) and that some longitudinal studies (e.g., Snyder et al., 2019) also follow children for three years.

could have already moved out; and (f) they spoke and understood English to a good level.

Fifteen participants took part in the study, following research practice in similar peer-reviewed qualitative studies (Sharma et al., 2024).

2.5. Recruitment

Participants were recruited via purposive sampling. The channels for recruitment were posts on Reddit, a forum-style social media platform and through three recruitment partners. These were: (1) the UK Hoarding Research Network, which comprises affiliated research staff from academic institutions across the UK, whose research interests and activities involve hoarding and (2) two organisations which provide support to people who hoard and their families (Hoarding Disorders UK and Clouds End CIC). Additional information on these recruitment channels is presented in the Recruitment section of Appendix C, while the gatekeeper consent of the three recruitment partners can be found in Appendices E, F and G, respectively.

The study was advertised through an online recruitment poster (Appendix H) and a short online advert (Appendix I), which were either posted on social media by the main researcher or were forwarded by gatekeepers to their network and members (see Appendix J for a sample email sent to the gatekeepers). Both contained a brief screening survey (Appendix K), hosted on Microsoft Forms, which participants could access via an electronic link and a QR code. The purpose of the survey was to assess if respondents met the inclusion criteria to be invited for an interview. At the end eligible respondents were able to sign up for participation by leaving their name and preferred contact details, so the researcher could contact them to arrange an interview. A total of 54 eligible participants provided their details, from whom 14 were selected through a

combination of first-come, first-served selection, and random allocation, adopting a pragmatic approach to recruitment. An additional fifteenth participant who was put forward by a member of the UK Hoarding Research Network and was eligible to take part, approached the main researcher via email, was also interviewed.

2.6. Data Collection and Measures

Demographic information was collected from all participants via a short questionnaire, covering gender, age, disability, relationship to the person who hoards, whether they had siblings or not, the geographical area they grew up in, how long they lived with the person who hoards, and if applicable, the age when they moved out (see Appendix L).

The Clutter Image Rating (CIR; Frost et al., 2008) which is a popular screening tool for hoarding disorder, was used at the start of the interview (see Appendix M). This was to elicit contextual information from respondents about their childhood exposure to the hoarding behaviour (rather than to measure its severity), consistent with Yardley's (2000) sensitivity to context guideline. The CIR is a pictorial scale consisting of nine colour photographs of a room presented simultaneously, each differing solely in the level of clutter. The severity of clutter increases progressively across the photos, ranging from 1 (minimal clutter) to 9 (maximum clutter). Participants are instructed to choose the picture that best represents the amount of clutter in the corresponding room of their home. Additionally, the measure is repeated for each of the three main rooms in most people's homes: living room, kitchen, and bedroom. According to Frost et al. (2008), a mean composite score of 4 and above, is indicative of "significant clutter, requiring clinical attention" (Frost et al., 2008, p.201).

The primary data collection method for this study was gathering narrative data from participants via semi-structured interviews.

The questions in the topic guide were devised based on the selected elements of Bronfenbrenner's model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006), namely: the four key microsystems (i.e., the participants' family environment, school, friends and neighbours), the interactions between these (mesosystem); and participants' characteristics (the person in context; see Appendix N). All interviews were audio recorded and transcribed verbatim by the main researcher (SD) to ensure accuracy and align with Yardley's (2000) principle of transparency. Reflective notes were taken during the interviews to support the reflective process during analysis.

2.7. Procedure

All selected participants were contacted via email by the main researcher to confirm their continued interest and were provided an electronic copy of the Participant Information Sheet and Consent Form (see Appendix O & P, respectively). This approach allowed participants enough time to review the information and reach out to the researcher if they had any questions. Those who chose to participate returned their completed consent forms via email and liaised with the researcher to schedule a convenient date and time for the interview. All interviews were conducted remotely via Microsoft Teams© and recorded on a password-protected digital voice recorder.

At the start of the interview participants were reminded of the importance of being in a safe, quiet space where they could not be overheard. It was also ensured that the interviewer occupied such a space to preserve their confidentiality and minimise distraction. The session took around one hour of participants' time. Furthermore, before the start, informed consent was also

reviewed, the interviewer summarised what would happen during the session and confirmed that participants agreed for the interview to be audio recorded. Demographic information was gathered from each participant verbally, while the interviewer recorded their answers on a printed version of the form. Following this, the interviewer introduced the CIR and shared it on their screen for participants to view. A semi-structed interview with each participant followed in the format outlined in the topic guide, with the use of prompts (Appendix N). At the end of the interview participants were offered the opportunity to discuss verbally anything concerning the study or their participation with the main researcher. They were also emailed a written debrief form (Appendix Q) and a £20 Amazon gift voucher following the interview. Additionally, after the first interview, the researcher met with one of their supervisors (SH) to review the interview process and participant feedback. Regular meetings with the supervisory team continued throughout the study, providing a space to assess potential refinements to the procedure and session contents. These discussions also facilitated a critical reflection on the researcher's role, including the emotional load associated with such work and its potential impact on the researcher. This process supported the main researcher's well-being, ensured methodological rigour, and enhanced the trustworthiness of the study.

2.8. Data Analysis

Reflexive thematic analysis (rTA; Braun & Clarke, 2019) was used to analyse the interview data. Braun and Clarke's (2022) six-phase process was followed in which the main researcher moved in a non-linear, iterative manner between the following steps: (1) familiarisation with the data, (2) generation of initial codes, (3) generation of themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. Given that the aim of the study

was to explore participants' subjective experiences, the main researcher adopted an experiential orientation to data interpretation as they were interested in the meaning-making ascribed by participants. Both, an inductive (data-driven) and deductive (theory-driven) approach to data analysis was taken (Braun & Clarke, 2022; Byrne, 2022) to ensure that the emerging data-based meanings were relevant to both the research question and the chosen theoretical framework, so respondents' stories were studied through the lens of Bronfenbrenner's model (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Data were coded using both semantic (explicit) and latent (implicit) codes, acknowledging the active role of the researcher in the co-creation of the analysis (Byrne, 2022; Braun & Clarke, 2012, 2013, 2020). Guided by Braun and Clarke's (2023) best practice for conducting rTA, effort was put to produce themes that were meaning-united, rather than summary-based ones (purely providing answers to the questions in the topic guide).

Line-by-line coding was performed on the transcripts (see Appendix R). Coding was done manually on paper and Microsoft Word by the main researcher to facilitate depth of engagement with the data and embrace the inherently subjective nature of data production in rTA, which are key features of conducting a good analysis (Braun & Clarke, 2022, 2023). Initial themes and subthemes were then discussed with the research team to ensure that only distinct, meaning-based themes had been identified, minimising any overlap among them. As already mentioned, the main researcher kept a reflexive journal throughout the study to reflect on their subjectivity and how it might shape the research process and their findings.

To preserve participants' anonymity, each was assigned a pseudonym and their age was reported within an age range.

3. Findings

3.1. Demographic and CIR data

In total, 15 participants were interviewed about their childhood experience of living with a relative who hoarded. Full demographic characteristics and CIR composite score are presented in Table 2.1.

Ten of the interviewees were female while five were male. At the time of the interview, ten were living in the United Kingdom (UK), four were in the United States (US) and one was in Uganda. Two had grown up in a different country – one UK respondent was originally from the US and one US participant was born and raised in a country in Africa (exact name of country not mentioned during the interview). There was diversity in terms of the type of relative who hoarded – mother (n = 8) stepmother (n = 1); either an older or a younger sibling (n = 4), grandparents (n = 2). All had lived with the person who hoarded for at least 13 years, and most were no longer living with them (n = 12). Most participants had grown up in the countryside (n = 6), followed by a city (n = 4), a suburban area (n = 3) and a town (n = 2). Twelve participants reported a level of clutter equal to or higher than four, suggesting a significant clutter, requiring clinical attention (Frost et al., 2008). A lower level of clutter was typically reported when the person who hoarded was the respondent's sibling, which would be expected, as children usually have less power to accumulate belongings, especially in communal areas as these are normally controlled by an adult (Storch et al., 2011).

Table 2.1.

Demographic Characteristics of Interview Participants

Interviewee Pseudonym	Location	Gender	Age range	Relative who hoards	Years living together[1]	Still living together	Type of area growing up	CIR composite score
Jessica	US/UK	F	26-30	mother	18	No	suburban	5.3
Bob	UK	M	18-25	brother (older)	17	No	city	3.3
Rebecca	UK	F	18-25	stepmother	10	No[2]	countryside	4.3
Rosemary	UK	F	26-30	mother	20+	Yes	countryside	5.0
Jack	UK	M	26-30	brother (younger)	21	Yes	city	4.0
Connor	UK	M	26-30	sister (younger)	17	No	city	2.7
Martin	Country in Africa[3]/US	M	18-25	grandmother	13	No	countryside	5.3
Valerie	US	F	18-25	mother	20+	Yes	countryside	5.3
Ursula	UK	F	18-25	grandparents	15	No	suburban	3.4
Fillip	US	M	18-25	brother (older)	18	No	suburban	4.3
June	Uganda	F	26-30	mother	19	No	countryside	6.0
Penelope	UK	F	18-25	mother	13[4]	No	countryside	4.7
Christa	US	F	26-30	mother	18	No	town	5.3
Juliet	UK	F	26-30	mother	20	No	town	5.7
Faith	UK	F	26-30	mother	19	No	city	6.0

[1]on two occasions the specific number of years has been withheld to preserve anonymity
[2]but live together intermittently
[3]exact country not known
[4]this interviewee went to boarding school and then moved out when of legal age

3.2. Reflexive Thematic Analysis

Six main themes, each containing two or three subthemes, were identified through the analysis (Table 2.2). Given the richness of information collected across the 15 narratives, themes that were less novel or aligned less closely thematically to the rest were excluded to preserve the focus of the empirical study and ensure it is of a manageable length. The two additional themes, identified during the analysis are presented in Appendix S.

Bronfenbrenner's model (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) was applied to provide the overarching structure of the main findings, which mirrored the child's journey of growing up, from the realisation that they were living in an unusual environment, to describing the contents and essence of their childhood, to the adult they have become (Table 2.2). This offered an opportunity to examine how participants' experience evolved over time through proximal processes and while they were developing as "biopsychological human organism[s]" in this environment (Bronfenbrenner & Morris, 2006, p. 797). Additionally, the model was important to shape the final theme which reflected how participants' lived experiences might have interacted with some of their individual attributes.

The six identified themes are presented below:

(1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager

(2) A different type of childhood: on anxiety, fear and stress

(3) My needs: was there ever *enough room* for me?

(4) Alone with it: on helplessness, feeling alone and the silence of others

(5) Wait, was I ever a child?: on growing up early

(6) Who have I become?

Table 2.2 below presents the thematic map illustrating the relationships between the key themes and subthemes identified during the analysis.

Table 2.2.

A Representation of the Key Themes and their Corresponding Subthemes Identified during the Analysis

Themes	Subthemes
(1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager	Unaware at first How I knew Existential shock
(2) A different type of childhood: on anxiety, fear and stress	Anxiety, fear Stress
(3) My needs: was there ever *enough room* for me?	Love and resources My need to belong
(4) Alone with it: on helplessness, feeling alone and the silence of others	Unhelpful assumptions and cycles The silence of others
(5) Wait, was I ever a child?: on growing up early	Responsibility and sacrifice Independence
(6) Who have I become?	The good The bad

3.2.1. Theme 1: Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager

This theme captured meaning around what was described as a very poignant moment in many of respondents' stories – transitioning from a state of unawareness to the realisation that their relatives' behaviour was problematic. It emphasises how adolescence is a period of major biopsychological and cognitive changes (e.g., critical thinking) when individuals also begin to expand their friends microsystem (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). It also poses questions about social norms, which fall into the macrosystem in Bronfenbrenner's terms (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006), the pursuit of *normality*, comparisons with others – both intentional and unintentional, and the intersectionality between identity and internal beliefs.

3.2.1.1. Unaware at First

Virtually all informants spoke about not knowing the hoarding behaviour was a problem at first. For children, it is nearly impossible to recognise an issue when it is all they have ever known:

"…*as a child I didn't know there was anything unusual about it.*" (Jessica)

"*At first, I thought it was normal*." (Rebecca)

"*When I was young, I didn't see a problem with it but as I grew older, I started noticing*." (June)

"… *when you live with something it kind of becomes normal to you, so you wouldn't think much about it*." (Christa)

This subtheme highlights the pronounced vulnerability of a child who is entirely dependent on the adults around them to understand and navigate the

world. Unlike adults, who can critically evaluate their circumstances and assert independence, children often lack the tools to recognise dysfunction:

"*Okay. You see like when you are a kid, when you are five or six, you look up to everything your parents do, you see it as positive… It was not until I was eight I started seeing it; it's kind of weird she has all these things*." (Penelope)

At the same time, hoarding was not seen as problematic in all communities and cultures that interviewees came from:

"…*hoarding was something normal… back in the eighties, the African continent was experiencing a lot of poverty… They almost saw use in everything, they wanted to hold to everything, clothes, baskets, they would keep them*." (Martin)

This excerpt highlights how, depending on the macrosystem of cultural values and societal norms, hoarding could be reframed, and normalised as a functional response. As everyone else around this participant seemed to engage in the behaviour to some extent, it was not seen as dysfunctional in this setting. Additionally, what Martin described also seemed like a warmer, cohesive community where people were close and knew each other well:

"… *even some of my teachers were our neighbours and my grandmother's friends.*" (Martin)

Furthermore, it seemed like Martin did not experience the typical psychological distress that participants coming from western societies shared:

"…*some family members and friends … would make jokes but it did not make me feel that bad. In that community she was an important member. She used to interact a lot with the neighbours*." (Martin)

Additionally, his grandmother's strong social standing might have been another important factor that had positively contributed to the normalisation and acceptance of her hoarding behaviour within the community.

3.2.1.2. How I Knew

For most the realisation came as they were approaching adolescence, often through visiting their friends' homes and comparing them to their own:

"*When I was younger, the house wasn't too much of an issue for me necessarily but when I got older, the more I saw other people's houses, the more I thought, "this is very different… It was probably in middle school, maybe 13 (years) when I started going over to other people's houses frequently. They didn't have as much stuff. Their houses, like… smelled better*…" (Ursula)

Provoked by the comparisons with others and possibly, further supported by the developing critical thinking in adolescence, participants also began to reflect on their environment and ask questions:

"*… but then you get to the point you maybe go to a friend's house, and you wonder … like… you see it's different … and you start wondering and you talk about it but she [my mother] didn't want to listen, so I started wondering, why?*" (Penelope)

3.2.1.3. Existential Shock

One participant explicitly shared how the process of realisation was difficult for them as it made them question what they had known so far and their reality:

"*I feel like when I was growing up, he was my role model. I looked up to him for everything, I thought he simply liked these gadgets, so I loved them, too… I wanted to be like him… But later on, when I realised it was an illness... I really started questioning what I knew*." (Fillip)

This excerpt highlights the power imbalance between the child and, in this case, their older brother. Likely without full awareness, the older sibling might

have influenced not only the child's physical environment but also their internal world, shaping their beliefs, values, and even aspects of their identity.

Along these lines, Juliet spoke about the stark mismatch between the reality at home and the image that was being portrayed to the outside world, which is likely to be particularly disorienting for a child:

"… *to an outsider you'd never know because we were brought up well, we were looked after, we went to school, but then it's only when you come inside you see it and you go … this is like…abnormal*." (Juliet)

3.2.2. Theme 2: A different type of childhood: on anxiety, fear, and stress

This theme encapsulated the daily emotional experiences of many interviewees during their childhood living with a relative who hoarded. These were often dominated by three unpleasant emotions: anxiety, fear and stress, which became defining features of their day-to-day lives. However, a small subset of participants who felt that their needs were largely met during their childhood (quotes illustrating this have been presented in the next theme subsection), did not resonate with this theme, highlighting the diversity in participants' narratives.

3.2.2.1. Anxiety, Fear

Many respondents described frequent feelings of anxiety and fear during their childhood, which they attributed to their relative's hoarding behaviour. Based on the ICD-11 classification (WHO, 2019), anxiety here is understood as a reaction to a perceived or anticipated threat in the future, whereas fear is used to refer to such a reaction to a more imminent perceived threat. Understandably, some respondents reported experiencing these separately but for many these were also interlinked.

Jack, for example, recalled often worrying about his younger brother who hoards and the uncertainty of how he was going to cope in the future:

"*I would hear my mom telling my dad that he would not always live with them, that maybe when he gets his own space, he is going to get married but she isn't sure… So now they are both worrying about my brother's future …I would hate to say this but he's been a burden to me. Whenever we would go out, I'd always be checking what he was doing, I'm always making sure he is comfortable. I'm making sure he's organised…in his room he'd be so disorganised, things were everywhere, so he's vulnerable to maybe injuring himself by falling down. So, I'm there again to make sure he's comfortable, he is safe*." (Jack)

For many, anxiety was also associated with the need to keep the hoarding a secret. Some respondents described going to great lengths to manage perceptions and minimise the impact of the hoarded environment on their lives. Valerie shared how she prepared for social interactions and work:

"*If we tried to have people over, everything would get pushed into a bedroom and like a back room and leave like one or two spaces that looked somewhat normal*. …*to keep my work uniform from getting a smell from the house or something, I would wash it and then immediately take it outside and keep it in my car*." (Valerie)

Similarly, Faith talked about how she felt compelled to prepare her friends in advance before they entered her home, suggesting she might have perhaps been fearing their reaction:

"*I had a couple of friends…who would go around my house. So, I did have to give them like a big speech being like okay this is what the deal … this is my mom like just go in, don't talk to her, that kind of thing*." (Faith)

Others, by contrast, explicitly acknowledged their preoccupation with being judged by others:

"*I actually did avoid inviting friends home because of that, because I didn't want them to judge me based on where I came from*." (Rosemary)

For Rosemary, the latter was also interlinked with shame, which made her intentionally limit her social interactions (discussed in the *My need to belong* subtheme in Theme 3 below).

While anxiety revolved around future concerns, respondents also spoke about experiencing acute fear, sometimes daily, for a variety of reasons.

For instance, Juliet described a feeling of panic whenever someone wanted to enter her house:

"…what if they need to use the toilet, or what if they need to come in. Or like if we got dropped off by someone from like, you get down with someone, they're like, what's this, oh, can I just use the toilet? I don't know, no, we don't have one. Or like, sorry, it's broken. There's just those kind of excuses you have to make in the heat of the moment to stop people coming in and think, again, that's something that sort of impacts the way you build relationships with people because you're always scared that they'll come near your house." (Juliet)

Rosemary and Faith, instead, reflected on their fear as stemming from the potential repercussions if they were to disrupt the hoarded environment:

"*It was like walking on eggshells in your own home, I would say. Because you didn't really know what to touch and what not to touch. …things were just around, there was no space… "If you broke something that had been in the house for like a year or more, then you would have serious problems*." (Rosemary)

"*…my mom [was]… very explosive and angry if you did anything, like move something or throw something away. I didn't feel safe with that person, I didn't feel safe with either of them [mom or dad] really*." (Faith)

For Juliet fear arose from the frequent arguments between family members about the state of the home. She shared how these moments of conflict left her feeling vulnerable and afraid:

"*I remember there being quite a lot of arguments around like, my dad and my older brothers would try and tidy up. My mum would get very aggressive, not physically, but like very verbally aggressive, very distressed… I remember being quite upset and quite scared of all the arguments and it's not really like an appropriate environment for a young child.*" (Juliet)

3.2.2.2. Stress

Following the ICD-11 classification, stress is understood as the state of mental tension being experienced in the context of *an identifiable stressor* (trigger) (WHO, 2019). By presenting stress as distinct from anxiety and fear, which reflected the respondents' sense of perceived threat, the current subsection aims to highlight some of the tangible daily stressors that were part of the respondents' reality growing up.

All interviewees described living in an environment characterised by daily chaos, which was leaving them feeling confused, overwhelmed, and stressed:

"*Going to school was chaotic. I couldn't find my bag in the morning, I couldn't find my uniform, my paper, I would find only one shoe, a few times I went to school with home shoes… Maybe the shoe was wrapped around something in the house, maybe it was under something and then something fell over it and I couldn't find it. It was so stressful*." (June)

"*You know, sometimes it was hard to find clean clothes…In terms of getting ready, I remember the mornings being quite stressed*." (Jessica)

Beyond logistical difficulties, respondents spoke of the difficulty being able to work and focus their attention amidst the chaos:

"… *it was like a chest of drawers, so you'd have to push everything off to get to that, and there was not enough space for me to put a chair, so I'd have to weirdly angle it…it's cluttered, if feels overwhelming, you can't really concentrate, and then you look around, everything else is cluttered*." (Faith)

Additionally, some recalled the stress of being bullied in school either directly or indirectly because of their relative's hoarding behaviour. Fillip described experiencing social exclusion and ridicule in school because of him and his brother who hoards used to go to the same school:

"*They were making fun of us because we were related, we walked together and were seen together everywhere…. People would also make gestures to us… the impolite kind of ones*." (Fillip)

While for June, the hoarding behaviour indirectly led to her being perceived negatively in school and being bullied:

"*Most of the time my clothes would smell funny. Others did not want to sit with me or play with me. They'd say, this is the girl who smells, they would ask me: Why don't you shower*?" (June)

3.2.3. Theme 3: My needs: was there ever enough room for me?

This theme examined the continuous change in biopsychological characteristics that takes place in childhood (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) and how it requires a dynamic expansion in the family microsystem for these needs (e.g., time, space, and love) to be accommodated accordingly. This raises the question: how can these needs be

met in a home which is hoarded, where material possessions often take precedence over a child's needs? It was felt this was the central, if not the most important theme in participants' narratives. The answer to this question, was there *enough room* for them during their childhood, would largely determine if interviewees felt that the hoarding had impacted on them negatively or not. Importantly, as always, this was based on their perceptions of the experience, rather than an objective measure of how their needs were met.

3.2.3.1. Love and Resources

This subtheme explored the love and resources (e.g., time, space, finances), the relative who hoarded would directly allocate to the child. When enough resources were allocated to meet their needs, they perceived they were loved and cared for and overall had a positive experience of their childhood:

"*My mom did always make sure we had a packed lunch, … my clothes appeared clean. I think in terms of like being emotionally available, like my mother was good at that and she did care about us, but she was like definitely struggling to keep the house tidy…. I think I would describe myself as having a pretty happy childhood*." (Jessica)

"*I would say my childhood was good… I was grateful to my grandma for raising me. …she was collecting lots of stuff and she could not get rid of stuff but I was not bothered by it*." (Martin)

Participants vividly described how the accumulation of belongings increasingly occupied more and more space, both in a literal and figurative sense:

"*I always had this feeling of suffocation during my childhood. So, when there's lots of things, you don't have enough space to move around and to play*." (Rosemary)

"*…first few Christmases I remember we had decorations up and it was very kind of Christmassy but then slowly as the hoarding grows you don't have space for a Christmas tree any more or you don't have space to sit down and have Christmas dinner at a table… there wasn't any sort of money really to do clubs or sports or music lessons, which is probably something I would have liked to do*." (Juliet)

Many reflected on the ways in which the hoarding consumed their own time and mental space:

"*I spent most of my time with him to keep him company and also to protect him. I didn't really have a lot of spare time to spend with my friends… I didn't really have time for extracurricular activities. I wanted to do some but he didn't. So, I thought, rather than doing those activities, I should just stay with him*. " (Fillip)

"*… why didn't I go to the library to study…just never entered my head, nothing to be like, oh I could do this, it was just like one, two, three, go home, sit down, go to school, go to work. It was really difficult [for me] to see.*" (Faith)

It was painful to hear how some respondents were wondering if they were loved by the relative who hoarded:

"*It was kind of difficult. A lot of times I felt like I wasn't as important as the stuff... my mom wouldn't clear off the couch, so I had no place to sit for dinner because our kitchen table hadn't been usable for a long time. I eventually started eating in my room and I did that for about three months before she realised why I was upset about that*." (Valerie)

"*They always make you wonder if they love you or they love the things more*." (Rosemary)

3.2.3.2. My Need to Belong

Many participants' spoke about how their relative's hoarding had affected their need to belong. The narratives overwhelmingly revealed how the hoarding would limit opportunities for them to expand their microsystems outside of the immediate family environment (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006).

For some, these would be behaviours that their relative who hoarded would directly engage in:

"… *I remember a couple of years ago, my uncles would come round to bring Christmas presents and my mum would pretend we weren't in…I'm not close to my mum's family at all now because we saw them at their house and we'd see them at my grandparents' house and we'd go to their parties but it probably did impact my relationship with them*." (Juliet)

"…*we all had a bad relationship with the neighbours because sometimes when they would come around the house, my brother would start shouting at them… if one of her little kids would touch something. So, our neighbour who was also a childhood friend of ours, didn't want her kids to come to our house anymore*." (Bob)

Sometimes, the distancing would just happen consequently to what the hoarding behaviour was preventing participants from doing:

"*We never visited each other [the neighbours], so, really there wasn't any relationship there. In the place I grew up in, if you didn't invite people to your house, you'll never get invited anywhere*." (Rebecca)

Two respondents mentioned intentionally limiting their social interactions due to feelings of shame related to their family situation and a fear that they might be judged by others:

"*I wouldn't want anybody outside my inner circle to know much about me. Maybe it's from the shame, I'm not sure. But I would make sure to keep the interaction at a minimum*." (Rosemary)

"*You know, when you have that kind of home you are afraid to bring your friends home, you are afraid to invite friends over, so you literally cut off your social life … you learn to keep to yourself somehow.*" (Penelope)

However, sometimes the problematic hoarding would bring some family members together:

"*I feel like it brought me and my sister and brother closer, because she was angry at us for the same things.*" (Penelope)

3.2.4. Theme four: Alone with it: on helplessness, feeling alone and the silence of others.

This theme explored the actual and perceived isolation often experienced by interviewees in their childhood, making them feel like they were on their own when it came to their relative's hoarding behaviour. Moreover, it captures the intersection between participants' loneliness due to their unhelpful internal beliefs and assumptions, preventing them to seek help, and the lack of adequate response by others, creating a feeling of helplessness.

3.2.4.1. Unhelpful Assumptions and Cycles

Most interviewees felt unable to discuss with others what was happening in their home. For some, this reluctance stemmed from deeply held beliefs that talking about it was inconceivable:

"…*when you're little, you can't say, you can't come to my house because my mom's a hoarder, people would look at me* …" (Juliet)

Another common belief, interviewees held was that those, outside the household would not be able to understand:

"*If you were given a paper to read on that day and you lost it, it would be so hard trying to find it in the morning. So, you'd rather just skip school because you weren't going to explain to the teachers. They'd think you were lying…and that you just want attention*." (Christa)

Children often felt stuck in unhelpful cycles, leaving them feeling helpless and alone:

"…you try and ask a neighbour to talk to her, she gets furious at them, so they [the neighbour] come to me and they are angry at me now…so you just go back to … you kind of stop." (Penelope)

"*… our house was sort of put in order at that time. It was cleaned and some things were … disposed. And … as you can imagine, in no time, it went back to our situation*." (Christa)

3.2.4.2. The Silence of Others

The other prominent subtheme that emerged from the narratives was the noticeable lack of curiosity and action from the others around the family, that participants encountered on a daily basis:

"…if they were thinking it, they kept it to themselves." (Jessica)

Others would rather leave, rather than intervene:

"…I was in high school and there was this friend of mine who came to visit me… I could tell from the moment she walked in, from her facial expression. She didn't say anything, but I noticed something about her, she was shocked…funny enough she never came home again…we kind of disconnected." (June)

It seemed that *the others* would only take action if their own sense of comfort had been disturbed:

"No one normally said anything. Just that time she had packed up the communal corridor with bikes, she had [the bikes] locked to those pipes that were running across, so this neighbour who was moving out had to wait for us for three, four hours, so they started arguing with us…" (Connor)

For some an action would be taken, however, this would not be followed up and eventually the child would remain unsupported:

"I think we had social services once, I think this was due to somebody…somebody's parent worrying about us. That was when I was a lot younger and had no idea… basically my mom managed to get them to leave…that was it." (Faith)

Unfortunately, sometimes others would go so far as to invalidate the respondents' experiences:

"It's frustrating that if I told my father or some other people about it, their superficial response is, why don't you just stop moving stuff? It just sounds like I am being a brat… overstepping my bounds and what not…it makes me look bad trying to help." (Ursula)

Finally, in the rare instances that the others reacted or spoke up, even if this was experienced as painful for participants, it also led to some revelations for them:

"I do remember her husband making quips about things being left in our garden…but I didn't really know what he meant back then. But [his wife] said "Don't say that that's rude". It definitely stuck with me that if we were to put something in our garden, it was visible to other people, people would have an opinion on that." (Jessica)

In fact, some explicitly said they would have wanted others to intervene:

"*… mom never used to put things there. …sometimes I wish she did because maybe we'd get help from our neighbours*" (Christa)

The narratives also highlighted the lack of understanding of the problem by extended family, who sometimes offered practical support with cleaning. While well-meaning, these efforts were ineffective in the long-term:

"…*both of my grandmothers tried to come over and help clean up some, but obviously space got filled back up pretty quickly*…" (Valerie)

3.2.5. Theme 5: Wait, was I ever a child?: on growing up early

Many of the narratives described how growing up with a relative who hoarded *propelled* their child-self into adulthood long before their time. Respondents recalled how as children, instead of receiving care, they would sometimes be the ones providing it. Being part of this dynamic also meant that they had to be independent and make a number of sacrifices, not normally expected from a child.

3.2.5.1. Responsibility and Sacrifice

Respondents described how they often found themselves having to take responsibility for the person who hoarded from a young age. Children would get into role reversals where a child would parent their mother, a younger brother would be taking care of their older brother. Fillip, a younger sibling, reflected on how this dynamic had impacted on his identity:

"*And it made me become an adult first because I was more likely the one with the responsibility because he wasn't really that buoyant or responsible… I was responsible for him, but I was still his younger brother, so I became another person*." (Fillip)

Being part of this dynamic also entailed making sacrifices. Connor, an older sibling, recalled some of the negative consequences helping his sister who hoarded had on his education:

"*…I really had to help her, you know, to find something…On Mondays my first class was History and I always used to miss it because over the weekend she had lost her homework, her bag, she had always lost something and then on Monday we were late…Actually I failed all my history examinations as I had missed most of the classes*." (Connor)

3.2.5.2. Independence

All participants spoke about becoming independent from an early age. Daily tasks such as autonomously doing their homework, preparing for school and managing house chores became part of their routine:

"*I'd get breakfast for myself from a very young age. And I'd get on the bus, and I'd go to school…*" (Jessica)

The majority had also started working from a young age and had moved out to live on their own from a young age:

"*I remember the first time I moved out when I was 18. I went to live with my sister, and I felt a sense of relief like, "I'm out of that place!". I never looked back*." (Rebecca)

Christa, who also moved out at the age of 18, reflected on how her home environment had reinforced her seeking independence, blurring the boundary between choice and necessity (i.e., after moving out from her mother's house, she could finally breathe):

"… *when I moved out, I'd say our relationship wasn't that great as I first stayed for two years without going back home. And I say this because when I started living independently, I felt that "It's like I was drowning when I was at*

home and getting out was like coming out for fresh air". I couldn't bring myself to go back home and she wouldn't understand that." (Christa)

3.2.6. Theme 6: Who have I become?

Respondents also reflected on the psychological characteristics they had developed, i.e., the person they have become now. In line with Bronfenbrenner's model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) the question was purposefully not framed around their relative's hoarding behaviour. This was to acknowledge the influence of participants' individual attributes and their dynamic interactions with the microsystems and the others, beyond their household. Despite this, the majority talked about having developed qualities, many of which seemed to be directly associated with the exposure to the hoarding behaviour in their childhood.

3.2.6.1. The Good

Many participants spoke of possessing positive characteristics and engaging in enriching hobbies. A shared love for reading and writing emerged as a common interest, suggesting curiosity and reflexivity. Several participants also highlighted their empathetic, gentle, and kind nature:

"*I'm really empathic… I am a very good listener. People say I'm sweet*." (Christa)

"*I'm compassionate and I think I'm talented. I love writing, I write a lot and I also like reading novels*." (Penelope)

A lot of respondents also described themselves and sociable and friendly. The extent of this varied across individuals but interestingly, for some it was a way to counterbalance the environments they came from:

"*I am an extrovert I like people and I like socialising. I can basically talk to anybody. I think part of the reason for this is that I had to grow up fast, I took on a lot of responsibility and became an adult*." (Fillip)

"*People always reacted to him negatively and this was scaring me. I didn't really want that; I didn't want to be associated with that…[this] pushed me to be the opposite... I wanted to be different, to be good… I am friendly…I like being with others, working in a group, sharing ideas… "* (Bob)

Related to Theme Five: on growing up early, many participants spoke of themselves as having become responsible and mature adults:

"*I'm this kind of a person who is so responsible, cause that's what I've been doing my entire life… people, they always call me whenever they are going through some kind of a problem … anything to do with family issues, relationships, like anything*." (Jack)

3.2.6.2. The Bad

However, many respondents also reflected on having developed some undesirables characterises which they related to the hoarding behaviour they had experienced as children. Some spoke about being socially anxious:

"*I think I have some social anxiety which I wouldn't have had just because it made it hard to have friends and high school and stuff…*" (Valerie)

"*So, I think it's something that I still have, I'm not so much a social person. So, yeah, so it kind of inhibited my ability to socialise*." (Penelope)

Others described heightened vigilance and being overly alert to their surroundings:

"*… still to this day, my alert system can be very easily pinged off in terms of like sound … I'm quite scared of motorbikes… I'm alert to threats. I can be quite*

sensitive to smell. I know smell links to memories I'm pretty sure, so especially when I smell rotten fruit…it makes me emotional." (Faith)

Faith reflected on how her mother's hoarding behaviour had negatively impacted on her self-image:

"… *there's also things like self-worth and self-doubt. I think when you grow up in a really dirty, difficult environment, you just kind of think, oh, well, I'm not good enough… am I worthy enough to speak to people, or do I have something to say*? "(Faith)

Even though the majority had physically distanced themselves from the hoarded home by moving out to live on their own, thoughts about clutter were still invading their mental space on a daily basis. For example, Jessica described her persistent fears of falling into the same pattern:

"*[My wife and I] try to keep clutter low and take things to the tip when it's time to do that. But there are times when I'm not well and I'm not able to do the weekly cleaning. I kind of have this fear that I will just start neglecting all of that….it just made my fear even worse that if we didn't really stay on top of things that that that could happen so easily*." (Jessica)

Rosemary would even try and control the accumulation of clutter in spaces, outside her own:

"*I always advise others to declutter and it's not always what they want to hear…I've actually noticed it's a habit I'm developing*." (Rosemary)

4. Discussion

This study qualitatively explored the childhood experiences of young adults who grew up with a relative who hoarded through the lens of Bronfenbrenner's bioecological systems model (Bronfenbrenner, 2005; Bronfenbrenner & Morris,

2006). It is the first to examine the wider impact of living in such an environment on the developing child, while acknowledging the broader context in which the child exists and interacts with and the effects that these interactions might have on aspects of their development. Additionally, this is the first study to explore young adults' perspective as it aimed to gain participants' relatively recent accounts of the experience. Six themes were identified through a reflexive thematic analysis of the data, following the child's developmental journey in this environment: (1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager; (2) A different type of childhood: on anxiety, fear and stress; (3) My needs: was there ever *enough room* for me?; (4) Alone with it: on helplessness, feeling alone and the silence of others; (5) Wait, was I ever a child?: on growing up early; (6) Who have I become?. Finally, the study included a heterogeneous sample of participants to give a voice to diversity in the narratives.

4.1. Interpretation and Links to the Literature

These findings highlight the unique experiences of growing up in a hoarding environment. They offer new insights on the topic and build on previous qualitative studies on the experiences of partners, carers and children (Rees et al., 2018; Sampson, 2013; Wilbram et al., 2008).

Different from previous work, the current study emphasises the process through which the child realises that the hoarding behaviour they are experiencing at home deviates from societal norms. The use of Bronfenbrenner's model (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) to structure the findings highlighted how participants' experience had evolved over time, due to changes in both the type of proximal processes they engaged in and their biopsychological and cognitive characteristics as they were growing up in this

environment. For example, the realisation that the hoarding behaviour deviated from normality came for most as they were approaching adolescence. The findings emphasised how this realisation was possibly driven by multiple developmental processes happening in parallel such as the adolescence-specific development of critical thinking and the deepening child-friends interactions (proximal process), leading children to naturally start expanding their friends microsystem (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). It seems like these intricate changes might have then enabled participants to start engaging in social comparisons with others outside their home, helping children to start learning and recognising the social norms of their broader context (i.e., their macrosystem; Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). These findings help to provide insight into the unique vulnerability of a child in such an environment, and how their perspective is largely shaped by what they are exposed to, especially in the absence of many other external reference points, also potentially making the moment of realisation traumatic for some of these children. Additionally, this study adds depth to previous findings by suggesting that in communities where hoarding is not perceived as problematic, children may have a more positive experience and even not feel marginalised. The latter highlights how broader cultural attitudes can shape individual experiences, illustrating the dynamic interactions between the micro- and the macrosystems around the individual (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006).

The narratives also provided insight into participants' emotional experiences while growing up in such a household, with the majority reporting stress and anxiety as daily occurrences, and some even describing feelings of fear. These findings expand on Wilbram et al. (2008), Rees et al. (2018) and Sampson

(2013) who primarily described their participants' anger, resentment, and sadness towards the hoarding behaviour. From a bioecological perspective (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) the present results highlight how interviewees' home environment (the microsystem), in the context of growing up with a relative who hoards, can become a significant source of chronic stress which can then have implications for participants' emotional development, providing an additional reminder of the child's vulnerability in this context. For instance, some of the findings in the final theme, suggested that some of the participants believed they have become socially anxious and that their self-image has been affected negatively as a result of their lived experience. These results are consistent with the literature studying the needs of children of parents with mental illness (COPMI). For instance, the World Psychiatric Association (WPA) guidelines on COPMI emphasise that such children are at a risk of exposure to excessive, prolonged, and inappropriate anger, as well as disturbed behaviour, such as impulsivity and extreme mood swings due to their parent's condition (Brockington et al., 2013). In line with the literature on toxic stress, experiencing chronic stress is associated with a number of harmful effects for children, including poorer physical and mental health and impaired learning and memory (Franke, 2014; Johnson et al., 2013). Furthermore, similarly to Sampson (2013), despite physically distancing themselves from the hoarding environment in adulthood, clutter remained psychologically significant for many of the interviewees in the present study. This raises the question whether these lived experiences may have been traumatising for some participants, and if clutter might act as a trigger to the emotions from the past. While not all of the narratives described this level of distress, the

findings highlight the risks that some children growing up in such an environment may be exposed to.

A novel and particularly important theme identified in the present study was the role reversal (i.e., role confusion) many children experienced, taking on caregiving responsibilities typically beyond their years. In Bronfenbrenner's terms these narratives reflect how the family microsystem in such context would sometimes place developmentally inappropriate demands on children (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Examples included younger siblings caring for older ones or children looking after parents. This is a common finding in the literature on parental psychopathology (Thompson et al., 2024). The premature adoption of adult roles could potentially have negative implications for the child's social, emotional, and cognitive development, attachment style and health (Macfie et al., 2015), including an increased risk for the child of developing psychopathology (Obsuth et al., 2014). This finding could be explained by the possibility that some developmentally appropriate proximal processes (i.e., child receiving consistent care) could potentially be disrupted in some of these contexts, therefore, contributing negatively to the child's healthy development (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006).

Consistent with Sampson (2013), the present study identified some of the internal barriers preventing children in such situations to seek support. While in this earlier paper participants mainly worried about being judged by others, the interviewees in the present study recalled assuming as children that others would not understand their situation. Therefore, some of the current interviewees remembered deliberately limiting their social interactions. The present findings also highlighted that the others would generally not intervene or provide support. While extended family sometimes offered some practical

assistance, such efforts often backfired or failed to make a meaningful impact. In Bronfenbrenner's terms this could reflect micro-macrosystemic dynamics concerning social norms about privacy and family boundaries (i.e., how appropriate is for one to intervene), resulting in many children feeling *alone with it* in this context. Moreover, these could also be explained with a problematic mesosystem where relationships between the family and the other microsystems (e.g., friends, school, neighbours) were underdeveloped or non-existent. In addition, the self-imposed isolation that some participants described might potentially reflect unhelpful interactions between the child and these micro- and macrosystems, which could have then further reinforced no or only very limited support being offered by others within these systems.

Finally, despite all interviewees having grown up with a relative who hoarded, there was considerable variability in their lived experiences and perceived outcomes. In contrast to the more challenging accounts reported above, some recalled their childhood as largely positive, reporting that the hoarding had little impact on them. Consistent with Rees et al. (2018), several participants described possessing a number of positive individual attributes. This aligns with the wider literature suggesting that some children remain resilient despite growing up with parents with severe mental illness (Fraser & Pakenham, 2009). In line with Bronfenbrenner's model (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) interviewees articulated how some of their dispositions had been partly shaped by their context, likely through an interplay with their inherent temperamental dispositions. For example, a degree of Bob's extroversion appeared to have resulted from him adaptively responding to social cues in his microsystem ("I didn't want to be associated with [my brother who hoards] … [this] pushed me to be the opposite... I wanted to be different, to be good").

Moreover, some of the reported dispositions also acted as demand characteristics that influenced what responses children received from those around them. For instance, Valerie's and Penelope's introversion may have been interpreted as negative social cues, potentially leading to further restrictions in social interaction. Additionally, some participants' strong interests in reading and writing could be viewed as resource characteristics, reflecting curiosity, reflexivity, and a capacity for meaning-making. Such attributes may have served a protective role in how these children interpreted and navigated their environment. Therefore, children's more adaptive individual characteristics (e.g., empathy, kindness, extroversion) might have also facilitated their engagement in developmentally appropriate proximal processes (i.e., receiving care, engaging consistently in play, etc.), even if these were sometimes situated outside of the family setting (e.g., teachers, friends, other family members; Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Conversely, these processes may have been disrupted for children with less protective attributes (e.g., shyness, lack of curiosity). In some cases, however, positive characteristics may have also helped to sustain interactions with the relative who hoarded. For example, an empathetic child might more effectively elicit care by being able to still *tune in* to their carer, even in an otherwise challenging familial microsystem (Bronfenbrenner & Morris, 2006). Finally, on some occasions the latter may have also interplayed with the individual attributes of the relative who hoarded. As illustrated in the present narratives, some of these carers remained emotionally attuned and responsive to the child's practical and emotional needs. These were also the households where children felt happy and loved while growing up. This aligns with the COPMI literature suggesting that parental psychopathology does not always lead to negative outcomes for

children, and that some of these parents can be excellent caregivers (Brockington et al., 2013). Lastly, Martin's narrative illustrated how the cultural values of the macrosystem can also contribute to shaping the child's lived experience through these being reflected in the microsystems. For example, in his cultural context where hoarding seemed to be relatively normalised, this interviewee did not experience the typical psychological distress often associated with living in such an environment.

4.2. Clinical Implications

The study has some noteworthy research and clinical implications. To begin with, it provided new insights into the experiences of being a child growing up with a relative who hoards. It is the first study to emphasise the striking vulnerability of a child living in such an environment and to highlight how their experience might differ from that of an adult in similar circumstances. In this way, the work also draws attention to some of the potential risks children in such a context could be exposed to, such as toxic stress and developmental trauma. In light with the finding that the others around the child tend not to intervene, the present study suggests that an increasing awareness of HD among the general public and professionals might be beneficial for affected families. This might help family members feel validated and better equipped in managing the situation at home but also to seek formal support. These, in turn could also be helpful to reduce stigma in the general population, stemming from myths and misunderstandings about the condition. The results support the need for establishing specialised care pathways for HD to assist affected individuals and their families. Specifically, key areas of focus could include understanding the impact on family dynamics, conducting comprehensive risk assessments, safeguarding vulnerable individuals, particularly children, and guiding families

toward specialist support corresponding to their needs. Finally, given the lasting psychological effects of the experience on some of the respondents, similarly to Rees et al. (2018), the present work provides evidence in favour of offering support groups for children who have grown up in such environments.

4.3. Research Implications

This study is the second focused exploration of the experiences of children growing up with a relative who hoards, with the only prior research concentrating solely on the impact on female offspring (Rees et al., 2018). It is the first to apply a systemic model of human development to investigate these lived experiences, examining the effects of the hoarding behaviour on the child, in the context of the various systems they are part of and interact with. Different from previous work (Rees et al., 2018; Sampson, 2013; Wilbram et al., 2008), this study keeps the focus on the child in context, also acknowledging the importance of individual differences rather than interpreting the child's experience in relation to the hoarding behaviour and the person who hoards, only. A final research implication is that this work included a higher number of male participants in qualitative research on the topic[15], thus offering richer, more nuanced data and addressing a methodological limitation, noted in previous research (Sampson, 2013).

4.4. Strengths and Limitations

This research has a number of strengths. First, by studying participants' experiences through Bronfenbrenner's bioecological model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006), it allowed for a more in-depth

[15] The overrepresentation of females in the samples has been common in other studies investigating the impact of hoarding behaviour on family members (Sampson et al., 2013; Park et al., 2014; Tolin et al., 2008).

exploration of the child's experience, appreciating the interaction between the different systems they were a part of and actively interacting with. By interviewing young adults only, the study provided relatively recent narratives, potentially subject to less memory decay and distortion. It also included a diverse sample which allowed for more nuance in the data, illustrating a wider range of perspectives and experiences. As already mentioned in the previous section, the current research also offered a better male representation among participants in as compared to Rees et al. (2018) whose sample only comprised female interviewees and Sampson (2013) who had only two male participants. Finally, the present work adhered to Yardley's (2000) principles for quality assurance, demonstrating sensitivity to the context of both participants' and the researcher, that commitment, rigour, transparency and coherence were maintained in the data analysis and the study made an important impact by generating new knowledge on the topic. A limitation of the study was that the relatives who hoarded did not have a formal diagnosis of hoarding disorder. Therefore, there was no objective measure of the problematic behaviour or its severity. This, however, is not uncommon in research on hoarding and reflects the relatively new recognition of the condition as a disorder in its own right and the lack of specialised service provision. Furthermore, the study also did not consider participants' ethnicity which limited the possibility to explore how this element of their identity might have shaped their meaning-making regarding hoarding disorder and their lived experience, as well as how this might have interacted with the other parts of their identity. Importantly, it was not within the remit of the study to quantify participants' experiences to the severity of the disorganisation they had grown up in but rather to use such information as a context to their stories. Related to this, another limitation was that data on the

relative's physical or mental health was not collected. In this way it remains uncertain if some of the reported difficulties might have been associated with the relatives' comorbid conditions. Future research might look into addressing these limitations.

4.5. Conclusion

This study provided novel insights into the childhood experiences of growing up with a relative who hoarded, by exploring the accounts of young adults through the lens of Bronfenbrenner's bioecological systems model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006). By following the child's developmental journey, six themes in the participants' narratives were identified: are we normal?: on the transition from the blissfully unknowing child to the wondering teenager; a different type of childhood: on anxiety, fear and stress; my needs: was there ever *enough room* for me?; alone with it: on helplessness, feeling alone and the silence of others; wait, was I ever a child?: on growing up early and who have I become?. Collectively, these highlighted the unique aspects of growing up in such an environment and further emphasised the inherent vulnerability of a child compared to an adult. The findings revealed some of the risks such children might be exposed to, their psychological strengths and how the interplay between the individual and the broader systems shaped their lived experiences. This work has valuable implications by expanding the understanding of how problematic hoarding might affect children growing up in such an environment. It highlights the need for increased professional awareness, specialised services, and providing training to staff to better support family members and especially children.

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CHAPTER 5: Discussion and Critical Evaluation

Discussion and Critical Evaluation

This chapter brings together the findings from the systematic review and the empirical paper. It presents the main author's reflections on the research process and summarises the findings and the strengths and weaknesses of the work. It also discusses the wider implications of the results for clinical practice and future research and concludes with a summary of its key insights.

Reflections on the Research Process

Looking back, I must admit that in the very beginning of this project I somewhat struggled to see beyond my then-dominant positivist researcher stance. This perspective, deeply ingrained through my quantitative PhD training in Psychology and subsequent years working as a quantitative researcher, had shaped much of how I approached research. However, engaging in consistent and intentional reflection during the Clinical Psychology doctorate, together with choosing to complete a qualitative thesis portfolio, has become instrumental in broadening my outlook. This process challenged my long-held assumptions and helped me to appreciate the limitations of positivism, including its emphasis on objectivity and measurement.

Initially, I saw qualitative methods as merely another *tool in my research toolkit* to master. At the time, I had not fully internalised that doing qualitative research was much more than that, that it represented a different way of seeing the world and appreciating every voice, even when it was not the dominant one. It is less about measuring and more about listening, interpreting, and making sense of experiences. I also became comfortable with the concept of researcher subjectivity not necessarily being problematic, provided that one remained aware of their biases and preconceptions throughout the process.

The transition from being an experienced quantitative researcher to venturing into qualitative work as a novice was not without challenges. At times, I felt *out of my depth*, which was both uncomfortable and intimidating. For instance, I vividly remember my reluctance to begin the data analysis for my empirical chapter. My instinct was to overprepare— to read all the key theoretical pieces and empirical articles to get examples of *how to do it right*. The thought of *diving deep into the unknown* was making me uncomfortable and I was unconsciously avoiding the process. However, even when I believed *I have gotten the hang of it*, positivism was still creeping in from time to time. For example, in the beginning I was referring to my participants with a "P" initial, followed by a number (i.e., P1, P2…), probably motivated by my ingrained need to count. However, at this point I was also much better equipped to catch myself on time and soon changed these to pseudonyms, thus symbolically *restoring* my participants' human identity, a decision that sits much better with my personal and research values.

Despite these challenges, my natural curiosity and drive to be always developing helped me to successfully continue my research journey. In fact, these personal qualities are the main reason why I chose to embark on doing two pieces of qualitative work for my thesis portfolio, rather than to rely on familiar methods. Once I allowed myself to immerse fully in the interview data from the empirical chapter, I surprised myself as I saw it as a highly enjoyable activity and in fact, I could not stop. I truly enjoyed reading and rereading each interview, together with excerpts of my reflective diary.

Although I was initially concerned that I might not know how to go beyond descriptive summaries of my data (Braun & Clarke, 2022), I was instead able to

start generating latent as well as semantic codes and begin hypothesising about possible meaning-generating themes quite quickly. The discussions with my supervisors further helped me to refine my thinking, allowing me to *see the same data with fresh eyes*. Similarly, when it came to the systematic review chapter, I managed to resist the urge to take the familiar path of conducting a meta-analysis, a method I had successfully used in the past. Instead, I challenged myself to undertake a narrative synthesis, a choice that allowed me to deepen my understanding and expand my methodological repertoire.

In hindsight, this research journey has revealed just how much my thinking has evolved over the course of this doctorate. I have grown more adept at holding multiple, sometimes conflicting perspectives, tolerating uncertainty, and approaching new challenges with curiosity and flexibility. This transformation is the result of engaging with all aspects of the Clinical Psychology programme, from therapeutic work with diverse clients and modalities to academic learning, writing patient letters and assignments, all of which require and encourage a level of self-reflection. As such I see writing this thesis portfolio as the culmination of my learning over the past three years.

Summary of Findings

Building on the recent advancements and challenges in the field of HD, this research addressed two key gaps in the literature. The systematic review and the empirical chapter each focused on distinct, yet interconnected aspects of complexity and vulnerability in HD, offering new insights into its multifaceted nature.

Systematic Review

The systematic review studied complexity in HD at an individual level, focusing on the presentation profile of the disorder. Using narrative synthesis, it integrated the relevant published research on HD in the last ten years in community and outpatient samples to identify other mental health conditions that commonly co-occur with HD. It focused on exploring these beyond conditions for which this link has either already been established (i.e., OCD, anxiety-related disorders and depressive disorders) or would be expected (i.e., compulsive buying disorder). A comprehensive literature search strategy was adopted where 11 890 records were screened by their title, abstract and methods sections. From these, 21 studies were finally selected. The results indicated that the following MH conditions were comorbid with HD: disorders specifically associated with stress, bipolar and related disorders, personality disorder, eating disorders, disorders due to substance use or addictive behaviours, schizophrenia or other primary psychotic disorders and obsessive-compulsive and related disorders. Additionally, individuals with HD were more likely than healthy controls to present with PTSD, bipolar disorder, binge-eating disorder, bulimia nervosa, anorexia nervosa, alcohol use disorder, substance use disorder, or nicotine dependence, with all of the observed rates being higher than those in the general population. Although findings on MH comorbidity rates compared to other clinical groups were mixed, one study highlighted qualitative differences in the traumatic experiences reported by individuals with HD. Finally, aggression, emotion dysregulation and cognitive failures emerged as potential mechanisms that might possibly be mediating the observed association between HD and some of the other MH conditions. The results were largely consistent

with those of the only prior review on the topic (Wheaton & Van Meter, 2014) but also offered new insights that expanded upon their findings.

Empirical Chapter

The empirical chapter was a study into another aspect of complexity and vulnerability associated with the disorder, this time evaluating the impact of HD on others from a systemic perspective. It qualitatively explored the childhood experiences of young adults (18-30 years old) who had grown up with a relative who hoarded. Semi-structured interviews with 15 adults (5 males, 10 females) were conducted online and analysed using reflexive thematic analysis. The sample included participants from different backgrounds and cultures, with the relatives who hoarded being their sibling, parent or grandparent. Participants' stories were examined through aspects of a systemic model of human development, Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006). This allowed for a more in-depth exploration of participants' experiences, also acknowledging the interaction between the different systems they were a part of, and actively engaging with in their childhood and their individual characteristics. Six themes, which followed the child's journey developing in this environment, were identified: (1) Are we normal?: on the transition from the blissfully unknowing child to the wondering teenager; (2) A different type of childhood: on anxiety, fear and stress; (3) My needs: was there ever enough room for me?; (4) Alone with it: on helplessness, feeling alone and the silence of others; (5) Wait, was I ever a child?: on growing up early; (6) Who have I become?. A number of novel findings emerged from this work. These built on previous qualitative studies on the experiences of partners, carers and children, living in a home where someone hoards (Rees et

al., 2018; Sampson, 2013; Wilbram et al., 2008) by emphasising the unique and inherent vulnerability of a child, compared to an adult. Furthermore, these findings alarmingly highlighted the exposure to daily psychological distress and the role reversal with the adult who hoarded that many participants reported experiencing in their childhood. Expanding on Sampson (2013), these findings suggested that the others around the person who hoarded often refrained from intervening or offering support, sometimes leaving these children isolated and less likely to seek help. Finally, in line with Rees et al. (2018) several participants described developing psychological strengths despite their childhood experiences. For many, however, these also seemed to have been traumatising, with *clutter* retaining psychological significance, even after they had left the hoarding environment. The application of Bronfenbrenner's model (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) as a theoretical framework illustrated the importance of the child's regular interactions with their immediate microsystems (e.g., family, friends, school) in shaping their development. These suggested that the family microsystem provided individuals with their primary reference points, which in the context of the study further emphasised the inherent vulnerability of the child. The model also helped explain how participants' lived experiences could vary according to the interaction of multiple factors, including their personal characteristics. Finally, one of the narratives illustrated the influence of the higher-order systems (e.g., cultural values within the macrosystem) on the microsystems and the child (e.g., growing up in a culture where hoarding was relatively normalised was also associated with positive childhood experiences).

Taken together, the two chapters enhance the current understanding of HD by studying its multifaceted nature at an individual and systemic level. The

systematic review provided a detailed account of HD's complex comorbidity profile, identifying a broad range of co-occurring mental health conditions and their higher prevalence among individuals with HD as compared to controls. Complementing these, the empirical chapter highlighted a number of challenges faced by some children, raised by a relative who hoards, offering an in-depth exploration of the interviewees' lived experiences. Together, these findings contribute to a deeper understanding of HD as a condition characterised by complexity and vulnerability, spanning both the individual and in Bronfenbrenner's (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) terms, the immediate systems' level.

Strengths and Limitations of the Systematic Review

There are several strengths to the systematic review. Importantly, it addressed a key gap in the literature by being the first ever systematic review conducted on the topic. This work was timely, reflecting the change in the diagnostic classification of HD as a standalone condition in 2013 (APA, 2013) and the recently published systematic review by Bates (2021) on physical health comorbidities in HD. In terms of methodological strengths, the quality of the review was ensured by following the PRISMA guidelines (Page et al., 2021), having a pre-registered protocol on PROSPERO, and the quality appraisal for the selected studies having been performed by two independent raters using a well-established and validated tool (i.e., the QualSyst Quality Assessment Tool for quantitative studies; Kmet et al., 2004). Moreover, it adopted a particularly comprehensive literature search strategy by screening the Methods sections of all articles instead of restricting the search with specific search terms. This helped reduce the chance of missing studies relevant to the review. Additionally,

findings were only extracted from papers where both HD and MH were assessed with validated measures, thus increasing the construct validity of the study. Finally, it included studies from a range of countries and a combined HD sample with a mean age representative of the one normally reported for HD participants in research (Thew & Salkovskis, 2016).

The systematic review also had several limitations. First, the exclusion of commonly studied and assumed MH comorbidities with HD limited its findings by for example, not allowing for interaction effects with more frequently co-occurring conditions to be studied. A related limitation was the inclusion of comorbidity data from quantitative studies only, which may have resulted in some relevant studies having been missed, potentially reducing the comprehensiveness of the findings. Additionally, the existent heterogeneity between studies in design, participant characteristics, and assessment tools precluded the use of a meta-analysis to compare statistically aggregated effect sizes. Furthermore, in some of the studies participants were excluded on the basis of having a MH condition of interest to this review, suggesting that the present results might be underestimating the actual prevalence of these comorbidities in HD. Papers also varied in the use of control groups, which were not always matched for size or age, therefore, making comparisons between groups and across studies difficult, even when these reported the same type of HD and MH comorbidity. Finally, although most of the selected studies achieved a strong quality rating, methodological problems were not uncommon, with studies having small samples and including participants who are not necessarily representative of the population.

Strengths and Limitations of the Empirical Study

This empirical study had a number of strengths. First, it presented novel findings on a very under-researched topic in the field. In terms of methodological strengths, its quality was ensured by consulting both Braun and Clarke's (2022) and Yardley's (2000) recommendations on how to conduct qualitative research and striving to adhere to these throughout the research process. For example, to address the researcher's subjectivity and ensure reflexivity the main author kept a reflexive journal to interrogate how their assumptions, expectations and even emotions, experienced throughout the process might have shaped their decisions and interpretations. The use of Bronfenbrenner's model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) as a theoretical framework for the study allowed for a more in-depth exploration of participants' lived experiences, acknowledging that one's environment is made up of multiple layers and that individuals have an active role in engaging with these. Conducting the interviews remotely was a further strength of the study as it allowed for a more diverse sample to be recruited. This approach facilitated a greater level of nuance in the narratives, illustrating a wider range of perspectives. For example, it gave a voice to male participants who have previously been underrepresented in research on the topic (Rees et al., 2018; Sampson, 2013). Finally, given that the narratives were retrospective, only young adults were interviewed, in an attempt to increase the reliability of the data by reducing the potential for memory decay and distortion.

The empirical chapter was, however, not without its limitations. First, the study did not consider participants' ethnicity, which limited the ability to examine how this aspect of participants' identity may have directly or indirectly influenced their lived experience and meaning-making. Furthermore, there was no objective

measure of the problematic behaviour or its severity as the relatives who hoarded did not have a formal diagnosis of HD. A related and final limitation was that information about the relative's physical or mental health status were not collected. This could have potentially linked the empirical chapter more succinctly to the systematic review and left the question open as to whether some of the interviewees' experiences might have been attributable to their relatives' comorbid conditions.

Implications for Clinical Practice and Services

This portfolio highlights the importance of recognising and acknowledging the muti-faceted nature of HD and how its complexity can evoke vulnerability at both the individual and the system's level.

The systematic review chapter has several clinical practice implications. First, the results raise awareness about the complex clinical profile of the hoarding patient in the community. This might be helpful to patients and family members who may be unaware that HD and other mental health conditions could coexist in parallel. This, in turn might positively influence their approach to managing the condition and seeking formal support. The findings could also contribute to improving clinical practice by encouraging professionals to consider if additional mental health conditions might be contributing to their patients' difficulties, therefore, warranting more comprehensive mental health assessments to be routinely completed, especially for disorders less commonly associated with HD. Such a shift in practice could potentially enhance treatment outcomes by fostering a deeper understanding of the patients' needs and developing more effective treatment plans. Related to this, the findings highlight the need for patient-tailored multiagency working in HD, so professionals can more successfully meet patients' complex needs. Finally, given that the review

provides a synthesis of the most recent research on the topic, it could, potentially, influence the development of clinical guidelines for assessment and treatment.

The empirical study also has important clinical implications. It is the first to emphasise the pronounced vulnerability of children growing up in such environments, thus highlighting that their experiences likely differ from those of adults. By doing so, this research draws attention to the potential risks some of these children may face, such as toxic stress and developmental trauma. These findings support the need for an increased awareness of HD among the general public and professionals, also in light of the finding that the others around the child tend not to intervene. Increasing awareness among the public about hoarding and its effect on others might be helpful for family members to feel validated and better equipped in managing the situation at home but also to seek formal support. These, in turn could also be helpful to reduce stigma in the general population, stemming from misunderstandings about the condition. Additionally, the findings highlight the need for establishing a specialised care pathway for HD to assist affected individuals and their families. Specifically, key areas of focus could include understanding the impact on family dynamics, conducting comprehensive risk assessments, safeguarding vulnerable individuals (particularly children), and guiding families toward specialist support corresponding to their needs. Finally, given the lasting psychological effects of the experience on some interviewees, similarly to Rees et al. (2018), the present work provides evidence in favour of offering support groups for children who have grown up in such environments.

Together, the two chapters emphasise the profound complexity of HD, the need for a greater public and professional awareness of the condition, and the

importance of establishing specialised care pathways, offering formal assistance to patients and families. Moreover, the results provide evidence to support a muti-disciplinary, holistic approach to managing HD as best practice. Integrating these findings into clinical work, policy, and services could better address the needs of affected individuals and their families, with particular emphasis on supporting the most vulnerable, such as the children growing up in such households.

Implications for Future Research

The two chapters have a number of research implications by contributing novel findings to the field of HD, which future studies can build and expand on.

This is the first systematic review conducted on the topic; it also draws attention to MH conditions, for which the link with HD is not well-established. In the present work, comorbidity information was primarily drawn from studies on other HD topics, such as comparisons of different treatment types or examinations of various aspects of cognitive performance in individuals who hoard, rather than from studies focusing specifically on co-occurring MH conditions associated with the disorder. It might, therefore, be helpful if more future studies explored comorbidity in HD where this topic is the primary research focus. This will help provide clarity regarding the prevalence rates of conditions that studies routinely exclude for, such as bipolar, personality disorders and eating disorders. Additionally, separate meta-analyses could examine comorbidity between HD and the MH conditions that were excluded from the present review, as well as explore the link between HD and neurodevelopmental conditions. Future work could also compare the prevalence rates of MH comorbidity in different clinical and non-clinical HD samples. Finally, studies could also focus on exploring additional factors that might underpin the

observed relationships such as gender, socioeconomic status, physical health and other MH correlates.

In terms of the research implications of the empirical chapter, it offers a study into a very under-researched topic in the field. It is also the first to present a comprehensive account of the lived experiences of children growing up with a relative who hoards, which goes beyond their relative's hoarding behaviour and focuses on studying the child in context. To expand the work, future research could, for example, consider applying the complete version of Bronfenbrenner's bioecological systems model (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) to explore participants' experiences, as opposed to the selected aspects of the model used in the current study. This would enable an examination of how indirect environments in the child's experience (e.g., the economic and political conditions, situated in the exosystem) and the broader cultural norms and values (i.e., the macrosystem) influence the child within the context of living in a household where a close relative hoards. Whilst some insights on the impact of the macrosystem were reported in the present research, these occurred spontaneously in the narratives, rather than being directly examined. Related to the latter, it would be helpful for future research to purposefully aim to recruit more diverse samples in terms of demographic characteristics to get a richer, more complete picture of these lived experiences. In this respect, previous research has highlighted the common overrepresentation of female (Park et al., 2014; Rees et al., 2018; Tolin et al., 2008) and Caucasian participants from Western countries in research on HD (Sampson, 2013; Tolin, 2023). Therefore, future studies that include more balanced male-to-female ratios and cross-cultural insights would be particularly valuable.

Conclusion

The present thesis portfolio offered an exploration into two aspects of complexity and vulnerability in HD, one at an individual and one at a system's level. While the systematic review provided a detailed account of HD's complex comorbidity profile, the empirical chapter highlighted the difficulties that the disorder can bring into the lives of some children, raised in such households. These findings have implications for clinical practice as they offer evidence for the importance of considering the multi-faceted nature of the condition at all stages of care planning. They also emphasise the profound impact HD can have on others, particularly those in vulnerable positions, such as children. Finally, both chapters also have research implications as they contribute novel findings to the field and provide a basis for future work to build upon and expand the understanding of HD in these two important areas.

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Appendices

Appendix A

Author Guidelines for the Journal of Obsessive-Compulsive and Related Disorders

Article types

Research paper:

Clinical and non-clinical research dealing with all aspects of obsessive-compulsive disorder (OCD) and related conditions (OC spectrum disorders; e.g., trichotillomania, hoarding, body dysmorphic disorder)

Review:

The journal welcomes systematic reviews and meta-analysis that make valuable contributions on all aspects of OCD-related disorders.

Short communication:

A condensed paper with a brief scientific message. This option is designed to allow publication of research reports that are not suitable for publication as regular articles. Shorter Communications or Brief Reports are appropriate for articles with a specialized focus or of particular didactic value. Manuscripts should be between 3000-5000 words, and must not exceed the upper word limit. This limit includes the abstract, text, and references, but not the title page, tables and figures.

Correspondence:

Letters in response to papers published in journal.

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These are concise review articles on new and emerging topics, summarizing current information and advances in the field. The review should be approximately 2000 words (not including references or reference notes), with up to 50 references.

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- Avoid references. If any are essential to include, ensure that you cite the author(s) and year(s).
- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

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You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

We recommend that you only use abbreviations in keywords if they are firmly established in the field.

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You are required to provide article highlights at submission.
Highlights are a short collection of bullet points that should capture the novel results of your research as well as any new methods used during your study. Highlights will help increase the discoverability of your article via search engines. Some guidelines:

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Graphical abstract

You are encouraged to provide a graphical abstract at submission.
The graphical abstract should summarize the contents of your article in a concise, pictorial form which is designed to capture the attention of a wide readership. A graphical abstract will help draw more attention to your online article and support readers in digesting your research. Some guidelines:

- Submit your graphical abstract as a separate file in the online submission system.
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- Our preferred file types for graphical abstracts are TIFF, EPS, PDF or MS Office files.

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- Submit math equations as editable text, not as images.
- Present simple formulae in line with normal text, where possible.
- Use the solidus (/) instead of a horizontal line for small fractional terms such as X/Y.
- Present variables in italics.
- Denote powers of e by exp.
- Display equations separately from your text, numbering them consecutively in the order they are referred to within your text.

Tables

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manuscript is accepted. Payment of the APC may be covered by the corresponding author's institution, or the research funder.

Appendix B

Definitions of the Mental Health (MH) Conditions of Interest to This Review

Although this review included studies that used either the DSM-5 (APA, 2013) or ICD-11 (WHO, 2019) diagnostic criteria or earlier version of these, given that minor differences between the two exist, for clarity, only the ICD-11 (WHO, 2019) classification has been used here to generate the full list of eligible conditions of interest to this review.

Mental health disorder, for the purpose of this review, is defined as including the following diagnoses in accordance with the ICD-11 definition (06 Mental, behavioural and neurodevelopmental disorders), excluding neurodevelopmental and neurocognitive disorders, elimination disorders, disruptive behaviour or dissocial disorders, factitious disorders and secondary mental or behavioural syndromes associated with medical conditions:

Schizophrenia or other primary psychotic disorders (6A20 Schizophrenia 6A21 Schizoaffective disorder 6A22 Schizotypal disorder 6A23 Acute and transient psychotic disorder 6A24 Delusional disorder 6A25 Symptomatic manifestations of primary psychotic disorders 6A2Y Other specified primary psychotic disorder 6A2Z Schizophrenia or other primary psychotic disorders, unspecified);

Catatonia (6A40 Catatonia associated with another mental disorder 6A41 Catatonia induced by substances or medications 6A4Z Catatonia, unspecified);

Mood disorders: Bipolar or related disorders (6A60 Bipolar type I disorder 6A61 Bipolar type II disorder 6A62 Cyclothymic disorder 6A6Y Other specified bipolar or related disorders 6A6Z Bipolar or related disorders, unspecified);

OCD-related disorders (6B21 Body dysmorphic disorder 6B22 Olfactory reference disorder 6B23 Hypochondriasis 6B25 Body-focused repetitive behaviour disorders 6B2Y Other specified obsessive-compulsive or related disorders 6B2Z Obsessive-compulsive or related disorders, unspecified);

Disorders specifically associated with stress[16] (6B40 Post traumatic stress disorder 6B41 Complex post-traumatic stress disorder 6B42 Prolonged grief disorder 6B43 Adjustment disorder 6B44 Reactive attachment disorder 6B45 Disinhibited social engagement disorder 6B4Y Other specified disorders specifically associated with stress 6B4Z Disorders specifically associated with stress, unspecified);

Dissociative disorders (6B60 Dissociative neurological symptom disorder 6B61 Dissociative amnesia 6B62 Trance disorder 6B63 Possession trance disorder 6B64 Dissociative identity disorder 6B65 Partial dissociative identity disorder 6B66 Depersonalization-derealization disorder 6B6Y Other specified dissociative disorders 6B6Z Dissociative disorders, unspecified);

Feeding or eating disorders (6B80 Anorexia Nervosa 6B81 Bulimia Nervosa 6B82 Binge eating disorder 6B83 Avoidant-restrictive food intake disorder 6B84 Pica 6B85 Rumination-regurgitation disorder 6B8Y Other specified feeding or eating disorders 6B8Z Feeding or eating disorders, unspecified);

Disorders of bodily distress or bodily experience (6C20 Bodily distress disorder 6C21 Body integrity dysphoria 6C2Y Other specified disorders of bodily

[16] Equivalent to Trauma- and stressor-related disorder in DSM-5 (APA, 2013).

distress or bodily experience 6C2Z Disorders of bodily distress or bodily experience, unspecified);

Disorders due to substance use or addictive behaviours (Disorders due to substance use or addictive behaviours Disorders due to substance use; Disorders due to addictive behaviours);

Impulse control disorders (6C70 Pyromania 6C71 Kleptomania 6C72 Compulsive sexual behaviour disorder 6C73 Intermittent explosive disorder 6C7Y Other specified impulse control disorders 6C7Z Impulse control disorders, unspecified);

Personality disorders and related traits (6D10 Personality disorder 6D11 Prominent personality traits or patterns);

Paraphilic disorders (6D30 Exhibitionistic disorder 6D31 Voyeuristic disorder 6D32 Pedophilic disorder 6D33 Coercive sexual sadism disorder 6D34 Frotteuristic disorder 6D35 Other paraphilic disorder involving non-consenting individuals 6D36 Paraphilic disorder involving solitary behaviour or consenting individuals 6D3Z Paraphilic disorders, unspecified);

Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium (6E20 Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium, without psychotic symptoms 6E21 Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium, with psychotic symptoms 6E2Z Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium, unspecified).

N. B. Additionally, in accordance with the focus of the review, the following were also excluded: Obsessive-compulsive disorder (OCD), Anxiety or fear-related

disorders, Compulsive buying disorder (Impulse control disorders) and Depressive disorders (Mood disorders).

Appendix C

Extended Methodology

This Appendix provides additional information on the empirical study presented in Chapter 4, including aspects of the study design, methodology and approach to data analysis.

Ethical Considerations

Storing of Personal Information

Storing of personal information adhered to the Data Protection Act 2018, the General Data Protection Regulations (GDPR) and the University of East Anglia (UEA)'s *Research Data Management Procedures and Guidance* document (2022).

Participants' data from the screening survey were automatically stored on Microsoft Forms, only accessible via the researcher's UEA student account, protected through two-factor authentication (2FA). These were the only data that were not anonymised as participants' personal details (name and preferred contact details) were needed for the researcher to be able to get in touch to invite them to the interview. Once contact had been established, personal details were permanently deleted from Microsoft Forms.

Participants' audio recordings, demographic questionnaires and consent forms were kept on the researcher's OneDrive file storage application, again securely stored on the researcher's UEA student account, protected through two-factor authentication (2FA). Interviews were recorded on a password-protected digital voice recorder and then securely transferred to OneDrive. Initially, the name of

each of the participants' interview files was pseudonymised, so that the participant's real name was replaced with a pseudonym. The document that linked each participant name to the corresponding pseudonym was kept separate from participants' audio file on a restricted folder on the researcher's UEA OneDrive account. Once the transcription for this interview had been completed, this document was permanently deleted from the system. Any personally identifying information that participants mentioned during the interview (e.g., their name) was either omitted during transcription or replaced with a descriptor, instead (e.g., *said name*).

Audio recordings were permanently deleted from OneDrive once each interview had been fully transcribed and anonymised. Participants' demographic questionnaires were also anonymised. The supervisory team were given access to the anonymised demographic responses and transcribed interview data only. None of the participants disclosed that themselves or anyone else being at risk, which would have been the only exception when the researcher would have considered breaching participants' confidentiality.

Consent forms will be retained until the end of the study and will be destroyed prior to information being shared with the primary research supervisor. Only anonymised data will be shared and stored with the research supervisor who will then become the data custodian. In line with the UEA data policy, anonymised research data will be kept for a minimum of 10 years.

Impact on Participants

Given the sensitive nature of the topic, the potential for the interviews evoking distress in participants was considered throughout. The main researcher, therefore, adhered to Draucker et al.'s (2009) research distress protocol while

conducting the interviews. This involved: (1) monitoring participants' psychological state and reactions during the interview; (2) using psychological skills to manage distress as soon as it is detected; (3) checking with participants if they needed a break; (4) terminating the interview if after (2) and (3), distress was still high; (5) signposting participants to their GP and the telephone numbers of relevant support organisations they could contact if their distress persists. Although a few participants became tearful at certain moments during their interviews, they reported that participation in the study did not cause them significant distress. On the contrary, many expressed that they enjoyed taking part and appreciated the interviewer's warm and empathetic approach. For example, one of the participants who described themselves as typically *reserved* and *quiet* said she felt very much at ease during the interview.

Patient and Public Involvement (PPI)

It was initially planned for the study to benefit from Patient and Public Involvement (PPI) to ensure that it was accessible, relevant and acceptable to participants.

One expert by experience had been identified through contacts and agreed to this role early on during the research planning stage. The intention was that they would provide advice on the design of the recruitment advert and the topic guide, and make general comments regarding engagement, recruitment, and the most appropriate language to be used when communicating with this participant group. Unfortunately, after the introductory session with the main researcher, the contributor experienced serious physical health problems and was forced to withdraw from this role.

Recruitment

The study was advertised through various channels – (1) an academic research network (the UK Hoarding Research Network), (2) two organisations which provide support to people who hoard and their families (Hoarding Disorders UK and Clouds End CIC) and posts on Reddit, a forum-style social media platform.

The UK Hoarding Research Network comprises affiliated research staff from academic institutions across the UK, whose research interests and activities involve hoarding. Hoarding Disorders UK and Clouds End CIC are both community interest companies which provide decluttering support to individuals who hoard and their families, as well as support groups, coaching, education, and training on the topic.

The research was also advertised on Reddit, a forum-style social media platform where users can post text, media and external links and interact with each other. Reddit has become a popular source for participant recruitment (Richard et al., 2021; Shatz, 2017; Zapcic et al., 2023) due to Reddit-based data being considered of high-quality with good psychometric properties (Jamnik & Lane, 2017). The website consists of *subreddits* which are topic-specific communities, which interested users join (Zapcic et al., 2023). The study was advertised on four relevant subreddits (i.e., on the topics of children of people who hoard, decluttering, organising and general mental health). Importantly, all of the chosen subreddits permitted research recruitment posts to be published on their page and these posts could be published freely (i.e., they did not require a prior permission from a gatekeeper, such as the subreddit moderator).

Researcher Position

This study explored the childhood experiences of young adults who had grown up in a hoarding home within a theoretical model of human development. The researcher's intention was to elicit each participants' unique account of their experience, while formulating what factors and interactions might have been involved in their experience, based on Bronfenbrenner's (Bronfenbrenner, 2005, Bronfenbrenner & Morris, 2006) account.

As such, the main researcher adopted a critical realist perspective (Bhaskar, 2008; Maxwell, 2012) which assumes that while an objective reality exists, different people see it in a slightly different, subjective way. Therefore, on one hand, the researcher adhered to Epistemological Relativism as they wanted to explore each of the participants' subjective, socially constructed truths of how they perceived reality. On the other hand, the researcher is also an Ontological Realist as they used aspects of a formal theoretical model to study and interpret participants' narratives, reflecting the researcher's belief that human development largely follows an objective, universal course. Furthermore, from this position it follows that children's physical and cognitive development generally adhere to a universal course and that psychopathology represents an objective deviation from this norm. Finally, the researcher believes that universally, a stable and supportive environment is essential for a child's development, while also recognising that individual children may respond differently to adversity, based on their unique mix of personality traits, circumstances and experiences.

Reflexivity

The main researcher was interested in hoarding from a professional point of view only. They did not have any direct personal experience with it, either by having this condition or knowing someone in their personal life who did. The researcher was aware of the possible power imbalance between them, as a UK university-based researcher, and the participants. The researcher regularly consulted with both of her supervisors, one of whom has a substantial experience researching HD, on how to design the study in a way that might mitigate such power imbalance. Additionally, the main researcher adopted a friendly, rather informal tone when writing the Participant Information Sheet, as well as advertising on social media, using a URL link and QR codes. She also used her therapeutic skills as a Trainee Clinical Psychologist to try to minimise any such imbalance of power. The fact that the researcher visually did not appear much older than eligible participants for this study could perhaps also have been helpful. Finally, it was also the researcher's intention to involve a PPI member in the research development process. However, despite such a member having been identified and recruited, they unfortunately had to subsequently withdraw from the study due to a deterioration in their physical health (see PPI section above).

In line with Epistemological Relativism, it was particularly important to consider that the researcher on this project was also an individual. Therefore, it needs to be acknowledged that they, just like the participants in this study, experience the world through their own subjective perceptions and are affected by their background and life experiences. One example of this is the main researcher's role as a parent in their personal life. This aspect of their identity may have influenced their perspective on childhood development and adversity,

making it even more vital to adopt a reflexive standpoint throughout the entire research process to remain aware of how their experiences interacted with the study and what participants brought. As suggested by the literature, the researcher kept a reflexive journal to document their stance, preconceptions, and beliefs as they emerged throughout the research process (Lincoln & Guba, 1985; Polit & Beck, 2008). All excerpts were handwritten in a paper journal to encourage a natural flow in capturing the researcher's thoughts and feelings. This approach also allowed for insights to be documented as they emerged *in the moment*. Three excerpts from the main researcher's reflexive journal have been presented below, each accompanied by a short commentary, both of which have been written from a first-person perspective:

The first excerpt illustrates my reflections after my very first interview, thinking about how it made me feel but also how the narrative made me consider some new perspectives on the work:

I just did my first interview; I feel so excited (I have the sense of butterflies in the stomach). I was so nervous before starting and I'm so relieved it went well. The structure seemed to work well, and the conversation flowed naturally. This participant seemed to think of her childhood in positive terms, despite the hoarding, a perspective, which I have to say, I had not considered up to now. As far as I remember from the academic papers I've read, it seemed to be all negative… The more I think about it now, the more I think it makes sense, of course there are so many factors on which this would depend (e.g., my participant seemed very sociable, to have had good friendships and I think, she felt cared for in general…), people also differ in terms of what makes them distressed. Given this, I'm surprised no one else has documented this finding

before. I'm excited this work might contribute some new knowledge to the field…I'm very curious who I'll be meeting next and what they have to share.

The second excerpt represents the deep impression one of the interviews left me with and how I related to the experience on a personal level, together with the pros and cons of this:

This morning I had a particularly emotional interview with a participant who appeared deeply hurt by their mother's lack of time and space for them. The raw emotion with which she spoke and the contents of what she was saying deeply shocked me, making me see and hear her still… Something they said that made a particular impression on me was that they often felt less important than "the stuff". They felt like their mother would take space from them to give it to "the stuff". This made me think about my two little boys and how much they need me. I can also see it first-hand how much more they need as they are growing – bigger clothes, more food, more space to play, etc. This experience is making me reflect on how my role as a mother might influence my interpretation of the data. This is an important reminder that it is key I keep on documenting my thoughts and emotions throughout the process, particularly after each interview to remain aware of my first impressions and personal assumptions. At the same time, it is also a pleasant reminder of how having children myself, brings me closer to my participants' lived experiences, making me more reflective and sensitive to the topic.

The third excerpt depicts the challenges I experienced before starting the coding of my interviews. These revolved around getting to terms with my researcher position and managing the weight of responsibility I felt for *doing a good job* when telling my participants' stories:

I have started coding my data and I feel overwhelmed. There is so much data and I don't know where to start. Well, technically, I do know… I've already read all of B and C's key work and some published papers that use reflexive thematic analysis, including a worked-out example. I think, theoretically I know what to do but emotionally I feel stuck. I think it's the responsibility I hold towards my participants, I hope I will do justice to their powerful stories, and I'll be able to "accurately" represent their voices. Reading the B and C's very accessible book helps to keep me motivated and open to qualitative methods and this new-to-me approach of analysing data (as compared to positivism which I know well)?? … I need to keep on reminding myself that researcher's subjectivity is ok (and inevitable, really) as long as I keep on reflecting on my position and who I am as a researcher and person.

Data Analysis

As already mentioned in the empirical chapter (Chapter 4), data from the interviews were analysed using a reflexive thematic analysis (rTA; Braun & Clarke, 2019). Braun and Clarke's (2022) six-phase process was followed in which the main researcher moved in a non-linear, iterative manner between the following steps: (1) familiarisation with the data, (2) generation of initial codes, (3) generation of themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. A combination of a both an inductive and a deductive analysis, was performed on the data, consistent with the main researcher's stance, the use of a theoretical model and common practice in the field (Braun & Clarke, 2012; Byrne, 2022).

Guided by Braun and Clarke (2022) each transcript was first read and reread several times, together with relevant excerpts of the researcher's reflexive journal to ensure an intimate familiarisation with the data. Importantly, all transcripts had

been manually transcribed verbatim by the researcher herself, therefore the main researcher had already achieved a very good level of knowledge and immersion with the data, even prior to starting the more formal analysis (Byrne, 2022).

Codes were designed to be concise while still providing sufficient detail to convey independently the underlying commonality among the data items in relation to the research question and topic (Braun & Clarke, 2012). Coding was performed by the main researcher only, consistent with the values of rTA being a process of interpretation and meaning-making rather than objective truth-seeking. To illustrate, Braun and Clarke write "having only one person coding – usually the researcher – is normal practice, and indeed good practice, for reflexive TA" (2022, p. 115). Data were coded manually, directly on the paper copies of the transcripts as this was the researcher's preference as they felt more connected to the process in this way. Subsequent iterations of the coding were done on *Post-it* notes. Both semantic and latent codes were used, without prioritising one over the other but rather choosing one when it was felt this was more meaningful (Byrne, 2022). Using a combination of both semantic and latent codes allowed conveyance of what was communicated by respondents while also acknowledging the main researcher's active role in interpreting meaning (Byrne, 2022). Once all transcripts were coded, theme generation began through reviewing all codes and analysing which of these could be combined according to a shared meaning so that they may form themes or subthemes. Initially, this process led to the generation of multiple themes and subthemes (see Table 3.1), which were then further refined in supervision to produce the thematic map of themes and subthemes, included in the final analysis (see the Results section in Chapter 4). This process allowed for only distinctive themes to be identified by grouping together subthemes that mapped onto more than one theme.

Table 3.1.

A Representation of the Themes and their Corresponding Subthemes Initially Identified during the Analysis

Example codes/Helpful notes*	Subthemes	Theme
Physical: live far, be elsewhere, go out Status: marry, get a job Emotional: shame makes you distance from the shameful Behaviour: not talking about it, not showing, hiding it away, doing the opposite Language: (denial, depict as positive) it didn't affect me, I'm ok Relationship with person who hoards now: a phone type, cordial, boundaries	(1) Disconnecting from the experience	I. How have I managed to cope?
	(2) Accepting/coming to terms	
Rosemary (friends and siblings), Jessica – counselling, Ursula – gave me a strength to move on (validation from boyfriend, decided to move out after)	(3) Talking about it with others	
I control who comes home/what they touch; I would choose to go to others	(1) Then	II. Effort then and now ("I can make this work")
If I try hard enough, maybe things will be fine? Defend (what would others think?), hide the problem, not seek help Jack (p. 9)		
I'll do things for them – organise, take their stuff, tidy up		
Trying to be good – good at school, sport (overcompensate;		

something to be good at, to receive praise for)		
Control my space now, be reserved, well-informed, prepared	(2) Now	
I have to be in control of my space /Trying to organise their space Ursula – I hired a lady to help my mom June – organising while I was still there, hoping it will help		
	(1)Soft, kind, generous	III. On growing up early and who have I become?
	(2)Putting others first	
	(3)Mature	
	(4)Developed great sensitivity	
Child teaching parent/taking care of older sibling (Rosemary, Bob, Fillip)	(5)Role reversal	
	(6)Responsible	
	(7)I had to be strong	
Just in case someone tries to hurt me	(8)Reserved	
	(9)Friendly	
	(10)Overcompensate	
	(1)Left on my own	IV. What was lacking: On lack and emptiness
No relationship with neighbours, community, limited friendships/lack of roles/chores Person who hoards – no relationship with my interviewees' friends	(2)Isolation/Lack of belonging	
Sometimes I felt unloved/rejected – Do they really care more about the stuff? (Rosemary)	(3)Lack of love	
No space to study/store my things/hoarder putting stuff in their room	(4)Physical lack of space	
Connor, p.8 – do stuff for sister Other person monopolising it; always on my thoughts	(5)No mental space	

Prioritising their needs over mine –anticipate difficulties ((no mental space left for me) Rosemary; Fillip; Jack) conversation often drifted to the person who hoards, their difficulties and how the child had to accommodate, rearrange,		
No time to do my HM, I had to organise (Fillip), Jack, p.6 – we had other things to do but would go an organise as worried he might be in danger	(6)Lack of time	
	(1)I didn't know it was a problem then	V. Are we normal? A story about a child's world being shaken
Chaos was the normality for me, noticing others know differently	(2)When I started going to people's houses, I started seeing	
(Jack)	(3)I tried to organise, before I knew it, all was back to "our normal"	
My world has been shaken Questioning my world	Existential confusion	
Even when people knew, they would not comment, ask (neighbours, friends, siblings would not speak); Friends – get shocked, not say anything, the relationship breaks down – Valerie (my friends got spooked), June – she was clearly shocked, never came back or invited me back (feeling of hopelessness but also, I'm alone in this?)	(1)The silence of others	VI. Alone with it = feeling stuck
Jessica: him laughing made me realise it's odd) ☐ no one sought acknowledged, not big enough to seek help?	(2) Revelations for the child when others spoke, even if painful	
Rosemary – silent with teachers, siblings, friends	(3)Unable to find the words?	
They would not have understood, better not tell	(4)Unhelpful assumptions	

(not talk to friends. teachers)		
1)Anxiety about knocking things down 2) Worry: How are they going to cope? (younger brother) Fear – my mom would beat us if we broke something/knocked out	(1)Unpleasant emotions	VII. What was present in my reality then: Making space for something/one else
Stuff: Lots of unnecessary things filling the space Could not find shoes/clothes/homework	(2)Chaos	
Examples by Rebecca)/June (smelly clothes)	(3)Bullying	
	(4)Suffocation	

**Please, note that these do not represent an exhaustive list of the codes and examples, provided by respondents, rather these are examples of the iterative process.*

Appendix D

Empirical Research Ethical Approval Granted by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee), University of East Anglia

From: Ethics Monitor <no-reply@ethicsreview.uea.ac.uk>
Sent: 25 January 2024 08:15
To: Silviya Doneva (MED - Postgraduate Researcher) <S.Doneva@uea.ac.uk>
Subject: Decision - Ethics ETH2324-0029 : Mrs Silviya Doneva

University of East Anglia

Study title: Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

Application ID: ETH2324-0029

Dear Silviya,

Your application was considered on 25th January 2024 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).
The decision is: **approved**.
You are therefore able to start your project subject to any other necessary approvals being given.
If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.
This approval will expire on **26th September 2025**.
Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.
It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.
Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).
Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).
I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)
Yours sincerely,
Dr Paul Linsley

Ethics ETH2324-0029 : Mrs Silviya Doneva

Appendix E

Gatekeeper Consent from the UK Hoarding Research Network

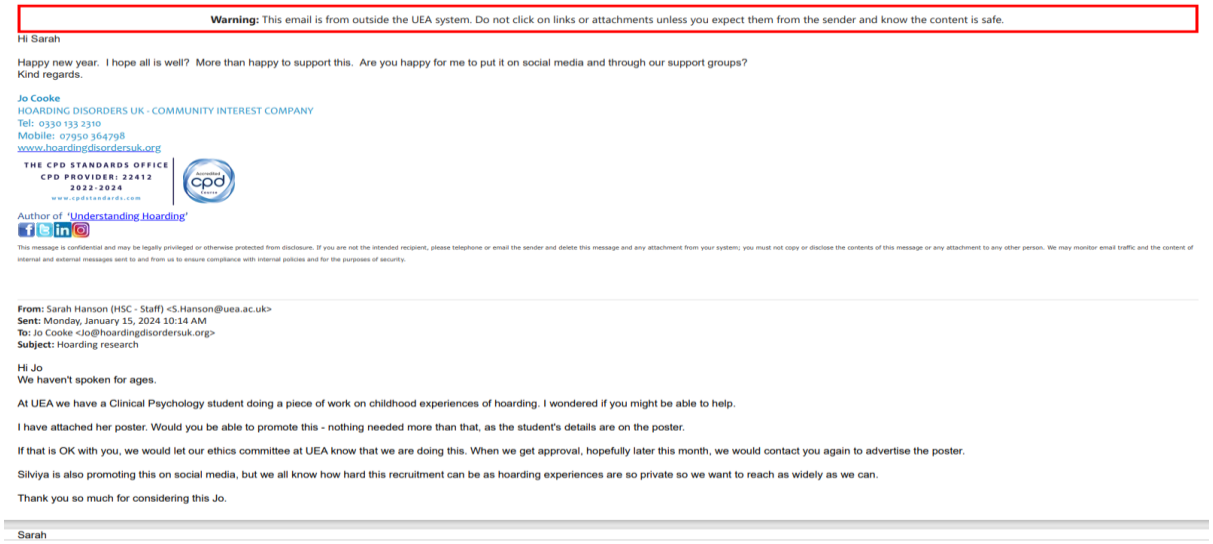
From: Morein, Sharon <sharon.morein@aru.ac.uk>
Sent: 11 January 2024 15:44
To: Sarah Hanson (HSC - Staff) <S.Hanson@uea.ac.uk>; nick.neave <nick.neave@northumbria.ac.uk>
Cc: Silviya Doneva (MED - Postgraduate Researcher) <S.Doneva@uea.ac.uk>; Imogen Rushworth (MED - Staff) <I.Rushworth@uea.ac.uk>
Subject: RE: general update and ethics amendments

Dear Imogen and Silviya,
Pleased to meet you. I can confirm that as head of the UK Hoarding Research Network, we can circulate the advert for your study which is looking to interview the adult children (18-30 years of age) who lived with a relative who hoarded. Please do not hesitate to contact me if any issues regarding the network,
Kind regards,
Sharon

Sharon Morein
Associate Professor
Director of the ARU Centre for Mind and Behaviour
Chair of the ARU Possessions and Hoarding Collective
School of Psychology and Sport Science
Anglia Ruskin University
East Road, Cambridge CB1 1PT
https://www.moreinlab.com/ | @moreinlab

Appendix F

Gatekeeper Consent from Hoarding Disorders UK



Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

Hi Sarah

Happy new year. I hope all is well? More than happy to support this. Are you happy for me to put it on social media and through our support groups?
Kind regards.

Jo Cooke
HOARDING DISORDERS UK - COMMUNITY INTEREST COMPANY
Tel: 0330 133 2310
Mobile: 07950 364798
www.hoardingdisordersuk.org

THE CPD STANDARDS OFFICE
CPD PROVIDER: 22412
2022-2024
www.cpdstandards.com

Author of 'Understanding Hoarding'

From: Sarah Hanson (HSC - Staff) <S.Hanson@uea.ac.uk>
Sent: Monday, January 15, 2024 10:14 AM
To: Jo Cooke <Jo@hoardingdisordersuk.org>
Subject: Hoarding research

Hi Jo
We haven't spoken for ages.

At UEA we have a Clinical Psychology student doing a piece of work on childhood experiences of hoarding. I wondered if you might be able to help.

I have attached her poster. Would you be able to promote this - nothing needed more than that, as the student's details are on the poster.

If that is OK with you, we would let our ethics committee at UEA know that we are doing this. When we get approval, hopefully later this month, we would contact you again to advertise the poster.

Silviya is also promoting this on social media, but we all know how hard this recruitment can be as hoarding experiences are so private so we want to reach as widely as we can.

Thank you so much for considering this Jo.

Sarah

Appendix G

Gatekeeper Consent from Clouds End CIC

From: Sarah Hanson (HSC - Staff) <S.Hanson@uea.ac.uk>
Sent: Monday, January 15, 2024 1:43:30 pm
To: Silviya Doneva (MED - Postgraduate Researcher) <S.Doneva@uea.ac.uk>
Cc: Imogen Rushworth (MED - Staff) <I.Rushworth@uea.ac.uk>
Subject: Fw: Request for help

You can now add Clouds End to your ethics list.
Please see email below

From: Heather Matuozzo <Heather@cloudsend.org.uk>
Sent: 15 January 2024 13:28
To: Sarah Hanson (HSC - Staff) <S.Hanson@uea.ac.uk>
Subject: RE: Request for help

Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

Hi yes,
I can share this on my Whats App support group.
When you get approval come back to me and Ill share the poster...

Heather Matuozzo
Director

Mob: 07939059470
Tel: 0121 680 5287
Web: cloudsend.org.uk

CLOUDS END
We can sort it together.

The CPD Standards Office
Proof It's Training You Can Trust

Appendix H

Online Recruitment Poster

Date first created: 29/06/2023
Date of final revision: 24/11/2023
Version Number: 1.0

As a child, did you live with a relative who hoarded?

University of East Anglia

☑ → You might be able to participate in this research project

We are looking for 18- to 30-year-olds who, as children, lived with a relative who hoarded.

We understand hoarding as the excessive accumulation of belongings, paired with a difficulty discarding, resulting in very cluttered spaces.

How can I take part?

Scan the QR code/follow the link **to see if you meet the criteria**:

https://forms.office.com/e/T7rJpZRbRQ

or s.doneva@uea.ac.uk

I meet the criteria, what next?

You will be invited to **1:1 interview** about your experience
This will be either **online or in-person**
It is going to last approx. 1 hr
Eligible participants will receive a voucher reward for their participation

Study approved by University of East Anglia (UEA)'s Faculty of Medicine and Health Sciences Research Ethics Committee.
The researcher on this project is Silviya P. Doneva, a Trainee Clinical Psychologist at UEA who can be contacted at s.doneva@uea.ac.uk.

Appendix I

Study Online Advert for Social Media

Date first created: 29/06/2023
Date of final revision: 24/11/2023
Version Number: 1.0

As a child, did you live with a relative who hoarded?

We are looking for 18- to 30-year-olds who lived with such a relative for at least 3 years. If this is you, we would like to interview you about your experience which can be either online or in-person. @UEAResearch#HelpUsUnderstand #Hoarding #HoardingAwareness #YoungPeopleMentalHealth.

Scan the QR code/follow the link to see if you are eligible:
https://forms.office.com/e/T7rJpZRbRQ

Alternatively, email s.doneva@uea.ac.uk

Appendix J

Sample Email to Gatekeeper

Date first created: 29/06/2023
Date of final revision: 24/11/2023
Version Number: 1.0

Dear [Gatekeeper],

My name is Silviya Doneva and I am a Trainee Clinical Psychologist at the University of East Anglia (UEA).

As a part of my doctoral thesis I am currently conducting a research study looking at the childhood experiences of young adults who grew up with a relative who hoarded. By young adults I mean, 18 – 30-year-olds.

I am contacting you to see whether you would be able to help me recruit participants for this study.

I have attached the online advert for this study and Participant Information Sheet, where you will find all the information about the project and how it will be conducted. This study has gained ethical approval from the University of East Anglia's Faculty of Medicine and Health Sciences Research Ethics Committee.

To support this project, all you need to do is to forward the study advert to your members. I will then liaise with interested members directly.

Thank you for your time and I very much hope you would be able to support this research. If so, please get in touch with me by replying to this email.

Kind Regards,
Silviya

Appendix K

Screening Survey Together with Survey Branching

Hoarding research screening questionnaire

Date first created: 29/06/2023
Date of final revision: 17/01/2024
Version Number: 1.0

Initial Screen

Thank you for showing interest in taking part in this research.

You are about to take part in a short survey. This is to check if you meet the criteria to take part in the research project on the experiences of growing up with a relative who hoards/hoarded.[1]

You are asked to answer 7 questions which should not take more than 5 minutes of your time.

If your answers show you are able to participate, at the end of this survey, you will be invited to leave your preferred contact details to show you are interested in this study.

The researcher will then invite you to take part in a 1:1 interview about your experience, which is going to take approximately 1 hour of your time. The interview could take place online or in-person.

After completing the interview you will receive a voucher reward for your participation.

Thanks in advance for taking the time to contribute to this survey.

---

[1] Project Title: Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

The researcher on this study is Silviya P. Doneva, a Trainee Clinical Psychologist at the Norwich Medical School at the University of East Anglia (UEA). Silviya can be contacted on s.doneva@uea.ac.uk. This research is part of Silviya's doctoral thesis for the ClinPsyD programme at UEA. Silviya's supervisors on this project are Dr Imogen Rushworth and Dr Sarah Hanson. If you would like to find out more information about this project, please do not hesitate to contact Silviya Doneva at s.doneva@uea.ac.uk

To acknowledge you have read and understood the above, please click here:

Your Data

Please, note, you are about to complete a short survey to check whether you meet the criteria to take part in the actual research study.

None of your data, generated from this survey, will be retained further or used as research data.

To acknowledge you have read and understood the above, please click here:

Screening survey together with survey branching

1. Do you speak and understand English to a good level (i.e., you can have a conversation in English without the need of an interpreter)?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

2. Have you ever lived with a relative who hoarded, i.e., someone who excessively accumulated and could not discard belongings, which resulted in a very cluttered space?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

3. Did you live together with this relative who hoarded when you were a child (0 – 17 years)?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

4. Did you live in this environment for a period of at least 3 years?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

5. Do you personally remember the experience, and not just remembering what you have been told?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

6. Are you currently between 18 and 30 years old?
    A. Yes → continue to next Q
    B. No → end survey; a "Thank you" message for the non-eligible is displayed

7. Do you believe you hoard?
    A. Yes → end survey; a "Thank you" message for the non-eligible is displayed
    B. No → continue to next section

If a respondent answered *Yes* to Qs 1, 2, 3, 4, 5 and 6 and a *No* to Q7, they are deemed eligible for an interview, so the following message is displayed:

You can take part in this research

Your answers indicate that you meet the criteria to take part in this research study. This will involve an 1-hour 1:1 interview with you where we will ask about your experience.
The interview could take place online or in-person and will be arranged further at a time and date that suit you.
Please now leave your preferred contact details in the box below so the researcher can get in touch with you.
After completing the interview you will receive a voucher reward as a thank you for your participation.

8. Your name and preferred contact details (email or phone number) are:

Final Screen/Participants Debrief (for eligible respondents)

Thank you very much for your time.

The researcher will be in touch with you soon. If you would like to get in touch with the researcher, Silviya P. Doneva, please email her at s.doneva@uea.ac.uk.

If, following answering these questions, you experience continued distress or become concerned about your mental health, please seek help. You can contact:

During working hours:

Your GP for mental health support;

Mind Mental Health Charity: https://www.mind.org.uk/information-support

Telephone number: 0300 123 3393

24/7, any time of the day:

Samaritan's 24/7 listening service: https://www.samaritans.org/how-we-can-help/contact-samaritan/ Telephone number: 116 123

NHS 111: 24-hour support for urgent physical and mental health support and guidance: https://111.nhs.uk/; Telephone number: 111.

Final Screen/Participants Debrief (for non-eligible respondents)

Thank you very much for your time.

Unfortunately, you do not meet the criteria to take part in this research.

However, if you would like to get in touch with the researcher, Silviya P Doneva, please email her at s.doneva@uea.ac.uk.

If, following answering these questions, you experience continued distress or become concerned about your mental health, please seek help. You can contact:

During working hours:

Your GP for mental health support;

Mind Mental Health Charity: https://www.mind.org.uk/information-support

Telephone number: 0300 123 3393

24/7, any time of the day:

Samaritan's 24/7 listening service: https://www.samaritans.org/how-we-can-help/contact-samaritan/ Telephone number: 116 123

NHS 111: 24-hour support for urgent physical and mental health support and guidance: https://111.nhs.uk/; Telephone number: 111.

Appendix L

Demographic Questionnaire

Date first created: 29/06/2023
Date of final revision: 04/08/2023
Version Number: 1.0

Information to be obtained from participants verbally. Participants are free to choose not to answer any of the following demographic questions.

1. What is your gender?
2. How old are you?
3. Do you identify as having a disability?
4. What is your relationship to the person who hoards (e.g., daughter, grandson, niece)?
5. Where did you grow up in (e.g., geographical area)?
6. Do you have any siblings? If yes – how many?
7. Do you still live with the person who hoards?
8. If not – When did you move out?

Appendix M

Clutter Image Rating (CIR)

Date first created: 29/06/2023
Date of final revision: 29/06/2023
Version Number: 1.0

CIR will be introduced to participants as an opening to the interview, with participants being asked the following questions:

1. Are you familiar with the Clutter Image Rating scale (explain what it is and how it is used i.e., the images are deliberately impersonal etc.)?
2. Can you talk me through this scale? What was it like during your growing up years? Was it always like that?

A. Bedroom

Please select the photo that most accurately reflects the amount of clutter in the room

1	2	3

4	5	6

7	8	9

B. Living Room

Please select the photo that most accurately reflects the amount of clutter in the room

1	2	3

4	5	6

7	8	9

C. Kitchen

Please select the photo that most accurately reflects the amount of clutter in the room

1	2	3

4	5	6

7	8	9

Appendix N

Topic Guide

Date first created: 29/06/2023
Date of final revision: 04/08/2023
Version Number: 1.0

To be used in conjunction with the Clutter Image Rating (CIR; Appendix M), which will be introduced first, with the questions from the topic guide to follow.

Thinking of your child and teenage years growing up with X:

A. Family environment: you and X

1. Could you describe what it was like living with X?
2. How do you think it affected your relationship with other family members (siblings/other parent/extended family)?
3. In what ways do you think X's hoarding has impacted on how you turned out to be the adult you are now?
4. What is your relationship with X now?

B. School: peers and teachers

1. Could you describe what going to school was like for you?
2. In what ways do you think X's hoarding affected your relationship with:
   a) your school peers;
   b) teachers;
   c) school performance (e.g., how you did at school).

Prompts:
In what way would X get involved/interact with your school peers/teachers?
Do you think your school peers knew X was someone who hoards?
Do you think your teachers knew X was someone who hoards? If yes – what were their attitudes towards X's tendencies?

C. Friendship circle

1. How do you think X's hoarding affected your relationship with your friends?

Prompts:
How did X get involved/interact with your friends?
Do you think your friends knew X was someone who hoards? If yes – what were their attitudes towards X's tendencies?

D. Neighbours

1. In what ways do you think X's hoarding affected your relationship with your neighbours?

Prompts:

How did X get involved/interact with your neighbours?
Do you think your neighbours knew X was a hoarder? If yes – what were their attitudes towards X's tendencies?

E. Who are you? - the person in context

1. How would you describe yourself? – to elicit dispositions
2. What are your strengths? – to elicit skills, resources
3. How do you think others perceive you? – to elicit demand characteristics.

F. Is there anything else you would like to mention?

Appendix O

Participant Information Sheet

Date first created: 29/06/2023
Date of final revision: 24/11/2023
Version Number: 1.0

Project Title: Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

Researcher: Silviya P. Doneva **Supervisors:** Dr Imogen Rushworth and Dr Sarah Hanson

PARTICIPANT INFORMATION SHEET

Who is conducting this study?
The researcher on this study is Silviya P. Doneva, a Trainee Clinical Psychologist within the Norwich Medical School at the University of East Anglia (UEA). Silviya can be contacted on s.doneva@uea.ac.uk
This research will comprise a part of Silviya's doctoral thesis for the ClinPsyD program at UEA.

What is the purpose of this study?
This study aims to understand more about the childhood experiences of young adults who have grown up with someone who hoarded.

Why have you been invited?
You have a unique story to tell which we can learn from and meet **all** study eligibility criteria.
You are eligible to take part if:

(**a**) you are currently 18 – 30 years old and do not hoard;
(**b**) when you were a child (0 – 17 years) you lived with a relative who hoarded (e.g., parent, grandparent, uncle, etc.);
(**c**) for a total of at least 3 years (could have been interrupted);
(**d**) in that time you lived in the same household and interacted daily;
(**e**) you remember the experience;
(**f**) you are still living with the person who hoards or have already moved out (either could be true);
(**g**) you speak and understand English to a good level (i.e., can have a conversation in English).

Please, note that if you meet only some (and not all) of the above criteria, you are not eligible to take part in this study.

What would your participation involve?
The study will involve completing a very short questionnaire and an interview with the researcher at your convenience. This could be online over Microsoft Teams or in-person (in

a private room on the UEA campus, Norwich). The whole session will take 1 hour of your time.

What is in for you?
As a thank you, you will receive a £20 Amazon voucher at the end of the study.

Do you have to take part?
No. Taking part in research is a personal decision and it is completely up to you whether you decide to take part or not.

What are the advantages and disadvantages of taking part?
Advantage: Your insights will help us learn more about how hoarding might impact on child development. This, for example, could help raise awareness about what support these children need.
Disadvantage: It is possible that during or after the interview you might experience some form of psychological distress due to the nature of the information you will be sharing. You are also giving up your valuable time to do this.

Will people know it is you?
Nothing we produce will have you name on it, your date of birth or where you live.
We will voice record your interview and then within 14 days, transcribe it and anonymise it, replacing your name with a number. We will then destroy your voice recording, so your identity is protected.
In our reports we will only use anonymised quotes from what you told us during your interview.

However, there are circumstances under which your confidentiality might have to be breached. For example, if you disclosed that either you or another person were at risk, this might need to be shared with the supervisors on this project, other relevant agencies or safeguarding teams. We will always aim to discuss this with you beforehand if this is the case.

Can you stop being involved?
Of course! At any time during the interview, you can decide you have had enough, and the interview will stop. No problem.
You can also ask for all your information to be taken out of the research up to 14 days after having completed the interview. After that, your interview will be fully anonymised. Therefore, we would not be able to identify you and remove your information after this period has passed.

How will the information you share be used?
The findings will be used for the researcher's doctoral thesis for the UEA ClinPsyD program.
We might also publish the research in an academic journal and present the work at UEA and at research conferences.

How will your personal information be stored and kept safe?
Research with people and the use of your information is strictly controlled. We comply with the Data Protection Act 2018 and the General Data Protection Regulation (GDPR) and the University's Research Degrees' Code of Practice 2012.

All information will be stored on OneDrive (an online file storage) under the researcher's UEA student account, which can be accessed only through two-factor authentication (2FA) by the researcher. The anonymised data will also be accessible by the researcher's two supervisors who are also UEA staff and are also subject to 2FA to get access to OneDrive.

All information from the study will be anonymised within 14 days of collection. Anonymised data will then be kept at UEA for a minimum of 10 years.

Who has checked that this research is ethical?
This research has gained ethical approval from the Faculty of Medicine and Health Ethics Committee at the University of East Anglia in Norwich to make sure that your best interests are protected.

What if you are unhappy about how this research was done and would like to talk to someone?
We really hope this will not happen but if you have any concerns at all, your first point of contact will be the researcher on this project, Silviya who can be contacted on s.doneva@uea.ac.uk.
If you would like to complain to someone independent from this research, then please contact the Programme Director (Prof Sian Coker) on s.coker@uea.ac.uk.

Your wellbeing and support during the interview
Thinking of these specific childhood experiences might be distressing to some. The researcher will be checking with you how you are feeling throughout the interview, allow for breaks and stop the interview if your distress is high. You are also free to withdraw your participation at any time throughout the interview and up to 14 days after.

Support Resources
If, following the interview you experience continued distress or become concerned about your mental health, please seek help. You can contact your GP for mental health support and Samaritans offer a 24/7 listening service via 116 123. More mental health services information is available on the NHS website (including the NHS urgent mental health helpline): https://www.nhs.uk/nhs-services/mental-health-services/.

Appendix P

Participant Consent Form

Date first created: 29/06/2023
Date of final revision: 24/11/2023
Version Number: 1.0

Project Title: Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

Researcher: Silviya P. Doneva **Supervisors:** Dr Imogen Rushworth and Dr Sarah Hanson

In giving my consent I state that:

1. I confirm that I have read the Participant Information Sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary.

3. I am free to withdraw at any time during the study without giving any reason and up to 14 days after my interview has been conducted.

4. I understand that my interview will be audio recorded.

5. What I disclose during the study is confidential. The only exception will be where it is strictly necessary to share this information with other trusted, selected professionals (e.g., a research supervisor, other relevant agencies or safeguarding teams). For example, when an imminent risk to self or others has been disclosed.

6. My data will be kept separate from any of my personally identifiable information (e.g., my name; a process referred to as pseudo anonymisation), so that only the researcher on this study will have access to both.

7. Following the completion of the data analysis, all personal data will be securely disposed of, so that both my demographic and interview transcript data will be in an anonymised form.

8. Anonymised research data will be passed to the primary supervisor at completion, and in line with the UEA data policy, kept for a minimum of 10 years.

9. My data will be stored securely (on an online file storage, which can be accessed only through two-factor authentication (2FA) by the researcher. The anonymised data will also be accessible by the researcher's two supervisors who are also UEA staff and are also subject to 2FA to get access to OneDrive. and their two supervisors.

10. My data will be used only for the purposes of this research.

11. I understand that the results of this study may be published, but these publications will not contain any identifiable information about me.

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

Name of Participant	Date	Signature
Silviya P. Doneva		
Name of Person taking consent	Date	Signature

Appendix Q

Participant Debrief Form

Date first created: 29/06/2023
Date of final revision: 29/06/2023
Version Number: 1.0

Growing up with a relative who has a hoarding disorder: A qualitative exploration with young adults using aspects of Bronfenbrenner's bioecological model.

Thank you for taking part in this study exploring the experiences of growing up with a relative who has a hoarding disorder. As outlined in the Participant Information Statement, if, following the interview you experience continued distress or become concerned about your mental health, please seek help.

You can contact:

During working hours:

- Your GP for mental health support;
- Mind Mental Health Charity: https://www.mind.org.uk/information-support Telephone number: 0300 123 3393

24/7, any time of the day:

- Samaritan's 24/7 listening service: https://www.samaritans.org/how-we-can-help/contact-samaritan/ Telephone number: 116 123
- NHS 111: 24-hour support for urgent physical and mental health support and guidance: https://111.nhs.uk/; Telephone number: 111

You can also contact the researcher to request a lay summary of the findings via the University at the following address:

Silviya P. Doneva
Norwich Medical School
Faculty of Medicine and Health Sciences
University of East Anglia
Norwich, NR4 7TJ
s.doneva@uea.ac.uk

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Programme Director (Prof Sian Coker) on s.coker@uea.ac.uk.

Kind regards,
Silviya Doneva

Appendix R

A Sample of a Transcript with Coding

Guide

Jessica = participant's pseudonym

I = Interviewer (the main researcher)

The original coding was performed directly on the paper copy of the transcripts. A typed example has been provided here for improved readability. Brackets following the highlighted text indicate the initial codes, while colour highlighting was used solely for visual separation and not as colour coding.

Jessica: I think as a child I didn't know there was anything unusual about it. (the hoarding behaviour felt normal to the child) But it sort of gets harder the older I get and the more I have my own home that's organized how I like going back does get more and more difficult I think. (it's difficult to "go back" to the past after being organised as an adult)

I: Yeah, absolutely. Okay, thank you very much for doing the first two bits. So now we're moving on to the interview. I would like you to think about your childhood growing up … and I am going to ask you questions about five different areas. These are your family environment, your school and peers, friendships and neighbours. And then lastly, about you as a person. Is that ok?

Jessica: Yes, that's fine.

I: So just thinking back to your childhood and teenage years, so from the age of 0 to 17. Would you like maybe to start with giving me an overview of your childhood.

Jessica: Yeah. So, yeah, big family. There were five kids, so it was always a bit hectic (big family, hectic childhood). My dad worked a lot. He had a full-time job

and also a few part-time jobs. He was away most of the time. (non-hoarding parent had a lot of work commitments) And my mother was a piano teacher, so we had people kind of coming in and out of the house every day for that. I, yeah, it was a religious upbringing. … My parents were quite religious, so that definitely kind of influenced our family's day-to-day life. We had a lot of church activities to go to and meetings and things like that (a religious household). But overall, it was actually quite a loving home. So I think in terms of like being emotionally available, like my mother was good at that and she did care about us (the child felt loved and cared for by the person who hoarded). But she was like definitely struggling to keep the house tidy. She didn't think of herself as good at keeping the house clean and she didn't tend to sort of, you know, bring things into the home without ever getting rid of things. So there would not be room for new things. (the house was untidy, cluttered, chaotic?). So yeah, that's pretty much what it was like.

I: Okay. Well, thank you. That was a very good description. So you said hectic?

Jessica: Yeah, hectic and yeah, they would struggle to basically throw things.

I: Interesting, what things?

Jessica: Yeah, and I just, I remember being on my own a lot as a child because there were a lot of kids and a lot of things and places for my parents to be in. Even if I wasn't alone in the house, I was just kind of left to my own devices a lot of the time. (child left often to their own devices)

I: I see, thank you. And how do you think your parent's hoarding affected your relationships with other family members, like with your siblings or with your extended family?

Jessica: My extended family lived quite far away, so they didn't necessarily come to the house very often. When they did, my mom would work really hard to sort

of make it look presentable in the rooms they would be in (hoarding person putting effort to organise). But in terms of my siblings, I think it was kind of a situation where we were all growing up in that all the time. And we didn't really have structured cleaning plans. I would say that we probably, most of us, didn't learn how to keep a house clean (lack of family routines and chores for cleaning and organising). And I think in adulthood, that has affected us, when we've kind of gone into relationships and had to learn all of these things as adults (had to learn how to clean as an adult). But at the time I'm sure it had an effect. I'm sure it kind of made things more stressful than they had to be day to day (hoarding made day to day things stressful). But again at the time because that's all we knew I don't think I would have known then that it was like the problem that it was (lack of awareness of the problem as a child).

I: That's very interesting. And I was wondering if you're going to other maybe kids' homes? And you were seeing…

Jessica: Yes. So yeah, I do remember that like there were a couple of families who had the same issues as our house whose house that's I went to but then I remember I'd sleep over the friend's house who had very organized parents and on Saturday morning they would all get up and do their chores and that felt so foreign to me. I'd visit a friend's house after school and her mother had asked her to do some washing up and you know see that she had this job as a member of the family to put in work to keep the house going and that's just something I couldn't relate to because we didn't have that kind of structure in my house. (the contrast with other children's houses/becoming exposed to how others live)

I: Thank you. And how would you describe your childhood as a whole?

Jessica: I think I would describe myself as having a pretty happy childhood (a happy childhood), but yeah, the home itself was just uncared for (uncared-for-

home) and yeah, and I can see now how it probably made it difficult to relax or to focus when my environment was like that (negative psychological impacts of the hoarded home) but at the time I didn't know anything different (lack of awareness of the problem as a child).

I: Yeah, thank you, that's such a thoughtful answer. And I think you've touched upon that a little bit already. In what ways do you think your parents' hoarding has impacted on how you turned out to be the adult you are now?

Jessica: Yeah. I think it causes me a lot of anxiety. I'm married now, I live here with my wife and you know we clean the house weekly and we like to keep clutter low and take things to the tip when it's time to do that. But there are times when I'm not well or something and I'm not able to do the weekly cleaning. I kind of have this fear that I'll just vote my hair instead and just start neglecting all of that (clutter is very much present for me now in my thoughts/ongoing fear of clutter and disorganisation even as an adult). And I think it wasn't so bad until my wife and I went and visited my family just this past autumn. It was sort of like showing her where I came from for the first time and I kind of prepared her for it but I don't think she really understood what it would be like in person and she's a really lovely person and she you know, she's kind about it and but I still think it surprised her and like her knowing that that was what I grew up in (physically going there and showing a third person made it real, my anxiety increased) and I think it just made my fear even worse that if we didn't really stay on top of things that, that it could happen so easily. So, if anything in adulthood it has caused me a lot of anxiety even when like generally things are actually okay at my house and I don't think I have a lot to worry about (fear of falling into old patterns, even when no objective reason present).

Appendix S

Additional Results from Empirical Study

Below are presented two additional themes that emerged from the empirical study (Chapter 4). The first one explored respondents' coping strategies to manage their lived experience. This theme was excluded from the primary results as a less novel one since similar findings have already been reported by some of the respondents in both Rees et al. (2018) and Wilbram et al. (2008). The second additional theme focused on the physical health hazards associated with living with a relative who hoards. This theme was excluded from the main analysis due to being less closely thematically aligned to the rest of the findings, which instead focused on the psychosocial aspects of this experience. The additional findings presented here compliment the primary ones as they provide further nuance to the experiences of children who have grown up in such an environment.

Additional Findings of Interest

Further to the key six themes reported in the empirical chapter (Chapter 4), two additional themes were identified:

(1) How have I managed to cope?

(2) Health hazards: on how my health was at risk.

Table 4.1 presents these, together with their respective subthemes, where applicable.

Table 4.1.

A Representation of the Additional Themes and their Respective Subthemes Identified during the Analysis

Themes	Subthemes
(1) How have I managed to cope?	Accepting/coming to terms Talking about it Disconnecting Other strategies
(2) Health hazards: on how my health was at risk	

Theme 1: How have I managed to cope?

This theme presents the various strategies respondents have used to navigate the challenges of living with a relative who hoarded. It incorporates both the views of their child- and adult selves as participants reflected on both what they thought had helped them in their childhood as well as on what strategies they use now.

Accepting/Coming to Terms

Many of the narratives highlighted that accepting their relative's hoarding has been one of their key coping mechanisms. This process involved coming to the conscious realisation of what was within their control and where their responsibility ended:

"… *I've kind of just accepted that, even if I were to take a month off work and go home and clear out their house, it's probably going to end up where it is again in a few years' time. So really, as an adult, I've had to let go of the idea of helping them in that way, particularly if they're not ready to make changes…So just letting go has been really important*." (Jessica)

Through coming to terms with her mother's hoarding Jessica has learned to accept that providing practical support in the form of cleaning and organising the space would not be effective. It sounds like learning to let go has also been protective for Jessica as it has allowed her to preserve her emotional wellbeing by not holding onto certain expectations.

Talking about it

Participants often took time to open up about their relative's problematic hoarding, with some still choosing not to share their experiences outside their household. This reluctance was particularly prominent during childhood and adolescence, likely reflecting feelings of shame and fear of judgment. It was typically in early adulthood that many began to talk about the issue:

"I: *What do you think helped you to deal with your mum's hoarding?* Rosemary: *I would say withdrawal, for me it was more mental. I just withdrew from everything and just secluded myself, I guess.*

I: *And did you say you talked to your friends?*

Rosemary: *Yes, but that was when I was older, not when I was a child."*

Having open conversations about the hoarding behaviour with others offered participants a sense of validation and connection. For instance, Rosemary reflected:

"*I wouldn't say support but yes, I talked about it with friends... It made me feel understood and could get things off my chest. …I also talked to my siblings because you know it's like a shared problem, so it made it bearable I guess*." (Rosemary)

Interestingly, this would often precede respondents permanently moving out of the household or would take place after they had already physically distanced

themselves from the person who hoarded. Feeling the support of others sometimes empowered participants to make transformative decisions. Ursula, for example, initially felt dismissed when discussing her grandfather's hoarding behaviour. However, having received validation from her boyfriend helped her take the difficult decision to eventually move out:

"*In the beginning he felt like I would initiate arguments, he would say, just leave things as they are, it's his house…at the end of our stay…he was even more frustrated than I was, and it made me feel a lot better*." (Ursula, who shortly after moved out)

Disconnecting

Virtually all participants spoke about seeking a way to distance themselves, physically and sometimes emotionally, from their relative's hoarding behaviour. Twelve out of the fifteen participants had moved out from the household, and all had done so from a young age. Additionally, many spoke about seeking opportunities to be spending time outside of their home, such as the library, school or going to a friend:

"*I will stay out and mostly just come home to sleep*." (Valerie)

Participants would try hard to establish rules and boundaries to protect their own space from the hoarding:

"*She would sometimes hoard in my room, I would pack all the clothes and put them in a box*." (Rebecca)

Connor shared an instance where he asserted his boundaries during a planned sleepover, where his sister had invaded his space due to a lack of such in her room:

"*We used to, if we had friends over, we'd host them in our own rooms… I had organised a sleepover with two friends, and we had planned to have a movie*

night but then she appeared with hers and wanted me to host them. We then argued quite a bit, I had booked this night before..." (Connor)

Participants also spoke about having a rather distanced relationship with the person who hoards now, which they described as "cordial", "a phony type one" and "strained":

"*It's quite standoffish. We live 10 minutes away from each other but rarely …I never go to see my mum*." (Faith)

"*I'd say it's cordial. It's not very close*…" (Rosemary)

"*I wouldn't say we are very close, like attached to the hip, you know*?" (June)

Several respondents discussed how they would consciously or subconsciously avoid reflecting on their home environment to protect themselves from the emotional impact of the hoarding. For example, June described how living her childhood without wondering about the situation at home had helped her to manage it:

"… I didn't know that I was being affected… I don't know whether it is because I didn't realise it, or I've never had the time to just sit down and think about how that situation affected me…I feel [this interview] was like a therapy session where I was talking through things." (June)

Other Strategies

Finally, some participants mentioned having received counselling support to process the emotional impact of the hoarding behaviour.

Others shared how holding religious beliefs had been helpful for them to manage the impact of their relative's hoarding behaviour:

"…my faith has been important. I'm a Christian and I feel like that has helped me." (Valerie)

Theme 2: Health hazards: on how my health was at risk

Many participants spoke about a number of health hazards they were exposed to in their childhood due to their home environment. These had caused physical health difficulties for some. For example, June shared:

"*There was a time we nearly had a fire accident as a result…*" (June)

Valerie and Penelope also remembered the unhygienic conditions they were living in:

"*… we had several animals, and the waste was not always cleaned up properly*." (Valerie)

"*You know with that kind of clutter there are a lot of rodents in the place … like rats, mostly rats*." (Penelope)

The hazardous living conditions directly impacted on some of the respondents' physical health, manifesting as chronic or recurring issues. For example, June and Juliet had respiratory difficulties due to living in poorly ventilated spaces with mould and dampness:

"*…most of the time when I was at home, my sinuses would swell, and I would feel very uncomfortable. Sometimes people used to say that I always had a flu but it's because of the conditions I was living in*." (June)

"*…the hoarding is so bad, there's like damp and mould and structural damage to the house that can't be resolved. It's bad for health. I remember when I lived there coughing and sneezing a lot because it's damp and mouldy*." (Juliet)

Conclusion and Relation to the Main Findings

The additional results reported here compliment the main findings of the empirical study presented in Chapter 4. Together, these provide a more complete picture of the multiple challenges that children, who grow up in a hoarding

environment, might face. At the same time, these also reflect how the relationship between the participants and their relative's problematic behaviour, could be of a dynamic and evolving, rather than of a static, fixed nature (i.e., which align well with the emphasising Bronfenbrenner's continuity and change principles as underpinning development; Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006).

For example, the coping strategies participants used that helped them to distance themselves physically and/or mentally from the experience tie well with *My need to belong* (Chapter 4) subtheme which revealed how some respondents had also purposefully decided to limit their social interactions when they were younger, due to feelings of shame. An additional finding reported in the present chapter was, that as they have grown older, some of the respondents have started opening up to friends and professionals (e.g., mental health counsellors) about the hoarding behaviour they had experienced at home. This likely illustrates how the child's perception and appraisal of the impact of the problematic behaviour, evolve as they become adults (i.e., that some might move from isolating themselves initially because of the hoarding to openly talking about it later on). Lastly, the number of physical health hazards that participants reported they had experienced build on how interviewees' home environment (the microsystem; Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006) in the context of growing up with a relative who hoards, can become a significant source of multiple chronic stressors. Thus, together these offer a more complete picture of the physical and psychological stressors that some children growing up with a relative who hoards, might become exposed to, as well as highlight the child's vulnerability in this context.

To conclude, the additional findings presented here further emphasise the complex challenges that such a home environment presents children with, as well as how these children's perception of the problematic behaviour, they were exposed to, can change and evolve over time.