Doctoral Thesis

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Word Counts by Component

Systematic Review of the Literature *Understanding Stigma in Hoarding Disorder: A Systematic Review*	6,996 words
Service Improvement Project *Understanding Older Adults Who Do Not Opt-In to Talking Therapies Berkshire: Which Older Adults Do Not Opt-in and Why?*	4,998 words
Theoretically Driven Research Project *Post-Traumatic Stress Disorder in Autistic and Non-Autistic Adults: The Impact of Appraisals on Reactions to Traumatic Events*	4,989 words
Executive Summary	713 words
Connecting Narrative	996 words
Total Word Count	18,692 words

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Systematic Review of the Literature

The degree to which hoarding disorder (HD) is stigmatised by the public, and that this is internalised by people with HD, is a relatively neglected research area. This review aimed to synthesise current understanding of stigma of HD and its impact on help-seeking. A systematic search was conducted to identify publications which investigated public or internalised stigma, or related concepts like shame and blame, in relation to HD. The electronic databases PsycINFO, PubMed, Embase, Scopus, Medline, CINAHL, and Web of Science were searched. Fifteen papers met inclusion criteria and were appraised for quality. Research exploring stigma in HD is limited and of variable quality. Nevertheless, the literature suggests that many (but not all) people who hoard and their families experience stigma, and that HD is stigmatised by the public and associated with more rejecting attitudes and frustration amongst professionals. Research exploring help-seeking in HD tentatively suggests a negative impact of stigma. Further research is needed to replicate and extend findings and address methodological limitations to provide an understanding of stigma on which approaches to enhance wellbeing and treatment uptake in HD can be developed.

Keywords: Stigma; Public Stigma; Internalised Stigma; Hoarding; Hoarding Disorder; Help-Seeking

Systematic review (PROSPERO) registration number: CRD42022375820

Service Improvement Project

Older adults are underrepresented in UK Talking Therapies services, a national priority for improvement in the NHS. A Talking Therapies service in England identified that many older adults who were referred did not opt-in to assessment. We aimed to explore the characteristics of these older adults and understand their experiences, to inform recommendations to support future opting-in. Demographic and referral characteristics were compared for older adults who did and did not opt-in, then surveys and semi-structured interviews were used to investigate older adults' reasons for not opting-in. Responses were thematically analysed, and themes were categorised using the COM-B model to inform recommendations. Older age, being from an ethnic minority group, having a previous referral, not being able to receive text messages, and not self-referring (e.g. being referred by GP) all significantly increased the chances of older adults not opting-in. Impersonal and confusing processes, as well as older adults' limited knowledge of Talking Therapies, beliefs about therapy, and physical, cognitive and life changes with age were identified as barriers to opting-in. Several recommendations are made, including ideas to increase accessibility of information, change procedures to improve personal connection, and address practical barriers.

Keywords: Older Adults; Service Evaluation; Improving Access; Talking Therapies

Theory Driven Research Project

Purpose: Research suggests autistic people experience greater post-traumatic stress disorder symptom severity (PTSD-SS) than non-autistic people following traumatic events. Post-trauma appraisals are fundamental in cognitive models of PTSD, but have not been explored in autistic people.

Methods: Two hundred forty-two autistic and non-autistic adults completed an online survey measuring trauma exposure, PTSD-SS, and post-trauma appraisals. Using group comparisons and mediation analyses, we assessed whether these differed between the groups and whether negative post-traumatic appraisals mediated the link between autism and PTSD-SS.

Results: Rate of exposure to types of traumatic events did not differ significantly between the groups, but the autistic group endorsed significantly more events that happened to them directly. PTSD-SS and negative post-traumatic appraisals were higher in the autistic group. Negative post-traumatic appraisals, specifically alienation, shame and fear, mediated the relationship between autism and PTSD-SS.

Conclusion: Greater endorsement of negative post-traumatic appraisals may increase PTSD-SS in autistic adults, however further longitudinal research is needed.

Keywords: Autism; ASD; Post-traumatic Stress Disorder; PTSD; Appraisals; Trauma; Mental Health

Systematic Review of the Literature

Understanding Stigma in Hoarding Disorder: A Systematic Review

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Published in: This report has been submitted to and published in the Journal of Obsessive-Compulsive and Related Disorders, and has been written and formatted in accordance with this (see Appendix 1.A and 1.B). This journal was selected as it is recognised for clinically-oriented research on hoarding, and matters related to effective treatment and support. The thesis and published version differ as the search was re-run prior to thesis submission, so the number of papers screened is higher.

Abstract

The degree to which hoarding disorder (HD) is stigmatised by the public, and that this is internalised by people with HD, is a relatively neglected research area. This review aimed to synthesise current understanding of stigma of HD and its impact on help-seeking. A systematic search was conducted to identify publications which investigated public or internalised stigma, or related concepts like shame and blame, in relation to HD. The electronic databases PsycINFO, PubMed, Embase, Scopus, Medline, CINAHL, and Web of Science were searched. Fifteen papers met inclusion criteria and were appraised for quality. Research exploring stigma in HD is limited and of variable quality. Nevertheless, the literature suggests that many (but not all) people who hoard and their families experience stigma, and that HD is stigmatised by the public and associated with more rejecting attitudes and frustration amongst professionals. Research exploring help-seeking in HD tentatively suggests a negative impact of stigma. Further research is needed to replicate and extend findings and address methodological limitations to provide an understanding of stigma on which approaches to enhance wellbeing and treatment uptake in HD can be developed.

Keywords: Stigma; Public Stigma; Internalised Stigma; Hoarding; Hoarding Disorder; Help-Seeking

Systematic review (PROSPERO) registration number: CRD42022375820

Introduction

Hoarding disorder (HD) is a condition associated with difficulty discarding material possessions (APA, 2013), affecting approximately 2.5% of the population (Postlethwaite et al., 2019). Although acquisition and retention of material possessions is a widespread and largely acceptable human behaviour, in HD such behaviours result in living spaces becoming *so* cluttered that they become unusable and cause significant distress or impairment in functioning (Gordon et al., 2013).

Hoarding is associated with increased suicide risk (Archer et al., 2019), social isolation, loneliness (Edwards et al., 2023; Yap et al., 2020) and impaired quality of life (Tolin et al., 2019). Hoarding can also be dangerous due to increased risk of fire, falls, pest infestation and food poisoning (Frost et al., 2000; Kim et al., 2001; Kysow et al., 2020) as a result of clutter. These factors may lead to decreased physical health (Bates et al., 2021), and can place individuals who hoard at risk of homelessness (Rodriguez et al., 2012). People with HD also report high levels of family conflict (Davidson et al., 2020; Drury et al., 2014), lower social support (Chen et al., 2022; Edwards et al., 2023), and impairment in employment (Mathes et al., 2019; Tolin, Frost, Steketee, Gray, et al., 2008). Evidently, hoarding conveys a considerable health, social and economic burden.

The need for effective support for HD is clear, but treating HD presents a major problem. This may be because hoarding is not a unitary disorder, with hypotheses that the behaviours of HD represent the ‘final common pathway’ of multiple psychological processes including harm avoidance, fear of material deprivation, and attachment disturbance (Gordon et al., 2013) and interpersonal factors (Edwards et al., 2023). If so, any intervention must address the underpinnings specific to the individual. Given this complexity, it is perhaps unsurprising that despite some trials of cognitive-behavioural therapy (CBT) for HD finding significant effects (Rodgers et al., 2021; Tolin et al., 2015), only 25-43% of treatment completers achieve clinically significant reduction in symptoms (Tolin et al., 2015).

Another obstacle to treatment of HD is that it is associated with delayed help-seeking and high drop-out rates (Mataix-Cols et al., 2002; Robertson et al., 2020; Rodriguez et al., 2012; Thew & Salkovskis, 2016). Hoarding symptoms are reported to begin by the age of 18 for 80% of patients (Grisham et al., 2006), however, few people seek help before age 50 (Thew & Salkovskis, 2016). Once in treatment, approximately one-third of individuals who hoard prematurely drop-out (Tolin et al., 2015). Such findings suggest that there are substantial barriers to help-seeking and treatment in HD.

One possible barrier is stigma. As awareness of HD has increased, the tendency has been to focus on the behavioural outcomes of clutter and squalor, which can draw a range of stigmatising judgements. The most public manifestation of this are television portrayals such as '*Britain's Biggest Hoarders*' which typically portray those with HD negatively. Accordingly, HD is frequently referred to as a stigmatised condition (Mataix-Cols & Fernández de la Cruz, 2018; Timpano et al., 2016).

The social-cognitive model of stigma describes how signals of a mental health condition can lead to stereotypes, prejudice and discriminatory behaviours (Corrigan & Kleinlein, 2005; Corrigan & Watson, 2002). Stigma is typically separated into two components: 1) Public stigma, ways in which the general public endorse stereotypes and prejudices about people with mental illnesses, which impact their behaviours and 2) Self-stigma, or internalised stigma, which occurs when people internalise public stigma of their condition (Corrigan & Watson, 2002). Corrigan and Rao (2012) propose that for self-stigma to occur there must be *awareness* of stigmatising beliefs, *agreement* with these, and *application to oneself*. This may then lead to harm, through low self-esteem, hopelessness and discriminating behaviours against themselves. It is also possible to be aware of stereotypes and expect prejudice, but not endorse them (Corrigan & Kleinlein, 2005), referred to as *perceived* and *anticipated* stigma.

Public stigma may reduce availability of social and professional support for people with HD. Additionally, anticipation of prejudice and discrimination may lead people who hoard to avoid being labelled as such, which may deter them from help-seeking (Corrigan, 2004; Corrigan et al., 2014). If stigma is internalised, self-discriminatory behaviours may also interfere with treatment-seeking due to the “why try” effect: “why bother, I’m not worthy of treatment” (Corrigan et al., 2009). Such issues may lead to delays in treatment and poorer long-term outcomes.

Stigma is frequently implicated as a barrier to psychological help-seeking (Andrade et al., 2014; Clement et al., 2015; Mojtabai et al., 2011). Consistent with this is the finding that stigma reduction campaigns can result in increased intention to seek help (Evans-Lacko et al., 2014; Henderson et al., 2017). Internalised stigma has also been associated with negative consequences including depression, low-self-esteem and increased symptom severity (Boyd et al., 2014).

Although people with *any* mental illness are stigmatised more than people with other health conditions (Corrigan, 2004), stigma varies by diagnosis. For example, stereotypes of dangerousness and responsibility have been implicated in mental health stigma (Feldman & Crandall, 2007). However, people with schizophrenia are more likely to be stereotyped as dangerous than people with anxiety, who may instead be viewed as weak, eliciting different reactions (Crisp et al., 2005; Curcio & Corboy, 2020; Parcesepe & Cabassa, 2013). Stereotypes of dangerousness may not apply to HD, as clutter is contained in the home. More recent conceptualisations suggest that difference (‘they aren’t like me’), disdain (‘they are bad’), and blame (‘they are to blame’) are key facets of public stigma (Corrigan et al., 2015), which may more readily apply to hoarding. Such considerations highlight the importance of understanding stigma specifically associated with HD.

Individuals who hoard are aware that their behaviour is generally looked down upon (Chasson et al., 2018), perhaps indicating perceived or internalised stigma. However, it is currently unclear how HD is stigmatised by the public, how this is experienced by people who hoard, and whether stigma impacts treatment-seeking and uptake in HD. Understanding this may enable stigma-reduction interventions to be developed that enhance treatment uptake and wellbeing. The current review aims to examine the literature exploring stigma related to HD, specifically:

1. Is there evidence that people with HD are subject to stigma?
2. How does stigma in HD compare to stigma related to other mental health difficulties?
3. Is there evidence that stigma impacts help-seeking in people with HD?

Methods

This review was conducted in accordance with preferred reporting for systematic reviews and meta-analyses guidelines (PRISMA; Liberati et al., 2009), and was registered with the PROSPERO international prospective register of systematic reviews (ID: CRD42022375820).

Search Strategy

PsycINFO, PubMed, Embase, Scopus, Medline, CINAHL, and Web of Science were electronically searched in August 2023, and again in May 2024. The search specified that within the title, abstract, keywords or topic the article must contain terms related to hoarding *("hoard*" OR "hoarding disorder" OR "hoarding behavio*" OR "diogenes syndrome" OR "compulsive hoarding" OR "hoarding symptom*" OR "compulsive acquiring")* AND stigma *("stigma*" OR "public-stigma*" OR "self-stigma*" OR "prejudic*" OR "stereotyp*" OR "discriminat*" OR "sham*" OR "blam*" OR "social accept*" OR "label*ing" OR "social approval")*. Results were restricted to publications since 1994, when the DSM-IV was introduced, to English Language articles, and to human studies.

Inclusion and Exclusion Criteria

Papers were relevant if they explored stigma or related concepts like shame, blame and embarrassment related to HD, or to hoarding behaviour without a diagnosis which interfered with functioning. Eligible samples included people who hoard, their families, professionals, or the public. Papers could be quantitative or qualitative.

Papers were excluded if they did not report original data, did not study humans, or were not published in English.

Study Selection

Titles and abstracts were scrutinised by the lead author, and 25% were screened by a second rater. Cohen’s *k* was .87 indicating excellent agreement, with two discrepancies discussed and resolved. Full texts of the remaining papers were examined by both raters. Cohen’s *k* was 1.00.

Data Extraction

Data was extracted for: details of publication; location; aims; design; sample size; inclusion/exclusion criteria; participant characteristics; stigma measures; HD measures; data analyses; key findings about stigma and help-seeking. Two authors extracted data.

Quality Appraisal

The QualSyst Quality Assessment Tool (Kmet et al., 2004) was used to assess study quality. It provides a quality checklist on which items are scored 0 (*does not meet criteria*), 1 (*partially meets criteria*), and 2 (*fully meets criteria*). A summary score is calculated for each study and we categorised quality based on this (strong [>.80], good [.71-.79], adequate [.50-.70], or limited [<.50]). Quality was assessed by two raters. Discrepancies were discussed and resolved with a third rater if required.

Data Synthesis and Analysis

A narrative synthesis of the findings was developed, structured around the aims of the review, and within that around whether the papers measured public or internalised stigma, or related concepts. Studies which aimed to directly explore stigma were prioritised.

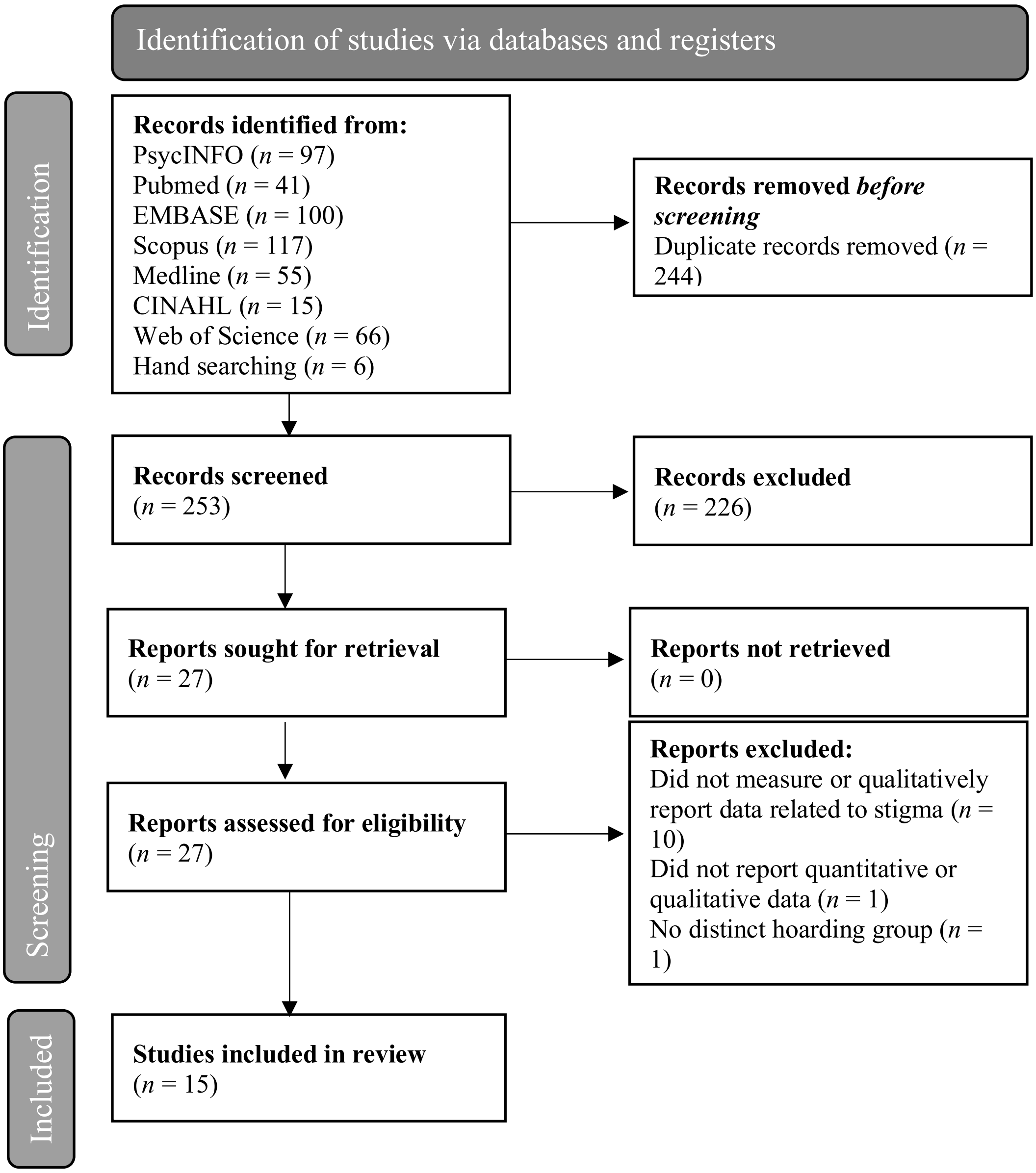
Results

Study Identification

The process of paper identification and selection is presented in Figure 1.

Figure 1.

PRISMA flowchart



Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Overview of Included Studies

Included studies are summarised in Table 1. They comprised 1874 participants, of whom 657 were non-hoarding members of public, 675 were friends or family of people who hoard, 84 were professionals who worked with people with HD, 438 were people who hoard (423 confirmed by hoarding measures or clinical interviews, 15 self-identified or identified by professionals), and 20 were collectors. Most studies were conducted in the United States (*n*= 8), followed by the United Kingdom (*n*=3), Australia (*n*=2), Ireland (*n*=1) and Singapore (*n*=1). Most participants were female, with men comprising 30.9% (*n*=550) of the sample overall, and 21.0% (*n*=92) of participants who hoarded, ranging in age from 18-85. Gender and age were not available for the study of professionals.

Six studies explored internalised stigma, one public stigma, and one both. However, stigma in hoarding was only the *focus* for three studies, with five measuring stigma in relation to other aims. Study designs varied. One study explored stigma qualitatively through interviews. Seven studies reported quantitative findings, and mainly utilised cross-sectional survey designs (*n*=4), two exploring associations between stigma and other variables within a single sample, one surveying HD criteria, and one making within-subjects comparisons of stigma related to different diagnoses. Two studies reported results from the same RCT which measured stigma as a process variable. Finally, one used a randomised experimental design to explore the impact of media portrayals of hoarding on stigma.

Seven studies explored stigma-related concepts. Three reported quantitative findings from cross-sectional surveys, one exploring the association between shame and self-criticism and hoarding symptoms in a single sample, one exploring familial rejection and embarrassment about hoarding through between-subjects comparisons of family members of people with HD, and one comparing frustration and rejection attitudes of professionals towards their clients with and without HD. Four studies were qualitative and identified themes within interviews of shame, embarrassment and marginalisation in relation to one's own or a family member's hoarding. The quantitative studies aimed to explore the stigma-related concepts related to hoarding, however the qualitative studies more broadly focused on the internal experiences and impacts of hoarding for people with HD and their families and identified stigma-related themes during analysis.

Just one study directly compared stigma related to HD with other mental health difficulties.

Three studies explored the impact of stigma on help-seeking for hoarding, one as part of interviews about hoarding stigma, one quantitatively examining barriers to help-seeking including stigma, and one which asked a subgroup of their sample about treatment-seeking willingness if they crossed a clinical cut-off for hoarding symptoms and looked at this in association with stigma ratings that were the focus of the study.

Table 1.

Study Characteristics

Study ID and Authors (Year)	Location	Quantitative or Qualitative	Study Design	Inclusion Criteria	Sample Size	Sample Characteristics	How Hoarding was Measured or Classified	How Stigma was Measured	QualSyst Quality Rating
Public Stigma									
1. Bates et al (2020)	United States	Quantitative	Randomised experimental design with three conditions: (a) hoarding TV show ('Hoarders') (b) clutter TV show ('Clean House') (c) non-clutter related house TV show ('House Hunters') exploring stigma ratings pre and post viewing	- Undergraduate students - Aged 18 or older - No diagnosis of hoarding disorder - Had not seen more than 20 minutes of 'Hoarders' or 'Clean House'	66 (22 per group).	- Undergraduate sample - Age range: 18-55 - Mean age: 21.21 (*SD*=5.54) - Gender: 51.5% male - Ethnicity: 42.4% Asian, 40.9% White or Caucasian, 4.5% Black or African American, 12.2% other	Hoarding was not measured in the sample as it looked at public stigma amongst undergraduates	Stigma (Public) Stigma of Hoarding Items (Chasson et al., 2018) Community Attitudes Towards the Mentally Ill Scale (Taylor & Dear, 1981) Social Distance Scale (Link et al., 1987)	Good
Public and Internalised Stigma									
2. Chasson et al (2018)	United States	Quantitative	Online survey with a within-subjects design in which participants ratings of facets of stigma across 5 different diagnoses were compared: Hoarding, OCD, Serious Mental Illness, Substance use disorder, and Jail	- Aged 18 or older - Connected to MTurk from the United States	591	- Mean age: 37.03 (*SD*=11.42) - Gender: 49.7% male - Ethnicity: 86.5% Caucasian or White, 6.4% Black or African American, 6.1% Asian, 3.0% Other - Co-occurring conditions self report: OCD 1.3%, hoarding 0.0%, no	Sample of people who did not identify as having hoarding disorder Saving Inventory-Revised (Frost et al., 2004) score of 41 or higher used as a cut off to create a sub group of people with hoarding difficulties	Stigma (Public and Self [if met threshold for Hoarding symptoms]) Each condition was rated on seven stigma items related to difference, disdain, and blame on a 9-point Likert scale	Strong

						other conditions asked about - Co-occurring conditions based on clinical cut-off scores: OCD 13.2%, hoarding 4.1%		Resource allocation measure	
Internalised Stigma									
3. Bates (2023)	United States	Qualitative	Individual interviews with people with hoarding disorder about stigma which were thematically analysed	- Aged 18 and older - Live in the United States - Self-identify as someone with hoarding difficulties	17 (+4 who developed the interview)	- Age range: 20-73 - Mean age: 43.09 (*SD*= 17.98) † - Gender: 35.0% male - Ethnicity: Asian 5.9%, Black or African 41.2%, White or Caucasian 47.1%, Other 5.9%	Recruited people who self-identified as people with hoarding disorder Used the Structured Interview for Hoarding Disorder (Nordsletten et al., 2013) to confirm this for eligibility, as well as the Saving Inventory – Revised (Frost et al., 2004) score of 41 or higher to illustrate hoarding severity	Stigma (internalised) HD stigma interview guide, developed for the study	Strong
4. Fontenelle et al (2021)	Australia (recruited internationally)	Quantitative	Online cross-sectional survey which explored the impact of hoarding symptoms, other psychopathology, and ‘psychosocial strengths’ including lower self-stigma on COVID related stressful events in a single sample using regressions	- Hoarding behaviours, confirmed by the Saving Inventory Revised (Frost et al., 2004) total score ≥39 - Aged 18 or older - Able to read and fill out forms	117	- Mean age: 48.38 (*SD*=12.74) - Gender: 9.5% male - Co-occurring conditions based on outcome measures: Depression 96.0%, Anxiety 99.0%, Stress 62.4%, OCD 92.1%	Recruited people who self-identified as people with hoarding disorder Saving Inventory-Revised (Frost et al., 2004) score of 39 or higher used to confirm eligibility	Stigma (internalised) The Internalised Stigma of Mental Illness scale-10 (Boyd et al., 2014)	Strong

5. Krafft (2022)	United States	Quantitative	Randomised, waitlist-controlled trial exploring the efficacy of an 8-week ACT self-help website for hoarding compared to waitlist. Measures completed at baseline, post-treatment, and 4-weeks follow up, including a self-stigma measure	- Aged 18 or older - Live in the USA - Seeking help for clutter or hoarding - Interested in testing a self-help website - Score ≥41 on the Saving Inventory Revised (Frost et al., 2004)	73 (38 in intervention, 35 on waitlist)*	- Mean age: 47.67 (*SD*= 14.34) - Gender: 12.3% male - Ethnicity: 76.7% White, 6.8% Asian, 5.5% bi/multiracial, 4.1% Black, and 6.8% other race	Recruited people who were seeking help for clutter or hoarding All participants met the clinical cut off of ≥41 on the Saving Inventory-Revised (Frost et al., 2004)	Stigma (internalised) Stigma of Hoarding Items (Chasson et al., 2018)	Good
6. Krafft et al (2023)	United States	Quantitative	Mediation and moderation analysis of data collected as part of the randomised waitlist-controlled trial above	- Aged 18 or older - Live in the USA - Seeking help for clutter or hoarding - Interested in testing a self-help website - Score ≥41 on Saving Inventory Revised (Frost et al., 2004)	73 (38 in intervention, 35 on waitlist)*	- Mean age: 47.67 (*SD*= 14.34) † - Gender: 12.3% male - Ethnicity: 76.7% White, 6.8% Asian, 5.5% bi/multiracial, 4.1% Black, and 6.8% other race	Recruited people who were seeking help for clutter or hoarding All participants met the clinical cut off of ≥41 on the Saving Inventory-Revised (Frost et al., 2004)	Stigma (internalised) Stigma of Hoarding Items (Chasson et al., 2018)	Good
7. Mataix-Cols et al (2013)	United Kingdom	Quantitative	Field trial testing DSM-5 hoarding disorder criteria, involving cross sectional questionnaires and clinical interviews	- Self-identify as a collector or person with hoarding difficulties	70 (50 identifying as having hoarding difficulties, 20 as collectors)	Self-identified people with hoarding difficulties (*N*=50) - Mean age: 55.44 (*SD*=12.53) - Gender: 40.0% male For those meeting HD criteria (*N*=29) - Mean age: 56.62 (*SD*=13.55) - Gender: 44.8% male - Comorbidities reported: 69.0% endorsed another mental disorder other than HD (more detail	Self-identified as people with hoarding difficulties or collectors The Structured Interview for Hoarding Disorder (Nordsletten et al., 2013) was used to diagnose HD The Clutter Image Rating (Frost et al., 2008) was used to objectively assess the degree of clutter	Stigma (internalised) Participants were asked 'according to the interview we have just performed, you would meet criteria for this new diagnosis (Hoarding Disorder). Would you find it stigmatising to receive such label?' and responded on a four point Likert scale	Adequate

						available but not reported here) Self-identified collectors (*N*=20) - Mean age: 55.50 (*SD*=10.75) - Gender: 75.0% male - Comorbidities reported: 40.0% endorsed another mental disorder other than HD	Also administered were the Hoarding Rating Scale–Self-Report (Tolin et al., 2010), Saving Inventory – Revised (Frost et al., 2004), Compulsive Acquisition Scale (Frost et al., 2002) and Saving Cognitions Inventory (Steketee et al., 2003)		
8. Robertson et al (2020)	Australia	Quantitative	Online cross-sectional survey with a single sample exploring barriers to treatment and variables which predicted help-seeking intention including stigma	- Live in Australia - Aged 18 or older - Able to read English - Score ≥14 on the Hoarding Rating Scale-Self Report (Tolin et al., 2010)	50	- Mean age: 47.82 (*SD*= 12.92) - Gender: 18.0% male - Co-occurring conditions: Clinically significant symptoms of depression on the PHQ-9 reported by 70.0%, no other co-morbidities asked about	Recruited people who identified as having hoarding difficulties All participants scored of ≥14 on the Hoarding Rating Scale-Self Report (Tolin et al., 2010)	Stigma (internalised) The Internalised Stigma of Mental Illness Scale-9 (Hammer & Toland, 2017)	Strong
				Stigma Related Concepts					
9. Brien et al (2018)	Ireland	Qualitative	Unstructured psychoanalytic interviews which were psychoanalytically analysed	- Aged 18 or older - History of or current hoarding difficulties requiring assessment or intervention - Referred by staff from local primary care health centre - Had capacity to partake in conversation for 1 hour - No condition affecting cognition such that	5	- Age range: 46-71 - Mean age: 60.80 - Gender: 40.0% male	Recruited through staff in local primary care health centres who identified them on the basis of current or historical hoarding	Shame Arose as a theme in interviews	Adequate

				they could not articulate their narrative					
10. Chou et al (2018)	United States	Quantitative	Cross sectional survey of a single sample exploring relationships between shame, self-criticism, hoarding beliefs and hoarding symptoms	- Hoarding difficulties (as screened by three hoarding measures) - No suicide risk - No psychotic symptoms - No intellectual disability - No severe dementia - No acute medical condition that might affect participation	104	- Age range: 41-85 - Mean age: 59.90 (*SD*=9.00) - Gender: 23.1% male - Co-occurring diagnoses: Depression 38.0%, PTSD 13.0%, Agoraphobia 11.0%, Generalised anxiety disorder 11.0%, Social phobia 5.0%, SUD 5.0%, Bipolar disorder 4.0%, Panic disorder 3.0%, OCD 1.0%	Participants screened and included if they met 2/3 of the following: Score of ≥42 Saving Inventory, Revised (Frost et al., 2004); Score of ≥ 20 on the UCLA Hoarding Symptom Scale (Saxena et al., 2015); Score of ≥ 12 on the Clutter Image Rating Scale-Revised (Frost et al., 2008) Those who screened positive were included if they met DSM-5 criteria for HD after clinical interview using the Structured Interview for Hoarding Disorder (SIHD; Nordsletten et al., 2013)	Shame and Self-Criticism Self-criticism- Inadequate-Self (9 items) and Hated-Self (5 items) subscales of the Forms of Self-Criticising/Attacking and Self-Reassuring Scale (FSCRS; Gilbert et al., 2004) Shame- 6 questions modified from the Experience of Shame Scale (Andrews et al., 2002). Assessed the extent to which one feels ashamed of, worries about what others think of, and tries to cover up oneself, and their hoarding problems	Strong
11. Orr et al (2019)	United Kingdom	Qualitative	Semi-structured interviews, analysed using the framework method and thematic analysis	- Identified by social workers as having hoarding difficulties	10	- Age range: 50-80 - Gender: 50.0% male	Self-identified as having hoarding difficulties, as were introduced to the researcher through social workers	Shame Arose as a theme in interviews	Adequate

							No quantitative screening measures of hoarding or structured clinical interviews were employed to confirm the diagnosis of hoarding disorder		
12. Subramaniam et al (2019)	Singapore	Qualitative	Semi-structured interviews that were thematically analysed	- Aged 21 and older - Able to converse in English, Chinese, Malay or Tamil - Assessed to be 'clinically stable' and capable of being interviewed - Identified as having hoarding difficulties	12	- Mean age: 56.70 (*SD*= 14.50) - Gender: 41.7% male - Ethnicity: Chinese 91.7%, Malay 8.3%	Either diagnosed with hoarding disorder by their clinician or identified by community workers using the Clutter-Image Rating Scale (Frost et al., 2008; Sagayadevan et al., 2016), associated with reports of hoarding related distress or functional impairment No quantitative screening measures of hoarding or structured clinical interviews were employed to confirm the diagnosis of hoarding disorder	Stigma (internalised) and Shame Arose as a theme in interviews	Strong
13. Tolin et al (2008)	United States	Quantitative	Online cross-sectional survey which made between subjects comparisons of distress related to a family member's hoarding, frequency of arguments and	- Age 18 and older - Self-identified as non-hoarding friends or family members of individuals with hoarding problems - Part of a database of individuals who	665	Family members of people meeting full criteria for HD (571 people) - Mean Age: 45.36 (*SD*= 12.46) - Gender: 16.3% male	Respondents self-identified as family members of someone with hoarding disorder Severity of hoarding of their family	Familial rejection and embarrassment (public stigma or associative stigma) Patient Rejection Scale (Kreisman et al., 1979)	Good

			patient rejection (e.g. between children vs. siblings of hoarding family members; family informants who lived with the hoarding family member before age 21 vs those who didn't). Predictors of distress and patient rejection were also explored through correlations	contacted the researchers about hoarding		Family members of people not meeting full criteria for HD (94 people) - Mean Age: 53.23 (*SD*= 12.76) - Gender: 19.4% male	member was determined using the Hoarding Rating Scale-Self-Report (Tolin et al., 2010). Family informants who described moderate (4) or greater clutter and difficulty discarding, as well as either moderate (4) or greater distress or impairment caused by hoarding were considered to have family members who met diagnostic criteria	Distress Ratings required participants to rate, from 0 (not at all) to 4 (very much), the following questions: "How happy was your childhood" "To what extent was it difficult for you to make friends when you were a child?" "How frequently did you have people over to your house (friends, relatives, etc.)?" "How frequently did you argue with your parents?" "How strained was your relationship with your parents?" "How embarrassed were you about your home?" "How frequently did you argue with [name] about his/her hoarding behaviour when you were living there?"	
14. Wilbram et al (2010)	United Kingdom	Qualitative	Semi-structured interviews that were thematically analysed.	- Identify as a key carer of a person who hoards - Descriptions and the investigators observations of the environmental impact	10	- Age range: 37-71 - Mean age: 56.00 - Gender: 40.0% male	Participants self-identified as key carers for a person who hoards	Shame, embarrassment and marginalisation (associative stigma)	Strong

				correspond with hoarding				Participants were included in the study based on their descriptions (and investigators observations) of the severity and environmental impact of the person with hoarding difficulties' behaviour, without clinical interviews		
15. Tolin et al (2012)	United States	Quantitative	Online cross-sectional survey of a single sample comparing patient rejection attitudes of professionals towards their clients with HD compared to those without	- Self-identified as healthcare or service professionals - Self-reported having worked with at least 1 client with HD and 1 without - Part of a database of individuals who contacted the researchers about hoarding	84	-	Healthcare or service professionals (71.4% professional organisers; 19.0% healthcare workers; 9.5% social service workers)	Respondents self-identified having worked with someone with hoarding disorder Severity of hoarding of their client was determined using the Hoarding Rating Scale-Self-Report (Tolin et al., 2010)	Patient rejection and frustration (public stigma) Patient Rejection Scale (Kreisman et al., 1979) Professionals also responded to questions developed for the study, regarding their clients' behaviour as well as their own feelings	Strong

Note.

*Report results from the same sample.

†Corrected figures obtained from the author as discrepancy noticed.

Quality Assessment

Study quality was assessed by the QualSyst Quality Assessment Tool (Kmet et al., 2004). Quality ranged from ‘adequate’ to ‘strong’ (Appendix C).

Quantitative Studies

Aims and objectives of quantitative studies were adequately described and all utilised appropriate designs. Descriptions of participant characteristics were sufficient, all including age and sex as a minimum except one study (15). However, one paper (13) made many sub-group comparisons without providing the demographics of these, hindering interpretation. Furthermore, incomplete reporting of co-occurring conditions (1,2,4,5,6,8,13) and ethnicity (4,7,8,10,13,15) limited generalisability of findings and could challenge inferences that experiences of stigma are related to hoarding alone.

All studies described their sampling methods, however two (7,10) only partially described their inclusion criteria. Some sampling methods used risked introducing bias, with many relying *exclusively* on participant self-selection including recruiting from support groups (4), families who had contacted researchers for support (13, 15), and undergraduates (1). Self-selecting participants may be a non-representative subset of people with HD, their families or professionals who have greater insight and/or higher levels of distress. Most studies relied on participants/respondents meeting clinical thresholds on hoarding measures (2,4,5,6,8,10,13,15), with some only requiring self-report of hoarding difficulties (14), and only one (7) conducting a clinical interview for HD meaning some may not meet criteria for HD. Sample size was mostly appropriate, however some samples seemed small (5,6,7,8), risking low statistical power, and only one paper (8) reported a-priori power analysis. Although outcome measures were described in adequate detail, the quality of measures varied. Some used validated measures, but often measures had poor psychometric properties and some were adapted for HD, meaning they were not validated in this population or format. Measures of stigma were predominately self-report, which may underestimate public stigma due to social desirability biases.

Four studies did not report analytic methods in sufficient detail (4,5,6,7), but none were obviously inappropriate or missing. Random allocation and blinding were rarely applicable, however when they were, random allocation was not fully described and blinding was not used (1,5,6). Control for confounding variables was often partially considered, but only two papers reported this fully. Although reporting of power and effect size was poor, estimates of variance were consistently provided. Results were generally reported in sufficient detail, although for some (5,6,13) these were hard to interpret due to insufficient detail.

Qualitative Studies

Aims and objectives were well described and were appropriately addressed with qualitative designs, with adequate context and connection to theory offered. Sampling and demographics were poorly reported, being clearly described for just two studies (3,12). One study did not sufficiently describe participant recruitment (11), another had a very small sample (9) and three did not report sufficient demographic characteristics (9,11,14). As with the quantitative studies, reporting of ethnicity varied (not reported in 9,11,14) and none reported co-occurring diagnoses. Few studies relied on participant self-selection (3,14), with many recruiting through healthcare professionals (9,11,12), however only one study (3) checked that their sample met HD criteria. These sampling approaches meant that participants were often those accessing help, possibly introducing bias, and may not have met HD criteria.

Methods were generally well described and thematic analysis supported with sufficient data. However, one study (9) used a psychoanalytic approach which was poorly described, and did not provide sufficient data to support their results. Credibility checks like triangulation and peer reviewing were well used, and conclusions drawn were appropriate. Interestingly, most papers did not demonstrate sufficient evidence of reflexivity.

Is there Evidence that People with HD are Subject to Stigma?

Internalised Stigma

Seven studies explored internalised stigma experienced by people with hoarding difficulties. Only Chasson et al. (2018) and Bates (2023) had stigma related aims, with other studies measuring internalised stigma in relation to other variables of interest.

Bates (2023) interviewed people with HD about their experience of stigma, including stereotypes, prejudice and discrimination, in a study with ‘strong’ quality. Respondents identified stereotypes that people with HD were *unclean*, *crazy*, and *lazy*, incorporating ideas that they were ‘dirty’, ‘unbalanced’, and different to ‘normal people’. These stereotypes weren’t always agreed with, but people with HD reported feelings of sadness, shame and guilt when presented with them, suggesting internalisation of stigma. Respondents experienced discrimination due to hoarding, including work conflict due to clutter, and rejection and criticism from friends and family about their homes. Where respondents did not report experiencing discrimination, this was attributed to others being unaware of their hoarding. Regarding self-discrimination, almost half reported that stigma prevented them seeking treatment for hoarding. Participants reported feeling pressure to appear organised at work to avoid hoarding stereotypes, and kept colleagues, friends and family at a distance to avoid revealing hoarding or developing relationships that may lead to expectations of socialising in their home, to which they limited access due to fear of judgement. This led to social distance and rejection. Thus, this study indicates that people with HD experience substantial internalised stigma, though the small self-selected sample limits generalisability.

Chasson et al. (2018) evaluated public stigma of HD in a cross-sectional survey of people *without* HD with 'strong' quality. A hoarding stigma scale was developed for this study, on which higher ratings on 9-point Likert scales indicated endorsement of more negative attitudes. However, 24 participants scored ≥41 on the Saving Inventory-Revised (SI-R; Frost et al., 2004). These participants rated people with HD neutrally to slightly negatively, rating them slightly different to others (*M*=5.51, *SD*=1.79), with slight disdain (*M*=5.92, *SD*=1.37) and as somewhat to blame for their difficulties (*M*=4.66, *SD*=2.30). Although interpreting this scale is challenging, it is unvalidated, and its psychometric properties are varied with low Cronbach's alphas for one subscale, it does suggest endorsement of slightly negative views of HD by people with hoarding difficulties.

Four studies measured internalised stigma as a predictor or process variable. Fontenelle et al. (2021) and Robertson et al. (2020), both 'strong' quality studies, gave the Internalised Stigma of Mental Illness scale (Hammer & Toland, 2017) to self-identified people with hoarding difficulties who met cut-off scores for hoarding (≥39 SI-R (Frost et al., 2004); ≥14 Hoarding Rating Scale-Self Report (Tolin et al., 2010)). 'High' internalised stigma (>2.50) was reported by 38% of Robertson's (2020) participants, and hoarding severity was significantly positively correlated with internalised stigma (*r*=.30, *p*<.05). Both studies identified that people with HD experienced 'minimal' to 'moderate' internalised stigma (*M*=2.42, *SD*=0.50*;* *M*=2.34, *SD*=0.42).

The 'good' quality RCT reported by Krafft (2022; 2023) used Chasson's (2018) hoarding stigma scale as a process measure of internalised stigma and found that people with hoarding difficulties endorsed slightly negative attitudes towards people with HD in terms of difference (Intervention *M*=6.62, *SD*=2.07; Waitlist *M*=6.41, *SD*=2.19), disdain (Intervention *M*=5.75, *SD*=2.27; Waitlist *M*=5.73, *SD*=1.81), and blame (Intervention *M*=4.62, *SD*=2.39; Waitlist *M*=5.76, *SD*=2.70). Hoarding severity was significantly correlated with ratings of difference (*r*=.31, *p*<.01), but not disdain or blame. However, this measure had poor psychometric properties and is hard to interpret.

Finally, Mataix-Cols et al. (2013), in an 'adequate' quality study, asked 50 self-identified people with hoarding difficulties whether the proposed diagnostic label of HD would be stigmatising: 58.6% reported that it would not, 27.6% felt it would be somewhat stigmatising and 13.8% considered it very stigmatising. Some participants worried that the label would connote being dirty and would be socially unacceptable, suggesting awareness of hoarding stereotypes.

Overall, research is limited but suggests that people with HD experience some internalised stigma. Qualitatively they identify negative stereotypes specific to hoarding, and these result in negative affect and isolation due to fear of judgement and deter help-seeking. Quantitative studies suggest that people with HD experience mild to moderate internalised stigma, but that stigma is not universal and may increase with hoarding severity.

Public Stigma

Two studies explored public stigma regarding HD.

In a large survey of 'strong' quality, Chasson et al. (2018) found that HD had a neutral to slightly negative public perception. On their hoarding stigma scale, people with HD were rated as slightly different (*M*=5.50, *SD*=1.79), slightly disdained (*M*=5.92, *SD*=1.37) and somewhat to blame for their difficulties (*M*=4.64, *SD*=2.29) indicating some public stigma. The more negatively participants rated people with HD in terms of blame (*r*=−.12,

$p<.001$) and disdain ($r=-.09$, $p=.034$), the fewer dollars they allocated hoarding services in a hypothetical budget allocation task, indicating that negative attitudes about HD may lead to discrimination. Additionally, participants who reported that a friend or family member had hoarding difficulties viewed HD more favourably in terms of difference, but with more disdain and blame ($F(2,589)=10.26$, $p<.001$, $\eta2=.03$). However, as mentioned previously the validity and psychometric properties of this measure limit conclusions. Additionally, budget allocation is rarely how stigma is enacted for the general population.

Bates et al. (2020) experimentally investigated how television depictions impact public stigma of HD, with a ‘good’ quality rating. Undergraduates rated people with HD very negatively in terms of difference and neutrally in terms of blame on Chasson’s (2018) scale, neutrally on the Community Attitudes Toward the Mentally Ill Scale (CAMI; Taylor & Dear, 1981), but preferred greater distance from people with HD on the Social Distance Scale (SDS; Link et al., 1987). Familiarity with people with HD did not moderate stigma ratings. Participants who then watched an episode of ‘Hoarders’ showed increased stigma ratings across all measures, and scores were significantly higher compared to people who watched ‘Clean House’ and ‘House Hunters’ on the SDS, the Social Restrictiveness subscale of the CAMI, and difference ratings, with large effect sizes (partial $\eta2=.13$ - .30), suggesting that media representations of HD increase public stigma. Subscales of both Chasson’s (2018) scale and the CAMI had unsatisfactory psychometric properties so weren’t reported. Additionally, the sample were students, and predominately young and white, limiting generalisability.

Again, research into public stigma of HD is limited, but suggests that people with HD are subject to attitudes that range from neutral to very negative in terms of difference, disdain and blame, and the public prefer distance from them. The impact of familiarity on public stigma is currently unclear.

Related Concepts

Four studies explored experiences that may reflect internalised stigma in people with HD.

Chou et al. (2018) conducted a ‘strong’ quality online single-sample survey and found that self-criticism (r=.20, p=.04) and shame (r=.23, p=.02) were significantly positively correlated with HD symptom severity in 104 people with HD (confirmed by clinical interview).

Two studies thematically analysed interviews with people identified by social workers or community staff as having HD. Participants in one ‘strong’ quality study described that family members were ashamed of their behaviour which led to anger and relationship breakdown, and that they were perceived by neighbours as ‘crazy’ and ‘bad’ which they found distressing (Subramaniam et al., 2020). In another study of ‘adequate’ quality (Orr et al., 2019), respondents felt the label of hoarding led to assumptions that their possessions were ‘rubbish’ and that they were ‘irrational’. Some respondents described feeling ashamed of their hoarding, so avoided letting others into their homes. Others disagreed with these assumptions and rejected the hoarding label, one describing not caring what others thought and another viewing their hoard as a positive reinforcer of social connections. For a few participants, understanding that hoarding was a mental health difficulty attenuated blame and reduced their belief that they were ‘nuts’.

Finally, Brien et al. (2018) conducted psychoanalytically informed interviews to explore the experiences of five people identified by primary-care staff as having HD, rated ‘adequate’ quality. They observed shame and guilt in the narratives of hoarding individuals, who often hid and avoided discussing their hoarded possessions. Participants described feeling ‘damaged’ or different, found the hoarding label ‘horrible’, and experienced feeling humiliated by professionals’ reactions to their hoarding.

Two studies explored concepts which may reflect public stigma regarding hoarding amongst families of people with HD.

Tolin, Frost, Steketee and Fitch (2008) conducted a ‘good’ quality survey of over 600 family members which measured frustration and hostility towards their hoarding family member using the Patient Rejection Scale (PRS; Kreisman et al., 1979). PRS scores range from 11-35, with higher scores indicating more rejecting attitudes. Participants reported high patient rejection attitudes (*M*=20.48, *SD*=4.57), irrespective of their relationship with the hoarding individual (e.g. partner, child, sibling). Rejecting attitudes were significantly associated with the individual’s hoarding symptom severity (r=.15, p=.003), clutter in the home (r=.12, p=.018), and lack of hoarding insight (r=.34, p<.001). Living with the hoarding individual during childhood was associated with greater distress, including having friends over less often, arguing more, and experiencing embarrassment about the condition of the home. Distress ratings were higher for children of people who hoard than for siblings. Rejection, embarrassment and social avoidance may indicate public stigma or associative stigma. However, family members surveyed had previously contacted the researchers about their hoarding family member, so may have biased results.

Wilbram et al. (2008) conducted a ‘strong’ quality interview study with 10 family members of hoarding individuals. Respondents felt that others did not understand, feared or did not tolerate hoarding, especially when clutter was visible, and described experiencing prejudice and discrimination including teasing and marginalisation as a result. They also described feeling embarrassment and shame about their home which resulted in social withdrawal, and anger towards the individual who hoarded, with hoarding being described by some as selfish.

One ‘strong’ quality survey by Tolin et al. (2012) explored concepts which may reflect public stigma regarding HD amongst professionals who worked with people with HD. They compared professionals’ ratings of frustration and hostility towards a hoarding compared to a non-hoarding client using the PRS (Kreisman et al., 1979), and found significantly higher frustration and hostility for hoarding clients. Rejecting attitudes were not significantly associated with the individual’s hoarding symptom severity. On survey questions designed for this study, professionals also rated themselves as feeling significantly more frustrated and irritated by their hoarding client, relieved when the client did not attend appointments, feeling hopeless or helpless, and wanting to transfer the client. Hoarding clients were rated as significantly more difficult to work with. Rejection and hostility, as well as frustration, relief related to non-attendance and desire to transfer clients, may indicate public stigma. However, professionals surveyed had previously contacted the researchers about hoarding clients, so may have biased results. They were also primarily professional organisers, who may be sought out by HD clients, compared to health or social care workers, who may be more likely to be referred HD clients who are not seeking support.

Studies exploring related concepts further illustrate people with HD’s awareness of negative public beliefs about hoarding, like being ‘crazy’ and surrounded by ‘rubbish’. Furthermore, people with HD’s internalisation of these stereotypes may be illustrated through experiences of shame, self-criticism and frustration, and consequent self-discriminatory behaviours like label avoidance and social withdrawal. These studies also support that experiences vary, with some disagreeing with stereotypes and reportedly feeling unaffected by negative public perception. Finally, studies of family members and professionals further our understanding of public stigma of hoarding through the rejecting and hostile attitudes and desire for distance endorsed. For family members this may also reflect associative stigma, as family members described their own shame about clutter, and resulting social withdrawal.

How Does Stigma in HD Compare to Stigma Related to Other Mental Health Difficulties?

Internalised Stigma

No studies compared the internalised stigma experienced by people with HD to people other mental health difficulties.

Public Stigma

Chasson et al. (2018) compared stigma ratings the public made about HD with their ratings of people with serious mental illness (SMI), substance use disorder (SUD), obsessive compulsive disorder (OCD), and people in jail. They utilised a within-subjects survey design, and the quality was rated ‘strong’. On their self-developed hoarding stigma scale, people with HD were viewed as significantly more different from the general population than SUD, Jail and OCD ($p<.01$, $d=0.19$; $p<.01$, $d=0.60$; $p<.01$, $d=0.78$), with similar disdain as SMI and more disdain than OCD ($p<.01$, $d=1.58$), and as more to blame for their condition than people with SMI ($p<.01$, $d=0.85$) and OCD ($p<.01$, $d=0.48$). Hoarding was consistently viewed with more stigmatising attitudes than OCD. Values reported here are corrected from the published paper, following correspondence with the author.

These findings suggest that hoarding is more publically stigmatised than other mental health conditions like OCD, particularly with regard to perceptions that people who hoard are to blame for their difficulties and are viewed with disdain. However, challenges with representativeness of the sample and validity of the measure used have been previously discussed.

Related Concepts

No studies *directly* compared concepts related to stigma between people with HD and people with other mental health difficulties. However, Tolin, Frost, Steketee and Fitch (2008) compared patient rejection attitudes of family members of people with HD with historical studies that administered the same measure, the PRS (Kreisman et al., 1979). Patient rejection attitudes were significantly higher among family members of hoarding individuals than families of people seeking treatment for OCD (Amir et al., 2000) (p<.001) and families of people with schizophrenia at hospital discharge (Kreisman et al., 1979) (p<.001), and were comparable to attitudes of families of outpatients with schizophrenia (Heresco-Levy et al., 1992) and staff working with inpatients with schizophrenia (Heresco-Levy et al., 1999).

These findings suggest people with HD may experience more hostile and rejecting attitudes than people with OCD and schizophrenia, possibly suggesting more stigma. However, care should be taken in interpreting these differences as the comparisons are made across studies conducted many years ago.

Is there Evidence that Stigma Impacts Help-Seeking in People with HD?

Internalised Stigma

Three studies, all with ‘strong’ quality ratings, explored the impact of internalised stigma on help-seeking in people with HD.

Chasson et al. (2018) found that ratings of disdain towards hoarding were negatively related to ratings of treatment-seeking willingness (r=−.48, p<.01) amongst a sub-sample of participants with clinically significant symptoms of HD on the SI-R (Frost et al., 2004).

However, these findings were exploratory due to the small sub-sample. A study with a larger and more representative sample of people who self-identified with HD and scored ≥ 14 on the Hoarding Rating Scale Self-report (Tolin et al., 2010) found that internalised stigma did not significantly predict ratings of help-seeking intention (Robertson et al., 2020). Fears of being ‘judged by a therapist’ and fears of ‘[finding] out that I’m crazy’, which seem stigma related, were endorsed as a barrier to treatment by ≤16% of participants. ‘Preference for working out problems independently’ was endorsed as a barrier by 58%, but whether this is related to stigma is unknown. However, during in-depth interviews, almost half of Bates (2023) participants indicated that stigma and negative stereotypes of hoarding had stopped them getting treatment, as hoarding was difficult to disclose. Other participants either reported that stigma hadn’t affected their help-seeking for hoarding, or were unsure about this. Some indicated that they did not seek help because they did not talk about their hoarding with others, which may indicate awareness that they may be negatively perceived if they did.

Overall, the impact of internalised stigma of hoarding on help-seeking is unclear, but stigma may negatively impact help-seeking for *some* with HD. Studies with adequately powered, representative samples are needed to clarify this.

Public Stigma

No studies explored whether public stigma of hoarding impacted help-seeking (or help availability).

Related Concepts

No studies explored impacts of stigma related concepts on help-seeking in HD.

Discussion

This review aimed to examine the evidence of public and internalised stigma related to HD, how this compares with other mental health conditions, and whether stigma impacts help-seeking in HD. Although literature addressing all three questions was very limited, it can be tentatively surmised that a significant proportion of people who hoard and their families are aware of and internalise stigma, and HD is stigmatised by the public. People who hoard identified stereotypes that people with HD are unclean, crazy and lazy, and experienced negative affect, shame and social withdrawal as a result. However, levels of internalised stigma endorsed varied within and between studies, from none to mild-moderate stigma. Public perceptions of people with HD also varied, ranging from neutral to negative in terms of difference, disdain and blame, with preference for greater social distance from them. This may be influenced by presentations of hoarding in the media. Furthermore, family members of people with HD and professionals working with people with HD endorsed rejecting attitudes towards them, possibly related to stigma. Families also experienced shame about clutter, and social withdrawal and discrimination due to hoarding, indicating possible associative stigma. Across public and internalised stigma and related concepts, heterogeneity of studies, sampling issues and unreliable measures made it difficult to draw firm conclusions. No studies compared internalised stigma related to HD with other conditions, however there is initial evidence that public stigma of HD *may* be higher than for OCD, and comparable to SMI, particularly regarding perceptions of blame and disdain. Finally, the limited research on the impact of stigma on help-seeking for HD was mixed but generally suggested that stigma negatively impacted help-seeking for some people with HD.

Our tentative findings are consistent with reviews of stigma experiences in other mental health conditions (Corrigan & Watson, 2002; Ellison et al., 2013; Livingston & Boyd, 2010). Furthermore, the preliminary findings that stigma had interfered with help-seeking for some people with HD and that endorsement of negative stereotypes like disdain was associated with reduced treatment-seeking willingness are consistent with multiple reviews documenting the harmful effects of stigma on help-seeking (Clement et al., 2015; Corrigan, 2004; García-Soriano et al., 2014). However, some studies found that stigma did not predict or was not cited as a barrier to help-seeking. Interestingly, whilst internalised stigma and self-discriminatory attitudes are consistently negatively associated with help-seeking, this association is weaker for perceived stigma (Clement et al., 2015; Schomerus et al., 2009). This conceptual distinction has not been explored in HD, but may explain the varied findings in relation to stigma and help-seeking, and should be further examined.

The existing literature explores some aspects of the social-cognitive model of stigma related to HD, primarily exploring the stereotypes about hoarding identified both by people who hoard and the public. It is unclear what prejudice and discrimination these stereotypes correspond with. Corrigan et al. (2002) identified pathways to account for stigmatising reactions to common mental health stereotypes (e.g. dangerousness→ fear→ avoidance), however the emotional reactions and corresponding behaviour in response to stereotypes about hoarding are unclear. Only one study directly measured how public stigma influenced behaviour, and this measure lacked ecological validity. Patient rejection attitudes identified amongst family members and professionals, and preferences for social distance may indicate prejudice and discrimination, however, this requires further study. Patient rejection may alternatively result from the operation of the social-cognitive model, which suggests that if individuals with HD internalise hoarding stigma and withdraw from others due to fear of negative reactions, as was reported in qualitative studies reviewed, this may ultimately lead to rejection by important people in their lives.

There is some support for the stage model of self-stigma (Corrigan and Rao, 2012) as people with HD were *aware* of stereotypes about hoarding, some *agreed* with these, and some *applied these to themselves*, indicated by feelings of shame, guilt and frustration described in many studies and self-discriminatory behaviours like social withdrawal and not seeking treatment ('why try'). However, not all people who hoarded agreed with stereotypes, or that hoarding was a negative or stigmatised part of their identity. Although, as expected, this corresponded with not all people with HD reporting internalised stigma, some still experienced the negative sequelae of internalised stigma like shame and social withdrawal. Lower stereotype endorsement in these cases may reflect limited insight into or shame about hoarding difficulties, raising questions around how to explore internalised stigma in HD. Part of the challenge in fitting hoarding to an overarching internalised stigma theory may be related to theories that hoarding represents a final common pathway of multiple psychological mechanisms, as these may each interact differently with stigma. Research into the relationship between people who differ in terms of the mechanisms underpinning hoarding and the occurrence of internalised stigma may improve understanding of what is clearly a complex relationship.

Research is required into both hoarding stereotypes *and* emotional and behavioural reactions to these in the public and people who hoard to explore the social-cognitive model of stigma more thoroughly. This would inform the development and validation of direct measures of internalised and public stigma suitable for use with people who hoard. Most likely this will involve the development of a specific measure, although adaptation of existing measures may be a viable alternative. Comparisons between people who hoard and other groups such as those with OCD, Depression or Psychosis in terms of internalised stigma would provide a benchmark. Studies should examine the impacts of internalised and perceived stigma on help-seeking in hoarding, alongside other self-discriminatory behaviours. Crucially, hoarding stigma has yet to be *directly* evaluated amongst health professionals, and this may have important implications for understanding barriers to people who hoard receiving treatment. Tolin et al. (2012) found that healthcare professionals experienced more frustration and poorer working alliance with hoarding compared to non-hoarding clients. This may indicate negative professional attitudes towards hoarding that could undermine the treatment effectiveness or accessibility. Studies using vignettes may be useful to elucidate stigma in both public and professionals. This should then be compared with other conditions, including subtypes of presentations like OCD which may be subject to different levels of stigma (Ponzini & Steinman, 2022).

One way that people seek support for mental health difficulties is through support and encouragement of loved ones, which may be a problem for people who hoard, who report having less social support (Edwards et al., 2023). It has been hypothesised that this may reflect both their *perception* of support and relationship quality and *actual* rejection by friends and family. Indeed, this review identified that family members may experience associative stigma as well as stigma towards people who hoard, however the scant research was limited by sampling which may have been biased towards those who experienced greater distress. This could have implications for how family are included in therapy, such as Family-As-Motivators Training (Chasson et al., 2014), however substantial further research is needed.

Regarding implications, research suggests that media presentations of hoarding may increase stigmatising attitudes, thus messages these convey should be carefully considered. Targeted stigma reduction campaigns, which have shown success in other mental health domains (Evans-Lacko et al., 2014; Watson & Corrigan, 2005) could also be helpful. Many stigma reduction interventions are based on contact, which has reduced desire for social distance and perceived dangerousness in other mental health problems by disconfirming negative stereotypes (Corrigan, 2007). However, the present review highlighted that familiarity with someone with HD either had no effect or increased ratings of disdain and blame, suggesting that interventions based on contact may be ineffective or actively unhelpful in hoarding if stereotypes are instead confirmed. Further research into the impact of familiarity on hoarding stigma is therefore needed.

A major limitation of the reviewed research was stigma measurement. Use of unvalidated measures of stigma and measures designed for other mental illnesses that may not be relevant to hoarding risked underestimating stigma and undermined the validity of findings.

This review itself has several limitations. First, by excluding research not published in English we may have limited generalisability of our findings to other cultural contexts. However, non-English language research did not appear in preliminary searches. A strength of the review is the inclusion of qualitative research, studies involving stigma related concepts, and the use of the “grey” literature. This allowed us to comprehensively synthesise all quantitative data and descriptions of stigma in a research area where little published literature currently exists, and reduced the risk of under-representation of null findings on account of publication bias. However, study heterogeneity made quality assessment challenging, particularly in light of limitations of the QualSyst tool. Exclusion of ‘inapplicable’ items and reliance on subjective ‘appropriateness’ meant scores assigned to papers varied depending on design and did not credit more rigorous designs, and scores did not necessarily indicate the study’s value in relation to understanding stigma. Additionally, key methodological issues which undermined findings were often only reflected in a small loss of points. However, the QualSyst enabled us to use a single quality appraisal tool for all studies.

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Service Improvement Project

Understanding Older Adults Who Do Not Opt-In to Talking Therapies Berkshire: Which Older Adults Do Not Opt-in and Why?

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Published in: This report has been submitted to and accepted for publication in the Cognitive Behavioural Therapist, and has been written and formatted in accordance with this (see Appendix 2.A and 2.B). This journal was selected as it accepts audits and service evaluations relevant to clinical practice of cognitive behavioural therapy (CBT), which is the primary model used within Talking Therapies services. It is geared towards an interdisciplinary audience who practice CBT, so it is hoped to reach clinicians within Talking Therapies services.

Abstract

Older adults are underrepresented in UK Talking Therapies services, a national priority for improvement in the NHS. A Talking Therapies service in England identified that many older adults who were referred did not opt-in to assessment. We aimed to explore the characteristics of these older adults and understand their experiences, to inform recommendations to support future opting-in. Demographic and referral characteristics were compared for older adults who did and did not opt-in, then surveys and semi-structured interviews were used to investigate older adults' reasons for not opting-in. Responses were thematically analysed, and themes were categorised using the COM-B model to inform recommendations. Older age, being from an ethnic minority group, having a previous referral, not being able to receive text messages, and not self-referring (e.g. being referred by GP) all significantly increased the chances of older adults not opting-in. Impersonal and confusing processes, as well as older adults' limited knowledge of Talking Therapies, beliefs about therapy, and physical, cognitive and life changes with age were identified as barriers to opting-in. Several recommendations are made, including ideas to increase accessibility of information, change procedures to improve personal connection, and address practical barriers.

Keywords: Older Adults; Service Evaluation; Improving Access; Talking Therapies

Introduction

Amongst older adults (OA), mental health difficulties are common, with depression affecting 22%-28% (Age UK, 2016) and anxiety affecting 5% (Bryant et al., 2007). Despite this, OA are less likely to be referred for psychological therapies than their working-age counterparts (Frost et al., 2019; Nair et al., 2020; Walters et al., 2018). Indeed, Cooper et al. (2010) found that younger adults were 80% more likely than OA with comparable mental health difficulties to receive therapy. This inequality increases with age, with those aged ≥85 five times less likely to be referred for psychological therapies than those aged 55–59 (Walters et al., 2018).

Such patterns are observed in Talking Therapies, the UK's initial treatment pathway for anxiety and depression. OA represent just 5.1% of their referrals (NHS Digital, 2021), significantly below government targets of 12%. However, when OA access Talking Therapies, they are more likely to complete treatment and experience better outcomes (NHS Digital, 2021; Pettit et al., 2017).

Numerous studies have explored why OA are under-referred for and under-accessing mental health support. Common barriers include the belief that poor mental health is an understandable part of ageing (amongst both OA and professionals), stigma, fear of burdensomeness, and discomfort talking about mental health (Frost et al., 2019; Nair et al., 2020; Wuthrich & Frei, 2015). In addition, practical barriers like mobility and frailty, transport to sessions, and confidence accessing online therapy may prevent OA from accessing treatment (Age UK, 2024). These barriers may interfere with access not only at referral, but also in decisions to opt-in to therapy once referred.

Service Context

In 2021, Talking Therapies Berkshire identified that <2% of clients accessing therapy were over 65, in line with national under-representation of OA, but lower than the national average. They also found that from July-August 2021, 35% of OA referred were not assessed. For many this was because the service decided that Talking Therapies was not a suitable referral, however in >50% of cases the OA did not opt-in for assessment, declined assessment, or did not attend their assessment (hereafter referred to as did not opt-in [DNOI]; Personal Communication, November 2021).

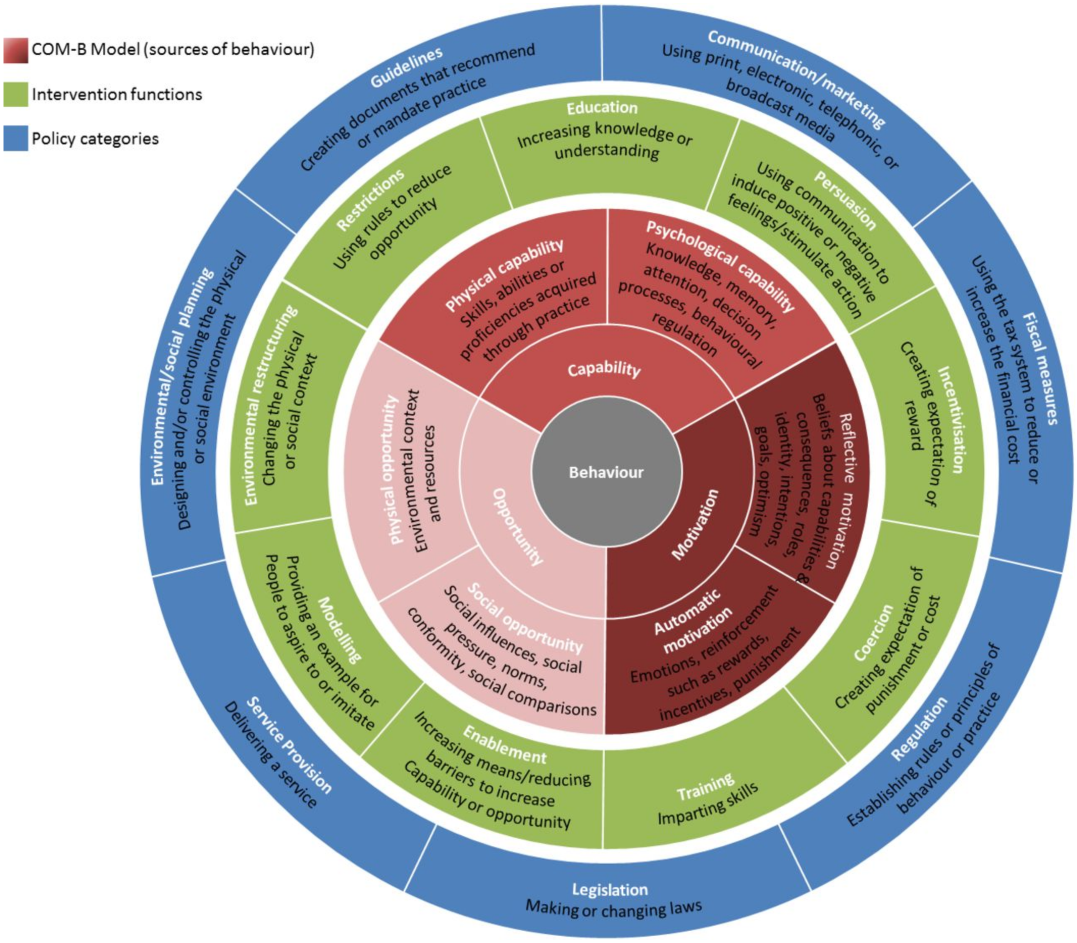
Increasing access to psychological therapies for OA is a national priority for mental health services, and increasing access to Talking Therapies for OA is a key NHS objective for 2023-2024 (NHS England, 2022). Staff were committed to increasing the number of OA seen, however, efforts-to-date had focused on increasing referrals. It was evident that alongside increasing referrals, understanding why so many OA who *were* referred DNOI was essential.

Theory of Behaviour Change

The COM-B model (Michie et al., 2011) proposes that for behaviours like opting-in to occur, people must have Capability (internal factors like skills and knowledge), Opportunity (external factors like physical and social circumstances), and Motivation (automatic processes like emotion, and reflective processes like beliefs). This framework can be used to help identify corresponding evidence-based intervention approaches for identified barriers (see Figure 1) and is increasingly used to inform behaviour-change recommendations in healthcare (e.g.Lau-Zhu et al., 2022).

Figure 1.

The Capability-Opportunity-Motivation-Behaviour (COM-B) Model at the Centre of the Behavioural Change Wheel



Note. The COM-B model is depicted with associated interventions and policy categories, each with a brief description. Reproduced from McDonagh et al. (2020) under Creative Commons Attribution 4.0 Unported (CC BY 4.0) license.

Aims

The service evaluation aimed:

1. To understand the characteristics of OA who DNOI to Talking Therapies.

2. To explore how OA who DNOI experience the process of opting-in at Talking Therapies, and their reasons for not opting-in.
3. To make recommendations for overcoming barriers to opting-in to increase the accessibility of Talking Therapies for OA.

Ethics and Approval

This project was approved by Berkshire Healthcare NHS Foundation Trust audit and service improvement team (BHFT Audit ID: 9353), deemed a service evaluation (Appendix C).

Phase 1

Methods

Design

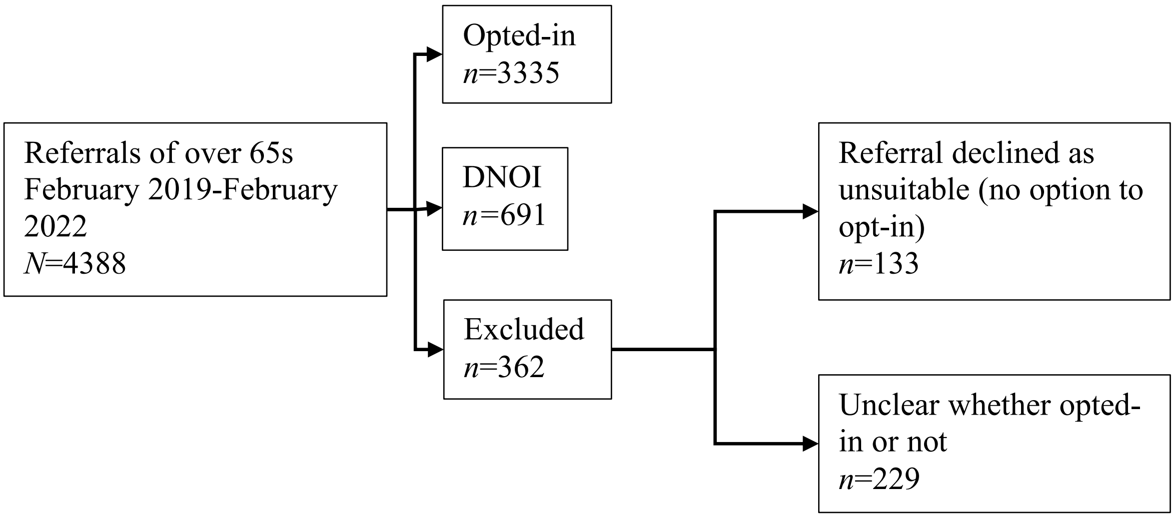
Phase 1 involved cross-sectional quantitative analysis of data collected by Talking Therapies at referral to understand differences between OA who do and DNOI.

Sample and Procedure

Anonymised data was extracted for people aged 65 and over who were referred to Talking Therapies between 1st February 2019 and 1st February 2022. In this time-period, 4388 referrals were made: 3335 opted-in, 691 DNOI, and 362 where opt-in was unclear or the option to opt-in was not offered so these were excluded (Figure 2). A retrospective dataset of 4026 referrals was formed. Some clients had multiple referrals in the time-period studied, thus the 4026 referrals were for 3796 clients.

Figure 2.

Process of Identifying Opted-In and DNOI Groups



Analysis

Analyses were conducted using IBM SPSS statistics version 28 (IBM Corp., 2021). The opted-in and DNOI groups were compared on demographic and referral characteristics using Chi-square test of homogeneity, *t*-tests or Mann Whitney *U*-test. Tests of normality determined which variables met criteria for parametric analysis. Due to small sample sizes within variable categories, many were simplified to ensure that expected frequencies met the assumptions of the analyses used.

Next, binomial logistic regression with simultaneous entry was used to establish the individual contributions of variables that differed between the groups to predicting not opting-in. Whether English was a first language was not included as 80% of cases were missing this data. In the regression, 3296 cases were included, 2919 who opted-in and 377 who DNOI.

Results

Sample Characteristics

Clients were 72.9 years old on average (*SD*=6.5), predominately female (67.9%, *n*=2732) and of White British ethnicity (79.5%, *n*=3202). The Index of Multiple Deprivation Decile, a measure of relative deprivation (1=most deprived, 10=least deprived; McLennan et al., 2019), had a median of 8 (range=1-10). A quarter of clients had a disability (25.3%; *n*=1018), and 52.7% had long-term conditions (*n*=2123).

A majority of the sample were self-referred (61.8%, *n*=2490), evenly split between the East and West of the county, and 43.7% of referrals (*n*=1760) had at least one previous referral (*M*=1.0, *SD*=1.6). Text messages were able to be received by 71.3% of referrals (*n*=2871). Full sample characteristics are reported in Appendix D. The proportion of OA who DNOI increased over the three-year audit period (Table 1).

Table 1.

Opt-In Status by Time Period

Opted in?	Overall (*N*=4388)		Feb 2019-Feb 2020 (*n*=1603)		March 2020-Feb 2021 (*n*=1232)		March 2021-Feb 2022 (*n*=1553)	
	n	%	*n*	%	*n*	%	*n*	%
Yes	3335	76.0	1279	79.8	918	74.5	1138	73.3
No	691	15.7	197	12.3	206	16.7	288	18.5
Not suitable for Talking Therapies	133	3.0	35	2.2	41	3.3	57	3.7
Ambiguous	229	5.2	92	5.7	67	5.4	70	4.5

Group Differences

The opted-in and DNOI groups differed significantly on 10 variables, presented in Table 2.

Demographics. The DNOI group were significantly older than the opted-in group. A significantly higher proportion of clients who were from ethnic minority backgrounds, had a disability, had a long-term condition, or did not speak English as their first language DNOI. However, these associations were weak and explained at most 1.1% of the variance in opt-in. There were no significant differences across gender, IMDD, relationship status or sexuality.

Referral Characteristics. A significantly higher proportion of clients who had no previous referral, were referred by others, were from the east of the county, and could not receive text messages DNOI. The proportion of clients who DNOI significantly increased with each referral period. However, these associations were weak and explained at most 6.3% of the variance in opt-in. There was no significant difference in number of previous referrals.

Table 2.

Comparisons of OA who Did and Did Not Opt-in

Variable	Opted-in (n= 3335)		Did not opt-in (n=691)		Test Statistic	Sig.	Effect Size
	n	%	n	%			
Age (*Mdn,* Range)	71.0	65-99	73.0	65-99	U= 981332.00*,* z= -6.16	p<.001	r=.10
Gender					$\chi2$(1, N=4026)= 0.01	p=.935	
Female	2264	82.9	468	17.1			
Male	1071	82.8	223	17.2			
Ethnicity*					$\chi2$(1, N=3547)= 23.73	p<.001	φ=.08
White	2820	88.1	382	11.9			
Ethnic Minority	272	78.8	73	21.2			
Sexuality*					$\chi2$(1, N=2694)= 2.61	p=.106	
Heterosexual	2342	89.0	289	11.0			
Non-Heterosexual	52	82.5	11	17.5			
Disability?					$\chi2$(1, N=3538)= 13.22	p<.001	φ=.06
Yes	861	84.6	157	15.4			
No	2243	89.0	277	11.0			
Long Term Condition?					$\chi2$(1, N=3689)= 7.56	p=.006	φ=.05
Yes	1819	85.7	304	14.3			

No	1390	88.8	176	11.2			
Relationship Status*					χ2(1, *N*=2903)=1.80	*p*=.180	
In a relationship	1475	86.6	172	10.4			
Not in a relationship	1105	88.0	151	12.0			
English First Language?						*p*=.007	φ=.10
Yes	710	88.3	94	11.7			
No	21	70.0	9	30.0			
IMDD (*Mdn*, Range)	8.0	1-10	8.0	1-10	*U*=1108740.00, *z*= -1.42	*p*=.155	
Referral Source*					χ2(1, *N*=4026)= 246.24,	*p*<.001	φ= .25
Self	2245	90.2	245	9.8			
Other	1090	71.0	446	29.0			
Locality					χ2(1, *N*=4026)= 9.69	*p*=.002	φ=.05
East	1593	80.9	375	19.1			
West	1742	84.6	316	15.4			
Previous Referral					χ2(1, *N*=4026)= 4.46	*p*=.035	φ=.03
Yes	1483	84.3	277	15.7			
No	1852	81.7	414	18.3			
Number of Previous Referrals (*Mdn, Range*)	0.0	0-16	0.0	0-11	*U*=1098575.50, *z*= -1.95	*p*=.052	
Text Messages Allowed?					χ2(1, *N*=4026)= 204.53	*p*<.001	φ=.23
Yes	2533	88.2	338	11.8			
No	802	69.4	353	30.6			
Referral period					χ2(2, *N*=4026)= 25.42	*p*<.001	*V*=.079
Feb19-Feb20	1279	86.7	197	13.3			
Mar20-Feb21	918	81.7	206	18.3			
Mar21-Feb22	1138	79.8	288	20.2			

Note. IMDD= Index of Multiple Deprivation Decile. Male includes trans men and female includes trans women.

Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroups.

Binomial Logistic Regression

A binomial logistic regression was performed to ascertain the relative odds of not-opting in whilst controlling for interrelationships between the variables (Table 3). The model was statistically significant, $\chi 2(10)=113.228$, $p<.001$, and explained 6.6% (Nagelkerke R^2) of the variance in opting-in. It correctly classified 88.6% of cases, but showed no discrimination ability. Only age, ethnicity, whether previously referred, whether text messages were allowed, and referral source remained significant as predictors of not opting-in. Increasing age was associated with increased likelihood of not-opting in. Not opting-in was 2.16 times more likely for people from ethnic minority groups, 1.74 times more likely if not able to receive text messages, and 1.92 times more likely if referred by others. People with a previous referral were more likely to not-opt in.

Table 3.

*Binomial Logistic Regression Model to Predict Not Opting-In (*N*= 3296)*

Variable	Parameter Coding	*B*	*SE B*	Sig.	*OR*	95% *CI* for *OR*	
						Lower	Upper
Age		.02	.01	.019	1.02	1.00	1.04
Ethnic group	White (0)						
	Ethnic Minority (1)	.77	.16	<.001	2.16	1.57	2.99
Disability?	No (0)						
	Yes (1)	.21	.12	.085	1.24	0.97	1.58
Long-term condition?	No (0)						
	Yes (1)	-.13	.12	.294	0.88	0.70	1.11
Locality	West (0)						
	East (1)	.15	.11	.192	1.16	0.93	1.45
Previous referral?	Yes (0)						
	No (1)	-.37	.11	.001	0.69	0.55	0.86
Text messages allowed?	Yes (0)						
	No (1)	.55	.13	<.001	1.74	1.34	2.25
Referral source	Self (0)						
	Other (1)	.65	.11	<.001	1.92	1.54	2.40
Referral period	Feb 19-Feb 20 (0)			.426			
	Mar 20-Feb 21 (1)	-.10	.14	.469	0.90	0.68	1.19
	Mar 21- Feb 22 (2)	.86	.13	.509	1.09	0.84	1.41
Constant		-4.02	.67	<.001	0.02		

Phase 2

Method

Design

Phase 2 involved qualitative analysis of OA clients’ reasons for not opting-in, elicited through surveys and interviews to contextualise phase 1 findings. Their ideas for improvements to support OA to opt-in were also sought.

Participants

Clients aged 65 and over who DNOI to Talking Therapies between September-November 2022 were invited to provide survey or interview feedback about their experience and reasons for not opting-in. Recruitment was repeated in December, January and February due to lower-than-expected response.

Thirty-nine of the 60 clients referred who did not opt-in were successfully contacted. Eighteen agreed to be sent the survey, and eight completed (44.4% response rate); five online, two by telephone, and one by post. Eight clients were interviewed.

Procedure

A survey was co-developed with the OA Workstream and reviewed by service users (Appendix E). Questions explored referral experiences, reasons for not opting in, and suggestions for improvement. These questions were subsequently developed into a semi-structured interview schedule (Appendix F).

The survey could be completed online, by telephone, or by post. Interviews took place between February-March 2023, were audio recorded, and lasted 15-60 minutes. All clients provided written or oral consent.

Analysis

Interviews were transcribed verbatim and anonymised. Transcripts and survey free-text were analysed using thematic analysis, following guidance from Braun and Clarke (2022), using NVivo 12 (QSR International., 1999). Each transcript was read several times to aid familiarisation. Key words and phrases were used to generate initial codes, which were then reviewed and grouped into candidate themes. An inductive stance was taken whilst coding. The COM-B model was then used to organise the themes and identify intervention functions. All authors, as well as clinicians in the OA Workstream, reviewed candidate and final themes to ensure credibility and coherence.

Results

Respondent Characteristics

Characteristics of survey and interview respondents are shown in Table 4.

Table 4.

Participant Characteristics for Surveys and Interviews

Characteristic	Surveys (*n*=8)		Interviews (*n*=8)	
	n	%	*n*	%
Age (*Mdn,* Range)	70.0	65-80	69.5	65-74
Gender				
Male	2	75.0	4	50.0
Female	6	25.0	4	50.0
Ethnicity*				
White	8	100.0	8	100.0
Ethnic Minority	0	0.0	0	0.0
English First Language?				
Yes	8	100.0	8	100.0
No	0	0.0	0	0.0
Locality				
East	4	50.0	5	62.5
West	4	50.0	3	37.5
Disability?				
Yes	1	12.5	3	37.5

	No	7	87.5	5	62.5
Long-term Condition					
	Yes	4	50.0	6	75.0
	No	4	50.0	2	25.0
Referral Source					
	Self	3	37.5	1	12.5
	Other	5	62.5	7	87.5

Note. Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroups.

Survey Results

Three respondents self-referred to Talking Therapies, with the remainder referred by their GP or another healthcare professional. Only five respondents recalled being contacted by Talking Therapies after referral, with contacts recalled including: telephone (4), email (2), letter (1) and text message (1).

Most respondents had no previous referrals to Talking Therapies (6) or previous therapy (5). The two who had previous experience of Talking Therapies rated the helpfulness of this experience as 5/10 and 8/10 (10=*very helpful*, 0=*not at all helpful*), suggesting their experiences ranged from neutral to moderately helpful. Three respondents had previous experiences of therapy elsewhere, and rated the helpfulness of this between 1-5/10, neutral to unhelpful experiences.

Five respondents arranged but then cancelled assessments, whilst three had not arranged an assessment. Multiple-choice statements endorsed as reasons for not opting-in are shown in Table 5.

Table 5.

Reasons Endorsed by Survey Respondents for Not Opting-In

Statement	Number who endorsed (%)
I felt I no longer needed the appointment / my symptoms had improved	5 (62.5)
I didn't think therapy would help me	3 (37.5)
I thought that other people were more deserving of support	3 (37.5)
Too complicated to arrange an appointment	2 (25.0)
I didn't think I had a problem with my mood/mental health	2 (25.0)
I did not think that my problems were bad enough to warrant therapy	2 (25.0)
I didn't receive any communications inviting me to arrange an appointment	2 (25.0)
I did not know who Talking Therapies were or what the service could offer me	1 (12.5)
I did not know what an assessment appointment would involve	1 (12.5)
I didn't have enough time to arrange an appointment	1 (12.5)
I was not aware that the appointment had been booked / I did not receive an appointment confirmation	1 (12.5)
I didn't know how to arrange an appointment	1 (12.5)
I don't have a computer or device to access the website links or attend an online appointment	1 (12.5)

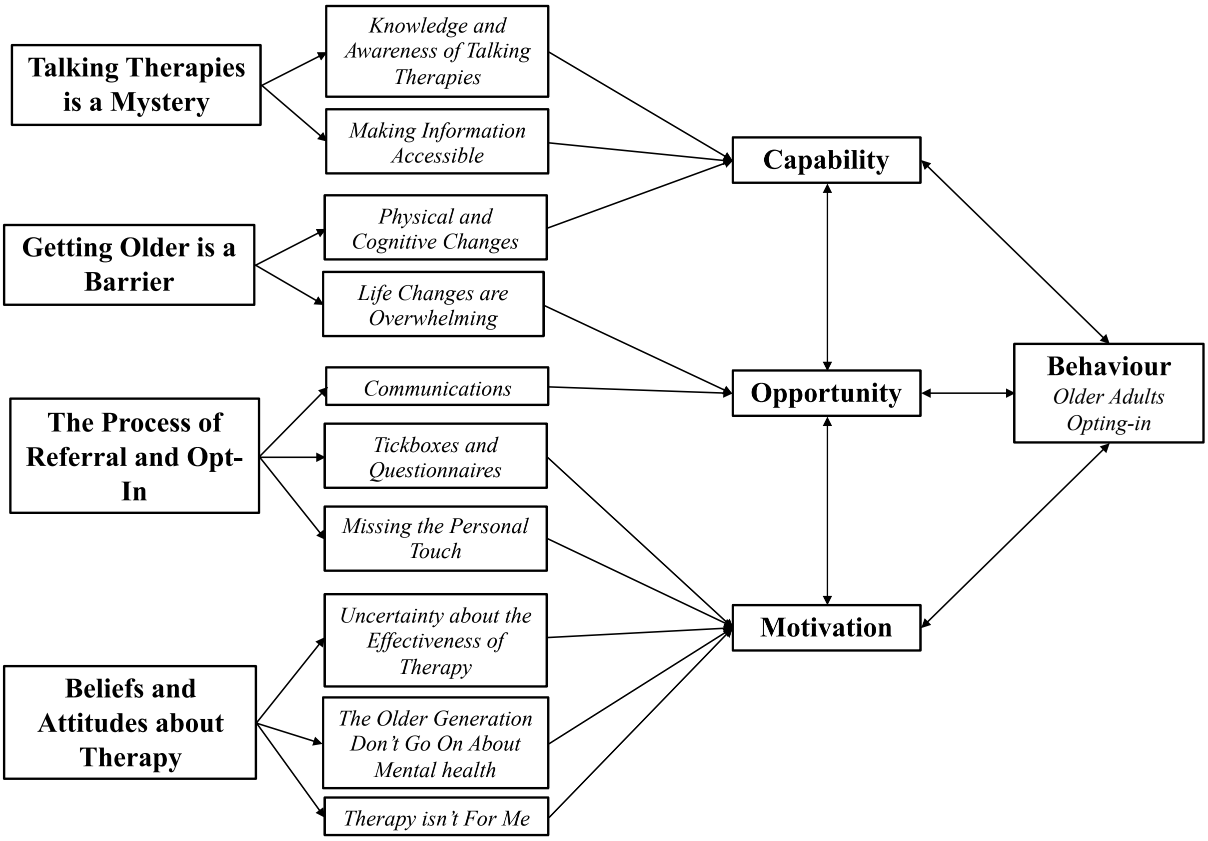
Note. A futher 18 statements were not endorsed by any respondents. Please see Appendix D for the full survey.

Thematic Analysis

Four themes and 10 subthemes were identified, corresponding to capability, opportunity and motivational domains of the COM-B model (Figure 3). Additional illustrative quotes are in Appendix G. Names are pseudonyms.

Figure 3.

Themes with Corresponding COM-B Domains



The Process of Referral and Opt-in. Some respondents experienced ***communications*** with Talking Therapies as happening "smoothly" (Angela), however for others these were "another process that wasn't working well" (Pam) and were confusing and time-consuming, especially due to "pushbutton" telephone services. For some, communication had been so poor that they were unaware of their referral until they were discharged. Others described communication issues like calls from withheld numbers and lack of voicemails, resulting in them feeling they had no opportunity to opt-in despite wanting to.

Furthermore, ***tickboxes and questionnaires*** in the process of opt-in were off-putting for many respondents as they made interactions feel scripted and made some feel like they were "wasting someone's time" as options "didn't really fit" (Survey Response).

Overall, the process was ***missing the personal touch*** that respondents felt was crucial in building the trust they required to opt-in. They emphasised the value of phone calls where they could speak with a human and ask questions, and recommended that OA might appreciate being followed-up by phone call after not opting-in.

Talking Therapies is a Mystery. Some respondents knew what Talking Therapies were, often through previous referrals, however the majority had limited ***knowledge and awareness of Talking Therapies*** and found them "a mystery" (Survey Response). Limited knowledge of the service meant respondents did not know what to expect after referral, with one commenting: "If people don't understand what it is they might just think, I don't know if that's what I want" (Pam). Many stressed that "more information about what to expect" (Survey Response) and information about "why it's worth doing and how it's helped other people" their age (Frank) would be helpful.

Regarding ***making information accessible***, online information was described as accessible for some OA, but that others "wouldn't even think of googling or looking online" (Survey Response) and may not have the capability or technology to access online resources. Respondents stressed that having information in multiple formats online and offline, with preference for interaction, was important.

Beliefs and Attitudes about Therapy. Many respondents expressed ***uncertainty about the effectiveness of therapy***, conflicted between awareness that it could be helpful but also believing that “rambling on” could not solve problems: “I don’t think you can talk yourself out of problems... Life’s life” (Paul). For some, these beliefs and their decision to not opt-in were influenced by previous therapy which they found unhelpful. Others felt that therapy effectiveness was therapist dependent and worried about the youthfulness of Talking Therapies clinicians, wondering “how could somebody inexperienced in life start to understand or help people, particularly if they’re stuck in their ways like I am?” (Douglas).

Respondents commented on a generational difference, whereby ***the older generation don’t “go on about mental health”***, preferring to get on with life and “sort yourself out” (Frank) rather than accept support. Mental health difficulties were still stigmatised for many OA: “a kind of shame that you’re not coping.” (Angela). This meant that many “wouldn’t go to the doctors unless [they were] really struggling” (Frank). Following up OA who DNOI was therefore stressed as important, as well as normalising mood difficulties.

Many felt that ***therapy isn’t for me***, for different reasons. Some “didn’t feel as if [they] needed it” (Susan). However, alongside this were narratives that their difficulties were not bad enough to warrant support, and worries that they would be in the way of “someone else who desperately needed help” (Paul). Many acknowledged the current pressure on NHS services, not wanting to “contribute to the backlog” (Pam) or “bother anybody” (Susan). Conversely, others felt that Talking Therapies were too “superficial” (Angela) to help with longstanding difficulties. Others believed that they were at the “wrong end of life” (Paul) for therapy, believing they were too old to be helped.

Getting Older is a Barrier. ***Physical and cognitive changes*** were discussed, with not “feeling well enough” (Maria) resulting in some respondents not opting-in. Although acute illness was an understandable barrier, others described longer-term health changes as barriers to opt-in: “because of my health difficulties and... disability, it takes quite a lot of energy to get appointments” (Angela). Online and telephone appointments could be helpful, however their impersonal nature was also off-putting for some. Cognitive changes also made remembering information they had been given and opting-in difficult for some: “I get confused utterly between care providers” (Douglas). Reminders and repetition of information were considered crucial for overcoming this.

More broadly, OA described how ***life changes are overwhelming*** and could leave them feeling too busy to opt-in, describing that life “becomes full of barriers” (Frank) including losses related to retirement, bereavement, and health. In particular, respondents who were carers highlighted that this role “takes over everything and [they] have little or no time or energy for anything else” (Survey Response) as they did not have sufficient support. It was suggested that asking OA about barriers and helping them problem solve may help, but that showing an understanding of the challenges of older age was essential.

Discussion

This service evaluation explored the characteristics of OA who DNOI to Talking Therapies and the barriers they identified to opting-in.

Results showed that 23.9% of OA referred to Talking Therapies in the time period audited were not seen, with 15.7% not opting-in, indicating an important point of attrition that could be targeted to increase the number of OA accessing therapy. Opt-in rates worsened over the three years audited, and although referrals increased post-COVID, a greater proportion of OA now DNOI, indicating that the pandemic may have exacerbated barriers to OA opting-in, potentially linked to concerns about burdening the NHS highlighted in interviews. This is worrying as the mental health of OA worsened throughout the pandemic

(Zaninotto et al., 2022) and Office for National Statistics (2022) data indicates that rates of depression remain at double pre-pandemic levels for over 70s, thus the level of unmet need may be growing.

Not opting-in was more likely with increasing age, in line with previous research which found that the proportion of clients referred to IAPT who took up assessments declined after age 64 (Pettit et al., 2017). Notably, over 80s were not represented in our interview sample. Different barriers and cohort beliefs about therapy are likely to be relevant to this group compared to 'younger' OA, and with longevity increasing it is crucial that the barriers to opting-in for different cohorts of older people are understood through further evaluation. OA from UK ethnic minority backgrounds were also less likely to opt-in. Racial and ethnic minority populations are less likely to access mental health services generally (Cooper et al., 2013; McManus et al., 2016), and were not represented in our interview sample. Exploring and addressing the barriers to opting-in experienced by OA from minority populations should be considered in future service evaluations. Similarly, a greater proportion of the DNOI group were disabled and had long-term conditions, however when interrelations with other variables were controlled for these were not significant.

People who were referred by others were much more likely to not opt-in compared to those who self-referred, an effect observed across all ages in IAPT (Sweetman et al., 2022). Talking Therapies may therefore wish to work with local referrers when implementing recommendations, and particularly consider OA who are not able to self-refer by the current processes. Finally, OA unable to receive text messages had higher odds of not opting-in, possibly indicating barriers related to access to and confidence using technology, but also highlighting a need for opt-in reminders to be offered in alternative formats.

Thematic analysis of survey and interview data showed that many OA found the process of opting-in to Talking Therapies confusing, and sometimes had no way of knowing they had been contacted, thus no opportunity to opt-in. Respondents also expressed a strong preference for speaking with clinicians rather than navigating automated systems and questionnaires. This preference extended to ways of accessing information about the service, with most respondents having limited knowledge of Talking Therapies and emphasising that information was inaccessible for many due to it mainly being online, affecting their capability to opt-in. Participants highlighted the importance of making more information about therapy and its benefits for OA available, and it has been shown that knowledge about treatment promotes participation (Kyle & Shaw, 2014). They valued opportunities to ask questions, indicating that allowing more time to speak with OA may be helpful to facilitate personal connection and increase knowledge of the service.

Some beliefs about therapy were barriers to opt-in, including uncertainty about the helpfulness of therapy, but also whether problems were bad enough and not wanting to be a burden on services or prevent someone who needed it more accessing support. Some also believed they were too old to change, or that therapists were too youthful to understand and help them. These attitudinal barriers have been acknowledged by numerous studies exploring barriers to referral and uptake of therapy by OA (Age UK, 2024; Berry et al., 2020; Frost et al., 2019). Some of these attitudes may reflect internalised ageism, excessively negative stereotypes and beliefs about growing old endorsed by older people and resulting in self-fulfilling limitations (Law et al., 2010; Levy, 2003). Allen and Ranger (2013) emphasise the importance of exploring and challenging ageist beliefs early in therapy as part of treatment socialisation, as beliefs that they are too old to change or that they are wasting the therapist’s time may increase the likelihood of disengagement. Exploring these beliefs with OA in early conversations with Talking Therapies and through outreach may therefore promote opt-in. Stigma was also identified as an important motivational barrier to opt-in. Mental health stigma is a significant barrier to help-seeking for people of all ages (Clement et al., 2015), however its impact has been found to be stronger amongst OA, possibly due to exposure to negative images of mental illness that used to be prevalent (Laidlaw & Knight, 2008), suggesting targeted interventions to improve this are indicated.

Cognitive and physical changes also affected respondents' capability and opportunity to opt in, making it harder to access technology, travel to appointments, and remember to opt-in, in line with previous research (Berry et al., 2020; Nair et al., 2020). Some OA wanted to access therapy but felt too overwhelmed by life changes, particularly evident for respondents with caring responsibilities, who are more likely to experience poor mental health (Carers UK, 2019). Increasing awareness and availability of home-based interventions may be helpful in supporting carers and people living with mobility difficulties to opt-in.

Many barriers to opting-in identified here have also been highlighted as barriers to referral, suggesting that these are not service or opt-in specific. Indeed, the IAPT Positive Practice Guide (Age UK, 2024) makes many recommendations which are echoed in this report. This suggests that service initiatives which have focused predominately on increasing referrals may not have adequately addressed the range of barriers experienced by OA, which then persist and affect opt-in, limiting effectiveness of efforts to increase the number of OA accessing therapy.

Recommendations

Respondents suggested many interventions to improve opt-in, which were elaborated on through consideration of the intervention functions recommended by the COM-B model. Recommended interventions are shown in Figure 4. Organisational culture which encourages attention to barriers faced by OA across service development decisions will also be needed to enable improvements. Adoption of one-size-fits-all procedures without considering the needs of OA and other underrepresented groups risks indirect discrimination.

Figure 4.

Recommended Interventions grouped by Themes and COM-B Domains

The Process of Referral and Opt-In

Communication

- To ensure that older adults have the **opportunity and capability** to opt-in, *enablement* via changes to communication procedures is required.
- For example: calls should not come from withheld numbers; if voicemails are left, detail should be given of who is calling with a number to return the call; opt-in deadline could be extended; in discharge letters emphasise that re-referral is allowed and explain different ways (online and offline) to do this; follow up calls to people who don't opt-in.

Tickboxes and Questionnaires, Missing the Personal Touch

- *Education* around why certain procedures like questionnaires are needed and *persuasion* by increasing personal connection could also be helpful in improving reflective **motivation** to opt-in.
- For example: explain in all initial letters and phone calls about why questionnaires are sent, and that if some statements don't apply this is not an indicator that therapy is not appropriate; in initial assessments time should be taken to develop rapport and personal connection before questionnaires; acknowledge that initial calls and measures can feel 'tickbox-y' and scripted and explain why.

Talking Therapies is a Mystery

Knowledge and Awareness of Talking Therapies, Making Information Accessible

- *Education* to increase older adults' knowledge of Talking Therapies and thus increase **capability** to opt-in is essential. This is likely to be most effective when it is responsive to older adults' needs and current understanding (e.g., considering other subthemes identified such as preference for personal touch).
- *Enablement*, by reducing barriers to accessing this education though providing it in multiple formats and settings, should increase **capability and opportunity** to opt-in.
- *Environmental restructuring*, including changes to letter templates and phone call standard operating procedures, may be needed for this to be implemented.
- For example: Ensure FAQs and leaflets are provided as standard in letters, not solely directing to websites or website links; testimonials of older adults could be included in leaflets and letters; work with referrers to encourage provision of more information about Talking Therapies and how it can specifically help older adults; outreach to community groups; check in all phone calls around referral and opt-in staff that older adults know what Talking Therapies is and how it can help; give space for questions.

Beliefs and Attitudes about Therapy
Uncertainty about the Effectiveness of Therapy, The Older Generation Don't Go on About Mental Health, Therapy isn't for Me

- *Education* should also be utilised to increase older adults' understanding of the effectiveness of therapy and thus increase reflective **motivation** to opt-in. This could also provide *persuasion*, inducing positive feelings and stimulating action, especially if conveyed with a personal touch.
- *Modelling* by same-age peers may provide a helpful way to impart this information whilst providing examples to reassure older adults that it is okay to talk about mental health and normalise therapy, reducing negative generational social norms that restrict opportunity and increasing **motivation.**
- *Environmental restructuring*, including changing standard operating procedures for following-up older adults may be needed for this to be implemented.
- For example: provide case studies of older adults with various levels of need; include older adult service users in outreach to community groups; consider terminology used and name and challenge negative stereotypes; ensure there are pictures of older adults on posters and leaflets; training for staff involved in administration and initial contacts about assumptions older adults may hold and how to acknowledge age differences and challenge negative beliefs around mental health difficulties and therapy.

Getting Older is a Barrier
Life Changes are Overwhelming, Physical and Cognitive Changes

- *Enablement* interventions will need to be tailored to the changes that interfere with older adults' **opportunity** to opt-in to therapy.
- For example: after building rapport, ask about barriers to engaging like life-stresses, caring responsibilities, cognitive difficulties, disability and help problem solve; offer choice of appointment time; offer a choice of different ways of being seen for assessment (e.g. face to face or online or phone); offer home visits or sessions at local GP; signposting to carers support if needed; training for staff involved in administration and initial contacts about adaptations for older people with hearing impairment, cognitive difficulties, frailty, or physical health conditions, as well as common changes in older age.

Dissemination and Response

Findings and recommendations were shared at Talking Therapies OA Workstream meetings and with the Talking Therapies Senior Leadership Team. Recommendations were positively received and generated reflection on systemic barriers to implementing changes, like movements to reduce telephone contact and increase online presence. Existing initiatives to improve access were also discussed, highlighting the importance of recognising barriers for many OA in accessing some initiatives, particularly where information was predominately online. The interest generated by these presentations led to findings being shared with Buckinghamshire and Oxfordshire Talking Therapies leadership, with leaders of OA mental health services within the region, and at the East of England OA Network.

The OA Workstream have started implementing recommendations, including: offering OA longer to opt-in; no calls being made from withheld numbers; all OA referred being called by a support worker to discuss the service and opt-in process; planning of outreach sessions to community groups. It is suggested that they review their progress in 12 months' time.

Strengths and Limitations

A strength of this service evaluation was the use of mixed-methodology, offering a comprehensive understanding of the differences between OA who do and DNOI, as well as elaboration on their experiences. The use of a psychological model was a further strength, harnessing a theory-driven approach to optimise recommendations to change opt-in behaviour. Consultation of both Talking Therapies clinicians and OA service users ensured that questions and their delivery were accessible and relevant, and helped to check the feasibility of recommendations, hopefully increasing the likelihood of their implementation. Co-production of future studies with OA may improve this further, as well as consultation of other OA services. Finally, the audit time-period allowed the impact of the COVID-19 pandemic on opt-in to be studied and controlled for, indicating that differences observed were enduring.

Key limitations must also be noted. In the audit there was substantial missing data across demographic variables, largely from the DNOI group. Data may have been more complete for clients with previous episodes of care, potentially biasing the regression. This also prevented more detailed analysis of effects of sexuality, employment, relationship status, and presenting difficulties on opt-in. Collecting more data at referral would enable future evaluations to consider these. Furthermore, the sample of interview and survey respondents was small and was not representative of characteristics least likely to opt-in (e.g. from ethnic minority background, older age). Different barriers may be important for those who did not (or were not able to) participate. More routine follow-up of clients who DNOI could increase opportunities to capture and understand the views of underrepresented groups.

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Theory Driven Research Project

Post-Traumatic Stress Disorder in Autistic and Non-Autistic Adults: The Impact of Appraisals on Reactions to Traumatic Events

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Proposed Journal: We hope to submit this report to Autism Research, and it has been written and formatted in accordance with this (see Appendix 3.A). This journal was selected as it is recognised for theoretical and applied research related to Autism, and has published prior research on the topic of PTSD in Autism.

Abstract

Purpose: Research suggests autistic people experience greater post-traumatic stress disorder symptom severity (PTSD-SS) than non-autistic people following traumatic events. Post-trauma appraisals are fundamental in cognitive models of PTSD, but have not been explored in autistic people.

Methods: Two hundred forty-two autistic and non-autistic adults completed an online survey measuring trauma exposure, PTSD-SS, and post-trauma appraisals. Using group comparisons and mediation analyses, we assessed whether these differed between the groups and whether negative post-traumatic appraisals mediated the link between autism and PTSD-SS.

Results: Rate of exposure to types of traumatic events did not differ significantly between the groups, but the autistic group endorsed significantly more events that happened to them directly. PTSD-SS and negative post-traumatic appraisals were higher in the autistic group. Negative post-traumatic appraisals, specifically alienation, shame and fear, mediated the relationship between autism and PTSD-SS.

Conclusion: Greater endorsement of negative post-traumatic appraisals may increase PTSD-SS in autistic adults, however further longitudinal research is needed.

Key words: Autism; ASD; Post-traumatic Stress Disorder; PTSD; Appraisals; Trauma; Mental Health

Introduction

Post-traumatic stress disorder (PTSD) is a reaction that can occur following exposure to traumatic events, which the DSM-5 defines as events involving actual or threatened serious injury, death or sexual violence (PTSD Criterion A; 1). PTSD is characterised by symptoms including intrusive recollections and reexperiencing of trauma, avoidance of stimuli that are reminders of the event, hyperarousal, and negative mood and cognitions (1). Many people experience these symptoms immediately after traumatic events, but for some these persist for over a month and PTSD is diagnosed. Prevalence estimates of PTSD vary, but are estimated at 8.9% for trauma-exposed adults (2).

The Ehlers and Clark (3) Cognitive Model of PTSD proposes that PTSD occurs if individuals process traumatic events in ways that make the threat seem 'current'. Two features are thought to cause this sense of current threat: 1) excessively negative appraisals about the trauma and/or its consequences, and 2) the nature of the trauma memories. Characteristics of traumatic events, cognitive processing during the trauma, and prior traumatic experiences are suggested to influence the nature of appraisals and trauma memories. Strategies intended to reduce the perceived threat, like thought suppression, rumination, safety-seeking behaviours and avoidance, then maintain difficulties by inadvertently preventing change in appraisals or updating of trauma memories.

Much research in support of this model has focused on the general population, however, recent reviews suggest that the prevalence rate of PTSD in autistic adults exposed to trauma may exceed that in the non-autistic general population, and they may develop PTSD symptoms with greater severity (4). Autism is a neurodevelopmental difference which affects the way people process the world, characterised by differences in social communication and interaction, sensory processing, as well as restricted and repetitive interests and behaviours (1). Approximately 1.1% of people in the UK are diagnosed autistic (5). Studies using self-report measures of PTSD symptoms have found that 32-45% of trauma-exposed autistic adults exceeded cut-off scores for PTSD, significantly higher than non-autistic comparison groups (4-4.5%; 6, 7), and PTSD symptom severity (PTSD-SS) is significantly higher in autistic compared to non-autistic adults (8-10). PTSD has a significant negative impact on quality of life (11), so understanding why autistic people may be more vulnerable to developing PTSD and identifying intervention targets is crucial.

One theory for increased PTSD-SS in autistic adults is that socio-communicative differences may render autistic people more vulnerable to victimisation from others (12, 13), increasing frequency of trauma exposure. Indeed, autistic people report greater trauma exposure compared to their non-autistic peers (7, 10, 14), particularly physical and sexual abuse (15) and maltreatment (16). This has also been observed in people with more autistic traits (17). In the general population, exposure to multiple traumas has been found to cumulatively increase risk of developing PTSD (18) and PTSD-SS (19), and this effect is especially observed for traumas involving others (hereafter 'interpersonal traumas'; 20). Consequently, exposure to multiple traumas may increase likelihood of autistic people developing PTSD symptoms, through their influence on the nature of trauma memories and post-traumatic appraisals.

Additionally, there may be differences in what is subjectively experienced as traumatic by autistic people, including events which would not meet DSM-5 Criterion A, further increasing trauma exposure (12, 13, 21). Defining what constitutes a traumatic event is subject to debate (22), and it is increasingly recognised that events which do not meet Criterion A can result in PTSD symptoms (21, 23). Among autistic people, Rumball, Happé (6) found that experiences including social misperceptions, bullying, and aversive sensory experiences were reported as “extremely unpleasant, stressful or traumatic” events and were associated with PTSD symptomatology as often as Criterion-A events. Furthermore, Haruvi-Lamdan, Horesh (7) found that autistic adults were more likely than non-autistic adults to identify non-Criterion-A negative social experiences like bullying as causing them the “most significant distress”, and frequency of these events was positively associated with PTSD-SS only for the autistic group, suggesting that such experiences may be more traumatic for autistic people. Non-Criterion-A negative experiences like bullying, ostracization and sensory overload are more common for autistic people (15, 24-29). The accumulation of both Criterion-A and non-Criterion-A experiences may significantly impact PTSD-SS, thus, it is recommended that research adopts a wide definition of trauma including non-Criterion-A events when studying PTSD-SS in autism (4).

Alongside trauma exposure, the Cognitive Model of PTSD (3) emphasises the importance of peri-trauma factors like sensory processing and detail-focused cognitive processing, and post-trauma factors including memory and strategies to control perceived threat. Accordingly, differences in sensation, perception, detail-focused processing, memory, and cognition associated with autism have been identified as factors which may influence the subjective experience of events as traumatic, and underpin susceptibility to PTSD symptoms and their maintenance (12, 13, 21, 30). Many of these factors are beginning to be investigated, with tendency towards ruminative thinking, thought suppression, sensory hypersensitivity, and memory differences being implicated as mediators in the relationship between autism and PTSD-SS (8, 10, 31, 32).

Despite increasing research into how PTSD-SS in autism might be understood through the Ehlers and Clark (3) model, negative post-traumatic appraisals and whether these differ in autistic adults remains unexplored. Numerous studies in the general population demonstrate that negative post-traumatic appraisals are risk factors for PTSD (33), are positively associated with PTSD-SS (34, 35), and prospectively predict PTSD-SS (36), over and above frequency of trauma exposure (37). Appraisals of fear, alienation, anger, betrayal, shame, and self-blame mediate the relationship between childhood trauma, cumulative trauma and PTSD-SS, with alienation appraisals particularly emphasised (34, 38, 39).

Appraisals are influenced by prior life experiences. We have highlighted that autistic people experience more traumatic events, especially victimisation by others which may or may not meet Criterion-A. It is also increasingly recognised that autistic people experience high levels of stigma (40, 41). Experiences of stigma, bullying and ostracization may understandably result in autistic people feeling alienated, illustrated by qualitative reports that negative social experiences make them feel ‘different’ in a negative way (for review see 42). Internalisation of negative social experiences and stigma has been found to result in negative self-concepts that contribute to poorer mental health (41, 43). This may also increase the salience of negative appraisals following traumatic events, in particular appraisals like self-blame, shame and alienation which are particularly associated with interpersonal traumas in the general population (44, 45). Increased salience and endorsement of negative post-traumatic appraisals may contribute to the increased PTSD-SS observed in autistic people.

Given the theoretical importance of negative post-traumatic appraisals in models of PTSD and the focus on modification of appraisals in PTSD treatment (33, 46, 47), examining whether endorsement of appraisals such as self-blame, shame and alienation differs between autistic and non-autistic trauma-exposed adults, and to what extent these mediate the relationship between autism and PTSD-SS is important to further our understanding of differences which contribute to increased PTSD-SS in this group.

The Present Study

We first hoped to evaluate whether self-reported trauma exposure, exposure to additional non-criterion-A traumas, and PTSD-SS in response to a traumatic event was higher in autistic compared to non-autistic adults, in line with existing findings. We planned to review differences in the types of traumatic events reported. We then aimed to investigate how negative post-traumatic appraisals affect the relationship between autism and PTSD-SS. We hypothesised that:

H1- The autistic group will endorse more negative post-traumatic appraisals than the non-autistic group.

H2- The autistic group will endorse more shame, self-blame and alienation appraisals than the non-autistic group.

H3- The relationship between autism group and PTSD-SS will be mediated by negative post-traumatic appraisals, with more negative post-traumatic appraisals being associated with higher PTSD-SS.

Method

Design

A cross-sectional between-groups design was employed. The dependent variable was PTSD-SS. The independent variable was self-reporting being autistic or not. Negative post-traumatic appraisals were investigated as possible mediators.

Participants

Participants were recruited through social media, autism charities, and support groups. Participants were required to live in the UK, be aged ≥18, report experiencing one or more events which they found “highly stressful or traumatic”, read and understand English, and not self-report diagnosis of an intellectual disability. No compensation was offered for participation.

Two hundred forty-two people took part, with one additional response excluded due to unusually fast response time and selection of the first option for every question. Participants were allocated to the autistic or non-autistic group according to self-report: 148 autistic (121 formally diagnosed, 8 awaiting diagnostic assessment, 19 self-identified) and 94 non-autistic. The autistic group scored significantly higher on the AQ (Autism Quotient; 48) than the non-autistic group (p<.001; Table 1), and 86.5% of the autistic group scored ≥32 on the AQ compared to 14.9% of the non-autistic group. This is in line with Baron-Cohen, Wheelwright (48) expected rates for autistic individuals but above the expected rate of 2.0% for non-autistic individuals. Analyses were therefore run with and without those whose AQ score did not match their self-reported group (see Appendix B), however, this did not qualitatively affect findings so all participants were retained. Table 1 presents demographic characteristics.

Our minimum sample size (53 per group) was determined by a-priori power calculation using G*Power, based on the assumption of a medium effect size of autism group and overall post-trauma appraisals on PTSD-SS (f=0.15), with α=0.05 and 95% power.

Table 1.

*Demographic Characteristics of the Autistic (*N*=148) and Non-Autistic (*N*=94) groups*

Characteristic	Autistic *N* (%)	Non-Autistic *N* (%)	Group Comparison
Gender			
Female	103 (69.6)	84 (89.4)	Fisher's exact *p*<.001*
Male	21 (14.2)	9 (9.6)	Fisher's exact *p*=.195
Non-binary/other	23 (15.5)	0 (0.0)	Fisher's exact *p*<.001*
Prefer not to say	1 (0.7)	1 (1.1)	Fisher's exact *p*=.627

Ethnicity		
Arab	1 (0.7)	0 (0.0)
Asian- Indian	1 (0.7)	0 (0.0)
Asian- Pakistani	2 (1.4)	0 (0.0)
Asian- Other	0 (0.0)	2 (2.1)
Black- Caribbean	2 (1.4)	2 (2.1)
Mixed- White and Black Caribbean	3 (2.0)	1 (1.1)
Mixed- White and Black African	1 (0.7)	0 (0.0)
Mixed- White and Asian	3 (2.0)	2 (2.1)
Mixed- Other	1 (0.7)	2 (2.1)
White-British	124 (83.8)	78 (83.0)
White- Irish	1 (0.7)	0 (0.0)
White- Other	5 (3.4)	5 (5.3)
Other ethnic group	2 (1.4)	0 (0.0)
Prefer not to say	2 (1.4)	0 (0.0)
Highest Degree of Education		
Secondary Education	18 (12.2)	7 (7.4)
Apprenticeship	18 (12.2)	7 (7.4)
Ordinary National Diploma	3 (2.0)	1 (1.1)
Higher National Diploma	4 (2.7)	1 (1.1)
Undergraduate Degree	51 (34.5)	30 (31.9)
Masters Degree	38 (25.7)	32 (34.0)
PhD	3 (2.0)	8 (8.5)
Professional Qualifications	7 (4.7)	7 (7.4)
Other	5 (3.4)	1 (1.1)
Prefer not to say	1 (0.7)	0 (0.0)
Employment Status		
Employed- Full Time	43 (29.1)	52 (55.3)
Employed- Part Time	26 (17.6)	17 (18.1)
Student	10 (6.8)	8 (8.5)
Unemployed	24 (16.2)	3 (3.2)
Retired	6 (4.1)	5 (5.3)
Volunteer	6 (4.1)	1 (1.1)
Homemaker/Parent/Carer	7 (4.7)	1 (1.1)
Unable to work	11 (7.4)	1 (1.1)
Other	6 (4.1)	2 (2.1)
Prefer not to say	1 (0.7)	0 (0.0)
Mental Health Difficulties- Current	102 (68.9)	46 (48.9)
Mental Health Difficulties- Lifetime	120 (81.1)	60 (63.8)

	M (SD)	*M (SD)*	Group Comparison
Age	41.6 (12.8)	37.8 (13.5)	*U*= 8258.0, *z*= 2.56, *p*=.011, *r*= .17
Anxiety (GAD-7)	11.1 (5.5)	8.5 (5.5)	*U*= 8829.5, *z*= 3.54, *p*<.001, *r*=.23
Depression (PHQ-8)	12.3 (6.2)	8.8 (5.9)	*t*(240)= -4.35, *p*<.001, *d*= 0.58.
Autistic Traits (AQ)	38.5 (6.7)	18.9 (10.0)	*U*=12979.0, *z*=11.36, *p*<.001, *r*= .73

Note. GAD-7= General Anxiety Disorder-7 (49), PHQ-8= Patient Health Questionnaire-8 (50), AQ= Autism Quotient (48).

*Bonferroni adjusted *p*-value for significance *p*<.0125

Procedure and Measures

The survey was reviewed and updated by three experts-by-experience, and was approved by the University of Oxford Medical Sciences ethics committee (Appendix C). Following confirmation of eligibility and informed consent, participants completed the survey via Qualtrics, beginning with a demographics form, then questionnaires in the order shown in Table 2, ending with a debrief. Signposting to support was available throughout the survey.

Table 2.

Self-Report Measures Used in the Study

Construct	Measure	Administration	Interpretation	Validation
Criterion-A Trauma Exposure	Life Events Checklist (LEC-5; 51)	17-item measure. Individuals report whether 16 types of traumatic events “happened to me”, “witnessed”, ‘learnt about it”, “part of my job” or “does not apply”. Item 17, which allows for “other” traumatic events to be self-reported, explored separately under the “non-Criterion-A Traumas” section	Trauma exposure calculated by summing the number of types of traumatic experiences endorsed	Good test re-test reliability (r=.82; 52)
Non-Criterion-A Trauma Exposure	Non-Criterion- A Traumas (based on Rumball, Antal (31))	Participants asked whether any other event had happened to them which “has felt like an extremely unpleasant, stressful or traumatic experience”, “has caused you to have nightmares about it or think about it when you did not want to”, “you have subsequently tried hard not to think about or go out or your way to avoid situations that remind you of it”. If affirmative, the individual was asked to briefly detail the nature of the event(s)	Qualitative descriptions assessed by two clinicians and coded as meeting Criterion-A or not	N/A
PTSD Symptom Severity (current and lifetime)	Post-Traumatic Stress Disorder Checklist for DSM-5 (PCL-5; 53)	20-item measure. Questions are answered on a 5-point Likert scale of 0 (“not at all”) to 4 (“extremely”). Completed in relation to the trauma that they reported caused them the most distress currently, and again if there had been any period lasting ≥1 month since this trauma where they were much more troubled by symptoms	Scores range from 0-80. Higher scores indicate greater PTSD-SS, and a score of ≥33 may indicate clinically significant PTSD (54)	Excellent internal consistency in autistic (α=.94; 7) and non-autistic adults (α=.94; 54)

Negative Post-Traumatic Appraisals	Trauma Appraisals Questionnaire (TAQ; 55)	54-item measure, with 6 subscales assessing fear, alienation, anger, betrayal, shame and self-blame. Items are rated on a 5-point Likert scale ranging from “strongly agree” to “strongly disagree”	Scores range from 54-270. Higher scores indicate greater endorsement of appraisals	Excellent internal consistency (α= 0.84–.93; 55) and good test-retest reliability (*r*= .73–.88)
Anxiety	General Anxiety Disorder-7 (GAD-7; 49)	7-item measure. Items are rated on a 4-point Likert scale ranging from 0 (“not at all”) to 3 (“nearly every day”)	Scores range from 0-21 with higher scores indicating more severe anxiety	Excellent internal consistency (α=.90) and good test-retest reliability (*r*=.83) in non-autistic people (49). Good internal consistency and construct validity in autistic people (56)
Depression	Patient Health Questionnaire-8 (PHQ-8; 57)	8-item measure. Items are rated on a 4-point Likert scale ranging from 0 (“not at all”) to 3 (“nearly every day”)	Scores range from 0-24, with higher scores indicating more severe depressive symptoms	Excellent internal consistency and test-retest reliability (58). Exclusion item 9 does not affect sensitivity (50). Good internal consistency and construct validity in autistic people (56)
Autistic Traits	Autism Quotient (AQ; 48)	50-item measure. Questions are answered on a 4-point Likert-type scale ranging from “strongly agree” to “strongly disagree”	Higher scores indicate higher presence of autistic traits. 80% of autistic people score ≥32 (48), and this cut-off is highly predictive of autism diagnosis (59)	Good test–retest reliability (48) and moderate-strong internal consistency in autistic (α= .81; 60) and non-autistic samples (α= .67; 61)

Analysis

Descriptions of “worst” traumatic events were examined independently by two clinicians to determine whether they met Criterion-A (coded ‘Criterion-A’ or ‘non-Criterion-A’) and whether they were interpersonal (traumatic because of the actions or words of another person or people) or not. Coding criteria were agreed by four clinicians (Appendix D).

Statistical analysis was conducted using SPSS version 28 (62). Frequencies, chi-square, and t-tests (or non-parametric equivalents) were used to compare the groups on trauma exposure, PTSD-SS and negative post-traumatic appraisals. Mediation models using PROCESS for SPSS (63) were used to assess the role of appraisals in the association between autism and PTSD-SS. The first model had a single mediator (TAQ total), with autism group as a binary predictor variable and PTSD symptoms as the outcome variable. In the second model, TAQ subscales were included as mediators, permitting the calculation of the indirect effect of each appraisal type while others were controlled. 5000 bias-corrected bootstrap samples were used to generate 95% confidence intervals and point estimates for indirect effects.

For group comparisons, variables were tested for normality, variance homogeneity and outliers to determine appropriate analyses. For mediation, residuals met assumptions of normality, homoscedasticity and linearity, and there were no problems with multicollinearity. Outliers were assessed within the autistic and non-autistic groups separately as recommended by Sullivan, Warkentin (64), identifying three outliers in studentised deleted residuals in model 1, and four in model 2, but none with high leverage based on mahalanobis distance, so these were retained.

Results

Descriptive Statistics

The autistic and non-autistic groups differed significantly by age (*p*=.011) and in the proportion of the autistic group who identified as female or non-binary compared to the non-autistic group (fisher's exact *p*<.001), shown in Table 1. Differences in the proportions of each group identifying as male were not significant. Age was not associated with PTSD-SS or TAQ score in the autistic (*r*=.13, *p*=.117; *r*=.02, *p*=.822) or non-autistic group (*r*=.06, *p*=.549; *r*=.01, *p*=.945). The three-level variable for gender (male, female, non-binary/other) also did not predict PTSD-SS or TAQ in the autistic (*F*(2, 146)=0.05, *p*=.948; *F*(2, 146)=1.29, *p*=.280) or non-autistic group (*F*(1, 92)=2.95, *p*=.089; *F*(1, 92)=1.15, *p*=.286). As age and gender were not related to our key outcome variables, they were not controlled for in our main analyses.

Preliminary Hypotheses

Number of LEC-5 traumatic life event types exposed to overall did not differ significantly between the autistic and non-autistic group. However, the number of event types exposed to directly ('happened to me') was significantly higher in the autistic group (*p*=.002; Table 3)

One-hundred-and-three autistic (69.6%) and 61 non-autistic participants (64.9%) reported experiencing 'other' traumatic events which did not meet Criterion A, a non-significant difference (*p*=.491). A further 4 participants (2 per group) reported experiencing 'other' traumatic events but provided no details so could not be coded.

Current PTSD-SS was significantly higher in the autistic group (*p*<.001; Table 3). A significantly greater proportion of the autistic group (62.8%), compared to the non-autistic group (40.4%), crossed the cut-off for current PTSD on the PCL-5 (*p*<.001).

Of participants who reported that there had been a time since the trauma where their symptoms were worse, lifetime PTSD-SS was significantly higher in the autistic group (*n*=120) than the non-autistic group (*n*=77; *p*=.014; Table 3). Of the autistic group, 79.7% crossed the cut-off for PTSD in their lifetime compared to 76.6% of the non-autistic group, a non-significant difference (*p*=.074).

Nature of Traumas Endorsed

Similar proportions of the autistic (43.2%) and non-autistic group (37.2%) identified non-Criterion-A traumas as their 'worst' event (*p*=.389), and reported a 'worst' traumatic life event which was coded as 'interpersonal' (autistic 54.1%, non-autistic 53.2%; *p*=.813). Removal of traumas which were 'uncertain' to code did not affect these findings (Appendix E).

On the LEC-5 overall, both groups most frequently endorsed physical assault, unwanted sexual experiences, life-threatening illness or injury, sexual assault and transportation accidents. For events that 'happened to me' directly, uncomfortable sexual experiences were reported by the highest proportion of each group, followed by physical assault. Except for natural disaster, exposure to war/combat, captivity, and sudden unexpected death of someone close to you, a higher proportion of the autistic group directly experienced each trauma type than the non-autistic group.

Of 103 autistic and 61 non-autistic participants who reported additional non-Criterion-A traumatic events, the autistic group reported more non-Criterion-A events on average. The autistic group most frequently reported bullying (26.2%, *n*=27), bereavement (21.4%, *n*=22), and emotional abuse (14.6%, *n*=15). The non-autistic group most frequently reported bereavement (18.0%, *n*=11), illness, medical procedures and hospitalisation (16.4%, *n*=10), pregnancy and childbirth (11.5%, *n*=7), and illness or injury of a family member or friend (11.5%, *n*=7).

For detail of the LEC-5 and non-Criterion-A traumatic events endorsed and reported by each group, see Appendix F and G.

Table 3.

Descriptive Statistics and Effect Sizes for Group Differences in Trauma Exposure, PTSD-SS and Appraisals

Measure		Autistic				Non-Autistic						
		M	*SD*	*Mdn*	Range	*M*	*SD*	*Mdn*	Range	Statistic	*p*	*r/d*
LEC-5	*Total*	6.85	3.39	7.00	0-15	6.68	3.47	6.50	0-15	U = 7261.5, z = 0.58	.563	.04
	Happened to me	3.76	2.46	3.00	0-13	2.81	2.04	3.00	0-11	*U* = 8558.0, *z* = 3.05	.002	.20
PCL-Current		38.68	1.41	39.00	4-80	29.90	1.85	26.00	0-80	*U* = 9037.0, *z* = 3.92	<.001	.25
PCL-Lifetime*		62.95	1.10	64.50	22-80	57.52	1.74	59.00	18-80	*U* = 5583.5, *z* = 2.47	.014	.18
TAQ Total		167.39	39.02	170.00	71-263	144.62	44.01	148.00	54-239	*t*(240) = -4.10	<.001	0.55
	Betrayal	22.07	0.71	22.50	7-35	20.41	0.97	20.50	7-35	*U* = 7697.0, *z* = 1.40	.162	.09
	Self-Blame	24.97	0.94	25.00	9-45	21.37	1.07	19.50	9-45	*U* = 8173.5, *z* = 2.30	.022	.15
	Fear	37.49	0.83	38.00	11-55	30.93	1.06	30.50	11-55	*U* = 9432.5, *z* = 4.67	<.001	.30
	Alienation	37.20	0.68	39.00	12-50	32.53	1.10	33.50	10-50	*U* = 8809.0, *z* = 3.49	<.001	.23
	Anger	21.93	0.70	22.00	9-45	19.90	0.75	19.50	9-39	*U* = 7820.0, *z* = 1.63	.103	.11
	Shame	20.61	0.66	21.50	7-35	16.79	0.88	15.00	7-35	*U* = 8823.0, *z* = 3.52	<.001	.23

Note. LEC-5= Life Events Checklist (51), PCL-5= Post-Traumatic Stress Disorder Checklist for DSM-5 (53), TAQ= Trauma Appraisals Questionnaire (55).

* Only participants who reported that there had been a time since the traumatic event when their symptoms were worse completed this measure, 120 autistic and 77 non-autistic participants.

H1- The autistic group will endorse more negative post-traumatic appraisals than the non-autistic group

The autistic group reported higher scores on the TAQ overall than the non-autistic group, a statistically significant difference (p<.001; Table 3).

H2- The autistic group will endorse more shame, self-blame and alienation appraisals than the non-autistic group

The autistic group had higher scores across all TAQ subscales than the non-autistic group, however this difference was statistically significant for self-blame (p=.022), fear (p<.001), alienation (p<.001) and shame (p<.001; Table 3).

H3- The relationship between autism group and PTSD-SS will be mediated by negative post trauma appraisals, with more negative post-traumatic appraisals being associated with higher PTSD-SS

A mediation model was run to explore the effect of negative post-trauma appraisals on the relationship between group and PTSD-SS following a traumatic event. Results based on 5000 bootstrapped samples indicated that TAQ total score significantly mediated the relationship between group and PTSD-SS (Table 4); significant total effects were found between autism group and PTSD-SS, and when TAQ total scores were entered as a mediator of this relationship, a significant indirect effect was observed. The direct effect was no longer significant and the bias-corrected 95% confidence interval for the indirect effects did not pass through 0. Autistic adults had more negative appraisals following a traumatic event, and via this expressed higher PTSD-SS compared to non-autistic adults (Figure 1a).

The above model was then tested again, but with TAQ subscales included as parallel mediators. Results showed that alienation, fear and shame appraisals mediated the relationship between autism group and PTSD-SS; there was a significant total effect, and significant indirect effects were observed for alienation, fear and shame appraisals, suggesting these appraisals mediate the relationship between group and PTSD-SS when other appraisals are controlled for. The direct effect was not significant and the bias-corrected 95% confidence intervals for the indirect effects did not pass through 0, suggesting full mediation via these appraisals (Figure 1b).

Table 4.

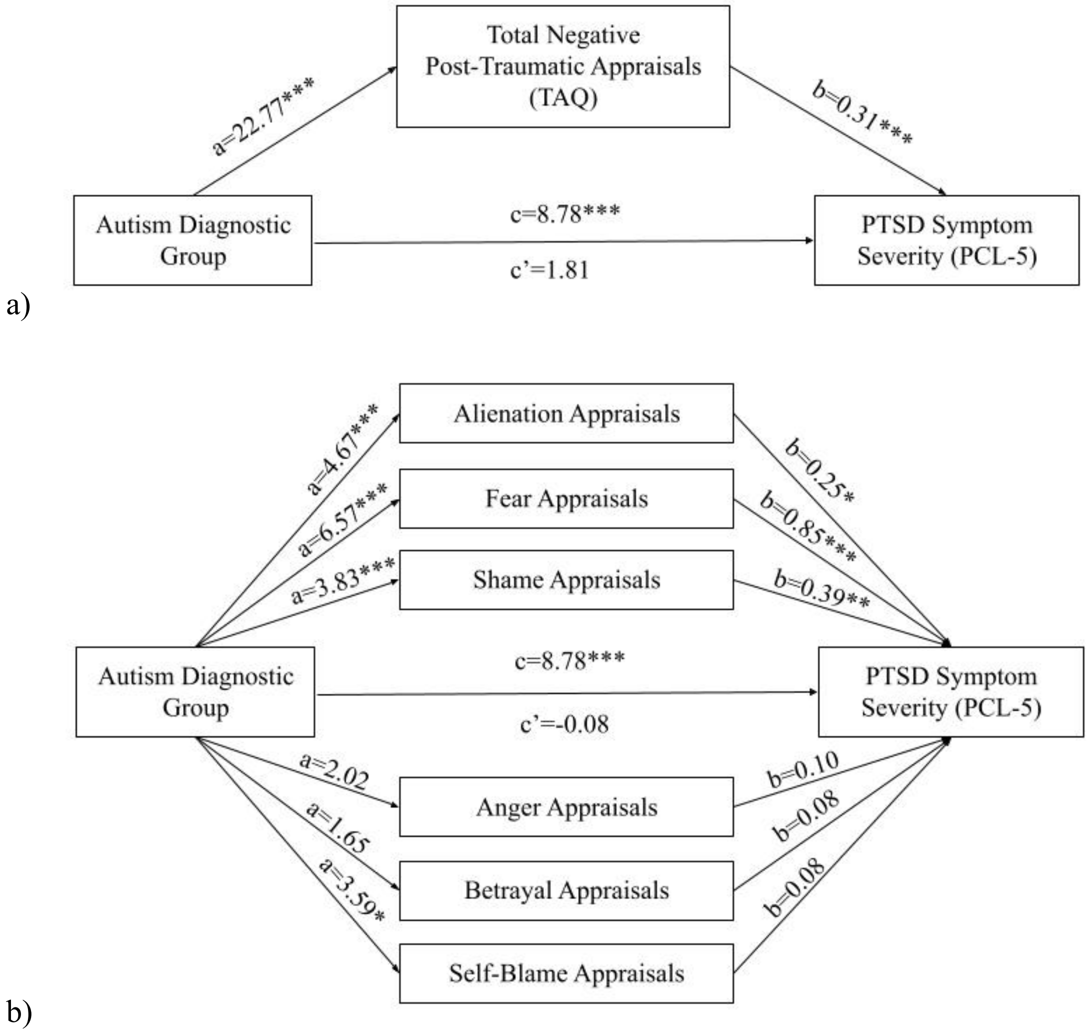
Appraisal Mediation Models Based on 5000 Bootstrapped Samples for the Relationship Between Group (Autistic/Non-Autistic) and PTSD-SS

Model 1 Mediator	Total effect (c)	Direct effect (c')	Indirect effect
TAQ Total Score	$b=8.78$, $t(240)= 3.82$, $p<.001$, 95% CI [4.25, 13.31]	$b=1.81$, $t(239)= 1.09$, $p=.276$, 95% CI [-1.45, 5.07]	$b=6.97$, $SE= 1.68$, 95% CI [3.64, 10.31]
Model 2 Mediators	Total effect (c)	Direct effect (c')	Indirect effect
Betrayal	$b=8.78$, $t(240)= 3.82$, $p<.001$, 95% CI [4.25, 13.31]	$b=-0.08$, $t(234)= -.05$, $p=.960$, 95% CI [-3.14, 2.98]	$b=0.13$, $SE=1.87$, 95% CI [-0.20, 0.65]
Self-Blame			$b=0.30$, $SE=.37$, 95% CI [-0.37, 1.14]
Fear			$b=5.57$, $SE=1.34$, 95% CI [3.08, 8.35]
Alienation			$b=1.18$, $SE=.57$, 95% CI [0.23, 2.45]
Anger			$b=0.19$, $SE=.24$, 95% CI [-0.22, 0.77]
Shame			$b=1.49$, $SE= .68$, 95% CI [0.37, 3.04]

Note. TAQ= Trauma Appraisals Questionnaire (55).

Figure 1.

Mediation Models Showing the Unstandardised Regression Coefficients for the Association between Autism Diagnostic Group and PTSD-SS, via a) Total Negative Post Traumatic Appraisals, b) Appraisal Subscales.



Note. Non-Autistic group coded 0 (*N*=94), Autistic group coded 1 (*N*=148).

**p*<.05, ***p*<.01, ****p*<.001.

Discussion

This study aimed to evaluate whether, compared to trauma-exposed non-autistic adults, autistic adults were exposed to more traumatic life events, found a broader range of events traumatic, and reported greater PTSD-SS in line with existing findings. We then aimed to explore whether negative post-traumatic appraisals differed between the groups, and whether these mediated the relationship between autism and PTSD-SS.

In line with previous findings, PTSD-SS was significantly higher in the autistic compared to the non-autistic group, and autistic people were more likely to meet the threshold for PTSD diagnosis following traumatic life events (13). Although on the LEC-5 autistic people did not report exposure to significantly more types of traumatic life event overall, they reported that more types had happened to them directly. The autistic group also reported more types of non-Criterion-A events on average. Concerningly, incidence of physical assault, sexual assault, uncomfortable sexual experiences, bullying and emotional abuse was very high in the autistic group, higher than the non-autistic group, in line with previous studies (6, 10, 31). Nevertheless, as the groups did not differ in overall trauma exposure on the LEC-5, or nature of their 'worst' trauma with regards to whether it was interpersonal or not or met DSM-5 Criterion A, there may be characteristics of autism beyond trauma exposure which impart susceptibility to PTSD-SS.

Similar proportions of each group completed the PCL-5 in relation to non-Criterion-A events, in line with research which repeatedly demonstrates that people can experience PTSD symptoms following non-Criterion-A events (21, 65-67). This challenges the clinical utility of the DSM-5 conceptualisation of trauma. The ICD-11 (68) definition of trauma as 'an extremely threatening or horrific event or series of events' may be preferable in PTSD assessment to ensure that people who would benefit from support receive a diagnosis.

We extend knowledge in the field by showing that negative post-traumatic appraisals are elevated in autistic people, in particular alienation, shame and self-blame appraisals, and fear appraisals. Negative appraisals mediated the positive relationship between autism and PTSD-SS, providing empirical plausibility of the indirect paths from experiencing trauma, to PTSD-SS, via negative appraisals emphasised in cognitive models of PTSD (3), which has not been previously demonstrated in autistic people.

Increased propensity to negatively appraise traumatic experiences may be influenced by several factors in autistic people. Exposure to stigma and traumatic experiences throughout life may understandably lead to development of negative beliefs about themselves and the threat posed by the world and other people, which may prime autistic people to more negative appraisals following traumatic events which are seen as a confirmation of these beliefs. Sensory sensitivity may additionally result in the world feeling more overwhelming and dangerous. Furthermore, tendency towards perseverative thinking and thought suppression observed in autistic people and associated with PTSD-SS (31, 69) may result in difficulty disengaging from negative appraisals, or their more frequent intrusion due to 'bounce back' effect of suppression (70), increasing their intensity.

Alienation appraisals, related to feelings of disconnectedness from self and other people, are implicated as important for PTSD development in general population samples (38) and mediated the relationship between autism and PTSD-SS in this study. Research has highlighted that autistic people are aware of their differences from non-autistic people and that these are often perceived negatively (40, 71). Internalisation of stigma, reflected in qualitative research in which autistic people describe themselves as "weird" (40; p.10), may increase sense of 'otherness', increasing salience of alienation appraisals following trauma. Alienation appraisals may alternatively reflect autistic people struggling to understand and being misunderstood by non-autistic others, termed the double-empathy problem (72). This may contribute to feeling disconnected, and possibly to actual reduced accessibility of social support observed in autistic people (73), which contributes to PTSD in the general population (74), and worsened mental health in autistic people (75).

Shame-based appraisals are implicated in PTSD-SS in the general population (34), and were higher in our autistic group and mediated PTSD-SS. These may also be related to internalised stigma, which has been associated with feelings of shame about being autistic, identified as a reason for camouflaging of autistic characteristics (76). Furthermore, if autistic people perceive that traumatic experiences occurred due to being autistic (e.g. bullying), this may be particularly likely to result in shame appraisals as an aspect of the self is implicated in the traumatic event. This may be especially relevant following interpersonal traumas, associated with more shame-based appraisals in the general population (44). Although the ’worst’ events reported by autistic people were not more likely to be interpersonal, there was high incidence of interpersonal traumas like physical and sexual abuse and bullying, and these were higher in the autistic group.

We had not anticipated that fear appraisals would be higher in the autistic group, however it is plausible that these are developed and reinforced through repeated experiences of the world not being safe or supportive for autistic people. Additionally, factors like intolerance of uncertainty and alexithymia which are elevated in autistic people (77, 78) may predispose them to fear appraisals. Intolerance of uncertainty is robustly linked with increased anxiety in autistic people (79), and may reinforce appraisals that the world is unpredictable and thus unsafe following trauma. Furthermore, if some autistic people have difficulties recognising their own or others’ emotional states, processing feelings of fear or safety may be more difficult. These individuals may also experience more uncertainty and fear appraisals in social situations if other people have been experienced as dangerous before and are hard to read. Future research could examine these possible autism-related vulnerability factors for PTSD.

The current findings imply that therapeutic approaches that focus on negative appraisals in PTSD, with enquiry about appraisals of alienation, shame and fear, are supported for autistic people. Interventions must be sensitive and require strong therapeutic relationships so as not to invalidate these experiences. Compassion-focused approaches may be indicated in the context of increased shame (80), and approaches to support positive autistic social identity may also be helpful to improve wellbeing (43). It is also important that measures are put in place to protect autistic people from trauma exposure and tackle societal stigmatising attitudes towards autism which can negatively impact wellbeing if internalised (41, 81).

Limitations

Several factors influence the generalisability and validity of our current results. Firstly, the use of a cross-sectional methodology means that the mediations presented cannot indicate causality of relationships. Prospective longitudinal studies examining trauma exposure, appraisals and later development of PTSD symptoms are required to strengthen directional conclusions.

There are also limitations to the representativeness of our sample. It is possible that participants may have self-selected with heightened severity of trauma experiences or PTSD symptoms. Indeed, rates of probable PTSD and of exposure to specific trauma types like sexual assault are significantly higher in both groups than general population prevalence rates (2) and large-scale epidemiological studies of trauma exposure (82). However as both groups self-selected, group comparisons remain valid. Additionally, participants were predominately

White British, female, and university educated, and individuals with a learning disability were excluded. Consequently, the experiences of some autistic and non-autistic people, especially those with additional support needs and from ethnic minority groups, are not reflected. People with multiple minoritised identities may experience heightened stigma and victimisation (83), thus more effort is needed to reach these groups in future studies.

A strength of the current study is the large sample size and high number of autistic female and non-binary people, who have not been well represented previously and experience higher rates of PTSD in the general population (84, 85). However the high proportion of female respondents may have influenced our findings, as female gender is a risk factor for PTSD (86). Gender differences in PTSD-SS were not found in either group so gender disaggregated analyses were not conducted. However, gender differences in exposure to specific trauma types amongst autistic people, like sexual assault which is more frequent in women and is associated with risk of PTSD (87), may warrant further investigation. A strength of this study is that similar proportions of each group reported interpersonal traumas as their 'worst', as these are more likely to result in PTSD (86). However, trauma type is also implicated, thus future studies could match for trauma type across autistic and non-autistic groups.

By determining autism grouping by self-report, we reduced bias towards including only those who have the means to access an autism diagnosis in our sample. However, this may mean that some participants were not accurately grouped as we did not verify diagnoses. AQ scores were higher than expected in the non-autistic group, which may be a product of recruitment through autism charities, with family members of autistic people who may have more traits possibly being recruited. However, this may alternatively be an artifact of measurement, with some studies suggesting that the AQ poorly differentiates autism from constructs like ADHD and Personality Disorders (88, 89), although this has not been explored in relation to PSTD symptomatology.

Finally, the PCL-5 and TAQ have not been validated in autistic individuals, indeed there are currently no PTSD or post-traumatic appraisal scales validated for use with autistic people. Research is needed to validate or develop tools to assess PTSD symptoms and appraisals for autistic people, with consideration of possible autism-specific presentations. Additionally, the LEC-5 was not designed to measure trauma frequency, nor did we record frequency of non-Criterion-A traumas, limiting the validity of our findings in relation to frequency of trauma exposure.

Conclusion

These findings add to the growing literature highlighting increased PTSD-SS experienced by autistic adults following traumatic events. The mediating effect of negative post-traumatic appraisals is in line with cognitive models of PTSD in the general population, suggesting that similar mechanisms are involved in development of PTSD for autistic adults. Negative appraisals of shame, fear and alienation are particularly implicated. Longitudinal designs are now required to confirm the direction of these effects, and understand factors precipitating more negative appraisals in autistic people.

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Executive Summary

Why did we do this study?

Post-traumatic stress disorder (PTSD) is a reaction that can occur after people experience traumatic events. Lots of people might experience symptoms of PTSD immediately after traumatic events, but for some people these last for longer and they might then be diagnosed with PTSD.

Some research suggests that people who are autistic are more likely than non-autistic people to develop PTSD after traumatic events, and experience more severe PTSD symptoms. Research has looked at different reasons for why this is:

- Autistic people sadly experience more traumatic events, especially things like physical or sexual abuse.
- Autistic people might find different types of events traumatic, and experience these more often than non-autistic people, like bullying or sensory overload.
- There might be differences in how autistic people take in information and remember things.
- Autistic people are more likely to cope with difficult events by ruminating or trying to avoid thoughts.

All these things have been found to be linked to worse PTSD symptoms in autistic people.

One thing that we know is important in PTSD development is how people think about the traumatic event and what happened afterwards, like thinking “It was my fault”, “I’m not safe”, “I’m disconnected from other people”, “I’m embarrassed”. There hasn’t been research into whether these types of thoughts, called ‘appraisals’, are different in autistic people, and whether this might explain higher PTSD symptom severity.

By investigating the impact of appraisals, we hope to improve our understanding of PTSD in autistic people and pave the way for more effective interventions and support, as lots of treatments for PTSD focus on appraisals.

What did we do?

Autistic people and people with PTSD acted as advisors in the design of the study, and changes they recommended were incorporated into the final survey.

Autistic and non-autistic adults from the UK who said they had experienced something that they found very stressful or traumatic were recruited through social media and support groups. Charities like the National Autistic Society, Autistica, and Autism Oxford and Berkshire also shared the study.

Two hundred forty-two people took part, 148 autistic people and 94 non-autistic people. Both groups completed an online survey with measures of trauma exposure, PTSD symptoms and post-traumatic appraisals. Most participants were white and identified as female.

What did we find?

Like previous research, we found that autistic people had experienced more types of traumatic events that happened to them directly. Interestingly, similar proportions of people in *both* groups described events as traumatic that would not meet diagnostic criteria for PTSD, like bereavement, bullying and illness. As we expected, the autistic group reported worse PTSD symptoms and more people in this group met a cut-off score for PTSD.

Autistic people reported more negative post-traumatic appraisals than the non-autistic group, in particular related to shame, self-blame, alienation and fear. We found that the difference in appraisals between the autistic and non-autistic groups acts as a link between being autistic and experiencing more severe PTSD symptoms.

What did we conclude?

Appraisals are an important part of models used to understand and treat PTSD in the general population, so knowing that they are higher in autistic people and impact PTSD symptom severity suggests that these models may work for autistic people too. We recommend further research to confirm the direction of these effects, and better understand things that might predispose autistic people to more negative post-traumatic appraisals, especially shame, alienation and fear.

Ensuring autistic people can access appropriate support following traumatic experiences is crucial, given that they show higher PTSD symptom severity than non-autistic people also exposed to traumatic events. As PTSD symptoms can be experienced in relation to events which may be subjectively traumatic and not necessarily meet diagnostic criteria, we remind clinicians to bear this in mind so as not to 'screen out' people who would benefit from PTSD support.

Our findings suggest that therapies targeting negative appraisals, especially of alienation, shame, and fear, could be beneficial for autistic individuals with PTSD. These must be sensitive and compassionate to difficult and varied life experiences that may have impacted these appraisals. Efforts to support positive autistic identity, prevent trauma exposure, and combat societal stigma towards autism are also important to prevent negative experiences and support autistic people's wellbeing.

Connecting Narrative

SRL

I developed an interest in hoarding during my undergraduate degree, where I worked with a researcher to organise a conference for public service workers about supporting people with hoarding difficulties. I was struck by the frustrated and stigmatising narratives many professionals voiced about these clients, and was curious about how this influenced support available. When Prof. Salkovskis and I discussed possible research directions, stigma of hoarding therefore stood out.

Through brief scoping searches, I noticed that despite many sources referring to hoarding as a stigmatised condition, research was limited. I initially worried that this indicated that the area was not yet developed sufficiently to review, however the research team suggested that given stigma of hoarding was widely accepted, it may be possible to broaden my search to understand the stigma-related concepts that may have informed this assumption. They also highlighted that many reviews highlight areas for future research, which I thought could be helpful given that understanding of hoarding is still developing. Given the eventual heterogeneity of the studies included, it was helpful to have early conversations in supervision about how best to structure the narrative synthesis, as this made it easier for me to organise my thoughts and identify gaps.

Something I found particularly challenging in this project was quality appraisal. Whilst many tools were helpful in assessing whether studies were appropriately designed and reported necessary information, their ‘checklist’ nature often meant that significant methodological problems did not considerably affect quality scores. I began keeping additional notes of issues so that these could be discussed in supervision and accounted for in my narrative, which helped me develop my skills in critical appraisal. I hope this would support my design of more robust research of my own in the future.

SIP

My interest in this project began through discussion with Dr Grace Jell about how older adults were underrepresented in Talking Therapies. Having worked in older adults' mental health services prior to training, I am passionate about supporting older adults to access mental health support if needed and to challenge internalised stigma about aging. Underutilisation of Talking Therapies by older adults particularly worried me, as I was aware of research into the harmful impact that the COVID pandemic had had on older people's mental health.

Initially, it was uncertain whether it would be ethical to contact people who had not opted-in, as there were queries about whether they could expect to be contacted if not open to the service. This posed a dilemma, as I felt that the project would only be helpful if we spoke to people who had not opted-in. Talking Therapies met frequently to explore ways to improve services for older adults, but had not consulted older adults, which made me wonder whether their efforts were targeting the right issues. Through consultation with the trust audit team and reviews of trust 'use of patient information' agreements, the project was approved with the proviso that initial contact was made by Talking Therapies staff and limited to three months post not opting-in. This meant I had to rely on the limited time of Talking Therapies staff for recruitment and possibly presented a barrier to some older adults taking part, as barriers which existed at opt-in may have applied to these contacts.

I felt motivated to develop a project which enabled older people's voices to be heard, in its design as well as findings, so it was important to me that I consulted older people during project development. I have emphasised the value of this to the service, with the hope that changes and outreach sessions could be co-produced and co-facilitated with older people, as this may help address motivational barriers to opting-in through accessible role models. Through this project I have become more motivated to identify service improvement opportunities, especially with service user involvement, which I hope to continue to pursue in qualified roles.

TDRP

I worked as a research assistant in autism research for many years prior to training and was aware that mental health and access to mental healthcare, as well as how trauma is experienced, were often identified as research priorities by autistic people. Through my subsequent work in a specialist PTSD service, I had observed that many clients accessing the service were autistic, and I was interested in exploring this. I contacted Dr. Freya Rumball, whose research into this area I had read, and through discussion we identified that a key aspect of the PTSD model yet to be explored in autistic people were appraisals.

My previous work instilled in me a strong ethos of ‘nothing about us without us’, so I was disappointed not to be able to co-produce this project with autistic people due to the academic and financial constraints of our project proposal process. However, I was pleased to be able to shape the project with autistic consultants once it was approved.

I was initially concerned about recruitment, however the support of several autism charities was helpful and reinforced to me the value of this topic. One downside of this was that some advertising was outside of my control, meaning I received an influx of responses whilst I was on leave, resulting in over-recruitment in the autistic group. To ensure that the time and responses given by these participants were valued, my supervisor and I decided to continue recruitment in the non-autistic group so that they were more balanced.

Connection

Although my projects seemed separate as I developed them, on reflection, they are connected by my passion for supporting people who experience stigma, feel misunderstood or ‘different’, and may not always have a voice or be represented in mental health services. My projects broadly consider the impact of these factors on the appropriateness and accessibility of psychological support, and how consideration of stigma, neurodiversity, and difference in life experiences can inform adjustments which support people to access compassionate, person-centred care. Involving service users in their care and research is something I will continue advocating for once qualified.

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Finally, Kieran, thank you for your unwavering support and belief in me, and for being by my side every step of the way. I don’t know what I would have done without you keeping the house in order, making sure I was fed and watered, and prising me away from my laptop to rest and have fun during the busier times. I can’t wait for the next, less stressful, chapter with you.

Appendix 1- Systematic Review of Literature

Appendix 1.A- Journal of Obsessive-Compulsive and Related Disorders Instructions for Authors

To assist the reader, all tables and figures have been integrated into the main text, as opposed to submitted separately.

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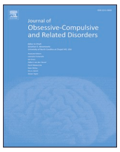

Understanding stigma in hoarding disorder: A systematic review

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ARTICLE INFO

Keywords:
Stigma
Public stigma
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ABSTRACT

The degree to which hoarding disorder (HD) is stigmatised by the public, and that this is internalised by people with HD, is a relatively neglected research area. This review aimed to synthesise current understanding of stigma of HD and its impact on help-seeking. A systematic search was conducted to identify publications which investigated public or internalised stigma, or related concepts like shame and blame, in relation to HD. The electronic databases PsycINFO, PubMed, Embase, Scopus, Medline, CINAHL, and Web of Science were searched. Fifteen papers met inclusion criteria and were appraised for quality using the QualSyst tool. There is very little literature exploring stigma in HD and quality of research is variable. Nevertheless, the literature suggests that a significant proportion of people who hoard and their families experience stigma, and HD is stigmatised by the public and associated with more rejecting attitudes and frustration amongst professionals. Finally, research exploring the impact of stigma on help-seeking in HD tentatively suggested a negative impact of stigma. Further research is needed to replicate and extend findings and address methodological limitations to provide an understanding of stigma on which approaches to enhance wellbeing and treatment uptake in HD can be developed. Systematic review (PROSPERO) registration number: CRD42022375820.

1. Introduction

Hoarding disorder (HD) is a condition associated with difficulty discarding material possessions (APA, 2013). HD is a relatively common problem, affecting approximately 2.5% of the population (Postlethwaite et al., 2019). Although acquisition and retention of material possessions is a widespread and largely acceptable human behaviour, HD is characterised by such behaviours resulting in living spaces becoming *so* cluttered that they become unusable and cause significant distress or impairment in functioning (Gordon et al., 2013).

Psychological suffering noted in HD includes increased suicide risk (Archer et al., 2019), social isolation, loneliness (Edwards et al., 2023; Yap et al., 2020) and impaired quality of life (Tolin et al., 2019). Hoarding can also be dangerous due to increased risk of fire, falls, pest infestation and food poisoning (Frost et al., 2000; Kim et al., 2001; Kysow et al., 2020) as a result of clutter interfering with ability to carry out usual household activities. These factors may lead to decreased physical health (Bates et al., 2021), and can place individuals who hoard at risk of homelessness (Rodriguez et al., 2012). People with HD also report high levels of family conflict (Davidson et al., 2020; Drury et al., 2014), lower social support (Chen et al., 2022; Edwards et al., 2023), and impairment in employment (Mathes et al., 2019; Tolin, Frost, Steketee, Gray, & Fitch, 2008). Evidently, hoarding conveys a considerable health, social and economic burden.

Given the significant risks associated with HD, the need for effective support is clear, but treating HD presents a major problem. This may be because hoarding is not a unitary disorder, with hypotheses that the behaviours of HD represent the 'final common pathway' of multiple psychological processes including harm avoidance, fear of material deprivation, and attachment disturbance (Gordon et al., 2013) and interpersonal factors (Edwards et al., 2023). If this is so, any intervention must address the underpinnings specific to the individual. Given this complexity, it is perhaps unsurprising that despite some trials of cognitive-behavioural therapy (CBT) for HD finding significant effects (Rodgers et al., 2021; Tolin et al., 2015), only 25–43% of treatment completers achieve clinically significant reduction in symptoms (Tolin et al., 2015).

Another obstacle to treatment of HD is that it is associated with delayed help-seeking and high drop-out rates (Mataix-Cols et al., 2002; Robertson et al., 2020; Rodriguez et al., 2012; Thew & Salkovskis, 2016). 80% of patients report that hoarding symptoms began by the age of 18 (Grisham et al., 2006), however very few people seek help before

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the age of 50 (Thew & Salkovskis, 2016). Once in treatment, approximately one third of individuals who hoard prematurely drop out (Tolin et al., 2015). Such findings suggest that there are substantial barriers to help-seeking and treatment in HD.

One possible barrier is stigma. As awareness of HD has increased, the tendency has been to focus on the behavioural outcomes of clutter and squalor, which can draw a range of stigmatizing judgements. The most public manifestation of this are the semi-mocking narratives around television portrayals such as '*Britain's Biggest Hoarders*' which typically portray those with HD negatively. Such media portrayals of HD have been found to increase stigmatizing attitudes towards HD in undergraduate samples (Bates et al., 2020). Accordingly, HD is frequently referred to as a stigmatised condition (Mataix-Cols & Fernández de la Cruz, 2018; Timpano et al., 2016).

The social-cognitive model of stigma describes how signals that indicate a mental health condition can lead to stereotypes, prejudice and discriminatory behaviours (Corrigan & Kleinlein, 2005; Corrigan & Watson, 2002). Stigma is typically separated into two components: 1) Public stigma, ways in which the general public endorse stereotypes and prejudices about people with mental illnesses, which impact their behaviours (e.g. avoidance) and 2) Self-stigma, also called internalised stigma, which occurs when people internalise public stigma of their condition (Corrigan & Watson, 2002). Corrigan and Rao (2012) propose that for self-stigma to occur there must be *awareness* of stigmatizing beliefs, *agreement* with these, and *application to oneself*. This may then lead to harm, through low self-esteem, hopelessness and discriminating behaviours against themselves. It is also possible to be aware of stereotypes and not endorse them (Corrigan & Kleinlein, 2005), and distinctions have been made between perceived and *anticipated* stigma, whereby individuals are aware of stereotypes and expect prejudice or discrimination, and internalised stigma, whereby these are also agreed with and applied to themselves.

Public stigma may be damaging for people who hoard in terms of availability of social and professional support. Additionally, anticipation of prejudice and discrimination may lead people who hoard to avoid being labelled as such. This may be particularly challenging when label avoidance deters people from help-seeking (Corrigan, 2004; Corrigan et al., 2014). If stigma is internalised, self-discriminatory behaviours may also interfere with treatment-seeking due to the "why try" effect: "why bother, I'm not worthy of treatment" (Corrigan et al., 2009). Such issues may lead to delays in treatment and poorer long-term outcomes.

Stigma is frequently implicated as a barrier to psychological help-seeking (Andrade et al., 2014; Clement et al., 2015; Mojtabai et al., 2011). Consistent with this view is the finding that stigma reduction campaigns can result in increased intention to seek help (Evans-Lacko et al., 2014; Henderson et al., 2017). Internalised stigma has also been associated with negative consequences including depression, low-self-esteem and increased symptom severity (Boyd et al., 2014).

Although people labelled with *any* mental illness are stigmatised more severely than people with other health conditions (Corrigan, 2004), stigma varies by diagnosis. Stereotypes of dangerousness and responsibility have been previously implicated as key in mental health stigma (Feldman & Crandall, 2007), however people with schizophrenia are more likely to be stereotyped as dangerous than people with anxiety, who may instead be viewed as weak, eliciting different stigmatizing reactions (Crisp et al., 2005; Curcio & Corboy, 2020; Parcesepe & Cabassa, 2013). Stereotypes of dangerousness may not be applicable to HD, as clutter is contained in the home. More recent conceptualisations suggest that difference ('they aren't like me'), disdain ('they are bad'), and blame ('they are to blame') are key facets of public stigma (Corrigan et al., 2015), which may more readily apply to hoarding. Such considerations highlight the importance of understanding the public and internalised stigma specifically associated with HD.

Individuals who hoard are aware that their behaviour is generally looked down upon (Chasson et al., 2018), perhaps indicating internalised stigma, and recent studies have suggested that stigma related to HD may interfere with treatment-seeking willingness (Chasson et al., 2018; Robertson et al., 2020). It is however currently unclear how HD is stigmatised by the public, how this is experienced by people who hoard, and whether stigma impacts treatment-seeking and uptake in people with HD. Understanding this may enable stigma reduction interventions to be developed that enhance treatment uptake and wellbeing.

The purpose of the current review is to examine the literature exploring stigma related to HD, considering the following:

1. Is there evidence that people with HD are subject to significant stigma?
2. How does stigma in HD compare to stigma related to other mental health difficulties?
3. Is there evidence that stigma impacts help-seeking in people with HD?

It is hoped that this review should drive further research in this area and improve research into approaches to enhance treatment uptake in this population.

2. Methods

This review was conducted in accordance with preferred reporting for systematic reviews and meta-analyses guidelines (PRISMA; Liberati et al., 2009), and was registered with the PROSPERO international prospective register of systematic reviews, registration ID: CRD42022375820.

2.1. Search strategy

PsycINFO, PubMed, Embase, Scopus, Medline, CINAHL, and Web of Science were electronically searched in August 2023. The search specified that within the title, abstract, keywords or topic the article must contain terms related to hoarding *("hoard*" OR "hoarding disorder" OR "hoarding behavio*" OR "diogenes syndrome" OR "compulsive hoarding" OR "hoarding symptom*" OR "compulsive acquiring"*) AND stigma *("stigma*" OR "public-stigma*" OR "self-stigma*" OR "prejudic*" OR "stereotyp*" OR "discriminat*" OR "sham*" OR "blam*" OR "social accept*" OR "label*ing" OR "social approval"*). Results were restricted to publications since 1994, when the DSM-IV was introduced, to English Language articles, and to human studies.

2.2. Inclusion and exclusion criteria

Papers were relevant if they referred to stigma (public or internalised, and related concepts like shame, blame, embarrassment) related to HD, or to hoarding behaviour which interferes with functioning without a diagnosis of HD. Eligible study samples were those which included people who hoard, their families, professionals, or the public. Papers could be quantitative or qualitative.

Papers were excluded if they did not report original study data, did not study humans, were published in a non-English language, or were published before 1994.

2.3. Study selection

Titles and abstracts were scrutinised by the lead author, and 25% were screened by a second rater. Cohen's k was 0.87 indicating excellent agreement, with two discrepancies discussed and resolved. Full texts of the remaining papers were examined by both raters. Cohen's k was 1.00.

3. Data extraction

Data was extracted for the following: details of publication; location; aims; design; sample size; inclusion/exclusion criteria; participant characteristics; stigma measures; HD measures; method of data analyses;

key findings about stigma and help-seeking. Two authors extracted data to ensure accuracy.

3.1. Quality appraisal

The QualSyst Quality Assessment Tool (Kmet et al., 2004) was used to assess the quality of included studies. It provides a systematic approach to assessing the quality of quantitative and qualitative studies, using checklists on which items are scored 0 (does not meet criteria), 1 (partially meets criteria), and 2 (fully meets criteria). A summary score was calculated for each study and we categorised quality based on these (strong [>0.8], good [0.71–0.79], adequate [0.50–0.70], or limited [<0.50]) and factored this into our narrative synthesis. Study quality was assessed by two raters. Discrepancies were discussed and resolved with a third rater if required.

3.2. Data synthesis and analysis

A narrative synthesis of the findings was developed, structured around the aims of the review, and within that around whether the papers measured public or internalised stigma, or related concepts. Studies which aimed to directly explore stigma were prioritised in the narrative.

4. Results

4.1. Identification of studies

The process of paper identification selection is presented in Fig. 1.

4.2. Overview of included studies

The 15 included studies are summarised in Table 1. They comprised 1864 participants, of whom 657 were non-hoarding members of the public, 675 were close friends or family of people who hoard, 84 were professionals who worked with people with HD, 438 were people who hoard (423 confirmed by hoarding measures or clinical interviews, 15 self-identified or identified by professionals), and 20 were collectors. Most studies were conducted in the United States (*n* = 8), followed by the United Kingdom (*n* = 3), Australia (*n* = 2), Ireland (*n* = 1) and Singapore (*n* = 1). Where available, most participants were female, with men comprising 30.9% (*n* = 550) of the sample overall, and 21.0% (*n* = 92) of participants who hoarded, and ranged in age from 18 to 85. Gender and age were not available for the included study of professionals.

Six studies explored internalised stigma, one public stigma, and one both public and internalised stigma related to hoarding. However, stigma in hoarding was only the *focus* for three studies, with five measuring stigma as a variable of interest related to other aims. Study

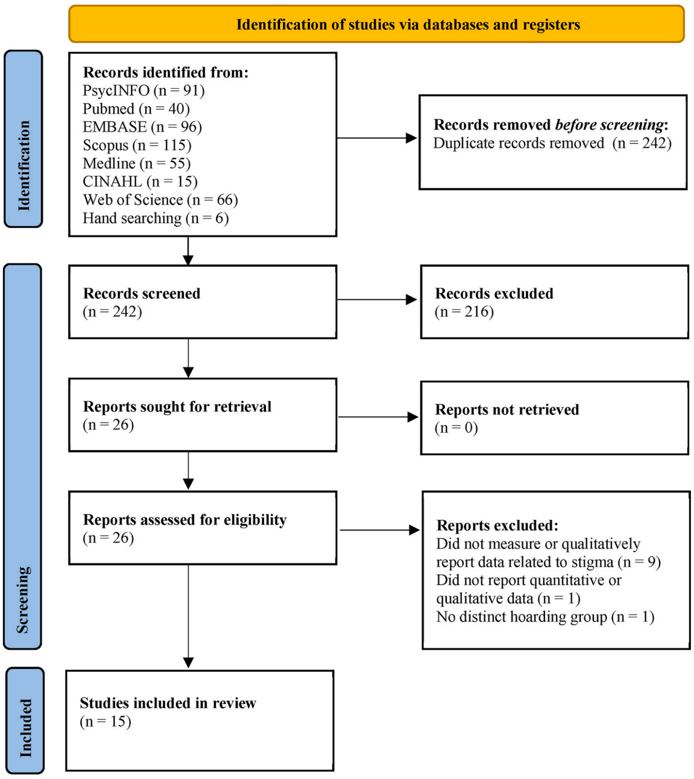

Fig. 1. PRISMA flowchart
Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 1
Study characteristics.

Study ID and authors (year)	Location	Quantitative or qualitative	Study design	Inclusion criteria	Sample size	Sample characteristics	How hoarding was measured or classified	How stigma was measured	Kmet quality rating
Public Stigma									
1. Bates et al. (2020)	United States	Quantitative	Randomised experimental design with three conditions: (a) hoarding TV show ('Hoarders') (b) clutter TV show ('Clean House') (c) non-clutter related house TV show ('House Hunters') exploring stigma ratings pre and post viewing.	- Undergraduate students -Aged 18 or older -No diagnosis of hoarding disorder -Had not seen more than 20 min of 'Hoarders' or 'Clean House'	66 (22 per group)	-Undergraduate sample -Age range: 18-55 -Mean age: 21.21 (SD = 5.54) -Gender: 51.5% male -Ethnicity: 42.4% Asian, 40.9% White or Caucasian, 4.5% Black or African American, 12.2% other	Hoarding was not measured in the sample as it looked at public stigma amongst undergraduates.	Stigma (Public) Stigma of Hoarding Items (Chasson et al., 2018). Community Attitudes Towards the Mentally Ill Scale (Taylor & Dear, 1981) Social Distance Scale (Link et al., 1987)	Good
Public and Internalised Stigma									
2. Chasson et al. (2018)	United States	Quantitative	Online survey with a within-subjects design in which participants ratings of facets of stigma across 5 different diagnoses were compared: Hoarding, OCD, Serious Mental Illness, Substance use disorder, and Jail.	-Aged 18 or older -Connected to MTurk from the United States	591	-Mean age: 37.03 (SD = 11.42) -Gender: 49.70% male -Ethnicity: 86.49% Caucasian or White, 6.42% Black or African American, 6.08 Asian, 3.04% Other -Co-occurring conditions self report: OCD 1.3%, hoarding 0%, no other conditions asked about. -Co-occurring conditions based on clinical cut-off scores: OCD 13.20%, hoarding 4.06%	Sample of people who did not identify as having hoarding disorder. Saving Inventory-Revised (Frost et al., 2004) score of 41 or higher used as a cut off to create a sub group of people with hoarding difficulties.	Stigma (Public and Self [if met threshold for Hoarding symptoms]) Each condition was rated on seven stigma items related to difference, disdain, and blame on a 9-point likert scale. Resource allocation measure.	Strong
Internalised Stigma									
3. Bates (2023)	United States	Qualitative	Individual interviews with people with hoarding disorder about stigma which were thematically analysed.	-Aged 18 and older -Live in the United States -Self-identify as someone with hoarding difficulties	17 (+4 who developed the interview)	-Age range: 20-73 -Mean age: 43.09 (SD = 17.98) [a] -Gender: 35% male -Ethnicity: Asian 5.88%, Black or African 41.17%, White or Caucasian 47.06%, Other 5.88%	Recruited people who self-identified as people with hoarding disorder. Used the Structured Interview for Hoarding Disorder (Pertusa et al., 2011) to confirm this for eligibility, as well as the Saving Inventory – Revised (Frost et al., 2004) score of 41 or higher to illustrate hoarding severity.	Stigma (internalised) HD sigma interview guide, developed for the study.	Strong
4. Fontenelle et al. (2021)	Australia (recruited internationally)	Quantitative	Online cross-sectional survey which explored the impact of hoarding symptoms, other psychopathology, and 'psychosocial strengths' including lower self-stigma on COVID related stressful events in a single sample using regressions.	-Hoarding behaviours, confirmed by the Saving Inventory Revised (Frost et al., 2004) total score ≥39 -Aged 18 or older -Able to read and fill out forms	117	-Mean age: 48.38 (SD = 12.74) -Gender: 9.5% male -Co-occurring conditions based on outcome measures: Depression 96.0%, Anxiety 99%, Stress 62.4%, OCD 92.1%	Recruited people who self-identified as people with hoarding disorder. Saving Inventory-Revised (Frost et al., 2004) score of 39 or higher used to confirm eligibility.	Stigma (internalised) The Internalised Stigma of Mental Illness scale-10 (Boyd et al., 2014)	Strong

(*continued on next page*)

Table 1 (*continued*)

Study ID and authors (year)	Location	Quantitative or qualitative	Study design	Inclusion criteria	Sample size	Sample characteristics	How hoarding was measured or classified	How stigma was measured	Kmet quality rating
5. Krafft (2022)	United States	Quantitative	Randomised, waitlist-controlled trial exploring the efficacy of an 8-week ACT self-help website for hoarding compared to waitlist. Measures completed at baseline, post-treatment, and 4-weeks follow up, including a self-stigma measure.	-Aged 18 or older -Live in the USA -Seeking help for clutter or hoarding -Interested in testing a self-help website -Score ≥41 on the Saving Inventory Revised (Frost et al., 2004)	73 (38 in intervention, 35 on waitlist)*	- Mean age: 47.67 (SD = 14.34) - Gender: 12.33% male - Ethnicity: 76.71% White, 6.85% Asian, 5.48% bi/multiracial, 4.11% Black, and 6.85% other race.	Recruited people who were seeking help for clutter or hoarding. All participants met the clinical cut off of ≥41 on the Saving Inventory-Revised (Frost et al., 2004)	Stigma (internalised) Stigma of Hoarding Items (Chasson et al., 2018).	Good
6. Krafft et al. (2023)	United States	Quantitative	Mediation and moderation analysis of data collected as part of the randomised waitlist-controlled trial above.	-Aged 18 or older -Live in the USA -Seeking help for clutter or hoarding -Interested in testing a self-help website -Score ≥41 on the Saving Inventory Revised (Frost et al., 2004)	73 (38 in intervention, 35 on waitlist)*	-Mean age: 47.67 (SD = 14.34) [a] -Gender: 12.33% male -Ethnicity: 76.71% White, 6.85% Asian, 5.48% bi/multiracial, 4.11% Black, and 6.85% other race.	Recruited people who were seeking help for clutter or hoarding. All participants met the clinical cut off of ≥41 on the Saving Inventory-Revised (Frost et al., 2004)	Stigma (internalised) Stigma of Hoarding Items (Chasson et al., 2018).	Good
7. Mataix- Cols et al. (2013)	United Kingdom	Quantitative	Field trial testing DSM-5 hoarding disorder criteria, involving cross sectional questionnaires and clinical interviews.	-Self-identify as a collector or person with hoarding difficulties	70 (50 identifying as having hoarding difficulties, 20 as collectors)	Self-identified people with hoarding difficulties (N = 50) -Mean age: 55.44 (SD = 12.53) -Gender: 40% male For those meeting HD criteria (N = 29) -Mean age: 56.62 (SD = 13.55) -Gender: 44.8% male -Comorbidities reported: 69% endorsed another mental disorder other than HD (more detail available but not reported here) Self-identified collectors (N = 20) -Mean age: 55.50 (SD = 10.75) -Gender: 75% male -Comorbidities reported: 40% endorsed another mental disorder other than HD (more detail available but not reported here)	Self-identified as people with hoarding difficulties or collectors. The Structured Interview for Hoarding Disorder (Pertusa et al., 2011) was used to diagnose HD. The Clutter Image Rating (Frost et al., 2008) was used to objectively assess the degree of clutter. Also administered were the Hoarding Rating Scale–Self- Report (Tolin et al., 2010), Saving Inventory – Revised (Frost et al., 2004), Compulsive Acquisition Scale (Frost et al., 2002) and Saving Cognitions Inventory (Steketee et al., 2003)	Stigma (internalised) Participants were asked 'according to the interview we have just performed, you would meet criteria for this new diagnosis (Hoarding Disorder). Would you find it stigmatizing to receive such label?' and responded on a four point Likert scale.	Adequate
8. Robertson et al. (2020)	Australia	Quantitative	Online cross sectional survey with a single sample exploring barriers to treatment and variables	-Live in Australia -Aged 18 or older -Able to read English -Score ≥14 on the Hoarding Rating	50	-Mean age: 47.82 (SD = 12.92) -Gender: 18% male -Co-occurring conditions: Clinically	Recruited people who identified as having hoarding difficulties. All participants scored of ≥14 on the Hoarding	Stigma (internalised) The Internalised Stigma of Mental Illness Scale-9 (Hammer & Toland, 2017)	Strong

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Table 1 (*continued*)

Study ID and authors (year)	Location	Quantitative or qualitative	Study design	Inclusion criteria	Sample size	Sample characteristics	How hoarding was measured or classified	How stigma was measured	Kmet quality rating
			which predicted help-seeking intention including stigma.	Scale-Self Report (Tolin et al., 2010)		significant symptoms of depression on the PHQ-9 reported by 70%, no other co-morbidities asked about.	Rating Scale-Self Report (Tolin et al., 2010)		
Stigma Related Concepts									
9. Brien et al. (2018)	Ireland	Qualitative	Unstructured psychoanalytic interviews which were psychoanalytically analysed.	-Aged 18 or older -History of or current hoarding difficulties requiring assessment or intervention -Referred by staff from local primary care health centre -Had capacity to partake in conversation for 1 h -No condition affecting cognition such that they could not articulate their narrative	5	-Age range: 46-71 -Mean age: 60.8 -Gender: 40% male	Recruited through staff in local primary care health centres who identified them on the basis of current or historical hoarding.	Shame Arose as a theme in interviews.	Adequate
10. Chou et al. (2018)	United States	Quantitative	Cross sectional survey of a single sample exploring relationships between shame, self-criticism, hoarding beliefs and hoarding symptoms.	-Hoarding difficulties (as screened by three hoarding measures) -No suicide risk -No psychotic symptoms -No intellectual disability -No severe dementia -No acute medical condition that might affect participation	104	-Age range: 41-85 -Mean age: 59.9 (SD = 9.0) -Gender: 23.1% male -Co-occurring diagnoses: Depression 38%, PTSD 13%, Agoraphobia 11%, Generalised anxiety disorder 11%, Social phobia 5%, SUD 5%, Bipolar disorder 4%, Panic disorder 3%, OCD 1%	Participants screened and included if they met 2/3 of the following: Score of ≥42 Saving Inventory, Revised (Frost et al., 2004); Score of ≥20 on the UCLA Hoarding Symptom Scale (Saxena et al., 2015); Score of ≥12 on the Clutter Image Rating Scale-Revised (Frost et al., 2008) Those who screened positive were included if they met DSM-5 criteria for HD after clinical interview using the Structured Interview for Hoarding Disorder (SIHD; Nordsletten et al., 2013)	Shame and Self-Criticism Self-criticism- Inadequate-Self (9 items) and Hated-Self (5 items) subscales of the Forms of Self-Criticizing/Attacking and Self-Reassuring Scale (FSCRS; Gilbert et al., 2004). Shame- 6 questions modified from the Experience of Shame Scale (Andrews et al., 2002). Assessed the extent to which one feels ashamed of, worries about what others think of, and tries to cover up oneself as a person, and their hoarding problems.	Strong
11. Orr et al. (2019)	United Kingdom	Qualitative	Semi-structured interviews, analysed using the framework method and thematic analysis	-Identified by social workers as having hoarding difficulties	10	-Age range: 50-80 -Gender: 50% male	Self-identified as having hoarding difficulties, as were introduced to the researcher through social workers. No quantitative screening measures of hoarding or structured clinical interviews were employed to confirm the diagnosis of hoarding disorder.	Shame Arose as a theme in interviews.	Adequate

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Table 1 (*continued*)

Study ID and authors (year)	Location	Quantitative or qualitative	Study design	Inclusion criteria	Sample size	Sample characteristics	How hoarding was measured or classified	How stigma was measured	Kmet quality rating
12. Subramaniam et al. (2020)	Singapore	Qualitative	Semi-structured interviews that were thematically analysed	-Aged 21 and older -Able to converse in English, Chinese, Malay or Tamil -Assessed to be 'clinically stable' and capable of being interviewed -Identified as having hoarding difficulties	12	-Mean age: 56.7 (SD = 14.5) -Gender: 41.7% male vEthnicity: Chinese 91.7%, Malay 8.3%	Either diagnosed with hoarding disorder by their clinician or identified by community workers using the Clutter-Image Rating Scale (Frost et al., 2008; Sagayadevan et al., 2016), associated with reports of hoarding related distress or functional impairment. No quantitative screening measures of hoarding or structured clinical interviews were employed to confirm the diagnosis of hoarding disorder.	Stigma (internalised) and Shame Arose as a theme in interviews.	Strong
13. Tolin, Frost, Steketee, Gray, and Fitch (2008)	United States	Quantitative	Online cross sectional survey which made between subjects comparisons of distress related to a family member's hoarding, frequency of arguments and patient rejection (e.g. between children vs. siblings of hoarding family members; family informants who lived with the hoarding family member before age 21 vs those who didn't). Predictors of distress and patient rejection were also explored through correlations.	-Age 18 and older -Self-identified as non-hoarding friends or family members of individuals with hoarding problems -Part of a database of individuals who contacted the researchers about hoarding	665	Family members of people meeting full criteria for HD (571 people) -Mean Age: 45.36 (SD = 12.46) -Gender: 16.3% male Family members of people not meeting full criteria for HD (94 people) -Mean Age: 53.23 (SD = 12.76) -Gender: 19.4% male	Respondents self-identified as family members of someone with hoarding disorder. Severity of hoarding of their family member was determined using the Hoarding Rating Scale-Self-Report (Tolin et al., 2010). Family informants who described moderate (4) or greater clutter and difficulty discarding, as well as either moderate (4) or greater distress or impairment caused by hoarding were considered to have family members who met diagnostic criteria.	Familial rejection and embarrassment (public stigma or associative stigma) Patient Rejection Scale (Kreisman et al., 1979b) Distress Ratings required participants to rate, from 0 (not at all) to 4 (very much), the following questions: "How happy was your childhood" "To what extent was it difficult for you to make friends when you were a child?" "How frequently did you have people over to your house (friends, relatives, etc.)?" "How frequently did you argue with your parents?" "How strained was your relationship with your parents?" "How embarrassed were you about your home?" "How frequently did you argue with [name] about his/her hoarding behavior when you were living there?"	Good
14. Wilbram et al. (2008)	United Kingdom	Qualitative	Semi-structured interviews that were thematically analysed.	-Identify as a key carer of a person who hoards -Descriptions and the investigators observations of the environmental	10	-Age range: 37-71 -Mean age: 56 -Gender: 40% male	Participants self-identified as key carers for a person who hoards. Participants were included in the study on the basis of their descriptions (and investigators observations)	Shame, embarrassment and marginalization (associative stigma)	Strong

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Table 1 (*continued*)

Study ID and authors (year)	Location	Quantitative or qualitative	Study design	Inclusion criteria	Sample size	Sample characteristics	How hoarding was measured or classified	How stigma was measured	Kmet quality rating
				impact correspond with hoarding.			of the severity and environmental impact of the person with hoarding difficulties' behaviour, without measures or clinical interviews.		
15. Tolin et al. (2012)	United States	Quantitative	Online cross sectional survey of a single sample comparing patient rejection attitudes of professionals towards their clients with HD compared to those without.	-Self-identified as healthcare or service professionals -Self-reported having worked with at least 1 client with HD and 1 without. -Part of a database of individuals who contacted the researchers about hoarding	84	-Healthcare or service professionals (71.4% professional organizers; 19.0% healthcare workers; 9.5% social service workers)	Respondents self-identified having worked with someone with hoarding disorder. Severity of hoarding of their client was determined using the Hoarding Rating Scale-Self-Report (Tolin et al., 2010).	Patient rejection and frustration (public stigma) Patient Rejection Scale (Kreisman et al., 1979b) Professionals also responded to a series of questions developed for the study, regarding their clients' behavior as well as their own feelings during the treatment or intervention.	Strong

Note. *Report results from the same sample.

[a] Corrected figures obtained from the author as discrepancy noticed.

designs varied. One study explored stigma qualitatively through interviews. Seven studies reported quantitative findings, and mainly utilised cross-sectional survey designs (n = 4), two exploring associations between stigma and other variables within a single sample, one surveying HD criteria, and one making within-subjects comparisons of stigma related to different diagnoses. Two studies reported results from the same RCT which measured stigma as a process variable. Finally, one used a randomised experimental design to explore the impact of media portrayals of hoarding on stigma.

Seven studies reported concepts related to stigma. Three reported quantitative findings from cross sectional surveys, one exploring the association between shame and self-criticism and hoarding symptoms in a single sample, one exploring familial rejection and embarrassment about hoarding through between-subjects comparisons of family members of people with HD, and one exploring frustration and patient rejection attitudes of professionals towards their clients with compared to without HD. Four studies were qualitative and identified themes within interviews of shame, embarrassment and marginalization in relation to one's own or a family member's hoarding. Three used thematic analysis, whilst one used psychoanalytic analysis. The quantitative studies aimed to explore the stigma-related concepts related to hoarding, however the qualitative studies more broadly focused on the internal experiences and impacts of hoarding for people with HD and their families and identified stigma related themes during analysis.

Just one study directly compared stigma related to HD with other mental health difficulties. Three studies explored the impact of stigma on help-seeking for hoarding, one as part of interviews about hoarding stigma broadly, one quantitatively examining barriers to help-seeking including stigma, and one which asked a subgroup of their sample about treatment seeking willingness if they crossed a clinical cut-off for hoarding symptoms and looked at this in association with stigma ratings that formed the main focus of the study.

4.3. *Quality assessment*

Study quality was assessed by the QualSyst Quality Assessment Tool (Kmet et al., 2004), with ratings used to assess internal validity and risk of bias for each study. Quality ranged from 'adequate' to 'strong'.

4.3.1. *Quantitative studies*

The aims and objectives of quantitative studies were adequately described and all utilised appropriate designs. Descriptions of participant characteristics were sufficient, all including age and sex as a minimum except one study (15) which gave no characteristics beyond professional group. However, one paper (13) made many sub-group comparisons without providing the demographics of these, hindering interpretation. Furthermore, reporting of co-occurring diagnoses and ethnicity varied widely. Incomplete reporting of co-occurring conditions (1,2,4,5,6,8,13) and ethnicity (4,7,8,10,13,15) limits generalisability of findings and may challenge inferences that experiences of stigma are related to hoarding alone.

All studies described their sampling methods; however two studies (7,10) only partially described their inclusion criteria. In other studies, the sampling methods used risked introducing bias, with many relying *exclusively* on participant self-selection including recruiting from support groups (4), families who had contacted researchers for support (13, 15), and undergraduates (1). Self-selecting participants may be a non-representative subset of people with HD, their families or professionals who have greater insight and/or higher levels of distress. Most studies relied on participants/respondents meeting clinical thresholds on hoarding measures (2,4,5,6,8,10,13,15), with some just requiring self-report of hoarding difficulties (14), and only one (7) conducting a clinical interview for HD meaning some may not meet criteria for HD. Sample size was mostly appropriate, however some samples seemed small (5,6,7,8), risking low statistical power, and only one paper (8) reported *a-priori* power analysis.

Although outcome measures were always described and usually in adequate detail, the quality of measures used varied. Some used validated measures, but often measures had poor psychometric properties and some were adapted to apply to HD, meaning they were not validated in this population or format. Measures of stigma were predominately self-report, which may underestimate stigma due to social desirability biases.

Four studies did not report analytic methods in sufficient detail (4,5,6,7), but none were obviously inappropriate or missing. Random allocation and blinding were rarely applicable for the designs used. However when they were, random allocation was not fully described and blinding was not used (1,5,6). Control for confounding variables was often partially considered, but only two papers reported this fully. Although reporting of power and effect size was poor, estimates of variance were consistently provided. Results were generally reported in sufficient detail, although for some (5,6,13) these were hard to interpret due to insufficient detail.

4.3.2. *Qualitative studies*

The aims and objectives were consistent with the exploratory aims of qualitative papers so designs were appropriate. Context and connection to theory were also adequately described. Sampling and demographics were very poorly reported overall, being clearly described and justified for just two studies (3,12). One study did not sufficiently describe participant recruitment (11), another had a very small sample (9) and three did not report sufficient demographic characteristics (9,11,14). As with the quantitative studies, reporting of ethnicity varied (not reported in 9,11,14) and none reported co-occurring diagnoses. Only a few qualitative studies relied on participant self-selection (3,14), with many recruiting through clinical staff or social workers (9,11,12), although only one study (3) checked that their sample met HD criteria. These sampling approaches meant that participants were often those accessing help from services, possibly introducing bias and may not have met HD criteria.

With one exception, methods of data collection were clearly described and thematic analysis supported with sufficient data. However, one study (9) used a psychoanalytic approach which was poorly described, and did not provide sufficient data to support their results. Credibility checks like triangulation and peer reviewing were well used, and conclusions drawn were appropriate. Interestingly, most papers did not demonstrate sufficient evidence of reflexivity.

4.4. *Is there evidence that people with HD are subject to significant stigma?*

4.4.1. *Internalised stigma*

Seven studies explored internalised stigma experienced by people with hoarding difficulties, but only Chasson et al. (2018) and Bates (2023) had stigma related aims, with other studies measuring internalised stigma in relation to other variables of interest.

Bates (2023) interviewed people with HD about their experience of stigma, including stereotypes, prejudice and discrimination, in a study with a 'strong' quality rating. People with HD identified stereotypes that people with HD were *unclean*, *crazy*, and *lazy*, incorporating ideas that they were 'dirty', 'unbalanced', different to 'normal people', and to be avoided. These stereotypes weren't always openly agreed with, but people with HD experienced feelings of sadness, shame, embarrassment and guilt when presented with them, suggesting internalization of stigma. Participants reported experiencing discrimination due to hoarding, including conflicts at work due to clutter, and rejection and criticism from friends and family about their homes. Where respondents did not report experiencing discrimination, this was attributed to others being unaware of their hoarding. Regarding self-discrimination, almost half reported that stigma prevented them seeking treatment for hoarding. Participants reported feeling pressure to appear organised at work to avoid hoarding stereotypes, and kept colleagues, friends and family at a distance to avoid revealing hoarding or developing relationships that may lead to expectations of socializing in their home, to which they limited access due to fear of judgement. This led to social distance and rejection. Thus this study indicates that people with HD experience substantial internalised stigma, though the small self-selected sample limits generalisability.

Chasson et al. (2018) evaluated public stigma of HD in a cross-sectional survey of people *without* HD with 'strong' quality. A hoarding stigma scale was developed for this study, on which higher ratings on 9-point Likert scales indicated endorsement of more negative attitudes. However, 24 participants scored ≥41 on the Saving Inventory-Revised (SI-R; Frost et al., 2004). These participants rated people with HD neutrally to slightly negatively, rating them slightly different to others (*M* = 5.51, *SD* = 1.79), with slight disdain (*M* = 5.92, *SD* = 1.37) and as somewhat to blame for their difficulties (*M* = 4.66, *SD* = 2.30). Although interpreting this scale is challenging, it is unvalidated, and its psychometric properties are varied with low Cronbach's alphas for one subscale, it does suggest endorsement of slightly negative views of HD by people with hoarding difficulties.

Four studies measured internalised stigma as a predictor or process variable. Fontenelle et al. (2021) and Robertson et al. (2020), both 'strong' quality studies, gave the well validated Internalised Stigma of Mental Illness scale (Hammer & Toland, 2017) to self-identified people with hoarding difficulties who met cut-off scores for hoarding (≥39 SI-R (Frost et al., 2004); ≥14 Hoarding Rating Scale-Self Report (Tolin et al., 2010)). 'High' internalised stigma (>2.50) was reported by 38% of Robertson et al., (2020) participants, and hoarding severity was significantly positively correlated with internalised stigma ($r = 0.30, p < .05$). Both studies identified that people with HD experienced 'minimal' to 'moderate' internalised stigma (*M* = 2.42, *SD* = 0.50*;* *M* = 2.34, *SD* = 0.42).

The 'good' quality RCT reported by Krafft (2022; 2023) used Chasson's (2018) hoarding stigma scale as a process measure of internalised stigma and found that people with hoarding difficulties endorsed slightly negative attitudes towards people with HD in terms of difference (Intervention *M* = 6.62, *SD* = 2.07; Waitlist *M* = 6.41, *SD* = 2.19), disdain (Intervention *M* = 5.75, *SD* = 2.27; Waitlist *M* = 5.73, *SD* = 1.81), and blame (Intervention *M* = 4.62, *SD* = 2.39; Waitlist *M* = 5.76, *SD* = 2.70). Hoarding severity was significantly correlated with ratings of difference ($r = 0.31, p < 0.01$), but not disdain or blame. However, this measure had poor psychometric properties and is hard to interpret.

Finally, Mataix-Cols et al. (2013) in an 'adequate' quality study asked 50 self-identified people with hoarding difficulties whether the proposed diagnostic label of hoarding would be stigmatizing. 58.6% reported that it would not, 27.6% felt it would be somewhat stigmatizing and 13.8% considered it could be very stigmatizing. Some participants worried that the label would connote being dirty and would be socially unacceptable, suggesting awareness of hoarding stereotypes.

Overall, research is limited but suggests that people with HD experience some internalised stigma. Qualitatively they identify negative stereotypes specific to hoarding, and these result in negative affect and isolation due to fear of judgement and deter help-seeking. Quantitative studies were limited by varying quality of measures and sampling, but suggest that people with HD experience mild to moderate internalised stigma, but that stigma is not universal and may increase with hoarding severity.

4.4.2. Public stigma

Only two studies explored public stigma regarding HD. In a large survey, with a 'strong' quality rating, Chasson et al. (2018) found that HD had a neutral to slightly negative public perception. On the hoarding stigma scale developed for this study, people with HD were rated as slightly different (*M* = 5.50, *SD* = 1.79), slightly disdained (*M* = 5.92, *SD* = 1.37) and somewhat to blame for their difficulties (*M* = 4.64, *SD* = 2.29) indicating some public stigma. The more negatively participants rated people with HD in terms of blame ($r = -0.121, p < 0.001$) and disdain ($r = -0.087, p = 0.034$), the fewer dollars they allocated hoarding services in a hypothetical budget allocation task, indicating that negative attitudes about HD may lead to prejudice and discrimination. Additionally, participants who reported that a friend or family member had hoarding difficulties viewed people with HD more favorably in terms of difference, but with more disdain and blame ($F(2,589) = 10.26, p < 0.001, \eta2 = 0.03$). However, as mentioned previously the validity and psychometric properties of this measure limit conclusions. Additionally, budget allocation is rarely how stigma is enacted for the general population.

Bates et al. (2020) experimentally investigated how television depictions impact the public stigma of HD, with a 'good' quality rating. Undergraduates rated people with HD very negatively in terms of difference and neutrally in terms of blame on Chasson et al., (2018) scale, neutrally on the Community Attitudes Toward the Mentally Ill Scale (CAMI; Taylor & Dear, 1981), but preferred greater distance from and low willingness to engage with people with HD on the Social Distance Scale (SDS; Link et al., 1987). Familiarity with people with HD did not moderate stigma ratings. Participants who then watched an episode of 'Hoarders' showed increased stigma ratings across all measures, and scores were significantly higher compared to people who watched 'Clean House' and 'House Hunters' on the SDS, the Social Restrictiveness subscale of the CAMI, and difference ratings, with large effect sizes (partial $\eta2 = 0.13$ - 0.30), suggesting that public stigma might be increased by media representations of HD. Subscales of both Chasson's (2018) scale and the CAMI had unsatisfactory psychometric properties so weren't reported. Additionally, the sample were students, and predominately young and white, limiting generalisability.

Again, research into public stigma of HD is limited, but suggests that people with HD are subject to attitudes that range from neutral to very negative in terms of difference, disdain and blame, and the public prefer distance from them. The impact of familiarity on public stigma is currently unclear. Studies are limited by the validity of stigma measures used.

4.4.3. Stigma related concepts

Four studies explored experiences that may reflect internalised stigma in people with HD.

Firstly, Chou et al. (2018) conducted a 'strong' quality online single sample survey and found that self-criticism ($r = 0.20, p = .04$) and shame ($r = 0.23, p = .02$) were significantly positively correlated with HD symptom severity in 104 people with HD (confirmed by measures and clinical interview).

Two studies thematically analysed interviews with people identified by social workers or community staff as having HD. Participants in one 'strong' quality study described that family members were ashamed of their behaviour which led to anger and relationship breakdown, and that they were perceived by neighbours as 'crazy' and 'bad' which they found distressing (Subramaniam et al., 2020). In another study of 'adequate' quality (Orr et al., 2019), respondents felt the label of hoarding led to assumptions that their possessions were 'rubbish' and that they were 'irrational'. Some respondents described feeling ashamed of their hoarding, so they avoided letting others into their homes. Others disagreed with these assumptions and rejected and avoided the hoarding label, one describing not caring what others thought and another viewing their hoard as a positive reinforcer of social connections. For a few participants, understanding that hoarding was a mental health difficulty attenuated blame and reduced their belief that they were 'nuts'.

Finally, Brien et al. (2018) conducted psychoanalytically informed interviews to explore the internal experiences of 5 people identified by primary care staff as having HD, rated 'adequate' quality. They observed that shame and guilt filled the narratives of hoarding individuals, who often hid and avoided discussing their hoarded possessions. Participants described feeling 'damaged' or different, found the hoarding label 'horrible', and experienced feeling humiliated and degraded by professionals' reactions to their hoarding.

Two studies explored concepts which may reflect public stigma regarding hoarding amongst families of people with HD.

Tolin, Frost, Steketee, and Fitch (2008) conducted a 'good' quality survey of over 600 family members which measured family frustration and hostility towards their hoarding family member using the Patient Rejection Scale (PRS; Kreisman et al., 1979b). PRS scores range from 11 to 35, with higher scores indicating more rejecting or hostile attitudes. Family members reported high patient rejection attitudes ($M = 20.48$, $SD = 4.57$), irrespective of their relationship with the hoarding individual (e.g. partner, child, sibling). Rejecting attitudes were significantly associated with the individual's hoarding symptom severity ($r = 0.148$, $p = 0.003$), clutter in the home ($r = 0.120$, $p = 0.018$), and lack of hoarding insight ($r = 0.339$, $p < 0.001$). Living with the hoarding individual during childhood was associated with greater distress, including having friends over less often, arguing more, and experiencing embarrassment about the condition of the home. Distress ratings were higher for children of people who hoard than for siblings. Rejection, embarrassment and social avoidance may indicate public stigma or associative stigma. However, family members surveyed had previously contacted the researchers about their hoarding family member, so may have biased results.

Wilbram et al. (2008) conducted a 'strong' quality interview study with 10 family members of hoarding individuals. Respondents felt that people did not understand, feared or did not tolerate hoarding, especially when clutter was visible outside the home, and they described experiencing prejudice and discrimination including teasing and marginalization as a result. They also described feeling embarrassment and shame about their home which resulted in social withdrawal, and anger and frustration towards the individual who hoarded, with hoarding being described by some as selfish.

One 'strong' quality survey by Tolin et al. (2012) explored concepts which may reflect public stigma regarding hoarding amongst professionals who had worked with people with HD. They compared professionals' ratings of frustration and hostility towards a hoarding compared to a non-hoarding client using the PRS (Kreisman et al., 1979b) mentioned above. Scores on the PRS were significantly higher for hoarding vs. non-hoarding clients, reflecting more frustration and hostility. Rejecting attitudes were not significantly associated with the individual's hoarding symptom severity. On survey questions designed for this study, professionals also rated themselves as feeling significantly more frustrated and irritated by their hoarding client, relieved when the client did not attend appointments, feeling hopeless or helpless, and wanting to transfer the client. Compared to non-hoarding clients, hoarding clients were rated as significantly more difficult to work with. Rejection and hostility, as well as frustration, relief related to non-attendance and desire to transfer clients, may indicate public stigma. However, professionals surveyed had previously contacted the researchers about hoarding clients, so may have biased results. They were also primarily professional organisers, who may be sought out by HD clients, compared to health or social care workers, who may be more likely to be referred HD clients who are not seeking support.

Studies exploring related concepts further illustrate people with HD's awareness of negative public beliefs about hoarding, like being 'crazy' and surrounded by 'rubbish'. Furthermore, quantitative and qualitative descriptions may indicate people with HD's internalization of these stereotypes in experiences of shame, self-criticism and frustration, and consequent self-discriminatory behaviours like label avoidance and social withdrawal. These studies also support that experiences vary, with some disagreeing with stereotypes and reportedly feeling unaffected by negative public perception. Finally, studies of family members and professionals further our understanding of public stigma of hoarding through the rejecting and hostile attitudes and desire for distance endorsed, but for family members may also reflect associative stigma, as family members described their own shame about clutter, and resulting social withdrawal.

4.5. How does stigma in HD compare to stigma related to other mental health difficulties?

4.5.1. Internalised stigma

No studies compared the internalised stigma experienced by people with HD to people other mental health difficulties.

4.5.2. Public stigma

Chasson et al. (2018) compared stigma ratings the public made about HD with their ratings of people with serious mental illness (SMI), substance use disorder (SUD), obsessive compulsive disorder (OCD), and people in jail. They utilised a within-subjects survey design, and the quality was rated 'strong'. On their self-developed hoarding stigma scale, people with HD were viewed as significantly more different from the general population than SUD, Jail and OCD ($p < .01$, $d = 0.19$; $p < .01$, $d = 0.60$; $p < .01$, $d = 0.78$), with similar disdain as SMI and more disdain than OCD ($p < .01$, $d = 1.58$), and as more to blame for their condition than people with SMI ($p < .01$, $d = 0.85$) and OCD ($p < .01$, $d = 0.48$). Hoarding was consistently viewed with more stigmatizing attitudes than OCD. Values reported here are corrected from the published paper, following correspondence with the author.

These findings suggest that hoarding is more publicly stigmatised than other mental health conditions like OCD, particularly with regard to perceptions that people who hoard are to blame for their difficulties and are viewed with disdain. However, challenges with representativeness of the sample and validity of the measure used have been previously discussed.

4.5.3. Related concepts

No studies *directly* compared concepts related to stigma between people with HD and people with other mental health difficulties. However, Tolin, Frost, Steketee, and Fitch (2008) compared patient rejection attitudes of family members of people with HD with historical studies that administered the same measure, the PRS (Kreisman et al., 1979b). Patient rejection attitudes were significantly higher among family members of hoarding individuals than families of people seeking treatment for OCD (Amir et al., 2000) ($p < 0.001$) and families of people with schizophrenia at hospital discharge (Kreisman et al., 1979a) ($p < 0.001$), and were comparable to attitudes of families of outpatients with schizophrenia (Heresco-Levy et al., 1992) and staff working with inpatients with schizophrenia (Heresco-Levy et al., 1999).

These findings suggest people with HD may experience more hostile and rejecting attitudes than people with OCD and schizophrenia, possibly suggesting more stigma. However, care should be taken in interpreting these differences as the comparisons are made across studies conducted many years ago.

4.6. Is there evidence that stigma impacts help-seeking in people with HD?

4.6.1. Internalised stigma

Three studies, all with 'strong' quality ratings, explored the impact of internalised stigma on help-seeking in people with HD.

Chasson et al. (2018) found that ratings of disdain towards hoarding were negatively related to ratings of treatment-seeking willingness ($r = -0.48$, $p < 0.01$) amongst a sub-sample of participants with clinically significant symptoms of HD on the SI-R (Frost et al., 2004). However, these findings were exploratory due to the small sample which undermined tests of statistical significance. A study with a larger and more representative sample of people who self-identified with HD and scored ≥ 14 on the Hoarding Rating Scale Self-report (Tolin et al., 2010) found that internalised stigma did not significantly predict ratings of help-seeking intention (Robertson et al., 2020). Furthermore, fears of being 'judged by a therapist' and fears of '[finding] out that I'm crazy', which seem stigma related, were endorsed as a barrier to treatment by $\leq$ 16% of participants. 58% endorsed 'preference for working out problems independently' as a barrier, but whether this is related to stigma is unknown. However, during in-depth interviews, almost half of Bates (2023) participants indicated that stigma and negative stereotypes of hoarding had stopped them getting treatment, as it made hoarding difficult to disclose. Half of these participants either reported that stigma hadn't affected their help-seeking for hoarding, or were unsure about this. Some indicated that they did not seek help because they did not talk about their hoarding with others, which may indicate awareness that they may be negatively perceived if they did so.

Overall, the impact of internalised stigma of hoarding on help-seeking is unclear, but stigma may negatively impact help-seeking for *some* with HD. Studies with adequately powered, representative samples of people with HD are needed to clarify this.

4.6.2. *Public stigma*

No studies explored whether public stigma of hoarding impacted help-seeking (or help availability).

4.6.3. *Related concepts*

No studies explored impacts of stigma related concepts on help-seeking in HD.

5. Discussion

This review aimed to examine the evidence of public and internalised stigma related to HD, how this compares with other mental health conditions, and whether stigma impacts help-seeking in HD. Although literature addressing all three questions was very limited, it can be tentatively surmised that a significant proportion of people who hoard and their families experience stigma, and HD is stigmatised by the public. People who hoard identified stereotypes that people with HD are unclean, crazy and lazy, and experienced negative affect, shame and social withdrawal as a result. However, levels of internalised stigma endorsed varied within and between studies, from none to mild-moderate stigma. Public perceptions of people with HD also varied, ranging from neutral to negative in terms of difference, disdain and blame, with preference for greater social distance from them. This may be influenced by presentations of hoarding in the media. Furthermore, family members of people with HD and professionals working with people with HD endorsed rejecting attitudes towards them, possibly related to stigma. Families also experienced shame about clutter, and social withdrawal and discrimination due to hoarding, indicating possible associative stigma. Across public and internalised stigma and related concepts, heterogeneity of studies, sampling issues and unreliable measures made it difficult to draw firm conclusions. No studies compared internalised stigma related to HD with other conditions, however there is initial evidence that public stigma of HD *may* be higher than for OCD, and comparable to SMI, particularly regarding perceptions of blame and disdain. Finally, the limited research on the impact of stigma on help-seeking for HD was mixed but generally suggested that stigma negatively impacted help-seeking for some people with HD.

Our tentative findings are consistent with reviews of stigma experiences in other mental health conditions (Corrigan & Watson, 2002; Ellison et al., 2013; Livingston & Boyd, 2010). Furthermore, the preliminary findings that stigma had interfered with help-seeking for some people with HD and that endorsement of negative stereotypes like disdain was associated with reduced treatment-seeking willingness are consistent with multiple reviews documenting the harmful effects of stigma on help-seeking (Clement et al., 2015; Corrigan, 2004; García-Soriano et al., 2014). However, some studies found that stigma did not predict or was not cited as a barrier to help-seeking. Interestingly, whilst internalised stigma and self-discriminatory attitudes are consistently negatively associated with help-seeking, this association is weaker for perceived stigma (Clement et al., 2015; Schomerus et al., 2009). This conceptual distinction has not been explored in HD, but may explain the varied findings in relation to stigma and help-seeking, and should be further examined.

The existing literature explores some aspects of the social-cognitive model of stigma related to HD, primarily exploring the stereotypes about hoarding identified both by people who hoard and the public. It is unclear what prejudice and discrimination these stereotypes correspond with. Corrigan et al. (2002) identified pathways to account for stigmatizing reactions to common mental health stereotypes (e.g. dangerousness→ fear → avoidance), however the emotional reactions and corresponding behaviour in response to stereotypes about hoarding are unclear. Only one study measured how public stigma influenced behaviour, and this measure lacked ecological validity. Patient rejection attitudes identified amongst family members and professionals and preferences for social distance may indicate prejudice and discrimination, however this requires further study. Fear of rejection may alternatively result from the operation of the social-cognitive model which suggests that if individuals with HD internalise hoarding stigma and withdraw from others due to fear of negative reactions as was reported in qualitative studies reviewed, this may ultimately lead to rejection by important people in their lives.

There is some support for the stage model of self-stigma (Corrigan & Rao, 2012) as people with HD were *aware* of stereotypes about hoarding, some *agreed* with these, and some *applied these to themselves*, indicated by feelings of shame, guilt and frustration described in many studies and self-discriminatory behaviours like social withdrawal and not seeking treatment ('why try'). However, not all people who hoarded agreed with stereotypes, or that hoarding was a negative or stigmatised part of their identity, and although as expected this corresponded with not all people with HD reporting internalised stigma, some still experienced the negative sequelae of internalised stigma like shame and social withdrawal. Lower stereotype endorsement in these cases may reflect limited insight into or shame about hoarding difficulties, raising questions around how to explore internalised stigma in HD. Part of the challenge in fitting hoarding to an overarching internalised stigma theory may be related to theories that hoarding represents a final common pathway of multiple psychological mechanisms, as these may each interact differently with stigma. Research into the relationship between people who differ in terms of the mechanisms underpinning hoarding and the occurrence of internalised stigma may improve understanding of what is clearly a complex relationship.

Research is required into both hoarding stereotypes *and* emotional and behavioural reactions to these in the public and people who hoard to explore the social-cognitive model of stigma more thoroughly. This would inform the development and validation of direct measures of internalised and public stigma suitable for use with people who hoard. Most likely this will involve the development of a specific measure, although adaptation of existing measures may be a viable alternative. Comparisons between people who hoard and other groups such as those with OCD, Depression or psychosis in terms of internalised stigma would provide a benchmark. Studies should examine the impacts of internalised and perceived stigma on help-seeking in hoarding, alongside other self-discriminatory behaviours. Crucially, hoarding stigma has yet to be *directly* evaluated amongst health professionals, and this may have important implications for understanding barriers to people who hoard receiving treatment. Tolin et al. (2012) found that healthcare professionals experienced more frustration and poorer working alliance with hoarding compared to non-hoarding clients. This may indicate negative professional attitudes towards hoarding that could undermine the treatment effectiveness or accessibility. Studies using vignettes may be useful to elucidate stigma in both public and professionals. This should then be compared with other conditions, including subtypes of presentations like OCD which may be subject to different levels of stigma (Ponzini & Steinman, 2022).

One way that people seek support for mental health difficulties is through support and encouragement of loved ones, which may be a problem for people who hoard, who report having less social support (Edwards et al., 2023). It has been hypothesised that this may reflect both their *perception* of support and relationship quality and *actual*

Table A1
Quantitative Study Quality Assessment Table using the QualSyst Tool

Study	**Q1-** Aims and Objectives	**Q2-** Appropriate Design	**Q3-** Sampling	**Q4-** Participant Characteristics	**Q5-** Random allocation	**Q6-** Blinding investigators	**Q7-** Blinding subjects	**Q8-** Measures	**Q9-** Sample size	**Q10-** Analysis	**Q11-** Estimates of variance	**Q12-** Controlled for confounding	**Q13-** Results	**Q14-** Conclusions	Summary Score	Kmet Quality Rating
2. Chasson et al. (2018)	2	2	2	2	NA	NA	NA	1	2	2	2	NA	2	2	0.95	Strong
8. Robertson et al. (2020)	2	2	2	2	NA	NA	NA	2	1	2	2	1	2	2	0.91	Strong
10. Chou et al. (2018)	1	2	1	2	NA	NA	NA	2	2	2	2	1	2	2	0.86	Strong
15. Tolin et al. (2012)	2	2	1	1	NA	NA	NA	1	2	2	2	1	2	2	0.82	Strong
4. Fontenelle et al. (2021)	1	2	1	2	NA	NA	NA	2	2	1	2	1	2	2	0.82	Strong
1. Bates et al. (2020)	2	2	1	2	1	NA	0	1	2	2	2	1	2	2	0.77	Good
5. Krafft (2022)	2	2	2	2	1	0	NA	1	1	1	2	2	1	2	0.73	Good
6. Krafft et al. (2023)	2	2	2	2	1	0	NA	1	1	1	2	2	1	2	0.73	Good
13. Tolin, Frost, Steketee, Gray, and Fitch (2008)	1	2	1	1	NA	NA	NA	1	2	2	2	1	1	2	0.73	Good
7. Mataix-Cols et al. (2013)	1	2	1	2	NA	NA	NA	1	1	1	2	0	2	1	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.

Table A2
Qualitative Study Quality Assessment Table using the QualSyst Tool

Study	Q1- Aims and Objectives	Q2- Appropriate Design	Q3- Context	Q4- Connection to theory	Q5- Sampling	Q6- Data collection	Q7- Analysis	Q8- Credibility checks	Q9- Conclusions	Q10- Reflexivity	Summary Score	Kmet Quality Rating
3. Bates (2023)	2	2	2	2	2	2	2	2	2	0	0.90	Strong
12. Subramaniam et al. (2020)	2	2	2	2	2	2	1	2	2	0	0.85	Strong
14. Wilbram et al. (2008)	1	2	2	2	1	2	2	2	2	1	0.85	Strong
9. Brien et al. (2018)	1	2	2	2	1	1	1	2	1	1	0.70	Adequate
11. Orr et al. (2019)	1	2	2	2	1	2	2	0	2	0	0.70	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 Kmet tool guidance which suggests that ‘NA’ scores should not count negatively towards the quality rating.

rejection by friends and family. Indeed, this review identified that family members may experience associative stigma as well as stigma towards people who hoard, however the scant research was limited by sampling which may have been biased towards those who experienced greater distress. This could have implications for how family are included in therapy, such as Family-As-Motivators Training (Chasson et al., 2014), however substantial further research is needed.

Regarding implications, research suggests that media presentations of hoarding may increase stigmatizing attitudes, thus messages these convey should be carefully considered. Targeted stigma reduction campaigns, which have shown success in other mental health domains (Evans-Lacko et al., 2014; Watson & Corrigan, 2005) could also be helpful. Often stigma reduction campaigns are based on biogenetic explanations of mental illness. Haslam and Kvaale (2015) in their Mixed-Blessings model suggest that there can be distinct disadvantages to such an approach, as whilst it may soften public and internalised stigma by diminishing blame as noted by some participants in our reviewed studies, it can have negative implications for both patients and the public by increasing pessimism for recovery, reinforcing stereotypes, and encouraging avoidance. Other stigma reduction interventions are based on contact, which has reduced desire for social distance and perceived dangerousness in other mental health problems by disconfirming negative stereotypes (Corrigan, 2007). However, the present review highlighted that familiarity with someone with HD either had no effect or increased ratings of disdain and blame, suggesting that interventions based on contact may be ineffective or actively unhelpful in hoarding if stereotypes are instead confirmed. Further research into the impact of familiarity on hoarding stigma is therefore needed.

A major limitation of the reviewed research was stigma measurement. Use of unvalidated measures of stigma and measures designed for other mental illnesses that may not be relevant to hoarding risked underestimating stigma and undermined the validity of findings.

This review itself has several limitations. First, by excluding research not published in English we may have limited generalisability of our findings to other cultural contexts. However, non-English language research did not appear in preliminary searches. A strength of the review is the inclusion of qualitative research, studies involving stigma related concepts, and the use of the “grey” literature. This allowed us to comprehensively synthesise all quantitative data and descriptions of stigma in a research area where little published literature currently exists, and reduced the risk of under-representation of null findings on account of publication bias. However, study heterogeneity made quality assessment challenging, particularly in light of limitations of the QualSyst tool. Exclusion of ‘inapplicable’ items and reliance on subjective ‘appropriateness’ meant scores assigned to papers varied depending on design and did not credit more rigorous designs, and scores did not necessarily indicate the study’s value in relation to understanding stigma. Additionally, key methodological issues which undermined findings were often only reflected in a small loss of points. However, the QualSyst enabled us to use a single quality appraisal tool for all studies.

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CRediT authorship contribution statement

Rachel M. Prosser: Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **James P. Dennis:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis. **Paul M. Salkovskis:** Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Given their role as editorial board member, Professor Salkovskis had no involvement in the peer review of the article and has no access to information regarding its peer review If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

No data was used for the research described in the article.

Appendix A

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Appendix 1.C- QualSyst Ratings

Table C1.

Quantitative Study Quality Assessment Table using the QualSyst Tool

Study	**Q1-** Aims and Objectives	**Q2-** Appropriate Design	**Q3-** Sampling	**Q4-** Participant Characteristics	**Q5-** Random allocation	**Q6-** Blinding investigators	**Q7-** Blinding subjects	**Q8-** Measures	**Q9-** Sample size	**Q10-** Analysis	**Q11-** Estimates of variance	**Q12-** Controlled for confounding	**Q13-** Results	**Q14-** Conclusions	Summary Score	QualSyst Quality Rating
2. Chasson et al (2018)	2	2	2	2	NA	NA	NA	1	2	2	2	NA	2	2	.95	Strong
8. Robertson et al (2020)	2	2	2	2	NA	NA	NA	2	1	2	2	1	2	2	.91	Strong
10. Chou et al (2018)	1	2	1	2	NA	NA	NA	2	2	2	2	1	2	2	.86	Strong
15. Tolin et al (2012)	2	2	1	1	NA	NA	NA	1	2	2	2	1	2	2	.82	Strong
4. Fontenelle et al (2021)	1	2	1	2	NA	NA	NA	2	2	1	2	1	2	2	.82	Strong
1. Bates et al (2020)	2	2	1	2	1	NA	0	1	2	2	2	1	2	2	.77	Good
5. Krafft (2022)	2	2	2	2	1	0	NA	1	1	1	2	2	1	2	.73	Good
6. Krafft et al (2023)	2	2	2	2	1	0	NA	1	1	1	2	2	1	2	.73	Good

13. Tolin et al (2008)	1	2	1	1	NA	NA	NA	1	2	2	2	1	1	2	.73	Good
7. Mataix-Cols et al (2013)	1	2	1	2	NA	NA	NA	1	1	1	2	0	2	1	.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 QualSyst tool guidance which suggests that “NA” scores should not count negatively towards the quality rating.

Table C2.

Qualitative Study Quality Assessment Table using the QualSyst Tool

Study	**Q1-** Aims and Objectives	**Q2-** Appropriate Design	**Q3-** Context	**Q4-** Connection to theory	**Q5-** Sampling	**Q6-** Data collection	**Q7-** Analysis	**Q8-** Credibility checks	**Q9-** Conclusions	**Q10-** Reflexivity	Summary Score	QualSyst Quality Rating
3. Bates (2023)	2	2	2	2	2	2	2	2	2	0	.90	Strong
12. Subramaniam et al (2019)	2	2	2	2	2	2	1	2	2	0	.85	Strong
14. Wilbram et al (2010)	1	2	2	2	1	2	2	2	2	1	.85	Strong
9. Brien et al (2018)	1	2	2	2	1	1	1	2	1	1	.70	Adequate
11. Orr et al (2019)	1	2	2	2	1	2	2	0	2	0	.70	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 QualSyst tool guidance which suggests that “NA” scores should not count negatively towards the quality rating.

Appendix 2- Service Improvement Project

Appendix 2.A- The Cognitive Behavioural Therapist Instructions for Authors

To assist the reader, all tables and figures have been integrated into the main text, as opposed to submitted separately. The key learning aims, key practice points, and further reading were provided for submission but are not included in the main body of the thesis.

Preparing your Materials

All articles must include the following sections:

1. **Key Learning Aims** (3 – 5 bullet points)
   - Position – After the Abstract and Keywords
   - Intention – What will the reader learn through reading the paper?
2. **Key Practice Points** (3 – 5 bullet points)
   - Position – before the references
   - Intention – a summary of the papers with clear and practical implications for the day-to-day practice of CBT therapists
3. **Further Reading**
   - Position – before the references and after the Key Practice Points
   - Intention – to direct the reader to other relevant follow up literature

This stipulation is in keeping with the practitioner and professional development aims of the journal.

The main types of articles published are detailed below as a guide. Many of these will be therapy related but tCBT also welcomes papers related to subject areas such as CBT supervision and training.

Most papers will have a subject area (e.g. therapy, assessment, supervision, training, service development) and a paper type (e.g. Original Research, Case Study, Review) e.g. a single case study looking at the impact of supervision, an empirically grounded clinical guidance paper focussing on a training method.

Research Transparency
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Types of Paper
Original Research*

Research evidence is at the heart of the practice of cognitive and behavioural psychotherapists. Original research will be published that directly relevant to the practice of CBT, such as the therapeutic relationship, therapeutic process and the evaluation of therapeutic strategies and techniques. It is expected that such reports meet both the necessary standards of scientific rigour and the journal's requirement of clear implications for the practice of CBT. Consequently, the description of the research and the presentation of results should be sufficiently brief to enable sufficient discussion of the practice implications. Consideration will be given to quantitative, qualitative and mixed approaches given appropriate fit between the question, methodology and research methods chosen.

For examples see:
Hutton, J., Ellett, L., & Berry, K. (2017). Adult attachment and paranoia: An experimental investigation. *The Cognitive Behaviour Therapist, 10*, E4. doi:10.1017/S1754470X17000058

Kobori, O., Salkovskis, P., Pagdin, R., Read, J., & Halldorsson, B. (2017). Carer's perception of and reaction to reassurance seeking in obsessive compulsive disorder. *The Cognitive Behaviour Therapist, 10*, E7. doi:10.1017/S1754470X17000095

McManus, F., Leung, C., Muse, K., & Williams, J. (2014). Understanding 'cyberchondria': An interpretive phenomenological analysis of the purpose, methods and impact of seeking health information online for those with health anxiety. *The Cognitive Behaviour Therapist, 7*, E21. doi:10.1017/S1754470X14000270

This category of paper type could also include single-case experimental design research or a case series.

For example see:
Thomson, C., Wilson, R., Collerton, D., Freeston, M., & Dudley, R. (2017). Cognitive behavioural therapy for visual hallucinations: An investigation using a single-case experimental design. *The Cognitive Behaviour Therapist, 10*, E10. doi:10.1017/S1754470X17000174

Empirically Grounded Clinical Guidance Papers*

Some of the most widely-read and discussed papers in tCBT have been those that are the synthesis of clinical experience, using informed reasoning to link limited direct evidence in the field with evidence from wider fields.

tCBT is very keen to consider submission of such papers in relevant fields that are of interest to CBT therapists, supervisors and trainers. These tend to be written by experts in the field and are designed to solve specific practical problems or clarify gaps in our knowledge. Ideally they lead to practical implications and recommendations whilst generating hypotheses for future research.

For examples see:
Barton, S., Armstrong, P., Wicks, L., Freeman, E., & Meyer, T. (2017). Treating complex depression with cognitive behavioural therapy. *the Cognitive Behaviour Therapist, 10*, E17.

Duffy, M., & Wild, J. (2017). A cognitive approach to persistent complex bereavement disorder (PCBD). *the Cognitive Behaviour Therapist, 10*, E16.

Freeston, M., Tiplady, A., Mawn, L., Bottesi, G., & Thwaites, S. (2020). Towards a model of uncertainty distress in the context of Coronavirus (COVID-19). *The Cognitive Behaviour Therapist, 13*, E31. doi:10.1017/S1754470X2000029X

Freeston, M., Thwaites, R., & Bennett-Levy, J. (2019). 'Courses for Horses': Designing, adapting and implementing self-practice/self-reflection programmes. *The Cognitive Behaviour Therapist, 12*, E28.

Menzies, R., & Menzies, R. (2020). Death anxiety in the time of COVID-19: Theoretical explanations and clinical implications. *The Cognitive Behaviour Therapist, 13*, E19. doi:10.1017/S1754470X20000215

Murray, H., Merritt, C., & Grey, N. (2015). Returning to the scene of the trauma in PTSD treatment - why, how and when? *the Cognitive Behaviour Therapist, 8*, 1–12.

Murray, H., Pethania, Y., & Medin, E. (2021). Survivor guilt: A cognitive approach. *The Cognitive Behaviour Therapist, 14*, E28. doi:10.1017/S1754470X21000246

Warnock-Parkes, E., Wild, J., Thew, G., Kerr, A., Grey, N., Stott, R., . . . Clark, D. (2020). Treating social anxiety disorder remotely with cognitive therapy. *The Cognitive Behaviour Therapist, 13*, E30. doi:10.1017/S1754470X2000032X

Young, K., Chessell, Z., Chisholm, A., Brady, F., Akbar, S., Vann, M., . . . Dixon, L. (2021). A cognitive behavioural therapy (CBT) approach for working with strong feelings of guilt after traumatic events. *The Cognitive Behaviour Therapist, 14*, E26. doi:10.1017/S1754470X21000192

Case Studies*

Dissemination of effective practice will be promoted through the publication of case studies that involve CBT with individuals, couples, groups and families. A suggested template is provided which is designed to ensure sufficient information is provided to allow other therapists to replicate successful therapy. All articles must include 3-5 learning objectives that will be achieved through reading the article. At the end of each paper a summary of the main practice points should be included with suggestions for follow-up reading. This stipulation is in keeping with the practitioner and professional development aims of the journal.

The case study should contribute to the development of theory or clinical practice, and feed into CBT practice as a whole rather than just relating to the specific case. Case studies should generally follow this structure:

- Abstract
- Key Learning Points
- Introduction: including an outline of theoretical research and clinical literature relevant to the case

- Presenting problem: including information on the presenting problem and associated goals of treatment, diagnosis, relevant history and development of problems, scores on standard and idiographic measures, relevant history
- Formulation: including a relevant theory-based CBT model used as a framework.
- Course of therapy: including methods used linked to theory and assessment of progress; difficulties encountered and any innovations in therapy
- Outcome: including clinical change, progress towards goals, change to measures, plans for follow-up
- Discussion: including relating to theory and evidence-base as well as reflections on own practice; implications for therapy and recommendations for other clinicians
- Key Practice Points
- Further Reading

For examples see:
Bernstein, R., Angell, K., & Dehle, C. (2013). A brief course of cognitive behavioural therapy for the treatment of misophonia: A case example. *The Cognitive Behaviour Therapist, 6*, E10. doi:10.1017/S1754470X13000172

Jenkins, P. (2017). Can temporary cessation of CBT really be therapeutic? A case study. *The Cognitive Behaviour Therapist, 10*, E8. doi:10.1017/S1754470X17000101

In addition to clinical case studies, there may be case studies related to training or supervision which would require a slightly amended structure to the one outline above.

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At times tCBT will invite papers on specific issues where there is a gap in the clinical literature. This may involve commissioning papers directly from experts in a particular area or this may be a call to the wider CBT community.

Reviews*
Reviews of historical, contemporary, or innovative approaches to practice are also sought providing that they demonstrate relevance to the practice of the current cognitive and behavioural psychotherapies. Prospective authors for review papers should initially discuss their proposals with the Editor-in-Chief.

Reviews of Assessment Tools and Methods*
Reviews of clinical scales and other assessment methods will also be considered.
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For examples see:

Hyland, P., Shevlin, M., Adamson, G., & Boduszek, D. (2013). The factor structure and composite reliability of the Profile of Emotional Distress. *The Cognitive Behaviour Therapist, 6*, E15. doi:10.1017/S1754470X13000214

Reiser, R., Cliffe, T., & Milne, D. (2018). An improved competence rating scale for CBT Supervision: Short-SAGE. *The Cognitive Behaviour Therapist, 11*, E7. doi:10.1017/S1754470X18000065

Service Models, Forms of Delivery and Cultural Adaptations of CBT*

The service model is the clinical and operational framework that exists to support the therapist with the delivery of cognitive behavioural therapies. Description and evaluation of innovative clinical service models (both in the UK and internationally) and delivery formats that can be generalised to other services will be considered for publication. Audits will only be considered if they are of wider interest and value in informing the work of other services. tCBT is keen to publish research that either expands the evidence base for previously under-represented groups or work that describes and evaluates cultural adaptations that are required for different populations.

For examples see:

Jankowska, M. (2019). Cultural modifications of cognitive behavioural treatment of social anxiety among culturally diverse clients: A systematic literature review. The Cognitive Behaviour Therapist, 12, E7. doi:10.1017/S1754470X18000211

King, D., & Said, G. (2019). Working with unaccompanied asylum-seeking young people: Cultural considerations and acceptability of a cognitive behavioural group approach. The Cognitive Behaviour Therapist, 12, E11. doi:10.1017/S1754470X18000260

Thew, G. (2020). IAPT and the internet: The current and future role of therapist-guided internet interventions within routine care settings. The Cognitive Behaviour Therapist, 13, E4. doi:10.1017/S1754470X20000033

Thew, G., MacCallam, J., Salkovskis, P., & Suntharalingam, J. (2017). Developing and evaluating psychological provision in the acute hospital setting for patients with chronic respiratory disease. The Cognitive Behaviour Therapist, 10, E5. doi:10.1017/S1754470X17000071

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Style Guide

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Data Availability Statement

This is a brief statement about whether the authors of an article have made the evidence supporting their findings available, and if so, where readers may access it. More information on Data Availability Statements and example statements can be found here. Please note that if you are not making your data publicly available, we ask you to state the reason why in your cover letter to the Editor. Also see information on Data Availability below in these instructions.

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This should summarize the article in no more than 250 words, references should not be included in the abstract.

Keywords

Please include up to six key words that could be used to effectively search for the article.

Key Learning Aims

Body of paper

This should begin with an introduction, succinctly introducing the point of the paper to those interested in the general area of the journal. Attention should be paid to the Editorial Statement. The appropriate positions of tables and figures should be indicated in the text. Footnotes should be avoided where possible.

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Key Practice Points

Further Reading

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Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm000...

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Study Protocols	SPIRIT	http://www.spirit-statement.org/

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Appendix 2.B- Manuscript Published in the Cognitive Behavioural Therapist

The Cognitive Behaviour Therapist (2024), vol. 00, page 1 of 17
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SERVICE MODELS, FORMS OF DELIVERY AND CULTURAL ADAPTATIONS OF CBT

Which older adults do not opt-in to Talking Therapies and why?

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Abstract

Older adults are under-represented in Talking Therapies (previously named IAPT) services in the UK, a national priority for improvement in the NHS. A Talking Therapies service in the south of England identified that many older adults who were referred did not opt-in to assessment. We aimed to explore the characteristics of these older adults and understand their experiences, to inform recommendations to support them to opt-in to the service in future. First, demographic and referral characteristics were compared for older adults who did and did not opt-in, to explore any that increased odds of not opting-in. Next, surveys and semi-structured interviews were used to investigate older adults' reasons for not opting-in. Responses were thematically analysed, and themes were categorised using the COM-B model to inform theory-based recommendations. Older age, being of from an ethnic minority group, having a previous referral, not being able to receive text messages, and not self-referring (e.g. being referred by GP) all significantly increased the chances of older adults not opting-in. Thematic analysis found that impersonal and confusing processes, as well as older adults' limited knowledge of Talking Therapies, beliefs about therapy, and physical, cognitive and life changes with age were barriers to opting-in. Several recommendations are made, including ideas to increase accessibility of information, change procedures to improve personal connection, and explore and overcome practical barriers. Improving routine data and feedback collection from people who do not opt-in will be important to inform and evaluate improvements.

Key learning aims

(1) To recognise that the ongoing issue of under-representation of older adults within Talking Therapies extends beyond barriers to referral.
(2) To understand demographic and referral characteristics that may increase the likelihood of older adults not opting-in to a Talking Therapies service following referral.
(3) To understand the experiences of older adults who do not opt-in and the barriers they cite, exploring factors that impacted their capability, opportunity and motivation to opt-in.
(4) To consider how services could change their procedures, information sharing, and community outreach to better serve older adults.

Keywords: Improving access; Older adults; Service evaluation; Talking Therapies

Introduction

Background

Amongst older adults, mental health difficulties are common, with depression affecting 22–28% (Age UK, 2016) and anxiety affecting 5% (Bryant *et al.*, 2007). Despite this, older adults are significantly less likely to be referred for psychological therapies than their working age counterparts (Frost *et al.*, 2019; Nair *et al.*, 2020; Walters *et al.*, 2018). In fact, Cooper *et al.* (2010) found that younger adults were 80% more likely than older adults with comparable mental health difficulties to receive therapy. This inequality increases with age, with those aged ≥85 years five times less likely to be referred for psychological therapies than those aged 55–59 years (Walters *et al.*, 2018).

Such patterns have been observed in Talking Therapies (previously called Improving Access to Psychological Therapies, IAPT), the UK's initial treatment pathway for anxiety and depression. Older adults represent just 5.1% of their referrals (NHS Digital, 2021), significantly below the government target of 12%. However, when older adults access Talking Therapies, they are more likely to complete treatment and experience better outcomes (NHS Digital, 2021; Pettit *et al.*, 2017).

Numerous studies have explored why older adults are under-referred for and are under-accessing mental health support. Common barriers have included the belief that poor mental health is an understandable part of ageing (amongst both older adults and healthcare professionals), stigma, fear of burdensomeness, and discomfort talking about mental health (Frost *et al.*, 2019; Nair *et al.*, 2020; Wuthrich and Frei, 2015). In addition, practical barriers such as mobility and frailty, transport to sessions, and confidence accessing online therapy may prevent older adults from accessing treatment (Age UK, 2024). These barriers may interfere with access not only at referral, but also in decisions to opt-in to therapy once referred.

Service context and background

In 2021, a Talking Therapies service in the South of England identified that under 2% of clients accessing therapy were over 65 years, in line with the national under-representation of older adults accessing psychological therapies, but lower than the national average. The service also found that from July to August 2021, 35% of older adults referred were not assessed. For many this was because the service decided that Talking Therapies was not a suitable referral for the client; however, in over half of these cases the older adults did not opt-in for assessment, declined assessment, or did not attend their assessment (hereafter referred to as did not opt-in [DNOI]; personal communication, November 2021).

Increasing access to psychological therapies for older adults is a national priority across all mental health services, and increasing access to Talking Therapies for older adults is one of the key NHS objectives for 2023–2024 (NHS England, 2022). Staff at Talking Therapies were committed to increasing the number of older adults seen; however, efforts to date had focused on increasing referrals. It was evident that alongside increasing referrals, understanding why so many older adults who *were* referred DNOI was essential, thus this project was commissioned.

Theory of behaviour change

Barriers to opting-in will be considered within the COM-B model (Michie *et al.*, 2011), a model of behaviour change. The COM-B model proposes that for behaviours like opting-in to occur, people must have Capability (internal factors like physical and psychological skills and knowledge), Opportunity (external factors like physical and social circumstances), and Motivation (automatic processes like emotion, and reflective processes like beliefs and plans).

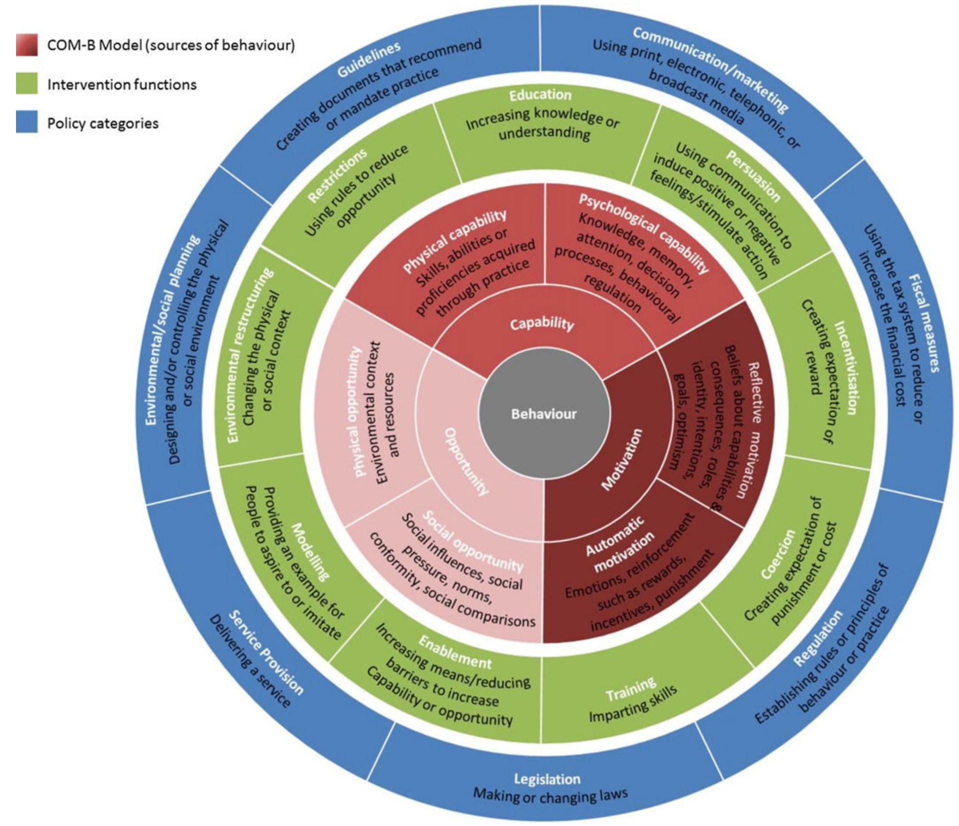

Figure 1. The Capability-Opportunity-Motivation-Behaviour (COM-B) model at the centre of the Behavioural Change Wheel. The COM-B model is depicted with associated interventions and policy categories, each with a brief description. Reproduced from McDonagh *et al*. (2020) under Creative Commons Attribution 4.0 Unported (CC BY 4.0) license.

This framework can be used to help identify corresponding evidence-based intervention approaches (see Fig. 1) and is increasingly used in healthcare research. It has informed recommendations to change the behaviours of healthcare professionals and service-users in areas like digital risk assessment (Lau-Zhu *et al*., 2022), medication adherence (Mishra *et al*., 2021) and social prescribing (Aughterson *et al*., 2020).

Aims

A service evaluation was consequently approved with the following aims:

(1) To understand the characteristics of older adults who DNOI to Talking Therapies.
(2) To explore how older adults who DNOI experience the process of opting-in at Talking Therapies, and their reasons for not opting-in.
(3) To make recommendations for overcoming barriers to opting-in to increase the accessibility of Talking Therapies for older adults.

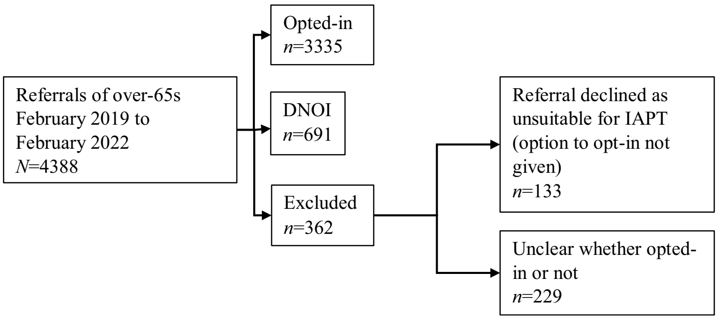

Figure 2. Process of identifying the opted-in and DNOI groups.

Phase 1 Method

Design

Phase 1 involved cross-sectional quantitative analysis of data routinely collected by Talking Therapies at referral, to understand differences between older adults who do and DNOI.

Sample and procedure

Anonymised data were extracted for people aged 65 years and over who were referred to Talking Therapies between 1 February 2019 and 1 February 2022; 4388 referrals were made in this time-period; 3335 where the client opted-in, 691 where the client DNOI, and 362 where this was unclear or the option to opt-in was not offered so these were excluded. The process of identifying referrals to be included and excluded is illustrated in Fig. 2. A retrospective dataset of 4026 referrals was formed. Some clients had multiple referrals in the time-period studied, thus the 4026 referrals in the dataset were for 3796 clients.

Analysis

Analyses were conducted using IBM SPSS statistics version 28 (IBM Corporation, 2021). The opted-in and DNOI groups were compared on demographic and referral characteristics using chi-square test of homogeneity, t-tests or Mann–Whitney U-test. Tests of normality determined which variables met criteria for parametric analysis. Due to small sample sizes within variable categories, many were simplified to ensure that expected frequencies met the assumptions of the analyses used.

Next, binomial logistic regression with simultaneous entry was used to establish the individual contributions of variables that differed between the groups to predicting not opting-in. Whether English was a first language was not included, as 80% of cases were excluded due to missing data; 3296 cases were included in the regression, 2919 who opted-in and 377 who DNOI.

Phase 1 Results

Sample characteristics

Clients were 72.9 years on average ($SD = 6.5$, range = 65–99), predominantly female (67.9%, $n = 2732$) and of White British ethnicity (79.5%, $n = 3202$). The Index of Multiple Deprivation Decile, a measure of relative deprivation (1 = most deprived, 10 = least deprived; McLennan *et al.*, 2019), had a median of 8 (range = 1–10); 25.3% of clients had a disability ($n = 1018$), and 52.7% had one or more long-term conditions ($n = 2123$).

Table 1. Opt-in status by time period

	Overall ($N = 4388$)		February 2019 to February 2020 ($n = 1603$)		March 2020 to February 2021 ($n = 1232$)		March 2021 to February 2022 ($n = 1553$)	
Opted in?	*n*	%	*n*	%	*n*	%	*n*	%
Yes	3335	76.0	1279	79.8	918	74.5	1138	73.3
No	691	15.7	197	12.3	206	16.7	288	18.5
Not suitable for Talking Therapies	133	3.0	35	2.2	41	3.3	57	3.7
Ambiguous	229	5.2	92	5.7	67	5.4	70	4.5

A majority of the sample were self-referred (61.8%, $n = 2490$), relatively evenly split between the East and West of the county; 43.7% of referrals ($n = 1760$) had at least one previous referral ($M = 1.0$, $SD = 1.6$); 71.3% of referrals ($n = 2871$) were able to receive text messages. Full sample characteristics are reported in Appendix A of the Supplementary material.

Table 1 shows the numbers of older adults referred and opting-in over the audit period. Notably, the proportion of older adults who DNOI increases.

Group differences

The opted-in and DNOI groups differed significantly on 10 variables, presented in Table 2.

Demographics

The DNOI group were significantly older on average than the opted-in group. A significantly higher proportion of clients who were from ethnic minority backgrounds, had a disability, had a long-term condition, or did not speak English as their first language DNOI. However, these associations were weak and explained at most 1.1% of the variance in opt-in. There were no significant differences across gender, Index of Multiple Deprivation Decile (IMDD), relationship status or sexuality.

Referral characteristics

A significantly higher proportion of clients who had no previous referral, were referred by others, were from the east of the county, and could not receive text messages DNOI. The proportion of clients who DNOI significantly increased with each referral period. However, these associations were weak and explained at most 6.3% of the variance in opt-in. There was no significant difference in number of previous referrals.

Binomial logistic regression

A binomial logistic regression was performed to ascertain the relative odds of not opting-in whilst controlling for inter-relationships between the variables (Table 3). The model was statistically significant, $\chi^2(10) = 113.228$, $p < .001$, and explained 6.6% (Nagelkerke R^2) of the variance in opting-in. It correctly classified 88.6% of cases, but showed no discrimination ability. Only age, ethnicity, whether previously referred, whether text messages were allowed, and referral source remained significant as predictors of not opting-in. Increasing age was associated with increased likelihood of not-opting in. Not opting-in was 2.16 times more likely for people from ethnic minority groups, 1.74 times more likely if not able to receive text messages, and 1.92 times more likely if referred by others. People with a previous referral were more likely to not-opt in.

Table 2. Comparisons of older adults who did and did not opt-in

	Opted-in ($n =$ 3335)		Did not opt-in ($n =$ 691)				
Variable	*n*	%	*n*	%	Test statistic	Significance	Effect size
Age (median, range)	71.0	65–99	73.0	65–99	$U = 981332.00$, $z = -6.157$	$p < .001$	$r = .10$
Gender					$\chi^2(1, N = 4026) = 0.01$	$p = .935$	
Female	2264	82.9	468	17.1			
Male	1071	82.8	223	17.2			
Ethnicity*					$\chi^2(1, N = 3547) = 23.73$	$p < .001$	$\phi = .08$
White	2820	88.1	382	11.9			
Ethnic Minority	272	78.8	73	21.2			
Sexuality*					$\chi^2(1, N = 2694) = 2.61$	$p = .106$	
Heterosexual	2342	89.0	289	11.0			
Non- heterosexual	52	82.5	11	17.5			
Disability?					$\chi^2(1, N = 3538) = 13.22$	$p < .001$	$\phi = .06$
Yes	861	84.6	157	15.4			
No	2243	89.0	277	11.0			
Long-term condition?					$\chi2(1, N = 3689) = 7.56$	$p = .006$	$\phi = .05$
Yes	1819	85.7	304	14.3			
No	1390	88.8	176	11.2			
Relationship status*					$\chi^2(1, N = 2903) = 1.80$	$p = .180$	
In a relationship	1475	86.6	172	10.4			
Not in a relationship	1105	88.0	151	12.0			
English first language?						$p = .007$	$\phi = .10$
Yes	710	88.3	94	11.7			
No	21	70.0	9	30.0			
IMDD (median, range)	8.0	1–10	8.0	1–10	$U = 1108740.00$, $z = -1.421$	$p = .155$	
Referral source*					$\chi^2(1, N = 4026) = 246.24$,	$p < .001$	$\phi = .25$
Self	2245	90.2	245	9.8			
Other	1090	71.0	446	29.0			
Locality					$\chi^2(1, N = 4026) = 9.69$	$p = .002$	$\phi = .05$
East	1593	80.9	375	19.1			
West	1742	84.6	316	15.4			
Previous referral					$\chi^2(1, N = 4026) = 4.46$	$p = .035$	$\phi = .03$
Yes	1483	84.3	277	15.7			
No	1852	81.7	414	18.3			
Number of previous referrals (median, range)	0.0	0–16	0.0	0–11	$U = 1098575.50$, $z = -1.947$	$p = .052$	
Text messages allowed?					$\chi^2(1, N = 4026) = 204.53$	$p < .001$	$\phi = .23$
Yes	2533	88.2	338	11.8			
No	802	69.4	353	30.6			
Referral period					$\chi^2(2, N = 4026) = 25.42$	$p < .001$	$V = .079$
Feb19–Feb20	1279	86.7	197	13.3			
Mar20–Feb21	918	81.7	206	18.3			
Mar21–Feb22	1138	79.8	288	20.2			

IMDD, Index of Multiple Deprivation Decile. Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroups. Male includes trans men, and female includes trans women.

Phase 2 Method

Design

Phase 2 involved qualitative analysis of older adult clients' reasons for not opting-in, elicited through surveys and interviews to contextualise Phase 1 findings. Their ideas for improvements to support older adults to opt-in were also sought.

Table 3. Binomial logistic regression model to predict not opting-in ($n = 3296$)

						95% CI for OR	
Variable	Parameter coding	*B*	*SE B*	Significance	OR	Lower	Upper
Age		.02	.01	.019	1.02	1.00	1.04
Ethnic group	White (0)						
	Ethnic minority (1)	.77	.16	<.001	2.16	1.57	2.99
Disability?	No (0)						
	Yes (1)	.21	.12	.085	1.24	0.97	1.58
Long-term condition?	No (0)						
	Yes (1)	−.13	.12	.294	0.88	0.70	1.11
Locality	West (0)						
	East (1)	.15	.11	.192	1.16	0.93	1.45
Previous referral?	Yes (0)						
	No (1)	−.37	.11	.001	0.69	0.55	0.86
Text messages allowed?	Yes (0)						
	No (1)	.55	.13	<.001	1.74	1.34	2.25
Referral source	Self (0)						
	Other (1)	.65	.11	<.001	1.92	1.54	2.40
Referral period	Feb 19–Feb 20 (0)			.426			
	Mar 20–Feb 21 (1)	−.10	.14	.469	0.90	0.68	1.19
	Mar 21–Feb 22 (2)	.86	.13	.509	1.09	0.84	1.41
Constant		−4.02	.67	<.001	0.02		

Participants

Clients aged 65 years and over who DNOI to Talking Therapies between September and November 2022 were invited to provide survey or interview feedback about their experience and reasons for not opting-in. Recruitment was repeated in December, January and February due to lower-than-expected response; 39 of the 60 clients referred were successfully contacted. Clients read and discussed an information sheet and gave written or oral informed consent if they agreed to participate; 18 agreed to be sent the survey, and eight completed (44.4% response rate); five online, two by telephone, and one by post. Eight clients were interviewed.

Procedure

A survey was co-developed with the Older Adult Workstream within Talking Therapies and reviewed by service users. Questions explored referral experiences, reasons for not opting in, and suggestions for improvement. These questions were subsequently developed into a semi-structured interview schedule. The survey could be completed online, by telephone, or by post. Interviews took place by telephone between February and March 2023, were audio recorded, and lasted 15–60 minutes.

Analysis

Interviews were transcribed verbatim and anonymised. Transcripts and survey free-text were analysed using thematic analysis, following guidance from Braun and Clarke (2022), using NVivo 12 (QSR International, 1999). Each transcript was read several times to aid familiarisation, and a reflexive log was kept. Keywords and phrases were used to generate initial codes, which were then reviewed and grouped into candidate themes. An inductive stance was taken whilst coding. The COM-B model was then used to organise the themes and identify intervention functions. All authors, as well as clinicians in the Older Adult Workstream, reviewed candidate and final themes to ensure credibility and coherence.

Table 4. Participant characteristics for surveys and interviews

Characteristic	Surveys ($n = 8$)		Interviews ($n = 8$)	
	n	%	*n*	%
Age (median, range)	70.0	65–80	69.5	65–74
Gender				
Male	2	75.0	4	50.0
Female	6	25.0	4	50.0
Ethnicity*				
White	8	100.0	8	100.0
Ethnic minority	0	0.0	0	0.0
English first language?				
Yes	8	100.0	8	100.0
No	0	0.0	0	0.0
Locality				
East	4	50.0	5	62.5
West	4	50.0	3	37.5
Disability?				
Yes	1	12.5	3	37.5
No	7	87.5	5	62.5
Long-term condition				
Yes	4	50.0	6	75.0
No	4	50.0	2	25.0
Referral source				
Self	3	37.5	1	12.5
Other	5	62.5	7	87.5

Male includes trans men, and female includes trans women. Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroups.

Phase 2 Results

Respondent characteristics

Characteristics of survey and interview respondents are shown in Table 4.

Thematic analysis

Four themes and 10 subthemes were identified, corresponding to capability, opportunity and motivational domains of the COM-B model (Fig. 3). Additional illustrative quotes are in Appendix B of the Supplementary material. Names are pseudonyms.

The process of referral and opt-in

Some respondents experienced ***communications*** with Talking Therapies as happening ‘smoothly’ (Angela); however, for others these were ‘another process that wasn’t working well’ (Pam) and were confusing and time-consuming, especially due to ‘pushbutton’ telephone services. For some, communication had been so poor that they were unaware of their referral until they were discharged. Others described communication issues like calls from withheld numbers and lack of voicemails, resulting in them feeling they had no opportunity to opt-in despite wanting to.

Furthermore, ***tickboxes and questionnaires*** in the process of opt-in were off-putting for many respondents as they made interactions feel scripted and made some feel like they were ‘wasting someone’s time’ as options ‘didn’t really fit’ (Survey Response).

Overall, the process was ***missing the personal touch*** that respondents felt was crucial in building the trust they required to opt-in. They emphasised the value of telephone calls where they could speak with a human and ask questions, and recommended that older adults might appreciate being followed-up by telephone call after not opting-in.

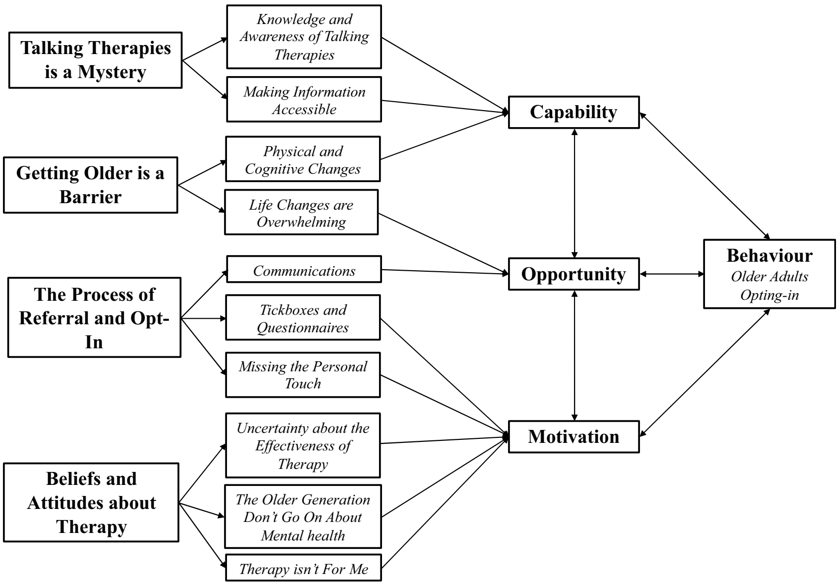

Figure 3. Themes with corresponding domains of the COM-B Model.

Talking Therapies is a mystery

Some respondents knew what Talking Therapies were, often through previous referrals, but the majority had limited ***knowledge and awareness of Talking Therapies*** and found them 'a mystery' (Survey Response). Limited knowledge of the service meant respondents did not know what to expect after referral, with one commenting: 'If people don't understand what it is they might just think, I don't know if that's what I want' (Pam). Many stressed that 'more information about what to expect' (Survey Response) and information about 'why it's worth doing and how it's helped other people' their age (Frank) would be helpful.

Regarding ***making information accessible***, online information was described as accessible for some older adults, but that others 'wouldn't even think of googling or looking online' (Survey Response) and may not have the capability or technology to access online resources. Respondents stressed that having information in multiple formats online and offline, with preference for interaction, was important.

Beliefs and attitudes about therapy

Many respondents expressed ***uncertainty about the effectiveness of therapy***, conflicted between awareness that it could be helpful but also believing that 'rambling on' could not solve problems: 'I don't think you can talk yourself out of problems . . . Life's life' (Paul). For some, these beliefs and their decision to not opt-in were influenced by previous therapy which they found unhelpful. Others felt that therapy effectiveness was therapist dependent, and worried about the youthfulness of Talking Therapies clinicians, wondering 'how could somebody inexperienced in life start to understand or help people, particularly if they're stuck in their ways like I am?' (Douglas).

Respondents commented on a generational difference, whereby ***the older generation don't 'go on about mental health'***, preferring to get on with life and 'sort yourself out' (Frank) rather than accept support. Mental health difficulties were still stigmatised for many older adults: 'a kind of shame that you're not coping' (Angela). This meant that many 'wouldn't go to the doctors unless [they were] really struggling' (Frank). Following up older adults who DNOI was therefore stressed as important, as well as normalising mood difficulties.

Many felt that ***therapy isn't for me***, for different reasons. Some 'didn't feel as if [they] needed it' (Susan). However, alongside this were narratives that their difficulties were not bad enough to warrant support, and worries that they would be in the way of 'someone else who desperately needed help' (Paul). Many acknowledged the current pressure on NHS services, not wanting to 'contribute to the backlog' (Pam) or 'bother anybody' (Susan). Conversely, others felt that Talking Therapies were too 'superficial' (Angela) to help with longstanding difficulties. Others believed that they were at the 'wrong end of life' (Paul) for therapy, believing they were too old to be helped.

Getting older is a barrier

Physical and cognitive changes were discussed, with not 'feeling well enough' (Maria) resulting in some respondents not opting-in. Although acute illness was an understandable barrier, others described longer-term health changes as barriers to opt-in: 'because of my health difficulties and . . . disability, it takes quite a lot of energy to get appointments' (Angela). Online and telephone appointments could be helpful; however, their impersonal nature was also off-putting for some. Cognitive changes also made remembering information they had been given and opting-in difficult for some: 'I get confused utterly between care providers' (Douglas). Reminders and repetition of information were considered crucial for overcoming this.

More broadly, older adults described how ***life changes are overwhelming*** and could leave them feeling too busy to opt-in, describing that life 'becomes full of barriers' (Frank) including losses related to retirement, bereavement, and health. In particular, respondents who were carers highlighted that this role 'takes over everything and [they] have little or no time or energy for anything else' (Survey Response) as they did not have sufficient support. It was suggested that asking older adults about barriers and helping them problem-solve may help, but that showing an understanding of the challenges of older age was essential.

Discussion

This service evaluation explored the characteristics of older adults who DNOI to Talking Therapies and the barriers they identified to opting-in.

Results showed that 23.9% of older adults referred to Talking Therapies in the time period audited were not seen, with 15.7% not opting-in, indicating an important point of attrition that could be targeted to increase the number of older adults accessing therapy. Opt-in rates worsened over the three years audited, and although referrals increased post-COVID, a greater proportion of older adults now DNOI, indicating that the pandemic may have exacerbated barriers to older adults opting-in, potentially linked to concerns about burdening the NHS highlighted in interviews. This is worrying as the mental health of older adults worsened throughout the pandemic (Zaninotto *et al.*, 2022) and Office for National Statistics (2022) data indicate that rates of depression remain at double pre-pandemic levels for over-70s, thus the level of unmet need may be growing.

Not opting-in was more likely with increasing age, in line with previous research which found that the proportion of clients referred to IAPT who took up assessments declined after age 64 (Pettit *et al.*, 2017). Notably, over-80s were not represented in our interview sample. Different barriers and cohort beliefs about therapy are likely to be relevant to this group compared with 'younger' older adults, and with longevity increasing it is crucial that the barriers to opting-in for different cohorts of older people are understood through further evaluation. Older adults from UK ethnic minority backgrounds were also less likely to opt-in. Racial and ethnic minority populations are less likely to access mental health services generally (Cooper *et al.*, 2013; McManus *et al.*, 2016), and were not represented in our interview sample. Exploring and addressing the barriers to opting-in experienced by older adults from minority populations should be considered in future service evaluations. Similarly, a greater proportion of the DNOI group were disabled and had long-term conditions; however, when inter-relations with other variables were controlled for these were not significant.

People who were referred by others were much more likely to not opt-in compared with those who self-referred, an effect observed across all ages in IAPT (Sweetman *et al.*, 2022). Talking Therapies may therefore wish to work with local referrers when implementing recommendations, and particularly consider older adults who are not able to self-refer by the current processes. Finally, older adults unable to receive text messages had higher odds of not opting-in, possibly indicating barriers related to access to and confidence using technology, but also highlighting a need for opt-in reminders to be offered in alternative formats.

Thematic analysis of survey and interview data showed that many older adults found the process of opting-in to Talking Therapies confusing, and sometimes had no way of knowing they had been contacted, thus no opportunity to opt-in. Respondents also expressed a strong preference for speaking with clinicians rather than navigating automated systems and questionnaires. This preference extended to ways of accessing information about the service, with most respondents having limited knowledge of Talking Therapies and emphasising that information was inaccessible for many due to it mainly being online, affecting their capability to opt-in. Participants highlighted the importance of making more information about therapy and its benefits for older adults available, and it has been shown that knowledge about treatment promotes participation (Kyle and Shaw, 2014). They valued opportunities to ask questions, indicating that allowing more time to speak with older adults may be helpful to facilitate personal connection and increase knowledge of the service.

Some beliefs about therapy were barriers to opt-in, including uncertainty about the helpfulness of therapy, but also whether problems were bad enough and not wanting to be a burden on services or prevent someone who needed it more accessing support. Some also believed they were too old to change, or that therapists were too youthful to understand and help them. These attitudinal barriers have been acknowledged by numerous studies exploring barriers to referral and uptake of therapy by older adults (Age UK, 2024; Berry *et al.*, 2020; Frost *et al.*, 2019). Some of these attitudes may reflect internalised ageism, excessively negative stereotypes and beliefs about growing old endorsed by older people and resulting in self-fulfilling limitations (Law *et al.*, 2010; Levy, 2003). Allen and Ranger (2013) emphasise the importance of exploring and challenging ageist beliefs early in therapy as part of treatment socialisation, as beliefs that they are too old to change or that they are wasting the therapist's time may increase the likelihood of disengagement. Exploring these beliefs with older adults in early conversations with Talking Therapies and through outreach may therefore promote opt-in. Stigma was also identified as an important motivational barrier to opt-in. Mental health stigma is a significant barrier to help-seeking for people of all ages (Clement *et al.*, 2015); however, its impact has been found to be stronger amongst older adults, possibly due to exposure to negative images of mental illness that used to be prevalent (Laidlaw and Knight, 2008), suggesting targeted interventions to improve this are indicated.

Cognitive and physical changes also affected respondents' capability and opportunity to opt in, making it harder to access technology, travel to appointments, and remember to opt-in, in line with previous research (Berry *et al.*, 2020; Nair *et al.*, 2020). Some older adults wanted to access therapy but felt too overwhelmed by life changes, particularly evident for respondents with caring responsibilities, who are more likely to experience poor mental health (Carers UK, 2019). Increasing awareness and availability of home-based interventions may be helpful in supporting carers and people living with mobility difficulties to opt-in.

Many barriers to opting-in identified here have also been highlighted as barriers to referral, suggesting that these are not service or opt-in specific. Indeed, the IAPT Positive Practice Guide (Age UK, 2024) makes many recommendations which are echoed in this report. This suggests that service initiatives which have focused predominantly on increasing referrals may not have

The Process of Referral and Opt-In

Communication

- To ensure that older adults have the **opportunity and capability** to opt-in, *enablement* via changes to communication procedures is required.
- For example: calls should not come from withheld numbers; if voicemails are left detail should be given of who is calling with a number to return the call; opt-in deadline could be extended; in discharge letters emphasize that re-referral is allowed and explain different ways (online and offline) to do this; follow up calls to people who don’t opt-in.

Tickboxes and Questionnaires, Missing the Personal Touch

- *Education* around why certain procedures like questionnaires are needed and *persuasion* by increasing personal connection could also be helpful in improving reflective **motivation** to opt-in.
- For example: explain in all initial letters and phone calls about why questionnaires are sent, and that if some statements don’t apply this is not an indicator that therapy is not appropriate; in initial assessments time should be taken to develop rapport and personal connection before questionnaires; acknowledge that initial calls and measures can feel ‘tickbox-y’ and scripted and explain why.

Talking Therapies is a Mystery

Knowledge and Awareness of Talking Therapies, Making Information Accessible

- *Education* to increase older adults’ knowledge of Talking Therapies and thus increase **capability** to opt-in is essential. This is likely to be most effective when it is responsive to older adults’ needs and current understanding (e.g. considering other subthemes identified such as preference for personal touch).
- *Enablement*, by reducing barriers to accessing this education though providing it in multiple formats and settings, should increase **capability and opportunity** to opt-in.
- *Environmental restructuring*, including changes to letter templates and phone call standard operating procedures, may be needed for this to be implemented.
- For example: Ensure FAQs and leaflets are provided as standard in letters, not solely directing to websites or website links; testimonials of older adults could be included in leaflets and letters; work with referrers to encourage provision of more information about Talking Therapies and how it can specifically help older adults; outreach to community groups; check in all phone calls around referral and opt-in staff that older adults know what Talking Therapies is and how it can help; give space for questions.

Figure 4. Recommended interventions grouped by themes and COM-B domains.

adequately addressed the range of barriers experienced by older adults, which then persist and affect opt-in, limiting effectiveness of efforts to increase the number of older adults accessing therapy.

Strengths and limitations

A strength of this service evaluation was the use of mixed-methodology, combining audit with surveys and interviews to offer a comprehensive understanding of the differences between

Beliefs and Attitudes about Therapy

Uncertainty about the Effectiveness of Therapy, The Older Generation Don't Go on About Mental Health, Therapy isn't for Me

- *Education* should also be utilised to increase older adults' understanding of the effectiveness of therapy and thus increase reflective **motivation** to opt-in. This could also provide *persuasion*, inducing positive feelings and stimulating action, especially if conveyed with a personal touch.
- *Modelling* by same-age peers may provide a helpful way to impart this information whilst providing examples to reassure older adults that it is okay to talk about mental health and normalise therapy, reducing negative generational social norms that restrict opportunity and increasing **motivation.**
- *Environmental restructuring*, including changes standard operating procedures for following-up older adults may be needed for this to be implemented.
- For example: provide case studies of older adults with various levels of need; include older adult service users in outreach to community groups; consider terminology used and name and challenge negative stereotypes; ensure there are pictures of older adults on posters and leaflets; training for staff involved in administration and initial contacts about assumptions older adults may hold and how to acknowledge age differences and challenge negative beliefs around mental health difficulties and therapy.

Getting Older is a Barrier

Life Changes are Overwhelming, Physical and Cognitive Changes

- *Enablement* interventions will need to be tailored to the changes that interfere with older adults' **opportunity** to opt-in to therapy.
- For example: after building rapport, ask about barriers to engaging like life stresses, caring responsibilities, cognitive difficulties, disability and help problem solve; offer choice of appointment time; offer a choice of different ways of being seen for assessment (e.g. face to face or online or phone); offer home visits or sessions at local GP; signposting to carers support if needed; training for staff involved in administration and initial contacts about adaptations for older people with hearing impairment, cognitive difficulties, frailty, or physical health conditions, as well as common changes in older age.

Figure 4. (Continued).

older adults who do and DNOI, as well as elaboration on their experiences. The use of a psychological model was a further strength, harnessing a theory-driven approach to optimise recommendations to change opt-in behaviour. Consultation of both Talking Therapies clinicians and older adult service users ensured that questions and their delivery were accessible and relevant, and additionally helped to check the feasibility of recommendations, hopefully increasing the likelihood of their implementation. Co-production of future studies with older adults may improve this further, as well as consultation of other services and charities who work with older adults. Finally, the audit time-period allowed the impact of the COVID-19 pandemic on opt-in to be studied and controlled for, indicating that differences observed were enduring.

Key limitations must also be noted. In the audit there was substantial missing data across demographic variables, largely from the DNOI group. Data may have been more complete for clients with previous episodes of care, potentially biasing the regression. This also prevented more detailed analysis of effects of sexuality, employment, relationship status, and presenting difficulties on opt-in. Collecting more data at referral would enable future evaluations to consider these. Furthermore, the sample of interview and survey respondents was small and was not representative of characteristics least likely to opt-in (e.g. from ethnic minority background, older age). Different barriers may be important for those who did not (or were not able) to participate. Feedback is currently collected from clients who have completed therapy. More routine follow-up of clients who DNOI could increase opportunities to capture and understand the views of under-represented groups.

Recommendations

Respondents suggested many potential interventions to improve opt-in behaviour of older adults, which were elaborated on after consideration of the intervention functions recommended by the COM-B model. These were provided to the service in detail and are summarised in Fig. 4 should they assist those developing or delivering services in similar settings. In addition to process changes and education, organisational culture which includes leadership encouraging attention to barriers faced by older adults across service development decisions will be needed to enable improvements. Adoption of one-size-fits-all procedures without considering the specific needs of older adults, and other underrepresented groups, risks indirect discrimination.

Conclusion

A proportion (15.7%) of older adults referred to Talking Therapies DNOI. This project has outlined which older adults may be less likely to opt-in following referral, and highlighted key barriers within domains of capability, opportunity and motivation which may negatively impact opting in. Several recommendations have been suggested to improve opt-in amongst older adults. It is hoped these recommendations will support the service to make changes to consider the needs of older adults and increase opt-in rates.

Key practice points

1. Mental health difficulties are common amongst older adults, yet they are consistently under-represented in mental health services. Considerable effort has focused on increasing referral; however, when they are referred a substantial proportion do not opt-in for support, indicating an important point of attrition that many services could target.
2. Impersonal and confusing processes, limited knowledge of who Talking Therapies are, stigma and beliefs about therapy, concerns that their problems were not severe enough and of burdening the NHS, and physical, cognitive and life changes with age were barriers to opting-in.
3. Strategies to increase accessibility of information, change procedures to improve personal connection, and explore and overcome practical and motivational barriers for older adults are suggested, which may be helpful for other services.
4. Many barriers to opting-in identified here echo research exploring barriers to referral and engaging with therapy, suggesting that they are not service or opt-in specific. Clinicians and those involved in developing services are encouraged to review the many existing materials and guidelines related to working with older people in therapy.
5. Services must consider barriers to accessing mental health services faced by older adults when considering any service developments, as otherwise these may be exacerbated and the unmet mental health needs of older adults will grow.

Further reading

Age UK (2024). NHS Talking Therapies Positive Practice Guide: Older People. //babcp.com/Therapists/Older-Adults-Positive-Practice-Guide

Charlesworth, G. (2022). Embedding the silver thread in all-age psychological services: training and supervising younger therapists to deliver CBT for anxiety or depression to older people with multi-morbidity. *the Cognitive Behavioural Therapist*, *15*, e49. https://doi.org/10.1017/S1754470X22000447

Frost, R., Bhanu, C., Walters, K., Beattie, A., & Ben-Shlomo, Y. (2019). Management of depression and referral of older people to psychological therapies: a systematic review of qualitative studies. *British Journal of General Practice*, *69*, 171–181. https://doi.org/10.3399/bjgp19X701297

Supplementary material. The supplementary material for this article can be found at //doi.org/10.1017/S1754470X24000151

Data availability statement. The anonymised quantitative data from this study is available from the corresponding author, A.C., upon reasonable request. We have not made the qualitative data used in this service evaluation publicly available as it would not be possible to be certain that the full transcripts were sufficiently anonymised, and this would not be in the best interest of the patients who participated.

Acknowledgements. The authors wish to thank the Talking Therapies service users who participated in this project. Additional thanks to Claire Hall, Natalie Holmes, Mark Hodgson, and the service users and staff members in the Berkshire Talking Therapies Older Adults Workstream who provided advice and support in the development of this project and its recommendations.

Author contributions. **Rachel Prosser:** Conceptualization (lead), Data curation (lead), Formal analysis (lead), Investigation (lead), Methodology (lead), Project administration (lead), Writing – original draft (lead), Writing – review & editing (lead); **Louisa Dosanjh:** Conceptualization (supporting), Data curation (equal), Project administration (supporting), Writing – review & editing (equal); **Grace Jell:** Conceptualization (equal), Data curation (supporting), Methodology (supporting), Writing – review & editing (equal); **Alasdair Churchard:** Conceptualization (equal), Formal analysis (supporting), Methodology (supporting), Supervision (lead), Writing – review & editing (supporting).

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Competing interests. Louisa Dosanjh and Grace Jell are employed by NHS Berkshire Talking Therapies. Rachel Prosser and Alasdair Churchard have no competing interests.

Ethical standards. The authors abided by the ethical Principles of Psychologists and Code of Conduct as set out by the BABCP and BPS. Both phases of this project were deemed service evaluation so did not require ethical approval. The project was discussed with the service research lead, then a detailed project proposal including methodology, materials and analysis was reviewed and approved by the relevant NHS Foundation Trust clinical audit and service improvement team (Audit ID: 9353).

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Appendix 2.C- Local Governance Approval

Tuesday, October 4, 2022 at 14:22:05 British Summer Time

Subject: Final Registration of Project
Date: Tuesday, 4 October 2022 at 12:45:35 British Summer Time
From: Emma Walsh
To: Rachel Prosser
CC: Louisa Dosanjh, Grace.Jell
Attachments: image001.jpg, image002.jpg, image003.jpg, image004.jpg, image005.jpg, Local Project Report Template (2021).doc

Dear Rachel,

Thank you for completing your project registration via Datix, entitled “SE - Understanding the Experiences of Older Adults who do not Opt-In to Talking Therapies Berkshire” and for your completed planning document. The project has now been registered by the team and allocated the ID number 9353. Please use this number in any correspondence to help us track the project.

The relevant Clinical Director will be made aware of your audit being undertaken within their Division. Please ensure that you liaise with the relevant Service Manager responsible for the service as they will need to be aware that you are undertaking this project within their area.

Once your audit has been completed, please send a copy of the project report and action plan to the Clinical Audit department by the review date stated. It is also expected that the completed report and action plan should be sent to the divisional PSQ meeting relevant to the audit for monitoring.

If you need any further information, please contact the Clinical audit team: clinical.audit@berkshire.nhs.uk.

Kind Regards,

Emma

Emma Walsh
Clinical Audit & Effectiveness Facilitator
Clinical Audit Department
Working from Home – please contact via Microsoft Teams or email
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Care Quality Commission Inspected and rated Outstanding
NHS Berkshire Healthcare NHS Foundation Trust

Appendix 2.D- Demographic and Referral Characteristics in Full

Table D1.

Demographic Characteristics of Overall Sample and by Opt-In Group

Characteristic	Overall (*N*= 4026)		Opted-in (*n*= 3335)		Did not opt-in (*n*= 691)	
	n	%	*n*	%	*n*	%
Age (*M, SD*)	72.9	6.5	72.6	6.3	74.4	7.1
Gender						
Female	2732	67.9	2264	67.9	468	67.7
Male	1294	32.1	1071	32.1	223	32.3
Ethnicity*						
White	3202	79.5	2820	84.6	382	55.3
Ethnic Minority	345	8.6	272	8.2	73	10.6
Missing	479	11.9	243	7.3	236	34.2
Sexuality*						
Heterosexual	2631	65.4	2342	70.2	289	41.8
Non-Heterosexual	63	1.6	52	1.6	11	1.6
Missing	1332	33.1	941	28.2	391	56.6
Disability?						
Yes	1018	25.3	861	25.8	157	22.7
No	2520	62.6	2243	67.3	277	40.1
Missing	488	12.1	231	6.9	257	37.2
Long Term Condition?						
Yes	2123	52.7	1819	54.5	304	44.0
No	1566	38.9	1390	41.7	176	25.5
Missing	337	8.4	126	3.8	211	30.5
Relationship Status*						
In a relationship	304	7.6	262	7.9	42	6.1
Not in a relationship	1524	37.9	1369	41.1	155	22.4
Missing	2198	54.6	1704	51.1	494	71.5
English First Language?						
Yes	804	20.0	710	21.3	94	13.6
No	30	0.8	21	0.6	9	1.3
Missing	3192	79.3	2604	78.1	588	85.1
IMDD (*Mdn,* Range*)*	8	1-10	8	1-10	8	1-10

Note. IMDD= Index of Multiple Deprivation Decile. Male includes trans men and female includes trans women.

Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroups.

Table D2.

Referral Characteristics of Overall Sample and by Opt-In Group

Characteristic	Overall (*N*=4026)		Opted in (*n*= 3335)		Did not opt in (*n*= 691)	
	n	%	*n*	%	*n*	%
Referral Source*						
Self	2490	61.8	2245	67.3	245	35.5
Other	1536	38.2	1090	32.7	446	64.5
Locality						
East	1968	48.9	1593	47.8	375	54.3
West	2058	51.1	1742	52.2	316	45.7
Previously Referred	1760	43.7	1483	44.5	277	40.1
Number of Previous Referrals (*M, SD)*	1.0	1.6	1.0	1.6	0.9	1.5
Text Messages Allowed	2871	71.3	2533	76.0	338	48.9

Note. Characteristics marked with * are those where the categories have been simplified to broader categories due to small sample sizes within subgroup

Appendix 2.E- Survey

Understanding the Experiences of Older Adults who disengage from Talking Therapies Berkshire before assessment

As a service, Talking Therapies in Berkshire have noticed that a lot of people referred to them who are over 65 do not arrange or attend their first assessment appointment. We would like to understand the reasons for this, so we are able to improve our service and make sure that people are able to access support when they need it.

You have been contacted as you were referred to Talking Therapies in the last three months but did not arrange or attend an assessment appointment. It would be helpful for us to hear about your recent experience, and the reasons that you did not arrange or attend your appointment.

Please note that your answers can not be linked back to you and will not impact any future care you might receive from us. As this is an *anonymised* survey, we will be unable to follow anything up with you if you require further help. Therefore, if you think you require further support from our team please do not hesitate to contact us:
Telephone: 0300 365 2000
Or visit our website: talkingtherapies.berkshirehealthcare.nhs.uk

We do not anticipate that this survey will take longer than 20 minutes of your time, but if you need additional time that is also okay. Please answer the questions below in as much detail and as honestly as you are able to.

Thank you in advance for your feedback. Please do not write your name anywhere on this form.

About You

We ask these questions so that we have some information about the type of people who have given feedback. If there are any questions you would prefer not to answer, this is okay.

1. What age range do you fall into? (Please tick one)
   - ☐ 65-70
   - ☐ 71-75
   - ☐ 76-80
   - ☐ 81-85
   - ☐ 86-90
   - ☐ 91-95
   - ☐ 96-100
   - ☐ Over 100
   - ☐ Prefer not to say

2. What gender do you identify as? (Please tick one)
   - ☐ Male
   - ☐ Female

- ☐ Non-binary/ third gender
- ☐ Other (please specify)

____

- ☐ Prefer not to say

3. Which of the following best describes your ethnicity? (Please tick one)

White
- ☐ English/Welsh/Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background

Mixed/Multiple ethnic groups
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/Multiple ethnic background

Asian/Asian British
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Black/ African/Caribbean/Black British
- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/Caribbean background

Other ethnic group
- ☐ Arab
- ☐ Any other ethnic group, please describe

____

- ☐ Prefer not to say

4. Is English your first language?
   - ☐ Yes
   - ☐ No
   - ☐ Prefer not to say

5. What is the highest degree or level of education you have completed? (Please tick one)
   - ☐ Primary school
   - ☐ CSE/GCSE/ BTEC
   - ☐ Apprenticeship
   - ☐ O-level/A-level
   - ☐ Ordinary National Diploma (OND)
   - ☐ Higher National Diploma (HND)

☐ Undergraduate degree
☐ Masters degree
☐ PhD
☐ Professional qualifications
☐ Other (please specify)

____

☐ Prefer not to say

6. What is your relationship status? (Please tick one)
   ☐ Single
   ☐ In a relationship
   ☐ Married
   ☐ Divorced/separated
   ☐ Widowed
   ☐ Other (please specify)

____

☐ Prefer not to say

7. Where in Berkshire do you live? (Please tick one)
   ☐ East Berkshire (Windsor, Maidenhead, Slough, Bracknell)
   ☐ West Berkshire (Reading, Newbury, Wokingham)
   ☐ I do not live in Berkshire
   ☐ Prefer not to say

8. Would you describe yourself as having a disability (any *physical or mental* difficulty that impacts your ability to carry out day-to-day activities)
   ☐ Yes
   ☐ No
   ☐ Unsure/ Prefer not to say

9. Do you have one or more long term physical health conditions?
   ☐ Yes
   ☐ No
   ☐ Unsure/ Prefer not to say

10. Do you have carers?
    ☐ Yes
    ☐ No
    ☐ Unsure/ Prefer not to say

11. Are you a carer?
    ☐ Yes
    ☐ No
    ☐ Unsure/ Prefer not to say

About your Referral

If you think you might have had more than one referral in the last three months, you should try to think about the referral which did not result in you attending an appointment. If you have had more than one referral which did not result in an appointment, please answer based on your most recent referral. Do not include any referrals that resulted in you having appointments.

12. Please can you let us know how the referral to Talking Therapies was made (Please tick the one option that best applies)
    - ☐ I made the referral myself (**self-referral**; either via our website or telephone) - please select this option even if our service was recommended to you by your GP or other healthcare professional
    - ☐ The referral was made on my behalf by a **friend or family member**
    - ☐ The referral was made on my behalf by my **doctor / GP**
    - ☐ The referral was made on my behalf by **another healthcare professional** (e.g. community nurse, physiotherapist)
    - ☐ The referral was made on my behalf by **another mental health team** (e.g. the 'Gateway' service, Community Mental Health Team, other mental health service)
    - ☐ I am unsure
    - ☐ I was unaware a referral had been made

13. After your referral was made to our service, did you receive any communication from us? (Please select <u>all</u> options that apply):
    - ☐ Yes - by telephone (including voicemails, missed calls)
    - ☐ Yes - by email
    - ☐ Yes - by SMS text message
    - ☐ Yes - by letter
    - ☐ No I did not receive any communication from the service
    - ☐ Maybe / Unsure / Cannot remember

14. If you did receive any communication from us, what was your experience of this? Was there anything we didn't do well?

15. Is there anything we could do differently to improve this communication?

16. Is there anything you would like to highlight that was done well?

17. Was this referral the first time you had been referred to Talking Therapies (either by you/a doctor/GP/other healthcare professional/other mental health service)? (Please tick one)
    - ☐ Yes, this was my first referral
    - ☐ No, I have been referred to Talking Therapies previously
    - ☐ I am unsure / can't remember
    - ☐ I was unaware a referral had been made

18. If you answered no to the question above, and you have previously had a referral to Talking Therapies, how would you rate the helpfulness of your previous experience with us? (Please circle/tick the number on the scale that best applies)

Not helpful at all					Neither helpful nor unhelpful					Very helpful
0	1	2	3	4	5	6	7	8	9	10

19. Have you previously had any other therapy for your mental health?
    - ☐ Yes
    - ☐ No
    - ☐ I am unsure / can’t remember
    - ☐ Prefer not to say

20. If you answered yes to the question above, how would you rate the helpfulness of your previous experience of therapy? (Please circle/tick the number on the scale that best applies)

Not helpful at all					Neither helpful nor unhelpful					Very helpful
0	1	2	3	4	5	6	7	8	9	10

Reasons for not arranging or attending your appointment

21. Did you have an initial assessment appointment booked? (Please select the one option that best applies):
    - ☐ Yes - but I could not attend/ cancelled my assessment appointment
    - ☐ No I did not have any appointments booked
    - ☐ Maybe / Unsure / Cannot remember

22. Why did you not arrange or attend your appointment with Talking Therapies? What influenced your decision?

23. Did any of the following factors influence your decision to arrange or attend your appointment? (Please tick <u>as many or as few as you like</u>)

Communication and Arranging Appointments

- ☐ I was not aware that I had been referred
- ☐ I did not know who Talking Therapies were or what the service could offer me
- ☐ I did not know what an assessment appointment would involve
- ☐ I didn’t receive any communications inviting me to arrange an appointment
- ☐ I didn’t have enough time to arrange an appointment

- ☐ I was not aware that the appointment had been booked / I did not receive an appointment confirmation
- ☐ Information was not available in my language
- ☐ I didn't know how to arrange an appointment
- ☐ It was too complicated to arrange an appointment
- ☐ I did not know how to use the computer/internet
- ☐ I could not use the telephone

Appointment Practicalities

- ☐ I don't have a computer or device to access the website links or attend an online appointment
- ☐ I did not have transport to attend the appointment (if appointment was face-to-face)
- ☐ The length of the appointment was not convenient (It was too short/too long)
- ☐ I could not attend the appointment at the time that was offered to me
- ☐ I was too physically unwell to arrange/attend the appointment
- ☐ I was too mentally unwell to arrange/attend the appointment
- ☐ I did not want to have my appointment over the telephone or online (I was not aware that I could request a face-to-face appointment)

Need for Therapy

- ☐ I felt I no longer needed the appointment / my symptoms had improved
- ☐ I didn't think I had a problem with my mood/mental health
- ☐ I didn't think therapy would help me
- ☐ I did not think that my problems were bad enough to warrant therapy
- ☐ I thought that other people were more deserving of support
- ☐ I had a bad experience with Talking Therapies Berkshire in the past so did not think that they could help me

Beliefs and Worries about Therapy

- ☐ I was scared or worried about what therapy would be like
- ☐ People of my generation do not talk about their feelings
- ☐ People of my generation see mental health difficulties as a sign of weakness
- ☐ I was worried what it would mean about me if I went to therapy
- ☐ I was worried about what other people would think of me
- ☐ I did not think that a therapist would understand me
- ☐ I find it difficult to talk about my feelings with someone else

24. Please use the text box below if you wish to expand on any factors that influenced your decision not to arrange or attend your assessment appointment

25. What did you think might be helpful about Talking Therapies?

26. What did you think wouldn't be helpful about Talking Therapies?

How could Talking Therapies Berkshire Improve?

27. Is there anything Talking Therapies could have done differently to improve your experience and support you and other over 65s to arrange and attend assessment appointments in the future?

28. Is there any information that it would have been useful to have to help you to arrange or attend an appointment?

29. Any other comments or feedback?

Thank you for your feedback!

Please note that your answers can not be linked back to you and will not impact any future care you might receive from us. As this is an *anonymised* survey, we will be unable to follow anything up with you if you require further help. Therefore, if you think you require further support and would like to be re-referred to Talking Therapies, you can self-refer by:
Telephone: 0300 365 2000
Or visit our website: talkingtherapies.berkshirehealthcare.nhs.uk

Appendix 2.F- Interview Schedule

Understanding the Experiences of Older Adults who disengage from Talking Therapies Berkshire before assessment- Interview Schedule

About You

We ask these questions so that we have some information about the type of people who have given feedback. If there are any questions you would prefer not to answer, this is okay.

1. How old are you?
2. What gender do you identify as?
3. How would you describe your ethnicity?
4. Is English your first language?
5. Where in Berkshire do you live?
6. Would you describe yourself as having a disability? (any *physical or mental* difficulty that impacts your ability to carry out day-to-day activities)
7. Do you have any long term physical health conditions?

About your Referral

I'm going to start off by asking you a little bit about your referral to Berkshire Talking Therapies

1. Can you remember being referred, or referring yourself? (If you have had more than one, can you please think about the referral which did not result in you attending an appointment)
2. How were you referred to Talking Therapies?
    a. Did you refer yourself, or did someone else do this on your behalf?
    b. What was your experience of this?
3. How did you next hear from Talking Therapies? When?
    a. How did you find this?
    b. Prompt questions may enquire about what was done well in these communications, and anything that was experienced as challenging or a barrier to continuing with the referral
    c. Enquire about any ways this process could be improved.
4. Did you arrange an appointment?
    a. How did you find the process of doing this?
    b. Was it easy to arrange, and to find a time that suited you?

Reasons for not arranging or attending your appointment

1. Why did you [not arrange/not attend/cancel] your appointment??
    a. What got in the way for you?
    b. What made you change your mind?
    c. May enquire about:
        i. Communicating or arranging the appointment (aware of referral, able to arrange appointment)
        ii. Understanding of what Talking Therapies was (what they offer, who they are for, what an assessment would involve)

        iii. Practicalities of attending an appointment (calls from unknown number, length of appointment, modality of appointment, illness at time of appointment)
        iv. Need for therapy (change in how felt, not thinking there was a problem, not thinking problems bad enough [what problems warrant therapy?], other people more deserving)
        v. Previous experiences or therapy, perception of what Talking Therapies were or would be like
        vi. Worries about attending therapy (what others would think, whether therapist would understand, what it would mean about you, difficult to talk about)
2. Have you subsequently been re-referred?
        i. What was different this time?
3. What did you think would be helpful about Talking Therapies?
4. Is there anything that puts you off Talking Therapies?
5. What do you think other people your age think about Talking Therapies?
    a. Is there anything you think might put other over 65s off attending if they were referred?

How could Talking Therapies Berkshire Improve? Ask throughout where barriers identified, tailoring to barriers.

Talking Therapies are asking for feedback like this because they are really keen to understand things that might get in the way of people attending appointments when they have been referred, and they would love ideas on how this can be improved.

1. Is there anything Talking Therapies could have done differently to improve your experience?
2. How do you think Talking Therapies could engage people like you who feel/worry X?
3. Is there any information that it would have been useful to have to help you to arrange or attend an appointment?

Appendix 2.G- Illustrative Quotes for Themes/Subthemes

Table G contains further illustrative quotes for themes and subthemes identified. The names are pseudonyms.

Table G.

Illustrative Quotes for Themes and Subthemes

Themes	Illustrative Quotes
The Process of Referral and Opt-In	
Communications	So many times, when you're on the phone these days when you're trying to contact people and contact services it's really challenging at the moment. It's all pushbutton service. It's all, push one for this, two for that. You know like, you can't get through to people easily. And so, I just looked at it and I just thought I can't be doing with this. (Pam) And then we just decided, not that we'd had enough because that sounds a bit blunt, but we just thought, let's leave that alone. We just didn't want to go through all these communications again. (Frank) It came out of the blue completely... The first I knew of it was when I found a letter laying on the mat saying that um I've been referred, and I think it was asking if I'd like to make an appointment. (Paul) They have assumed that I don't want an appointment. But what I'm saying is the letter arrives saying we haven't had any reply to our messages, and I just thought, what messages?... What I'm saying is if you look at your telephone and you look at calls that you've missed, if it says private number and there's no voice message, there's no way that you can actually contact that number. You don't know who it's from. It could be Talking Therapies. It could be from something else. So, you don't know? You don't know who's been trying to get in contact with you. (Pam)
Tickboxes and Questionnaires	You're presented with the questionnaire before you've actually spoken to anybody, maybe you just think, oh you know are they going to just talk through these categories... You do have to feel an element of trust with that person, obviously, when you do set about, you know, talking about things. I think sometimes the questionnaire may be off-putting in the initial stage (Pam) I know you have so much of what you're doing is scripted, and I know that as soon as I mention depression and or suicide that you then go through your ten questions or checklists and things like that that you're obliged to do. And every time you do that, as soon as you fall back into

	the format, that's where you risk losing the credibility as a therapist. (Douglas)
	I was really low but as soon as I got a mood questionnaire, I thought I was wasting someone's time...I wondered if I needed to talk to someone as it all hit me but then I thought actually I don't really need it...The questionnaire made it veer more into asking whether I was depressed and it didn't really fit me. (Survey Response)
Missing the Personal Touch	I think the first thing is get the 1:1 in first then go through the tick box, then come back to a 1;1, so you can fit the tick box in somewhere but if you do it at the front end, that's where you risk losing the uh, me. (Douglas)
	For me it felt very important to see somebody face to face, and I feel that quite strongly about therapy and counselling because I think you you just miss so much by not being in the room with your client. Because um, such a such a vast amount just communicated through body language. (Angela)
	A follow up call when you have cancelled to check whether you do need the appointment- lots of older people think they can't do it so they cancel and it would be useful for someone to check in and ask why and support people to know that they can do it if they need to... Someone taking time to ring them back might encourage someone who has bottled out to try. It is so unknown, and you think someone it wrong with you so that personal touch might help older people who are so much more used to talking to someone than using an online system might help get people through the door and feel reassured. (Survey response)
	I really think the personal touch, or being able to drop in and make and appointment or ask some questions that gives someone the confidence to get that appointment online, would be so good. If I hadn't been able to ask my friend about what to expect I might not have felt as able to. (Survey Response)
Talking Therapies is a Mystery	
Knowledge and Awareness of Talking Therapies	I think it's a fairly new thing and it would be useful to have more information about what to expect in an assessment- that you would be sent questionnaires, the types of questions that would be asked, that it would be private and confidential, what Talking Therapies actually were (it's a bit of a mystery), you need a bit of a guide. [Survey response]
	If Talking Therapies got on the line and said, right we think we can help you, explain the situation, here's some case studies of how we've helped

	people in similar situations, would you like to have a look at those, think about it and then come back to us and say whether you'd like to have some help or not, I’d probably have gone with that. (Frank)
Making information accessible	I know it's explained on the website to a point, but it just depends how you've got there, because if you've gone to your GP and they referred you, then the first thing you'll get is an invitation to an appointment and maybe you don’t know what for... I wonder if maybe technology and would be an issue for older people, that's all. Either accessing it, understanding it... and you know, and people assume that people have got access to it. (Pam)
	A leaflet with a guide to show you how to self-refer online, as well as the info about Talking Therapies, might be useful as if they aren't looking online actively, they might not find it. It needs to be quite a continual thing. Women in my age group wouldn't think of googling or looking online for their mental health so they may not know where to look and how to find it. (Survey Response)
	It needs to be in places other than doctors surgeries too, as people aren't going to the doctors as much. Adverts on TV could be good. Maybe GPs could send people texts with pointers and prompts to self-refer if they need, like they did during COVID. (Survey Response)
	If you can go into groups where people are looking for help... kinda go in as a speaker to come in and say, you know, I'm from Talking Therapies, we do this, we do that, does that apply to you? Can I help you? (Frank)
Beliefs and Attitudes about Therapy	
Uncertainty about the Effectiveness of Therapy	Talking to people can help you get through things and understand about yourself... I think it’s a great place to offload with someone listening as people don't always have someone to listen to them. Someone who can understand and help you understand more about yourself. (Survey Response) They are reputed to have a reasonable success rate... so I can't speak for everybody else, and I'm sure there are lots of people who can benefit from it, and it may well be something that helps turn their mind to something uh more productive, helpful...I’m sort of only sort of underwhelmed by the um, you know the success it may have on me... You know, it's sort of puts me in a sort of positive frame of mind for the time it takes to have the call and I fear that, you know, when the call ends, I just go back to being me... So far I haven't found a therapist who's managed to get me to change my mentality. (Douglas) The person I had it with was lovely and she let me ramble on but, um, I I didn’t feel like I really let anything out... I was hoping it would make me feel a bit better, but it didn’t you know. (Bob)

	When you uh end up talking to somebody who has just completed their course and who has the rudimentary understanding of the clinical attitudes as opposed to qualified by experience of having done it over the years...old people will automatically start thinking ‘what does this young person think that they can do to help me?’ because they are simply too inexperienced. (Douglas)
The Older Generation don’t go on about Mental Health	For people of our age I think every time you hear mental health talked about, we sort of groan a little bit because it sounds like the things that we've always dealt with during our lives, you know, we'd have to... you know, we've had enough issues with our jobs our parents our children, the finances everything, our health, you know, all sorts of distressing things throughout our lives, and we never go on about mental health... There’s this old-fashioned thing about, hold on, you know, you just sort yourself out. People help you, whatever. But you have to get on with things and cope at the end of the day. (Frank)
	Whatever may be said about mental health being more openly talked about, I think definitely from my generation I think there’s definitely still an area of kind of shame that you’re not coping. That you should be able to cope. (Angela)
	I won’t talk to people about my mental health if I can help it. Um that’s like me admitting that I’ve got something wrong mentally and I won’t do that... No one likes to admit they've got problems mentally um and I mean you think about it yourself, if you were a caller, would you like to admit to something like that? (Paul)
	I think there is now more knowledge that it is okay to talk about things in 'younger' older adults, and knowing there is nothing wrong with you is really important. I think a bit more normalisation of this for older adults is important. (Survey response)
Therapy isn’t for me	I don’t have difficulties; you know we’ve all got difficulties but I don’t think I’ve got that heavy uh difficulties. (Paul)
	My friend who has Talking Therapies is much worse than me and I thought I could see why she needed it but I didn’t as I’m not a depressive person. I thought I would be wasting someone’s time in an appointment for someone who really needed it. (Survey Response)
	I think that, you know, after the COVID crisis, so many businesses and so many support services, the NHS, we keep hearing it on a daily basis, they’re all under pressure. And I just thought, well, they're obviously under pressure. (Pam)

	I think the older people think that if they don't absolutely need it, they don’t bother anybody. You know, it's sort of all not bothering people. (Susan)
	I think um, my issues are very entrenched and probably quite complicated, and with Talking Therapies I do feel, due to the nature of them, they can only be fairly superficial with their help because, you know, you know you can’t, you don't have the resources to be seeing people you know for long in depth amounts of time. I think I was offered six sessions and because I think she felt that I had a need, I think she went on to, she may have gone on to 12. Um, but, you know, it's not it's not meant for long term, is it...I’'s a bit like just sort of watering a plant from the top, never getting into the into the roots. (Angela)
	But with me I’m too stuck in my ways unfortunately, uh, I fear, to make a change (Douglas)
Getting Older is a Barrier	
Physical and Cognitive Changes	I've been aware of just the remarkable change to my memory capacity. Uh, short term stuff particularly and I get confused utterly between uh care providers and uh people trying to organise the care around me and for me and things like that. (Douglas)
	I used to walk whole afternoons walking, but I won't do it anymore. I'm scared to do it in case I fall over (Paul)
	We have so much going on as it is in that health area with my wife and myself and that’s why I didn’t follow up the referral in the end. I think I said, thank you very much, but I think we're fine (Frank)
Life Changes are Overwhelming	Suddenly life becomes very full of all the barriers to doing that and the things that distract you from that, all the other things that you have to manage in terms of your health and the environment that you're in and what's going on...I think the mindset of being 65+ is an important point because people’s lives are so different at that stage. By definition, they're retiring, and I mean people might carry on working, but even so. And then it's what's going on with their families. And, you know, your career is ending, and you’ve spent all your life moving forward and planning, and having goals, and then all of a sudden you're retired and not everyone takes to that and finds a way of having a fulfilling life. And so, there's a lot of that going on...I think there's maybe a need to have a perspective of what life is like for them, not saying it's awful, you know, it's a lot better than a lot of people a lot younger, but it is different. (Frank)

I've got my hands full now as it is and I just didn't have the mental capacity left or the energy to go down that route. (Frank)

I just had so much going on at the time. I remember that... My wife used to organise everything you know, bills, everything, I was just struggling to handle it at the time. I just wasn’t used to it I suppose...I’m very overwhelmed with everything at the moment, with life in general. (Bob)

I put myself last, I put everybody else before me, and I run around trying to sort of other people out all the time at my own expense. And I'm fully aware of that and I should make more time for myself, but I find it like I said very difficult to switch from being a carer to uh having doing stuff for myself and it takes so long that it's simply easier if I just chill out for an hour and then go back to doing whatever I have to do... Everybody's saying ‘Oh, yeah you need to have a break, go do it’ well I can't do that because nobody is competent enough to come in and just take over from me without me having to have done everything already. (Douglas)

My caring roles seem to take over everything and I have little or no time or energy for anything else, despite the constant advice from all to ensure I have some 'me' time. (Survey Response)

Appendix 3- Theory Driven Research Project

Appendix 3.A- Autism Research Instructions for Authors

To assist the reader, all tables and figures have been integrated into the main text, as opposed to submitted separately. The lay summary will be provided for submission but has not been included in the main body of the thesis due to word restrictions.

Author Guidelines

GUIDELINE SECTIONS

1. SUBMISSION

Authors should note that submission implies that the content has not been published or submitted for publication elsewhere except possibly as a brief abstract in the proceedings of a scientific meeting or symposium. If there is a related paper under consideration at another journal, the corresponding author should inform the Editor in the cover letter and a copy of that paper should be submitted with the primary manuscript as supporting information.

Authors should follow the guidelines carefully; failure to do so will delay the processing of the manuscript. Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at manuscriptcentral.com/autismresearch. Authors unfamiliar with ScholarOne can find details on how to use the system here: www.wileyauthors.com/scholarone.

Free Format submission

Autism Research offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- ·Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. If the figures are not of sufficiently high quality, your manuscript may be delayed. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.

- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*
    - Statements relating to our ethics and integrity policies, which may include any of the following *(Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):*
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

Autism Research will consider submissions that have previously been made available online, either on a preprint server like arXiv, bioRxiv, or PeerJ PrePrints, or on the authors' own website. However, any such submissions must not have been published in a scientific journal, book or other venue that could be considered formal publication. Authors must inform the editorial office at submission if their paper has been made available as a preprint.

- Authors of accepted papers that were made available as preprints must be able to assign copyright to *Autism Research*, or agree to the terms of the Wiley Open Access agreement and pay the associated fee
- Given that the measurable impact of the article is diminished when citations are split between the preprint and the published article, authors are required to:
    - Update the entry on the preprint server so that it links to and cites the DOI for the published version
    - Cite only the published article themselves

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

For help with submissions, please contact the Editorial Office: autismres@wiley.com. When necessary, the Editorial Office staff may refer questions to the Editor-in-Chief or Associate Editors.

2. AIMS AND SCOPE

Autism Research is owned and supported by The International Society for Autism Research (INSAR), a scientific and professional organization devoted to advancing knowledge about Autism Spectrum Disorder (ASD). For more information, please visit the Society Information section of the journal homepage.

Autism Research covers research relevant to ASD and closely related neurodevelopmental disorders. The journal focuses on genetic, neurobiological, immunological, epidemiological and psychological mechanisms and how these influence developmental processes in ASD. The journal encourages the submission of original research papers (Research Articles and Short Reports) that take a developmental approach to the biology and psychology of autism, with a particular emphasis on identifying underlying mechanisms and integrating across different levels of analysis. Contributions are typically empirical, but the journal also publishes theoretical papers if they significantly advance thinking. The journal encourages papers reporting work on animals or cell or other model systems that are directly relevant to a better understanding of ASD.

Please note that the journal does not publish manuscripts of human research that are based solely on a neurotypical population. *Autism Research* does not publish papers that are based solely on qualitative data. While studies of this type are important in hypothesis generation, *Autism Research* focuses on quantitative studies that are designed to test hypotheses. *Autism Research* will consider mixed methods papers that provide data based both on qualitative and quantitative research. There are several journals that encourage submission of papers based solely on qualitative data and we encourage authors of this type of paper to seek out one of these journals for submission of their qualitative papers.

The journal also publishes reports of carefully conducted clinical trials of treatments for the core symptoms or one of the common co-morbid symptoms of ASD. Papers presenting clinical trials will be judged, in part, on whether there is an empirical justification for the reported treatment. Individuals included in research studies can span the full spectrum of ASD, including the broader phenotype, and there are no restrictions on study participants in terms of age or intellectual ability.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Autism Research publishes the following contribution types:

1. Research Articles
2. Short Reports
3. Review Articles
4. Commentaries
5. Letter to the Editor

Manuscripts should be prepared according to the descriptions below. Submissions that do not conform to one of the descriptions below will be returned to the author.

1. Research Articles.

The text of these articles should include a scientific Abstract (150–250 words), a Lay Summary (see details elsewhere), and they should follow the IMRaD guidelines (***I***ntroduction, ***M***ethods, ***R***esults, ***a***nd ***D***iscussion), which are recommended by the International Committee of Medical Journal Editors (ICMJE) (*J. Pharmacol. Pharmacother.* 2010, *1*, 42–58). Manuscripts should be a maximum of 5,000 words in length (excluding Abstracts and References). If there are extenuating circumstances that require an increased length, authors should contact the Editorial Office with specific details and rationale for the Editor-in-Chief's consideration.

2. Short Reports.

These are original research articles that report a well-conducted preliminary study or a novel finding of high potential impact. Typically these articles should not exceed 2,000 words in length (excluding Abstracts and References). The text of these articles should include a scientific Abstract (150–250 words), a Lay Summary (see details elsewhere), and while subsection headings are not specifically required, the flow of text should follow the IMRaD guidelines (***I***ntroduction, ***M***ethods, ***R***esults, ***a***nd ***D***iscussion), which are recommended by the International Committee of Medical Journal Editors (ICMJE) (*J. Pharmacol. Pharmacother.* 2010, *1*, 42–58).

3. Review Articles.

Review Articles are generally invited. However, authors are encouraged to contact the Editor-in-Chief if they are interested in preparing a Review on a timely topic that has not recently been covered by the journal. Permission of the Editor-in-Chief must be obtained prior to submission of a Review Article. Potential authors should send an e-mail to the Editor-in-Chief (dgamaral@ucdavis.edu) explaining the scope of the review and why it is timely to publish a review article on this topic at this time. If other similar review articles have appeared in other journals, the authors should explain what is different about the proposed article. Importantly, one or more of the authors should provide evidence that they have primary research experience in the topic by submitting a list of research papers related to the topic on which they are first or senior author.

Review Articles are typically up to 8,000 words in length (excluding Abstracts and References).

Review Articles should be accompanied by an Abstract of (150–250 words) and a Lay Summary (see details elsewhere). The manuscript can be organized as the authors wish, but should be logically structured to ensure readability.

4. Commentaries.

These are short articles (1500–3,000 words in length excluding Abstract and References) that are intended to 1) draw attention to developments or needs in a specific area of research, 2) bring together observations that point the field in a new direction, 3) give the authors' personal views on a controversial topic, or 4) direct well-reasoned and substantive criticism of some widely held theoretical view or widely used technique or practice. Commentaries may also provide a historical perspective on an area of autism research. Authors should make their Commentary understandable to a broad readership. As with all other contribution types, they should have an Abstract of (150–250 words) and a Lay Summary (see details elsewhere).

Potential authors are invited to submit a letter of interest to the Editor-in-Chief via email (dgamaral@ucdavis.edu), indicating the topic of a potential Commentary. The letter should also contain an outline of the contents and a brief statement on why it is a good time to review the topic in question. Commentaries will not be accepted for editorial processing unless pre-approved for submission.

5. Letters to the Editor.

From time to time, readers respond to an article published in *Autism Research* by writing a Letter to the Editor. Such letters may further the scientific discussion and provide meaningful context to the published work. Letters to the Editor do not have either an Abstract or a Lay Summary; they only have a few citations (always less than five) and those should be limited to the article in question and highly relevant references in support of the discourse. These contributions should be short (usually 300 words or less). They should be written in continuous prose without subsections. Letters to the Editor are only published after full consultation with the Editor-in-Chief, and if necessary the authors and/or reviewers of the published contribution under discussion. Authors wishing to publish a Letter to the Editor should first contact the Editor-in-Chief via email (dgamaral@ucdavis.edu), prior to formal submission of the manuscript, to ensure the intended manuscript meets the requirements of this contribution type.

4. PREPARING THE SUBMISSION

Cover Letters

During the submission process, authors will have the opportunity to provide a cover letter directly in a text field of the submission questionnaire within ScholarOne. Therein, details of any invitation received, any information pertinent to the submission, etc. should be provided. Authors wishing to upload a separate cover letter together with the submission files may do so, though this is not required.

Parts of the Manuscript

The submission should be uploaded in separate files: 1) manuscript main text file; 2) figures; 3) Supporting Information file(s).

1. Manuscript Main Text File

The text file should contain all of the manuscript text, including the tables and figure legends. The text should be presented in the following order:

1. Title
2. A short running title of less than 40 characters
3. The full names of all authors
4. The authors' institutional affiliations where the work was conducted, with a footnote for an author’s present address if different to where the work was carried out
5. Acknowledgments
6. Lay Summary
7. Abstract and Keywords

8. Main text
9. References
10. Tables (each table complete with title and footnotes)
11. Figure legends

Title
The title should be short and informative, containing major keywords related to the content. The title should not contain abbreviations (see Wiley's best practice SEO tips).

Authorship
For details on eligibility for author listing, please refer to the journal's Authorship policy outlined in Section 5 of these Author Guidelines.

In accordance with Wiley's Best Practice Guidelines on Research Integrity and Publishing Ethics and the Committee on Publication Ethics' guidance, *Autism Research* will allow authors to correct authorship on a submitted, accepted, or published article if a valid reason exists to do so. All authors - including those to be added or removed - must agree to any proposed change. To request a change to the author list, please complete the Request for Changes to a Journal Article Author List Form and contact either the journal's editorial or production office, depending on the status of the article. Authorship changes will not be considered without a fully completed Author Change form. [Correcting the authorship is different from changing an author's name; the relevant policy for that can be found in Wiley's Best Practice Guidelines under "Author name changes after publication."]

Acknowledgments
Contributions from individuals who do not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement
Authors will be asked to provide a conflict of interest statement during the submission process. See the journal's policy on Conflict of Interest outlined in Section 5 of these Author Guidelines. Authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Abstract
Please provide an abstract of 150–250 words containing the major keywords (see below). The abstract must be written in complete sentences. It should concisely state the questions addressed, the methods used, the main results and their significance. Importantly, the abstract should stand alone without references and with abbreviations appropriately defined. Note, the Abstract should not be structured; please do not include line breaks or paragraph headings.

Lay Summary
Autism Research and INSAR are committed to making scientific research accessible to both the scientific and non-scientific communities. In an effort to do this, since the journal's launch, authors have provided lay summaries intended to inform the non-scientific

community of important findings. In a continuing effort to refine this policy, each author is asked to provide an Lay Summary.

A brief statement of 2-3 sentences included at the end of the Abstract that summarizes the impact/importance/relevance/key findings of the study. The Lay Summary should be aimed at interested persons without a scientific background.

Authors are encouraged to use a readability analyzer to evaluate the accessibility of their Lay Summary to non-scientists. Free online analyzers such as https://datayze.com/readability-analyzer.php provide an indication of the reading level of a given text.

An article's Lay Summary appears immediately below the Abstract and appears together with the Abstract on Wiley Online Library, as well as in Abstract & Indexing services that cover the journal, such as PubMed. This ensures that the Lay Summary is available to any reader free of charge at the article level rather than the issue level.

Since its launch, *Autism Research* has sought to make scientific research accessible to non-scientists, particularly families with ASD. Like While the way in which the journal provides these lay abstracts has evolved over time, they are archived in a dedicated Special Features section of the journal's website: www.autismresearchjournal.com.

Keywords
Please provide five to seven keywords. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at www.nlm.nih.gov/mesh.

Main Text

- The text should be divided as outlined in Section 3 "Manuscript Categories and Requirements".
- Manuscripts reporting original research should follow the IMRaD guidelines (***I***ntroduction, ***M***ethods, ***R***esults, ***a***nd ***D***iscussion), which are recommended by the International Committee of Medical Journal Editors (ICMJE) (*J. Pharmacol. Pharmacother.* 2010, *1*, 42–58).
- The journal uses US spelling. Authors may submit using any form of English as the spelling of accepted papers is converted to US English during the production process.
- Authors for whom English is not their first language are encouraged to seek assistance from a native or fluent English speaker to proof read the manuscript prior to submission. Wiley offers a paid service that provides expert help in English language editing – further details are given below.
- Articles reporting data taken from or deposited elsewhere should refer to the journal policy on Data Storage and Documentation in Section 5 (below).

Reference Styles
This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the APA FAQ.

Tables

Each table must be numbered in order of appearance and be cited at an appropriate point in the text. Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files (i.e., created in Microsoft Word or similar), not pasted as images. Legends should be concise but comprehensive—the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Statistical measures such as standard deviation (SD) or standard error of the mean (SEM) should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive—the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement. Legends for each figure should not exceed 200 words.

2. Figures

Although authors are encouraged to send the highest quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Figures should be numbered in the order in which they appear in the text.

Figures should be supplied in as high resolution as possible.

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Appendix 3.B- Results Without Those Whose AQ Score Did Not Match Their Self-Reported Autism Group

Of the full sample of 242 participants, 34 had scores on the AQ which, based on the recommended cut-off score of 32, did not match their self-reported autism group. 14 in the non-autistic group scored greater than or equal to 32, and 20 in the autistic group scored less than 32. The results below are of the 208 (80 non-autistic, 128 autistic [105 formally diagnosed, seven awaiting diagnosis, 16 self-identified]) whose AQ scores and self-reported autism group correspond.

Table B1.

Demographic Characteristics

Characteristic	Autistic (*N*=128) *N* (%)	Non-Autistic (*N*=80) *N* (%)
Gender		
Female	89 (69.5)	71 (88.8)
Male	19 (14.8)	8 (10.0)
Non-binary/other	19 (14.8)	0 (0.0)
Prefer not to say	1 (0.8)	1 (1.3)
Ethnicity		
Arab	1 (0.8)	0 (0.0)
Asian- Pakistani	1 (0.8)	0 (0.0)
Asian- Other	0 (0.0)	2 (2.5)
Black- Caribbean	1 (0.8)	1 (1.3)
Mixed- White and Black Caribbean	3 (2.3)	0 (0.0)
Mixed- White and Black African	1 (0.8)	0 (0.0)
Mixed- White and Asian	3 (2.3)	2 (2.5)
Mixed- Other	1 (0.8)	1 (1.3)
White-British	106 (82.8)	68 (85.0)
White- Irish	1 (0.8)	0 (0.0)
White- Other	5 (3.9)	4 (5.0)
Other ethnic group	2 (1.6)	0 (0.0)
Prefer not to say	2 (1.6)	2 (2.5)
Highest Degree of Education		
Secondary Education	15 (11.7)	5 (6.3)
Apprenticeship	16 (12.5)	5 (6.3)
Ordinary National Diploma	3 (2.3)	1 (1.3)
Higher National Diploma	4 (3.1)	1 (1.3)
Undergraduate Degree	42 (32.8)	27 (33.8)

Masters Degree	34 (26.6)	25 (31.3)
PhD	2 (1.6)	8 (10.0)
Professional Qualifications	6 (4.7)	7 (8.8)
Other	5 (3.9)	1 (1.3)
Prefer not to say	1 (0.8)	0 (0.0)
Employment Status		
Employed- Full Time	39 (30.5)	43 (53.8)
Employed- Part Time	22 (17.2)	15 (18.8)
Student	7 (5.5)	5 (6.3)
Unemployed	22 (17.2)	3 (3.8)
Retired	5 (3.9)	5 (6.3)
Volunteer	4 (3.1)	1 (1.3)
Homemaker/Parent/Carer	6 (4.7)	1 (1.3)
Self Employed	6 (4.7)	4 (5.0)
Unable to work	11 (8.6)	1 (1.3)
Other	5 (3.9)	2 (2.5)
Prefer not to say	1 (0.8)	0 (0.0)
Mental Health Difficulties- Current	92 (71.9)	36 (45.0)
Mental Health Difficulties- Lifetime	107 (83.6)	48 (60.0)
	M (SD)	*M (SD)*
Age	41.76 (13.25)	38.11 (14.02)
Anxiety (GAD-7)	11.62 (5.63)	8.45 (5.46)
Depression (PHQ-8)	8.40 (5.53)	12.69 (6.19)
Autistic Traits (AQ)	40.52 (4.12)	15.86 (7.24)

Note. GAD-7= General Anxiety Disorder-7 (49), PHQ-8= Patient Health Questionnaire-8 (50), AQ= Autism Quotient (48).

Preliminary Hypotheses

The autistic group endorsed a similar number of trauma types on the LEC-5 as the non-autistic group, and there was not a statistically significant difference (*p*=.819; Table B2).

When comparing just LEC-5 traumatic events which were experienced directly (‘happened to me’), the number of events exposed to directly did differ significantly between the autistic and non-autistic groups (*p*=.005; Table B2).

One-hundred-and-thirty-eight participants, 88 autistic (68.8%) and 50 non-autistic (62.5%), reported having experienced ‘other’ event/s in their lifetime which they found traumatic which, based on qualitative descriptions given, would not be classified as trauma according to DSM-5 Criterion A for PTSD. This difference in proportions was not significant (*p*=.395; Chi Square test). A further 4 participants (2 per group) reported that they had experienced other traumatic events not covered by the LEC-5 but provided no details of the nature of these events so they could not be coded.

Current PTSD-SS was statistically significantly different between the autistic and non-autistic groups (*p*<.001; Table B2). A significantly greater proportion of the autistic group (64.8%), compared to the non-autistic group (37.5%), crossed the cut-off suggestive of probable current PTSD on the PCL-5 (*p*<.001).

Of participants who reported that there had been a time period since the trauma where their symptoms had been worse, lifetime PTSD-SS was statistically significantly different between the autistic and non-autistic groups *(p*<.001; Table B2).

Of the autistic group, 81.3% crossed the cut-off suggestive of PTSD in their lifetime compared to 73.8% in the non-autistic group, but this difference was not significant (*p*=.060).

H1- The autistic group will endorse more negative post-traumatic appraisals, scoring more highly on the TAQ than the non-autistic group.

The autistic group had higher TAQ scores than the non-autistic group, a statistically significant difference (*p*<.001; Table B2)

H2- The autistic group will score more highly on the shame, self-blame and alienation subscales of the TAQ than the non-autistic group.

The autistic group had higher scores across all TAQ subscales than the non-autistic group, however, this difference was statistically significant for self-blame, fear, alienation and shame (Table B2).

Table B2.

Descriptive Statistics and Effect Sizes for Group Differences in Trauma Exposure, PTSD-SS and Appraisals

Measure	Autistic				Non-Autistic						
	M	*SD*	*Mdn*	Range	*M*	*SD*	*Mdn*	Range	Statistic	*p*	*r/d*
LEC-5											
Total	6.83	3.53	7.00	0-15	6.71	3.54	6.50	0-15	$t(206) = -.229$	.819	.03
Happened to me	3.63	2.48	3.00	0-13	2.70	2.05	2.00	0-11	$U = 6291.5, z = 2.807$	.005	.20
PCL-Current	39.60	17.23	40.00	4-80	28.31	17.25	24.00	0-75	$U = 7031.5, z = 4.527$	<.001	.31
PCL-Lifetime	63.29	12.18	64.50	22-80	54.48	14.79	54.50	18-80	$U = 4629.5, z = 3.982$	<.001	.31
TAQ Total	169.97	38.08	170.50	73-263	139.96	44.47	139.00	54-239	$t(206) = -5.179$	<.001	0.73
Betrayal	22.20	8.66	23.00	7-35	19.66	9.66	19.50	7-35	$U = 5939, z = 1.943$	.052	.14
Self-Blame	25.60	11.54	25.50	9-45	20.64	10.31	17.50	9-45	$U = 6355.5, z = 2.928$	.003	.20
Fear	38.02	10.04	39.00	11-55	30.24	10.44	30.00	11-55	$U = 7222.5, z = 4.981$	<.001	.35
Alienation	37.89	7.77	39.00	17-50	31.13	10.68	32.00	10-50	$U = 7107.5, z = 4.710$	<.001	.33
Anger	21.95	8.62	22.00	9-45	19.64	6.93	19.50	9-38	$U = 5804.0, z = 1.622$	.105	.11
Shame	21.10	8.07	22.50	7-35	16.04	8.40	14.00	7-35	$U = 6907.0, z = 4.240$	<.001	.29

Note. LEC-5= Life Events Checklist (51), PCL-5= Post-Traumatic Stress Disorder Checklist for DSM-5 (53), TAQ= Trauma Appraisals Questionnaire (55).

H3. The relationship between autism group and PTSD-SS will be mediated by negative post trauma appraisals, with higher scores on the TAQ being associated with higher PTSD-SS.

A mediation model was run to explore the effect of negative post-trauma appraisals on the relationship between group (autistic and non-autistic) and PTSD-SS following a traumatic event. Results based on 5000 bootstrapped samples indicated that TAQ total score significantly mediated the relationship between group and PTSD-SS (Table B3); significant total effects were found between autism group and PTSD-SS, and when TAQ total scores were entered as a mediator of this relationship, a significant indirect effect was observed. The direct effect was no longer significant and the bias-corrected 95% confidence interval for the indirect effects did not pass through 0. Autistic adults had more negative appraisals following a traumatic event, and via this expressed higher PTSD-SS compared to non-autistic adults (Figure B1a).

The above model was then tested again, but with all six TAQ subscales included as parallel mediators. Results showed that alienation, fear and shame appraisals mediated the relationship between autism group and PTSD-SS; There was a significant total effect, and significant indirect effects were observed for alienation, fear and shame appraisals, suggesting that these appraisals mediate the relationship between group and PTSD-SS when other appraisals are controlled for. The direct effect was not significant and the bias-corrected 95% confidence intervals for the indirect effects did not pass through 0, suggesting full mediation via these appraisals (Figure B1b).

Table B3.

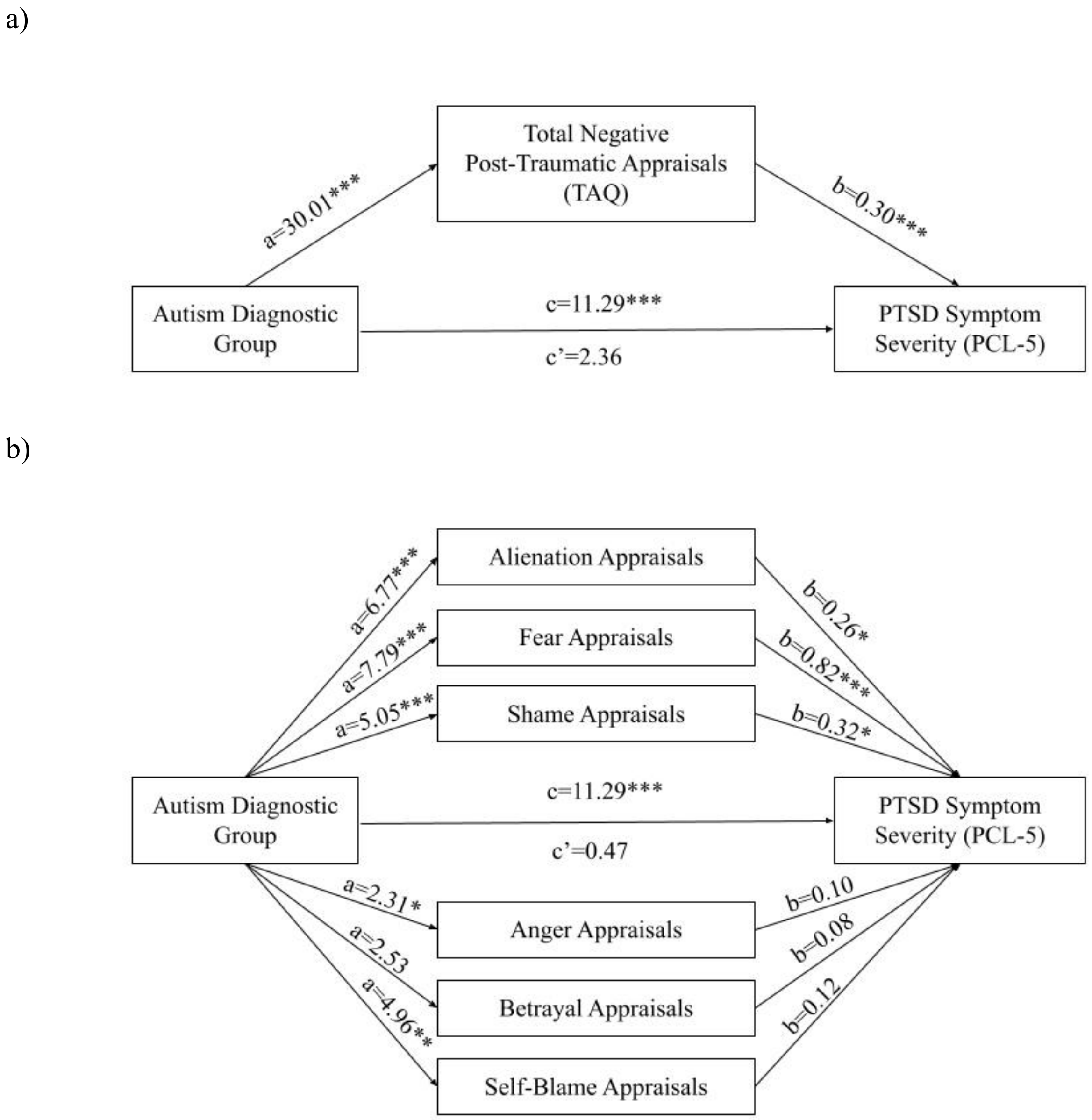
Appraisal Mediation Models Based on 5000 Bootstrapped Samples for the Relationship Between Group (Autistic/Non-Autistic) and PTSD-SS

Model 1 Mediator	Total effect (c)	Direct effect (c’)	Indirect effect
TAQ Total Score	*b*=11.29, *t*(206)= 4.60, *p*<.001, 95% *CI* [6.45, 16.13]	*b*=2.36, *t*(205)= 1.27, *p*=.207, 95% *CI* [-1.32, 6.03]	*b*=8.93, *SE*=1.76, 95% *CI* [5.46, 12.43]
Model 2 Mediators	**Total effect (c)**	**Direct effect (c’)**	**Indirect effect**
Betrayal	*b*=11.29, *t*(206)= 4.60, *p*<.001, 95% *CI* [6.45, 16.13]	*b*=0.47, *t*(200)=.26, *p*=.793, 95% *CI* [-3.03, 3.97]	*b*=0.19, *SE*=0.31, 95% *CI* [-0.32, 0.92]
Self-Blame			*b*=0.60, *SE*=0.56, 95% *CI* [-.39, 1.85]
Fear			*b*=6.39, *SE*=1.52, 95% *CI* [3.63, 9.59]
Alienation			*b*=1.77, *SE*=0.84, 95% *CI* [0.23, 3.55]
Anger			*b*=0.23, *SE*=0.31, 95% *CI* [-0.29, 0.95]
Shame			*b*=1.64, *SE*=0.85, 95% *CI* [0.22, 3.54]

Note. TAQ= Trauma Appraisals Questionnaire (55).

Figure B1.

Mediation Models Showing the Unstandardised Regression Coefficients for the Association between Autism Diagnostic Group and PTSD-SS, via a) Total Negative Post Traumatic Appraisals, b) Appraisal Subscales.



Note: Non-Autistic group coded 0 (*N*=80), Autistic group coded 1 (*N*=128).

**p*<.05, ***p*<.01, ****p*<.001.

Appendix 3.C- Ethical Approval Letter

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
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CONFIDENTIAL

Professor Craig Steel & Rachel Prosser
Oxford Institute for Clinical Psychology Training &
Research (OxICPTR)
Isis Education Centre
Warneford Hospital
Oxford

23 February 2023

Dear Professor Steel and Rachel,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R84859/RE001

Study title: The Impact of Appraisals on Reactions to Traumatic Life Events in Autistic and Non-Autistic Adults

Short title: The Impacts of Traumatic Life Events on Autistic and Non-Autistic Adults

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on **23rd February 2023.**

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for
Dr Helen Barnby-Porritt
Research Ethics Manager

Appendix 3.D- DSM- Criterion A Trauma Coding Criteria

DSM-5-TR was published in March 2022 to include scientific advances since the release of *DSM-5*. No changes were made to the PTSD diagnostic criteria for adults in this update so the scoring criteria below relate to the DSM-5

DSM-5 Criterion A (APA, 2013)

A. Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways:

1. Directly experiencing the traumatic event(s).

The directly experienced traumatic events in Criterion A include, but are not limited to, exposure to war as a combatant or civilian, threatened or actual physical assault (e.g., physical attack, robbery, mugging, childhood physical abuse), threatened or actual sexual violence (e.g., forced sexual penetration, alcohol/drug-facilitated sexual penetration, abusive sexual contact, noncontact sexual abuse, sexual trafficking), being kidnapped, being taken hostage, terrorist attack, torture, incarceration as a prisoner of war, natural or human-made disasters, and severe motor vehicle accidents.

For children, sexually violent events may include developmentally inappropriate sexual experiences without physical violence or injury.

A life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event. Medical incidents that qualify as traumatic events involve sudden, catastrophic events (e.g., waking during surgery, anaphylactic shock).

2. Witnessing, in person, the event(s) as it occurred to others.

Witnessed events include, but are not limited to, observing threatened or serious injury, unnatural death, physical or sexual abuse of another person due to violent assault, domestic violence, accident, war or disaster, or a medical catastrophe in one's child (e.g., a life threatening hemorrhage).

3. Learning that the traumatic event(s) occurred to a close family member or close friend. In cases of actual or threatened death of a family member or friend, the event(s) must have been violent or accidental.

Indirect exposure through learning about an event is limited to experiences affecting close relatives or friends and experiences that are violent or accidental (e.g., death due to natural causes does not qualify). Such events include violent personal assault, suicide, serious accident, and serious injury. The disorder may be especially severe or long-lasting when the stressor is interpersonal and intentional (e.g., torture, sexual violence).

4. Experiencing repeated or extreme exposure to aversive details of the traumatic event(s) (e.g., first responders collecting human remains; police officers repeatedly exposed to details of child abuse).

Note: Criterion A4 does not apply to exposure through electronic media, television, movies, or pictures, unless this exposure is work related.

Additional scoring notes:

- Participants are asked to identify which of the events reported was the "worst" or caused the most distress and give a brief description. Based on the criteria above, if:
  - They report trauma(s) with meet Criterion-A only- code 'Criterion-A'

    - They report trauma(s) which don't meet Criterion-A only- code 'Non-Criterion-A'
- When coding whether these traumas are interpersonal or not:
    - 'Interpersonal' is defined as- the event reported was traumatic as a result of the actions or words of another person or people (the interaction).
    - If more than one trauma is mentioned, or the event has both interpersonal and non-interpersonal aspects, can code as 'Interpersonal and Non-Interpersonal'
- For both Criterion-A/Non-Criterion-A and Interpersonal/Non-Interpersonal there will also be a column to mark a coding as 'uncertain' (detail on circumstances below) so that where decisions were challenging these can be removed to see if results are impacted.

Decisions on specific types of event reported:

- Suicide attempts and acts of *others* are included as Criterion A events, but non-interpersonal unless otherwise stated. Own suicide attempt is coded as non-Criterion-A, as life threatening alone is not sufficient. Within one's locus of control and thus might not reflect the underlying features of common PTSD traumas (e.g. sudden, unexpected).
- For bereavement related responses, unless further information is provided as to the exact nature of the death (such that it meets the above criteria), the event will be coded as NOT meeting Criterion-A. Also, non-interpersonal.
- If respondent reports emotional abuse only this will be coded as non-Criterion-A and interpersonal. If respondent reports emotional and physical abuse this would be coded as Criterion-A and interpersonal.

- Physical abuse or assault to be coded as Criterion-A and interpersonal.
- Domestic abuse to be coded as Criterion-A and interpersonal as this by definition is 'coercive, controlling AND violent behaviour' on Women's Aid.
- Car accidents to be coded as Criterion-A and non-interpersonal unless it is specified that there was intent from the other party. E.g. ‘Chased by car’ would be coded as Criterion-A and interpersonal as seems intentional (if you were chased by someone with a knife we would say interpersonal).
- Court cases/legal proceedings to be coded as non-Criterion-A and non-interpersonal unless sufficient detail is provided that suggests something in the interaction with others was what was traumatic.
- Admissions to hospital, sectioning, and medical negligence will be coded as non-Criterion-A unless detail provided that the events around this were sudden, unexpected, and catastrophic and involved threat to life or serious injury. Non-interpersonal unless detail indicates interactions related to that as most traumatic. *Also mark as uncertain so can be removed.*
- Imprisonment to be coded as non-Criterion-A and non-interpersonal (but definitely many interpersonal and Criterion-A traumas can happen in prison so if *insufficient detail also code uncertain*)
- Traumatic birth coded as non-Criterion-A unless it is specified that there was actual or threatened serious threat to their, or their partner, or their baby's life, the word traumatic *alone* is not sufficient. This may add some Criterion-A traumas that merely had insufficient detail to the non-DSM group, so *also mark these as uncertain so they can be removed from analyses.*

- Miscarriage to be coded as Criterion-A and non-interpersonal as it would inherently be sudden and unexpected death of someone close.
- Abortion to be coded as non-Criterion-A as even if felt lack of choice it is not sudden and unexpected. Caveat is that if the description suggests they were forced to have the procedure this could be Criterion-A as physical abuse (forced medical procedure), or if something went wrong during the procedure such that the person thought that they were at risk of serious injury or death. *If uncertain, mark as such so can be removed from analyses.*
- Medical conditions/events happening to people close to you where the medical condition/event is sudden, unexpected, and catastrophic (threat to life/injury) this is Criterion-A, however the word 'sudden' alone is not sufficient without enough information about what they died of (sudden death after three months of cancer is not 'sudden' by DSM-5 criteria). If they say sudden death and don’t specify, code as non-Criterion-A but *also as unsure so can be removed*. If they specify the type of event (e.g. stroke, haemorrhage, heart attack- sudden and unexpected) then code as Criterion-A.
- Attempted kidnap should be coded as Criterion-A and Interpersonal.
- Unrequited love is coded as non-Criterion-A and non-interpersonal (unless rejection event or interaction described then may be interpersonal- *also mark as unsure*).
- Job loss is coded as non-Criterion-A and non-interpersonal unless clear interactions with person or people as part of this are described. *Again add in unsure*
- Divorce is coded as interpersonal and non-Criterion-A
- Exposure to child abuse imagery is coded as Criterion-A and interpersonal as the event exposed to is interpersonal.

Appendix 3.E- Nature of 'Worst' Trauma by Group

Table E1 shows the nature of the events reported by participants in each group as the "worst"; the event which caused them the most distress. Participants' brief qualitative descriptions were used to code these events as 'Criterion-A' or 'Non-Criterion-A' and as 'Interpersonal', 'Non-Interpersonal', or both, based on the coding criteria in Appendix D. It was recognised that some events may feasibly have met Criterion A (e.g. "traumatic birth"), but due to the brevity of descriptions insufficient detail was available to ascertain this. In these instances, codes were marked as 'uncertain' so that proportions of Criterion-A and Non-Criterion-A traumas could be compared between the groups both with and without these events.

Table E1.

Nature of Worst Trauma by Group

	Full Sample		'Uncertain' removed	
	Autistic *n* (%)	Non-Autistic *n* (%)	Autistic *n* (%)	Non-Autistic *n* (%)
DSM-5 Criterion A				
Criterion-A trauma	84 (56.8)	58 (61.7)	74 (65.5)	55 (69.6)
Non-Criterion-A trauma	64 (43.2)	35 (37.2)	39 (34.5)	23 (29.1)
Could not code	0 (0.0)	1 (1.1)	0 (0.0)	1 (1.3)
Interpersonal Nature				
Interpersonal	80 (54.1)	50 (53.2)	75 (55.1)	47 (54.0)
Non-Interpersonal	60 (40.5)	40 (42.6)	55 (40.4)	37 (42.5)
Interpersonal and Non-Interpersonal	2 (1.4)	1 (1.1)	1 (0.7)	0 (0.0)
Could not code	6 (4.1)	3 (3.2)	6 (4.4)	3 (3.4)

Note. 50 traumatic life events, 15 in the non-autistic and 35 in the autistic groups, were 'uncertain' to code as meeting DSM-5 Criterion A or not. 19 traumatic life events, seven in the non-autistic and 12 in the autistic groups, were 'uncertain' to code as interpersonal or not.

Appendix 3.F- LEC-5 Trauma Types Endorsed by Group

Table F1 shows the number and percentage of the autistic and non-autistic group who endorsed exposure to each of the trauma types on the LEC-5, in total (exposed in any way) and by each form of exposure.

Table F1.

*Number (%) of Individuals Endorsing Traumas on the Life Events Checklist (LEC-5) across Autistic (*N*=148) and Non-Autistic (*N*=94) Groups*

	Happened to me		Witnessed it happen		Learnt about it		Part of my job		Total	
Traumatic Event	Autistic	Non-Autistic	Autistic	Non-Autistic	Autistic	Non-Autistic	Autistic	Non-Autistic	Autistic	Non-Autistic
Natural disaster	18 (12.2)	15 (16.0)	9 (6.1)	4 (4.3)	15 (10.1)	9 (9.6)	4 (2.7)	5 (5.3)	36 (24.3)	27 (28.7)
Fire or explosion	22 (14.9)	9 (9.6)	15 (10.1)	8 (8.5)	25 (16.9)	8 (8.5)	10 (6.8)	7 (7.4)	56 (37.8)	25 (26.6)
Transportation accident	73 (49.3)	40 (42.6)	25 (16.9)	12 (12.8)	36 (24.3)	24 (25.5)	6 (4.1)	7 (7.4)	100 (67.6)	62 (66.0)
Serious accident	25 (16.9)	11 (11.7)	17 (11.5)	9 (9.6)	26 (17.6)	21 (22.3)	7 (4.7)	10 (10.6)	59 (39.9)	42 (44.7)
Exposure to a toxic substance	6 (4.1)	1 (1.1)	1 (0.7)	0 (0.0)	10 (6.8)	5 (5.3)	5 (3.4)	0 (0.0)	17 (11.5)	6 (6.4)
Physical assault	91 (61.5)	48 (51.1)	39 (26.4)	25 (26.6)	47 (31.8)	28 (29.8)	17 (11.5)	27 (28.7)	117 (79.1)	75 (79.8)

Assault with a weapon	26 (17.6)	10 (10.6)	9 (6.1)	9 (9.6)	20 (13.5)	21 (22.3)	13 (8.8)	12 (12.8)	50 (33.8)	37 (39.4)
Sexual assault	80 (54.1)	33 (35.1)	8 (5.4)	2 (2.1)	53 (35.8)	35 (37.2)	13 (8.8)	14 (14.9)	102 (68.9)	58 (61.7)
Other uncomfortable sexual experience	104 (70.3)	58 (61.7)	12 (8.1)	8 (8.5)	50 (33.8)	28 (29.8)	16 (10.8)	10 (10.6)	116 (78.4)	67 (71.3)
Combat/ war zone	3 (2.0)	2 (2.1)	2 (1.4)	3 (3.2)	15 (10.1)	13 (13.8)	4 (2.7)	7 (7.4)	19 (12.8)	10 (21.3)
Captivity	11 (7.4)	9 (9.6)	2 (1.4)	1 (1.1)	9 (6.1)	6 (6.4)	2 (1.4)	5 (5.3)	19 (12.8)	19 (20.2)
Life threatening illness or injury	48 (32.4)	13 (13.8)	64 (43.2)	43 (45.7)	52 (35.1)	27 (28.7)	15 (10.1)	15 (16.0)	114 (77.0)	66 (70.2)
Severe human suffering	34 (23.0)	8 (8.5)	26 (17.6)	16 (17.0)	27 (18.2)	11 (11.7)	25 (16.9)	17 (18.1)	67 (45.3)	36 (38.3)
Sudden violent death	11 (7.4)	4 (4.3)	13 (8.8)	10 (10.6)	52 (35.1)	36 (38.3)	21 (14.2)	17 (18.1)	78 (52.7)	48 (51.1)
Sudden unexpected death of someone close to you	3 (2.0)	3 (3.2)	8 (5.4)	10 (10.6)	36 (24.3)	20 (21.3)	13 (8.8)	14 (14.9)	49 (33.1)	36 (38.3)
Serious injury, harm or death you caused	5 (3.4)	0 (0.0)	4 (2.7)	0 (0.0)	6 (4.1)	2 (2.1)	3 (2.0)	2 (2.1)	15 (10.1)	4 (4.3)

Appendix 3.G- Non-Criterion-A Traumas Reported by Group

Table G1 shows the range of events which were reported in response to being asked whether any other event had happened to them which “has felt like an extremely unpleasant, stressful or traumatic experience”, “has caused you to have nightmares about it or think about it when you did not want to”, “you have subsequently tried hard not to think about or go out or your way to avoid situations that remind you of it” and were coded by two clinicians as not meeting Criterion-A based on the coding criteria in Appendix D.

One hundred and three autistic and 61 non-autistic participants reported these additional non-Criterion-A traumatic events. Some respondents reported multiple non-Criterion-A traumatic events, hence the total number of events reported is higher than the number of autistic and non-autistic people who reported them. The autistic group reported more non-Criterion-A events on average.

Table G1.

Non-Criterion-A Traumas Reported by the Autistic and Non-Autistic Groups

	Autistic (*N*=103)		Non-Autistic (*N*=61)	
Event Reported as Traumatic	Number who Reported	%	Number who Reported	%
Pregnancy and Childbirth	6	5.8	7	11.5
Own Physical Illness, Hospitalisation or Medical Care	14	13.6	10	16.4
Sectioning and Psychiatric Hospitalisation	9	8.7	2	3.3
Emotional Abuse	15	14.6	6	9.8
Police Involvement with Family	3	2.9	2	3.3
Own Relationship Problem/Breakdown/Divorce	5	4.9	6	9.8

Got in Trouble	0	0.0	1	1.6
Bereavement	22	21.4	11	18.0
Abortion	4	3.9	2	3.3
Parents Relationship Problems/Breakdown/Divorce	6	5.8	2	3.3
Family Member or Friend Mental Illness	6	5.8	4	6.6
Financial Problems	3	2.9	2	3.3
Witnessing distress of others	0	0.0	3	4.9
Family Member or Friend Illness/Injury	9	8.7	7	11.5
Own Suicide Attempt	6	5.8	1	1.6
Own Mental Health	7	6.8	3	4.9
Bullying	27	26.2	5	8.2
School Trauma	4	3.9	2	3.3
Court Case/Investigation	3	2.9	3	4.9
Job Loss	6	5.8	1	1.6
Workplace Disciplinary Investigation	1	1.0	0	0.0
Harrassment	2	1.9	1	1.6
Feeling Silenced	0	0.0	1	1.6
Revenge Porn	0	0.0	1	1.6
Own Adoption/Experience of Foster Care	2	1.9	1	1.6
Argument	0	0.0	1	1.6
Difficult Family Relationship	2	1.9	0	0.0
Children Removed from Care	4	3.9	0	0.0
Interpersonal Difficulties	2	1.9	0	0.0
Moving home	5	4.9	0	0.0
Being Arrested/Police Interactions	5	4.9	0	0.0
Being Shouted At	2	1.9	0	0.0
Discrimination (Racism, Antisemitism, Homophobia)	2	1.9	0	0.0
Death of pet	1	1.0	0	0.0
Wedding	1	1.0	0	0.0
Betrayal	1	1.0	0	0.0
Child's School Trauma	1	1.0	0	0.0

Accessing Support for Autistic Child	2	1.9	0	0.0
Data Loss	1	1.0	0	0.0
Growing up Neurodivergent	2	1.9	0	0.0
Abandonment/Rejection by Family or Friends	7	6.8	0	0.0
Loneliness	1	1.0	0	0.0
Destruction of intellectual property	1	1.0	0	0.0
Lockdown	1	1.0	0	0.0
Unrequited love	1	1.0	0	0.0
Estrangement from Children	1	1.0	0	0.0
Social Services Involvement	1	1.0	0	0.0
Private Messages Being Shared	1	1.0	0	0.0
Therapy	2	1.9	0	0.0
Eviction/Homelessness	3	2.9	0	0.0
Misdiagnosis	1	1.0	0	0.0
Total Number of Non-Criterion-A Traumas Reported	211		85	