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Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology (DClinPsych).

Word Counts

Systematic Review of Literature (SRL) paper: 6668 words

Service Improvement Project (SIP) paper: 4996 words

Theoretically Driven Research (TDRP) paper: 5498 words

TDRP Executive Summary: 610 words

Connecting Narrative: 1000 words

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Paper Abstracts

(also included with individual project reports)

Abstract – Systematic Review of Literature

This systematic review sought to identify challenges to and facilitators of psychosocial wellbeing, as reported by autistic older adults. EMBASE, MEDLINE and psychINFO databases were searched on 08/05/2024 for quantitative and qualitative research sampling this population that addressed perceived challenges and enabling factors, beyond biological or neurocognitive aspects. 20 papers were included in the review, addressing a range of factors, e.g. mental health condition prevalence, quality of life compared to younger peers, the impact of diagnosis in later life and experiences of menopause. Most papers were rated as demonstrating acceptable quality with overall low risk of bias. Synthesis of findings was completed using a meta-integration approach, culminating in the presentation of mostly complementary qualitative and quantitative findings. The review identified a high prevalence of depression in this group and higher reported quality of life compared to younger peers. Quantitative findings regarding gender differences and qualitative findings about diagnostic experiences could not be integrated due to a lack of evidence from the respective methodological datasets. Limitations were identified, including low ethnic diversity in study samples and relatively low numbers of the oldest autistic older adults. Taken together, and applying ideas from the power threat meaning framework, this review indicates that clinicians must not underestimate the capability of this group in often having found, over time, inventive ways to

make features of their autism support their adaptive functioning. Additionally, there remain crucial gaps in service provision and social inequalities which highlight that more needs to be done to close a chasmic psychosocial wellbeing divide compared to non-autistic older adults.

Abstract – Service Improvement Project

Positive Behaviour Support (PBS) is the predominant framework used in the UK to promote patients' quality of life in intellectual disability (ID) services. However, effective implementation is limited by locally-specific operational and cultural factors. This service improvement project (SIP) investigated barriers to, and facilitators of, effective PBS-informed practice through asking frontline nurses and healthcare assistants (HCAs) about their experiences of supporting patients. Data from six semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA), resulting in three superordinate themes: *Following Your Heart*; *It's Really Tough – You Have to be Strong*; and *Just out of Reach – the Small Things That Make a Big Difference*. These themes highlighted how participants experienced close emotional ties to patients, responded to challenges in their roles and wished for more time for targeted patient wellbeing initiatives. These findings have been related to existing literature regarding PBS delivery and used to generate locally-informed service improvement recommendations for implementation by the senior leadership team (SLT). Recommendations include: recognising and providing support for the emotional efforts of staff; increasing confidence in PBS-orientated staff by generating meaningful outcome evidence that dissuades

colleagues from using alternative practices; and providing targeted training, making creative use of existing interest and skill in PBS within the team.

Abstract – Theoretically Driven Research Project

Hoarding difficulties (HD) affect many people and can cause upset and danger for the person, as well as friends and family, who themselves may experience distress and stigma as a result of clutter. Previous research found that people with HD feel less adequately socially supported compared to individuals with Obsessive Compulsive Disorder (OCD). To evaluate whether people with HD see their support differently, or there is a gap in support quality compared to those with OCD, this study presents the perspectives of 116 people offering support (POS) to people with these conditions (PWC). The research had a two-tailed hypothesis: a) that POS(HD) would not differ on support ratings compared to POS(OCD), or b) that POS(HD) would report comparatively lower ratings across support components. Support quality was measured using an adapted proxy version of the Revised Norbeck Social Support Questionnaire which focusses on the perspective of the supporter. Additional hypotheses predicted that HD would be the more stigmatised condition and that the POS(HD) group would report higher levels of associative stigma (internalised stigma by virtue of having a connection to a stigmatised individual). The design was cross sectional, comparing those supporting OCD with those supporting HD. POS(HD) rated both their wish to support and the perceived success in terms of the PWC's response as significantly lower, but did not differ in rating the impact support has on themselves. Public stigma was rated more highly by POS(HD)

relative to POS(OCD) and associative stigma felt more acutely by POS(HD). Further research involving POS and PWC dyads is needed to investigate what is causing this shortfall in support. Clinical research for HD interventions should also examine how involving POS could enhance treatment outcomes.

Systematic Review of Literature Paper

James Dennis, James.dennis@stx.ox.ac.uk

Title: Meta-Integration Systematic Review: What do Autistic Older Adults say About Facilitators and Challenges to their Psychosocial Wellbeing?

Word count: 6668 words (excluding titles, references and appendices)

Date of the report: original submission 07/11/2023, reviewed and updated 08/05/2024

Internal supervisor: Dr Kathryn Evans

Proposed journal: Journal of Autism and Developmental Disorders.

Journal choice rationale: Selected on the basis of a high impact rating and potential influence on policymaking relevant to autistic people.

Abstract

This systematic review sought to identify challenges to and facilitators of psychosocial wellbeing, as reported by autistic older adults. EMBASE, MEDLINE and psychINFO databases were searched on 08/05/2024 for quantitative and qualitative research sampling this population that addressed perceived challenges and enabling factors, beyond biological or neurocognitive aspects. 20 papers were included in the review, addressing a range of factors, e.g. mental health condition prevalence, quality of life compared to younger peers, the impact of diagnosis in later life and experiences of menopause. Most papers were rated as demonstrating acceptable quality with overall low risk of bias. Synthesis of findings was completed using a meta-integration approach, culminating in the presentation of mostly complementary qualitative and quantitative findings. The review identified a high prevalence of depression in this group and higher reported quality of life compared to younger peers. Quantitative findings regarding gender differences and qualitative findings about diagnostic experiences could not be integrated due to a lack of evidence from the respective methodological datasets. Limitations were identified, including low ethnic diversity in study samples and relatively low numbers of the oldest autistic older adults. Taken together, and applying ideas from the power threat meaning framework, this review indicates that clinicians must not underestimate the capability of this group in often having found, over time, inventive ways to make features of their autism support their adaptive functioning. Additionally, there remain crucial gaps in service provision and social inequalities which

highlight that more needs to be done to close a chasmic psychosocial wellbeing divide compared to non-autistic older adults.

Keywords: *Autism; Older adults; Psychosocial Wellbeing; Meta-Integration.*

No identical reviews were identified from searching the Prospero database and this review is registered under code CRD42023478220.

This report has been written using guidance from the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) guidelines (Page et al., 2021).

No conflict of interest is declared and no financial support was received for the review.

Materials and data are not currently publicly available.

Introduction

This report is a systemic review of literature concerning psychosocial wellbeing in autistic older adults aged 50+ years, without an intellectual disability. The review used a meta-integration framework (Frantzen & Fetters, 2016) to synthesise qualitative, quantitative and mixed methods papers and configured intra-method findings into an overarching synthesis. The review critiqued the evidence base from a positive ageing perspective (Stock et al., 2017) and considered findings in relation to the Power Threat Meaning Framework (PTMF) (Johnstone et al., 2018). The findings indicate that older autistic adults reported both facilitators to psychosocial wellbeing, by virtue of being older and having more life experience, and barriers in historic hostility and ongoing shortcomings in support provision, limiting ability to thrive in comparison to non-autistic counterparts. The review findings can be applied by all services which may be accessed by autistic older adults through recognising and celebrating features of autism that, over time, have become supportive to functioning. Clinicians should also note potential vulnerability in this group to depression and be vigilant to narratives of self-blame in relation to negative social interactions.

Background

Autism is defined by ‘persistent deficits in social communication and social interaction’ with the ‘presence of restricted, repetitive patterns of behaviour, interests or activities’ (American Psychiatric Association, 2013, p. 50). Global prevalence is estimated at 1/132, although quantification is complicated by autism frequently being conceptualised as a childhood condition, and diagnostic overshadowing with intellectual disability (Baxter et al., 2015). There has been a

paucity of research about autistic older adults, accounting for just 0.4% of autism studies over the past decade (Mason et al., 2022). While a minimum age of 65 is typical for older adult research, autistic older adult studies have included lower thresholds to account for higher mortality rate and earlier onset of age-related vulnerabilities, compared to non-autistic counterparts (Hirvikoski et al., 2016; Parchomiuk, 2021). Most commonly, existing research in the field has characterised autistic older adults as 50-years-old or above (e.g., Roestorf et al., 2022), as this is associated with the onset of cognitive ageing (Mason et al., 2022).

A recent review addressed aspects of ageing with autism, however, this operationalised psychosocial wellbeing primarily through the lens of neuropsychological functioning (Parchomiuk, 2021). The review author noted that this is characteristic of autistic older adult literature and may neglect the nuance of 'what it is like' to be an autistic older adult. A further review by Tse et al. (2022) represented a step closer to representing psychosocial issues such as social integration, however, was limited in considering quantitative research only. Additionally, some autism literature risks depersonalising individuals by focussing on 'burden' for services (Baxter et al., 2015). The intersectionality of autism and older adulthood may mean even greater marginalisation and experiences being reduced to a 'problem' (Hategan et al., 2017).

Despite reported difficulty in identifying research including older autistic adults due to a lack of specific keywords (Mason et al., 2022), there are further examples of reviews including data from this population. A review by Tobin et al. (2014) included participants aged 17-70 and concluded that autistic adults

commonly experience loneliness, but may be supported by informal social support or structured groups with a focus towards developing social skills. However, the mean sample ages in the review papers ranged from 19 to 43.52 (Tobin et al., 2014) and therefore the authors did not report any findings specific to older adults. Another review by Ayres et al. (2017) indicated that autistic adults typically report lower quality of life compared to non-autistic counterparts. The review limitations identified that the majority of measures used were not validated for use with autistic people and that there is a need for research to identify factors important to autistic adults, let alone how this may differ for older vs younger autistic adults (Ayres et al., 2017).

Finally, a previous mini-review has outlined what is known about early-adulthood transition and experiences for autistic people and discussed potential trajectories into older age, considering the shrinking of social networks and cognitive decline reported in non-autistic samples (Happe & Charlton, 2012). The authors suggested that solitary hobbies and interests and already having smaller social networks may limit negative sequalae of ageing for autistic adults but noted that research at that point in time could not evidence this claim (Happe & Charlton, 2012).

Systematic Review

The current review considered subsequent progress in the investigation of older autistic adults' experiences, discussing findings that are specific to this group. The review was conducted in respect to the notion of 'positive ageing', recognising older adults' strengths and aspirations in relation to potentially complex and difficult age-related challenges that are part of a 'normal' ageing

process, i.e. not attributable to degenerative neurological conditions, e.g. dementia (Stock et al., 2017). The intention was to present a more holistic account of what autistic older adults perceive to be facilitators of, and challenges to, broader psychosocial wellbeing. It is argued that research must do better in prioritising what older research participants have to say in order to inform policy and service development that meets older populations' needs more accurately (Stock et al., 2017).

The review used a meta-integration approach, as outlined by Frantzen and Fetters (2016), synthesising quantitative, qualitative and mixed-methods studies. This involves completing iterative intra-method syntheses, before a second round of inter-method synthesis is performed, considering convergence (Frantzen & Fetters, 2016). Whitley et al. (2020, p. 500) used this procedure in their review of acute pain management in children and advocated its advantage in 'supplying context and enriching the quantitative findings with qualitative data'. The Whitley et al. (2020) review also positioned the synthesised quantitative findings in relation to how qualitative evidence supported these findings, termed 'configuration' by Sandelowski et al. (2006). The current review used this guidance to assess "complement and conflict" in the inter-method synthesis, and identify "unexplained" findings (Sandelowski et al., 2006).

In an effort to contextualise the synthesised findings, the review also considers relevant ideas from the PTMF (Johnstone et al., 2018). The PTMF is a conceptual system incorporating social, psychological, and biological factors as an alternative to functional psychiatric diagnosis (Johnstone et al., 2018). An example of a review informed by the PTMF was conducted into parents'

experiences of compulsory child removal (Enlander et al., 2021). The authors described the PTMF as offering greater scope to consider social inequality, how individuals navigate system-level threats and how professionals might use their position of power more responsibly to effect positive change. A position statement on the PTMF, acknowledging criticism, is provided in *Appendix A*.

Method

Search

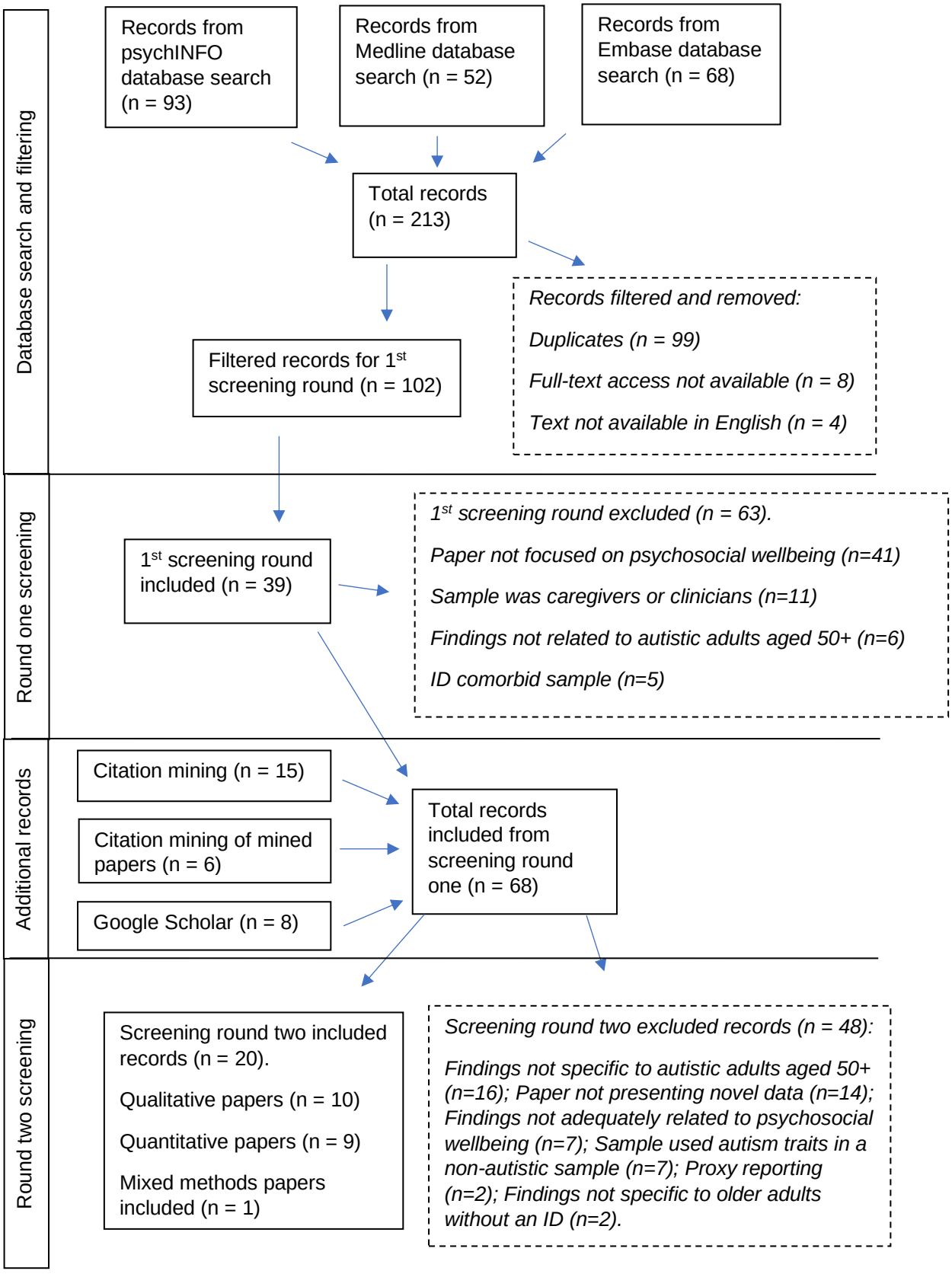
Papers were searched via the psychINFO and MEDLINE and EMBASE databases, which previously achieved greater recall in conjunction (Bramer et al., 2016), on 14/08/2023 and again on 08/05/2024. Additional papers were identified via citation mining and Google Scholar.

A multi-field search was run using the following search terms:

- In the ‘key terms’ field: “Autis*” AND “older adult* OR ag?ing”
- In ‘any field’: “wellbeing OR quality of life OR daily functioning OR mental health OR mood OR social”.

Terms were combined using the ‘AND’ function and additional limits were applied specifying papers from a peer-reviewed journal and published since 2013 to target research conducted post-consolidation of autism diagnoses in DSM-5 (for full search detail, see *Appendix B*).

Figure 1: Flow diagram of literature search and study selection



Screening

Screening was conducted in two rounds (see *Figure 1*). Independent title and abstract screening of the database search results produced 102 records, after removal of duplicates and inaccessible records. Inclusion criteria for screening round one were:

- Papers must refer to autistic older adults, or ageing in autistic adults, in the title or abstract.
- Papers must bear conceptual relevance to aspects of psychosocial wellbeing, e.g. quality of life, daily functioning, mental health and mood, social experience, etc.
- Papers must report findings in relation to a dedicated group aged 50+ years.
- Papers could comprise any format or publication type to enable a wider search pool for citation mining.

Despite evidence of an increased mortality rate, relative to non-autistic people, there is not an available average estimate, in years, suggesting how premature death may occur in the autistic population and previous findings note there may be differences between so-called higher and lower functioning groups (Hirvikoski et al., 2016). A threshold of 50 years of age and above was selected for the current review so as to be inclusive of relevant papers, many of which used this cut-off (Parchomiuk, 2021).

Exclusion criteria were also applied:

- Papers focusing on cognitive processes (e.g. memory) and/or degenerative neurological conditions (e.g. dementia) were excluded.
- Papers exclusively sampling individuals with intellectual disabilities were excluded to increase the review's specificity.
- Papers related to mortality and causes of death were excluded.
- Papers evaluating diagnostic tools were excluded, however, research about experiences or population factors regarding diagnosis in older adulthood were included.

25% of records were independently screened in parallel by a second researcher. All screening decisions were able to be resolved and mutually agreed, producing a total of 39 records. Papers were most commonly excluded by virtue of showing no apparent relevance to psychosocial wellbeing, often using brain imaging (e.g., Braden & Riecken, 2019). The references of these records were mined for potentially relevant additional papers and equivalent title and abstract screening conducted. The references of mined papers were also reviewed and screened, without further iterations. Explorative searches were also run via Google Scholar, using the database search terms listed above, as well as related terms: 'senior', 'geriatric', 'elderly', 'ASD', 'ASC', and 'Aspergers'. The related terms did not produce new results, however, eight additional papers were identified from Scholar searches using the main search terms. Citation mining and exploratory Scholar searches added to the initial papers search, resulting in a total list of 68 papers. These included quantitative studies, e.g. cohort studies, correlational studies, experimental studies, RCTs, qualitative

studies, e.g. using focus groups, interviews, content analyses, and mixed methods studies.

Full-text screening was conducted, also with 25% rated in duplicate and consensus reached. Criteria were as above with the additional limits:

- Papers must contribute novel data, i.e. not a review which does not generate new data or conference or network reports.
- Papers must concern autistic older adults, or ageing in autistic adults, as a central theme of the paper. Papers may compare to different age groups within the autistic community or compare to non-autistic comparison groups.
- Papers must present perspectives from the target population, such as interview data or self-report measures. Informant-only measures or autism characteristics assessed exclusively in the general population were excluded.

The majority of excluded papers were rejected because the findings were not specific to adults aged 50+ years (e.g. Hwang et al., 2020), or the papers did not present novel empirical data (e.g. Oakes, 2021). The final number of included papers was 20. For paper details see *Table 1*.

Quality appraisal

An initial 50% of papers were double-rated using either the Qualitative Studies or Cohort Study checklist (Critical Appraisal Skills Programme, 2022 (CASP)), with agreement reached for all criteria. Almost all studies had some quality criteria identified as 'partial', with four papers demonstrating more serious quality issues, but which were not thought to threaten the reliability or validity of the current review to an unacceptable degree. Of the four, two papers came from the qualitative papers (Barber, 2015; Elichaoff, 2015). The small sample size was considered a limitation of these papers individually but was not considered to merit exclusion from the review as these participants' data could be considered as part of the wider dataset. Similarly, there were 'no' ratings for a single quality metric for two of the quantitative papers. Insufficient follow-up time between data collection points to determine age-related change was found in the Roestorf et al. (2022) paper. However, for the purposes of the current review, the cross-sectional data were appropriate for considering age-related differences between older and younger groups within the overall sample, without this limitation affecting the review findings. Considering the Nylander et al. (2018) paper, the raters queried the generalisability of findings due to the recruitment strategy. For this reason, data extraction related to this paper was restricted to considering differences between older and younger autistic adults *who are accessing structured support*, omitting findings suggesting population-based differences between autistic and non-autistic people.

Risk of bias was assessed via CASP items relating to recruitment processes and believability of the findings. Three papers were considered to recruit in a

manner raising probability of bias: from a participant pool likely known to the researchers in a difference capacity (Barber, 2015) and from overly-specific population contexts, i.e. intensive service engagement (Nylander et al., 2018) and a special interest network (Elichaoff, 2015). For full quality ratings, see *Appendix C*. Further quality issues were noted by the researchers and were commented on in some of the papers. Typically, samples included a poverty of ethnic diversity (Charlton et al., 2022) and introduced potential specificity issues in individuals reporting multiple different autism-related diagnoses, such as Asperger's Syndrome, Childhood Autism, Pervasive Developmental Disorder, etc. (Nylander et al., 2018). There were also discrepancies between self and proxy reporting (Lever and Geurts 2018).

Data extraction

Direct excerpts relating to aspects of wellbeing in autistic older adults from each of the papers were identified and copied into an Excel spreadsheet. The mixed methods paper underwent two rounds of extraction, identifying qualitative and quantitative data respectively, referred to as fractionation by Frantzen and Fetters (2016). Extracted data included textual summaries of findings from statistical tests, direct quotes from qualitative interviews, or data describing features of the research sample. Relevant data were guided by deductive prompts, devised using broad concepts and measures of psychosocial wellbeing, including aspects potentially more relevant to autistic people as described by Henninger and Taylor (2012) and Bishop-Fitzpatrick et al. (2016). Outcomes described in the PTMF were also used to inform the list of deductive coding prompts:

Quality of life; Happiness; Wellbeing; Mood and emotions; Mental health; Physical health; Social life – family; Social life – friends; Social life – romantic; Support needs and access; Daily functioning; Leisure activity fulfilment; Purposeful activity fulfilment; Community connections; Accommodation and living conditions; Independence and agency.

Prompts for additional inductive codes enabled the researchers to capture paper excerpts relevant to the research question which did not correspond to the deductive codes. All extracted data were sorted into columns categorising the finding as a facilitating or challenging factor for psychosocial wellbeing.

Data not relating to older adults or ageing were excluded from extraction, as were data relating to neurocognitive features that were not directly related to psychosocial wellbeing. Findings specific to autistic older adults with comorbid intellectual disability were also omitted. For 50% of papers, data extraction was completed independently by two reviewers. Each verified the extracted data of the other, checking for accuracy in relevance and specificity to autistic older adults. There were no identified discrepancies and duplicated data were removed. At this stage, all items rated as ‘partial’ using the CASP quality appraisal tool across all papers were revisited to check that extracted data were not unduly influenced by issues with quality. No such violations were identified, however, the overall rate of ‘partial’ quality issues was considered as a limitation of the collective findings of the current review.

Extracted data from quantitative and qualitative papers were collated in a separate Excel spreadsheet, displaying 88 quantitative and 357 qualitative data entries.

Table 1: Papers included in review

Author/s	**Year**	**Focus**	**Design**	**Older autistic adult sample size**	**Age range and mean (years)**	**Additional participants**	**Country**
Barber	2015	Transition to older adult services	Qualitative: Focus group	n=4	56-64 (m=60.3)	-	United Kingdom
Brady et al.	2024	Menopausal transition	Qualitative: Focus groups and interviews	n=24	40-71 (m=50.3)	-	Canada and United Kingdom
Charlton, McQuaid & Wallace	2023	Social support associations with quality of life	Quantitative: Cohort study	n=200	50-83 (50-59.9 group m=52.2, 60+ group m=66.5)	Autistic adults aged 40-49.9 (n=188)	International
Elichaoff	2015	Experiences of ageing with autism	Qualitative: Semi-structured interviews	n=4	58-63 (mean not reported)	-	United Kingdom
Hickey, Crabtree & Stott	2018	Experiences of diagnosis, social support and getting older	Qualitative: Semi-structured interviews	n=13	51-71 (m=60.4)	-	United Kingdom

Author/s	Year	Focus	Design	Older autistic adult sample size	Age range and mean (years)	Additional participants	Country
Hwang, Foley & Trollor	2017	Ageing well	Qualitative: Semi-structured interviews	n=15	50-80 (mean not reported)	Autistic adults aged 31-43 (n=6). Carers of autistic adults (n=9) including carers of autistic adults with intellectual disabilities (n=3).	Australia
Hwang et al.	2023	Performing daily activities	Qualitative: Semi-structured interviews	n=15	50-73 (m=60.1)	-	Australia
Lever & Geurts	2016	Psychiatric symptoms and disorders	Quantitative: Cohort study	n=48	55-79 (mean not reported)	Autistic adults aged 19-38 (n=52). Autistic adults aged 39-54 (n=72). Non-autistic controls (n=172).	Netherlands
Lever & Geurts	2018	Autism characteristics	Quantitative: Cohort study	n=79	53-79 (mean not reported)	Autistic adults aged 19-40 (n=79). Autistic adults aged 40-53 (n=79). Non-autistic controls (n=198).	Netherlands

Author/s	Year	Focus	Design	Older autistic adult sample size	Age range and mean (years)	Additional participants	Country
Mason et al.	2019	Mental health conditions and associations with quality of life	Mixed methods: Cohort study and semi-structured interviews	Quantitative: n=69 Qualitative: n=8	Quantitative 55+ (m=61.5) Qualitative: 56-71 (m=63.1)	Quantitative sample included one participant reporting intellectual disability	United Kingdom
Moseley, Druce & Turner-Cobb	2020	Menopausal transition	Qualitative: Focus group	n=7	49-63 (m=54.8)	Sample included one participant aged 49	United Kingdom
Nylander et al.	2018	Psychiatric care and psychotropic medication use	Quantitative: Cohort study	n=345	55-96 (m=64.0)	Autistic older adults with comorbid intellectual disability (n=256)	Sweden
Roestorf, Howlin & Bowler	2022	Mental health, autistic traits and quality of life	Quantitative: Longitudinal cohort study	n=31	50+ (m=58.6)	Autistic adults aged 18-49 (n=37).	United Kingdom

Author/s	Year	Focus	Design	Older autistic adult sample size	Age range and mean (years)	Additional participants	Country
Stagg & Belcher	2019	Receiving a diagnosis in later life	Qualitative: Semi-structured interviews	n=9	52-54 (mean not reported)	-	United Kingdom
Uljarević et al.	2019	Anxiety and depression prevalence	Quantitative: Cohort study	n=11	65+ (mean not reported)	Autistic adults aged 15-21 (n=77). Autistic adults aged 22-39 (n=97). Autistic adults aged 40-64 (n=70).	Australia
Van Heijst & Geurts	2015	Quality of life	Quantitative: Cohort study	n=24	53-83 (m=63.7)	Non-autistic older adults (n=24)	Netherlands
Waldron, Coyle & Kramer	2022	Self-care practices	Qualitative: Semi-structured interviews	n=30	51-79 (m=61.0)	-	United States
Zheng et al	2022	Use of assistive technologies	Qualitative: Semi-structured interviews	n=15	50-73 (m=60.1)	-	Australia

Author/s	**Year**	**Focus**	**Design**	**Older autistic adult sample size**	**Age range and mean (years)**	**Additional participants**	**Country**
Zivrali-Yarar et al.	2020	Social cognition	Quantitative: Cohort study	n=29	50-71 (m=61.3)	Autistic adults aged 19-48 (n=29). Non-autistic younger and older adults (n=39)	United Kingdom
Zivrali-Yarar et al.	2022	Autism symptoms, mental health conditions and associations with quality of life	Quantitative: Cohort study	n=41	50-71 (m=57.0)	Autistic adults aged 19-48 (n=38). Non-autistic younger and older adults (n=57)	United Kingdom

Intra-Method Syntheses

Qualitative and quantitative data, including those extracted from the one mixed methods study, were reviewed independently, as per the advanced convergent meta-integration model by Frantzen and Fetters (2016, p.2268).

Quantitative

Additional columns were added to classify the data type for each entry (e.g. regression or statistical difference), summarise the findings and relate these to a thematic code. For full code list see *Appendix D*. Sorting the data by themes then enabled the proceeding synthesis.

Overall quality of life

Autistic older adults consistently reported lower quality of life compared to non-autistic counterparts. This was identified by comparison to previously reported datasets from non-autistic samples using the WHOQoL BREF measure (Roestorf et al., 2022), with Mason et al. (2019) finding that autistic older adults mostly reported scores more than one standard deviation below normative scores on the same measure. Comparing groups using the RAND-36 generic quality of life measure, van Heijst and Geurts (2014) found poorer quality of life in autistic older adults compared to controls ($F_{(1,46)} = 12.5$, $p = 0.001$).

There was varying evidence regarding age differences in quality of life for autistic adults. Charlton et al. (2022) compared autistic adults in their 40s, 50s and 60+, finding a difference in psychological quality of life, again using the WHOQoL BREF (F=3.24, p = .040), with the 60+ group reporting higher quality of life than those aged 40-49.9. Overall quality of life and social sub-domain

scores were higher for older adults compared to younger adults in the Roestorf et al. (2022) study and explorative analysis by Zivrali Yarar et al. (2020) indicated a curvilinear effect whereby quality of life was better for older autistic adults, compared to middle-age.

Autism traits

Similarly, Lever and Geurts (2018) found that autistic older adults reported lower scores on the Autism-Spectrum Quotient and Sensory Sensitivity Questionnaire measures, in contrast to the highest scores across the lifespan being reported by middle-aged individuals. Sensory hypersensitivities were also reported more in younger than older autistic adults in the Roestorf et al. (2022) paper. Theory of mind scores were not different between autistic adults of incremental age ranges ($F_{(1,55)} = 0.09$, $P = 0.77$), however there was an age-group effect as performance was poorer in older vs younger adults in a non-autistic comparison sample ($F_{(1,36)} = 12.57$, $p < 0.01$) (Zivrali Yarar et al., 2020).

Higher rates or severity of autistic traits, such as higher attention to detail (Lever & Geurts, 2018), more restricted interests and repetitive behaviours (Roestorf et al., 2022) and lower social responsiveness (Zivrali Yarar et al., 2022) were associated with lower quality of life across the lifespan. 51.7% of older autistic adults in the Zivrali Yarar et al. (2020) study met the cut-off indicating significance on the Toronto Alexithymia Scale and this rate was not different from younger counterparts.

Social experience

Social stressors, e.g. social anxiety, were commonly reported by autistic adults and subjective wellbeing was negatively associated with lack of personal relationships and community isolation across age groups (Roestorf et al., 2022). Older autistic adults reported significantly lower scores on the Social Responsiveness Scale, not differing from younger autistic adults (Zivrali Yarar et al., 2022). Similarly, older autistic adults reported greater personal distress in tense social settings than non-autistic individuals, according to the Interpersonal Reactivity Index, but had similar scores to younger counterparts (Zivrali Yarar et al., 2020). Despite this difference, older autistic adults outscored younger in terms of perceived quality of social relationships on the WHOQoL BREF ($F_{(1132)}$ = 7.58, p = 0.007) (Zivrali Yarar et al., 2022). Zivrali Yarar et al. (2022) found that non-autistic age groups did not differ significantly on a measure of social quality of life, but noted that the direction was inverted, with younger adults giving higher ratings than older non-autistic adults.

Lever and Geurts (2018) noted that age was positively correlated with improved self-reported social skills, whereas the opposite was found for non-autistic adults, i.e. lower social skill scores were associated with older age in the non-autistic group. Examining demographic factors, Uljarević et al. (2020) found that living alone predicted higher depression symptomology.

Social Support

Autistic older adults reported higher social support compared to younger, although this was not significant (t= −1.71, p = 0.80) (Roestorf et al., 2022).

Charlton et al. (2022) also found no age differences in instrumental or subjective support and in regression analyses found that better support predicted higher quality of life, even after controlling for demographic, health and mental health factors.

Mental health

Lever and Geurts (2016) found no difference in mental health symptoms between age group scores on the Symptom Checklist-90 Revised ($F_{(18, 660)}$ = 0.82, p = .672) but did find that more younger autistic people than older met clinical threshold for mental health conditions on the Mini International Neuropsychiatric Interview Plus. Similarly, Uljarević et al. (2020) found no age group differences in anxiety (F=1.23, p = .30) nor depression symptomology (F=2.28, p = .079), however did find that clinical presence of anxiety *and* depression increased from the youngest to middle-aged group before a sharp decline for older autistic adults.

Zivrali Yarar et al. (2022) found that older autistic adults met clinical thresholds specifically for anxiety, somatoform and eating disorders less frequently than younger counterparts, but similar rates of depression ($\chi^2_{(1)}$ = 3.65, p = 0.06). Comparatively, Roestorf et al. (2022) found that older autistic adults scored lower on a number of mental health scales (Patient Health Questionnaire–9-item, Beck Anxiety Inventory–second edition and Beck Depression Inventory–second edition) than younger autistic adults, but no significant differences between age groups were found in meeting clinical thresholds for any single investigated condition.

The rate of depression in the Roestorf et al. (2022) autistic older adults sample was 15.6%, making this the most common condition for this group. Mason et al. (2019) reported that scores on the Hospital Anxiety and Depression Scale were predictive of lower quality of life, however, Zivrali Yarar et al. (2022) found that depression presence was a unique predictor of poorer quality of life (β = -0.45, $p < 0.001$), whereas anxiety alone was not. The latter finding was support by Charlton et al. (2022) also finding that depression was the only condition able to predict lower quality of life scores (R^2=.472, F=67.67, p <.001). In the Nylander et al. (2018) study sample, older autistic adults without an intellectual disability were prescribed antipsychotic medication at a rate of 63%.

Gender differences

Females were more likely to meet clinical thresholds compared to males for anxiety (χ^2 =10.66, p=.001) and depression (χ^2 =22.31, p <.001) (Uljarević et al., 2020). Contrastingly, males reported higher rates of psychiatric contact (66%) compared to females (59%) (Nylander et al., 2018).

Qualitative

Synthesis of the qualitative data was achieved through adding a coding column to the dataset and an interactive process of clustering codes around superordinate themes. For full code list see *Appendix D*.

Living well as an autistic older adult

Awareness of features of autism and how these might be mitigated for using personally relevant practical steps was a common feature of participant accounts. For example, strategies to support consistency in eating habits and other self-care routines were reported in the study by Waldron et al. (2021) and Hickey et al. (2018) noted how many participants had found employment in a field that matched a special interest. Across the papers, the heterogeneity of participants was stark, however there was also a collective sense of individuals developing greater adaptability in line with more life experience accompanying getting older. This is summarised well in the Hwang et al. (2017) study which noted improved resilience and optimism in relation to challenges and by the following quote: 'I find there's more peace for me the older I get, the more I'm understanding people and social situations and that sort of thing' (p.2037). Autistic older adults reported finding ways to access support whilst maintaining agency in novel ways, such as a spouse completing most laundry tasks with the individual adding 'I'll help along where I can' (Mason et al., 2019, p. 19). Similarly, being older appeared to facilitate participants being more prescriptive in communicating their needs around social contact to make this more predictable and accessible. This included individuals specifying text-based messaging over phone calls (Zheng et al., 2021), requiring others to present only on appointment and with prior notice (Hwang et al., 2023) and advocating that periods of solitude, as opposed to isolation, were supportive and necessary (Hickey et al., 2018).

Gradually figuring things out

Having more experience of social situations with age seemed to foster greater awareness of how to check one's own limitations in a less self-critical way. For example, reflections on becoming more comfortable with viewing life through an autistic lens were described: 'I need a service that recognises that I am likely to interact differently with the environment and the people within that environment because of my Asperger's' (Barber, 2015, p. 1056). With practice seemingly comes more possibility of navigating the social world more confidently and having greater resilience and perspective when things do not go as planned; 'I'm not pressurising myself to be like everyone else. [y]ou know, it doesn't matter if I like being on my own, living on my own, [t]hat's fine.' (Hickey et al., 2018, p. 362). Having a potentially more stable adulthood and less pressure to reach normative lifespan milestones, respectively to non-autistic people, may offer an opportunity to dedicate more time to preferred activities, such as extensive reading (Zheng et al., 2021) or self-education through creative media (Hwang et al., 2017).

Experiences of diagnosis

For many, diagnosis in adulthood appears to have offered a mechanism for alleviating an overestimated sense of culpability in social hostility. For example, one quote from Elichaoff (2015, p. 1856) suggested 'now I know at least that it's not my moral character, it's not my basic character that's at fault'. Diagnosis often offered a new position from which to reflect on one's life and give a framework for considering how greater quality of life might be achieved in the

present and future. One participant noted ‘the social thing was a problem, I couldn’t do birthday parties, and I couldn’t really behave’ (Stagg & Belcher, 2019, p. 352), but since diagnosis had moved from a position of being ‘unable’ to being able to prepare accordingly. Similarly, this was important in identifying specific issues related to new challenges, such as an autism diagnosis empowering individuals to differentiate between sensory sensitivities and physical health phenomena (Brady et al., 2024). This process of integrating diagnosis may go hand in hand with seeking a closer relationship with a wider autistic community, described in Hickey et al. (2018). However, for others, diagnosis may raise reticence in it having come too late to have protected them from past harm, such as one person saying ‘I burst into tears and just said “you’re a bit late”, because right from childhood things had been a bit of a disaster’ (Elichaoff, 2015, p. 1856).

Legacy of exclusion

As much as ageing was viewed as enabling, there were also common ideas about older adulthood being the culmination of needing to develop resilience in response to hardship. Much reflection involved recounting a life history of painful rejections by others and feeling misunderstood and unwelcome; ‘he actually said to me “you’ve got the kind of personality people avoid”, which is like icicles in your heart, you know that is really skewering you where it hurt’ (Elichaoff, 2015, p. 1858). This extends to the notion of having to continue to be strong to manage adversity later in life, such as in relation to menopause (Moseley et al., 2020) or barriers to employment (Mason et al., 2019). Experiencing attempts to access professional support as missing specificity in

meeting autistic people's needs was said to reinforce wider discrimination. A participant said sarcastically of professionals: 'I have attended a one-day course on autism. I know everything that there is to know' (Barber, 2015, p. 1056). In various accounts, it was argued that autistic older adults are best served by support that values the person and their skills with an overt sense of accepting the individual (Hwang et al., 2017). Nonetheless, for this group, being shaped by years of feeling pressured to fit in with a non-autistic world was associated with long-term mental distress. Efforts to camouflage were sometimes considered a direct cause of suffering and awareness of struggle itself could make participants feel isolated (Brady et al., 2024). Mental health symptoms described included fluctuating mood to the point of threatening stable employment (Mason et al., 2019) and triggering meltdowns, anxiety and depression and feeling suicidal (Brady et al., 2024; Moseley et al., 2020).

Familiar unremitting challenges

In the context of ongoing challenges associated with aspects of autism, there was a narrative of participants wanting researchers not to underestimate continued hardship whilst recognising possible relative improvements in their situations over time. A common obstacle was the impact of sensory difficulties, described most prominently in the paper by Hwang et al. (2023, p. 2042), e.g. 'I can't get my hands wet or moist and that has quite a profound impact on my ability to cook'. Despite the development of protective factors over time, there was also a notion of stressful situations causing a rapid unravelling in coping (Brady et al., 2024). For example, in relation to menopausal symptoms one participant pondered 'it's like, your everyday life, just to appear 'normal' is bad

enough, but when M [the menopause] happens, it all gets too much … I wonder if the low life expectancy for autistic women is linked to menopause because it all gets too much' (Moseley et al., 2020, p. 1429). Usually supportive activities could quickly become sources of distress, such as driving (Zheng et al., 2021) or binge eating (Waldron et al., 2021). There was also recognition of barriers in systems beyond the individual's control; practical barriers in inadequate structured support (Brady et al., 2024; Stagg & Belcher, 2019), financial hardship (Hwang et al., 2023) and longing for a romantic relationship but seeing this as harder for autistic people (Hickey et al., 2018).

Meta-Integration

Table 2: Meta-Integration table detailing reported challenges and facilitators to psychosocial wellbeing for autistic older adults.

	Quantitative	**Qualitative**	**Integration**
Challenges	Autistic older adults reported lower quality of life compared to non-autistic counterparts and difficulties with social interactions and support.	**Familiar unremitting challenges** As well as practical barriers in inadequate support and financial hardship, overwhelm and sensory difficulties continue to negatively impact wellbeing and require constant attention.	**Complement** - Discrimination and gaps in support were salient for autistic older adults and an awareness of difference and being treated differently was linked to poorer quality of life.
	Depression was the most commonly reported mental health condition for older autistic adults. Depression consistently predicted lower quality of life.	**Legacy of exclusion** Study participants described longstanding pressure to fit in with a non-autistic world and experiencing mental distress when they perceived to have failed in this aim.	**Complement** - Depression was regularly mentioned in qualitative accounts and autistic older adults spoke of repeated experiences of wanting to fit in but experiencing rejection leading to reduced social engagement and low self-image.
	Autistic older adults who were female reported higher anxiety and depression symptoms, however, males reported higher rates of contact with psychiatric services.	NULL	**Unexplained** - Qualitative findings do not address gender differences in the experience of anxiety and depression symptoms nor in accessing mental health services.

Facilitators	Quality of life may be less influenced by the presence of autism traits for older autistic adults, compared to younger autistic adults.	**Gradually figuring things out** Having more experience of social situations gave greater awareness of how to check one's own limitations in recognising social cues and greater resilience when things did not go as planned. Having a potentially more stable later adulthood and less pressure to reach normative lifespan milestones, respectively to non-autistic people, may offer opportunities to for adaptive strategies to crystallise.	**Complement** - Reflecting on their experience, older autistic adults commonly spoke of having discovered adaptive strategies and ways of minimising the impact of autism-related phenomena over time.
	Older autistic adults typically reported similar levels of mental health symptoms than younger autistic adults, but less frequently met the threshold for clinically significant mental health difficulties.	**Living well as an autistic older adult** Many participants described awareness of autism and using practical steps to support their personal strengths and needs. Being older was linked to becoming more prescriptive in communicating one's needs and how others might offer more predictable and accessible social interactions.	**Complement** - Older autistic adults spoke of situations that they continued to find anxiety-provoking but also described more confidence as they aged in using problem-solving approaches.
	Overall quality of life was mostly higher for older autistic adults compared to younger, supported by improved scores in the social domain.		**Complement** - Older autistic adults described difficulty with unexpected social situations but also talked about exerting greater control over the way they conduct interactions in line with ageing and stating their preferences more explicitly.
	NULL	**Experiences of diagnosis** For many, diagnosis offered a mechanism to alleviating an overestimated sense of culpability in social hostility. Diagnosis offered a new position from which to reflect on one's life. For others, diagnosis may raise reticence in coming too late to have protected them from past harm.	**Unexplained** - There is not quantitative evidence to suggest that diagnosis is preferable to no diagnosis, nor research identifying factors associated with a more favourable view of receiving a diagnosis.

Consideration of fit between synthesised quantitative and qualitative findings culminated in the construction of *Table 2*, detailing evidence of challenges to and facilitators of psychosocial wellbeing, as reported by autistic older adults. These have been separated into factors that speak to barriers versus facilitators of psychosocial wellbeing. In some instances, rows summarising qualitative findings are deliberately presented as overlapping with multiple rows summarising quantitative findings. For example, the 'living well as an autistic older adult' qualitative theme was thought to relate to two quantitative ideas about older autistic adults reporting increased quality of life and lower rates of clinically significant mental health distress, relative to younger autistic adults. Overall, the meta-integration revealed the current status of evidence to be complementary. The integrated syntheses suggest that autistic older adults may both enjoy positions of relative security and insight, compared to younger autistic adults, and continue to experience greater interpersonal and systemic threats to psychosocial wellbeing, compared to non-autistic older adults. Gaps in integration were noted for the qualitative theme 'experiences of diagnosis' and quantitative theme 'gender differences', both of which are therefore designated 'unexplained'.

Discussion

The results of this meta-integration suggest that emerging research has begun to provide some insight into how autistic older adults experience psychosocial wellbeing and what helps and hinders this. The complementary evidence suggests that this group may find that features of their autism are more predictable over time and that their greater life experience has afforded greater opportunities to find ways to apply these features in a way that is protective. This might heighten individuals' resilience to adverse social interactions and ability to make purposeful demands of one's environment and available social support, in turn reducing the risk of mental health distress. Simultaneously, there remain significant difficulties in maintaining psychosocial wellbeing in the context of interpersonal difficulty and systemic obstacles in fitting into a non-autistic world. Repeated experiences of rejection from non-autistic others and disillusionment with professional services may contribute to depression being the predominant mental health risk for this group. As yet, there does not appear to be complementary quantitative and qualitative evidence to contextualise why being female is associated with higher risk of developing mental health conditions, yet males are reportedly more likely to access psychiatric services. Similarly, there is no current quantitative basis from which to position qualitative findings related to experiences of diagnosis and when and for whom this may be helpful or problematic.

Using meta-integration, and benefitting from intervening publications, this review was afforded scope to consider nuanced issues as reported directly by autistic older adults, moving beyond examining this group from the limitations of

a neurocognitive lens (Parchomiuk, 2021). As a result, the review has been able to recognise ongoing and substantial challenges alongside examples of older age being a time when autistic adults may experience relative empowerment and satisfaction. Perhaps the reported opportunities for developing social skills in the review by Tobin et al. (2014) may be more commonly realised by older adults, by virtue of having more time to pursue them. Although the quantitative findings in the current review are limited by use of measures not validated in autistic samples, as noted in the review by Ayres et al. (2017), the use of meta-integration adds validity in contextualising quantitative findings within first-hand accounts. The tentative conclusion in the previous Happe and Charlton (2012) mini-review that autistic older adults may be shielded from some negative social consequences of ageing reported in non-autistic older adults does appear to be supported by the current findings.

Considering these findings through the lens of the PTMF may shed light on the extent to which the reported differences between older and younger and middle-aged autistic adults are attributable to cohort effects versus lifespan phenomena. It would follow that repeated exposure to threats, such as childhood bullying and workplace discrimination, and the self-attribution of blame for such interpersonal distress might be interpreted by an autistic individual as meaning that their experience is less valid than so-called ‘neurotypicals’ and they must do more to assimilate. Resulting distress and shame in remaining unable to seamlessly integrate, according to the current review findings, have typically been responded to inappropriately by professional services through superficial engagement with autism-related

factors, or overuse of medication to treat understandable responses to marginalisation as mental illness. This may bear most relevance to the provisional general pattern 'surviving defeat, entrapment, disconnection and loss' (Johnstone et al., 2018, p. 232), which the framework itself suggests may map onto the experience of being autistic. Receiving and integrating new meaning in autism diagnosis, habituation to negative social experiences and finding relative stability in social contexts in later life, may culminate in revising the narrative of being 'less than' to one of 'difference' and assuming and demonstrating power in self-advocacy. Nonetheless, shifts in 'interpersonal power' will unlikely be matched by change in 'economic and material power' or 'social capital' (Johnstone et al., 2018, p. 206), due to acknowledged systemic discrimination. This may risk autistic older adults responding to perceived threats to wellbeing by continued avoidance of social arenas, experiencing low mood, engaging in self-blame and isolating themselves from wanted social interaction.

Identified gaps in the literature

It is recognised that many included papers were recently published, indicating that future reviews are required to keep pace with a rapidly increasing evidence base. In particular, scrutiny should be applied to how topics that have been researched in younger autistic adults, e.g. sexual relationships (Strunz et al., 2017), apply to older autistic adults. Similarly, issues relevant to non-autistic older adults, as yet unexplored for autistic counterparts, must be further examined. An unexpected finding of the current review is the lack of evidence

regarding how psychosocial welling is impacted by physical health in this group, a gap previously identified by Cashin et al. (2016).

Limitations

As reported in previous reviews, the literature base in this area is impacted by issues of quality. While overall quality of papers included in this review was deemed to be acceptable, and steps were taken to consider extracted data with reference to identified quality limitations, more high-quality research is needed to increase confidence in the validity and accuracy of findings detailing what it is like to be an autistic older adult. The samples of included papers in this review had a mean age of around 60 years old. This means that older adults are better represented than in previous reviews (Ayres et al., 2017; Tobin et al., 2014), however, there remains a lack of representation at the higher end of the lifespan. Despite known premature mortality in this group (Hirvikoski et al., 2016), more research is needed including more adults above 70-years-old. It is also acknowledged that there may a large number of autistic individuals who have not received a diagnosis not represented in these findings; this is a known historical shortcoming in diagnostic provision (Mason et al., 2022), potentially particularly relevant for those being born earlier on in the pathway to establishing the diagnostic channels we have today. Similarly, this review intentionally excluded autistic older adults with an intellectual disability, however, future research should consider similarities and differences for this group, who make up 20% of the autistic population (Cashin et al., 2016).

Several papers referenced a lack of representation of minority ethnic groups in research in this field (e.g. Hwang et al., 2017) and the studies included in this

review comprised mostly white participants. Further research should seek to privilege perspectives of autistic older adults from diverse backgrounds. There was also an unexplained finding regarding gender differences, indicating a literature gap. Relatedly, if this evidence were available, a limitation of incorporating the PTMF in the current discussion is that, while intersectionality is mentioned (Johnstone et al., 2018), the framework does little to suggest how this idea can be meaningfully applied beyond acknowledging its presence. Therefore, even tentative ideas regarding intersectionality are not explored in the current review.

Conclusion

This meta-integration review reveals novel insight into barriers and facilitators of psychosocial wellbeing as directly reported by autistic older adults. While notable gaps remain, the available evidence suggests that older adulthood can be a time of relative prosperity for autistic individuals, compared to younger peers. Simultaneously, participant accounts showed awareness of relative hardship compared to non-autistic people, a high rate of depression and shortcomings in available support. Services should ensure accessibility for this population and be open to suggestions of how to improve the suitability of offerings, noting that older autistic people may feel relatively more confident in stating their preferences. Clinicians should also seek to help older adults identify how features of their autism might be strategically employed in daily living and social situations to support psychosocial wellbeing in a way that both empowers these individuals and validates their experiences.

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Service Improvement Project Paper

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Title of the report: “Being PBS”: Frontline Staff Experiences of Supporting Patients with Intellectual Disabilities.

Word count: 4996 words (excluding titles, references & appendices)

Date of the report: Initial report completed 30/06/2023, reviewed and updated 23/04/2024

Internal supervisor: Dr Matthew Knight

External / field supervisor: Dr Julia Kelly

Proposed journal: Journal of Applied Research in Intellectual Disabilities

Journal choice rationale: Selected on the basis of the journal placing quality of life at the forefront of presented research in the field of Intellectual Disabilities. There is also an emphasis on research with local practical implications which matches the SIP project aims. There is conceptual relevance of the current paper in that key topics of JARID include quality of life, challenging behaviour, staff stress and service provision.

Abstract

Positive Behaviour Support (PBS) is the predominant framework used in the UK to promote patients' quality of life in intellectual disability (ID) services. However, effective implementation is limited by locally-specific operational and cultural factors. This service improvement project (SIP) investigated barriers to, and facilitators of, effective PBS-informed practice through asking frontline nurses and healthcare assistants (HCAs) about their experiences of supporting patients. Data from six semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA), resulting in three superordinate themes: *Following Your Heart*; *It's Really Tough – You Have to be Strong*; and *Just out of Reach – the Small Things That Make a Big Difference*. These themes highlighted how participants experienced close emotional ties to patients, responded to challenges in their roles and wished for more time for targeted patient wellbeing initiatives. These findings have been related to existing literature regarding PBS delivery and used to generate locally-informed service improvement recommendations for implementation by the senior leadership team (SLT). Recommendations include: recognising and providing support for the emotional efforts of staff; increasing confidence in PBS-orientated staff by generating meaningful outcome evidence that dissuades colleagues from using alternative practices; and providing targeted training, making creative use of existing interest and skill in PBS within the team.

Keywords: *Intellectual Disability; Staff; Positive Behaviour Support; IPA*

The term 'patients' is used in accordance with preference expressed by individuals living on the ward.

Introduction

This SIP evaluated how frontline staff experience PBS through everyday interactions with patients, aiming to identify factors influencing effective PBS application. The context, methodology and findings are discussed below, culminating in a set of recommendations for implementation by the service SLT, which have been generated in relation to themes derived from the interviews.

Background

Research consistently characterises ID services as challenging workplaces (Ryan et al., 2021). While there are notable positive aspects to providing support to vulnerable individuals, stress and burnout are commonly associated with holding such responsibility in physically and emotionally demanding settings (Flynn et al., 2018; Oliver et al., 2019; Outar & Rose, 2017). Behaviours that challenge (BtC), i.e. behaviours that pose risk of harm (e.g. self-harm, physical assault, etc.) are commonly reported in ID services and the frequency and severity of BtC have been found to predict staff intention to remain in post (Smyth et al., 2015). While negative consequences of BtC are mediated by individual team members' self-efficacy (Ryan et al., 2021) and hope that positive outcomes can be achieved (Oliver et al., 2019), organisational factors, such as perceived lack of resource, are related to poorer outcomes for staff (Finkelstein et al., 2018). To promote staff welfare and retention, and alternatives to harmful restrictive practices (Kruger & Northway, 2019), authors have called for ID services to prioritise behavioural intervention frameworks (Smyth et al., 2015; Whittington & Burns, 2005).

PBS has become the dominant approach across ID services (Grey et al., 2016), supported by a widely-endorsed PBS Framework (PBS Coalition UK, 2015). PBS comprises various initiatives and psychologically-informed interventions that promote improved quality of life for patients through functional assessment and formulation of maladaptive responses to internal and environmental stressors, and supportive facilitation of alternative channels of communication (Gore et al., 2022). PBS has been demonstrated to improve staff retention and reduce BtC (McKenzie et al., 2021), but is yet to show quantifiable and consistent improvement in patients' quality of life (Bruinsma et al., 2024; MacDonald & McGill, 2013; McGill et al., 2018; Murray et al., 2021). Research also suggests that PBS efficacy is reduced if services do not sufficiently tailor the programme to the particular service context (Hayward et al., 2021), or lack adequate staff resource (Grey et al., 2016; Hassiotis et al., 2018).

Given the importance of individualised service adaptation, it follows that qualitative research has been used to evaluate PBS initiatives locally. While research has tended to sample specialist or senior practitioners (Analytis et al., 2021; Carmichael et al., 2021; McKenzie et al., 2020; Stenfert Kroese & Smith, 2018), others advocate that "frontline" staff hold the key to unlocking improved outcomes in how they interpret and apply service guidance (Hutchison & Kroese, 2016). IPA (Smith et al., 2009) has been used to examine the lived experience of providing professional support, offering novel avenues to enhance staff competence and confidence. These studies recommended training that attends to emotional effects of BtC on staff to reduce burnout and increase capacity for holding psychological formulations (Whittington & Burns,

2005), and supporting greater reciprocity with senior colleagues through regular supervision (Hutchison & Kroese, 2016).

Service Improvement Project

This SIP was conducted in a medium-secure inpatient service in southern England, for men with an ID detained under the Mental Health Act. Previously, the service commissioned PBS training, aiming to embed the framework in the team culture. The SIP was devised in liaison with the service's SLT to inform ongoing service improvements aiming to enhance frontline staff confidence and investment in PBS. A qualitative SIP was deemed most appropriate to capture the nuance of the experiences of nurses and HCAs. The guiding research question was: 'how do frontline staff at [the service] experience supporting patients?'. This was chosen to invite broad perspectives from participants on their work, before focussing in on particular experiences of patient interactions and how PBS influences these.

Method

Design

The SIP entailed conducting semi-structured interviews with six members of staff and scrutinising the data using IPA. IPA is concerned with participants' experiential search for meaning, presented through the lens of a reflexive researcher whose interpretation in turn co-creates meaning (Smith, 2019). This focus on significance aligns with the project's aim to uncover a sense of staff

members' lived experience, and the invitation of reflexivity enabled the author to consider their personal experience of working in a secure ID service.

Data Collection

To inform the interview schedule, the author consulted with patients at the service. Central in patients' responses was a theme of 'tasks', which was included in the schedule to gather initial descriptive information about staff members' work before asking more investigative questions, in line with IPA recommendations (Smith et al., 2009). The full interview schedule is provided in *Appendix F*.

Staff were eligible if they had worked full- or part-time at the service as a nurse or HCA for at least one month. Recruitment was initially conducted via a poster with the intention of arranging individual interviews by email. One participant responded and the remaining participants were recruited via opportunity sampling during working shifts. Interviews were conducted in a meeting room adjacent to the secure unit. Four participants were members of the nursing team and two were HCAs. All participants had worked on the ward for over a year, with varying lengths of employment. Interviews ranged from 40-91 minutes (*M*=63 minutes) in length. Interviews were audio-recorded and transcribed verbatim.

Data Analysis

Data analysis was conducted as per guidance in Smith et al. (2009), with consideration to indicators of quality in qualitative health (Yardley, 2000) and IPA research (Nizza et al., 2021). Initial coding was completed using

descriptive, linguistic and conceptual lenses for each transcript in turn (Smith et al., 2009), before generating sub- and master themes within and then across accounts, allowing opportunity to interpret convergence and divergence in the data (Nizza et al., 2021). A detailed step-by-step explanation of the analytic process is provided in *Supplementary Information S1.1*. A visual representation of the iterative process of generating the superordinate themes, by synthesising sub-themes and validating through close examination of the transcript data, is presented in *Supplementary Information S1.2*. To aid transparency, tables showing individual participant sub- and master themes, and additional transcript excerpts coded to the across-participant themes discussed below, are provided in *Supplementary Information S1.3*. To support confidence in separating personal responses from the meaning participants interpreted from their experiences, the author exercised cyclic reflexivity (Smith et al., 2009), for example, engaging in a bracketing interview to highlight and limit the influence of pre-conceptions about the topic. A summary of resulting reflections is presented in *Appendix G*.

Ethical approval

Approval for the SIP was provided via the local NHS Trust's Forensic & Specialist Clinical Governance meeting, August 2022.

Results

Three superordinate themes were identified from the data. Each superordinate theme comprised three sub-themes which were present across most individual participant accounts, as shown in *Table 1*. Extended transcript quotes are shown in *Table 2*.

Table 1: Presence of sub-themes within individual participant accounts

Superordinate theme	**Sub- theme**	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**
Following Your Heart	A felt sense of duty	Y	Y	Y	Y	Y	Y
	Emotional rollercoaster	Y	Y	Y	Y	Y	Y
	Helping helps me	Y	Y	N	Y	Y	Y
It's Really Tough – You Have to be Strong	Managing uncertainty, what will we have to face next?	Y	Y	Y	Y	Y	Y
	Tired of having to compensate	Y	Y	Y	Y	Y	Y
	Having the will to fight	Y	Y	N	Y	Y	Y
Just out of Reach – the Small Things that Make a Big Difference	There just isn't time	Y	N	Y	Y	Y	Y
	Wanting small recognition of all the hard work	Y	N	Y	Y	Y	N
	Delicate but determined seeds of hope	Y	Y	Y	Y	Y	Y

Table 2: Extended Transcript Quotes

Quote ID	Participant	Quote and line number	Sub-Theme	Superordinate Theme
2.1	P6	'I can see him- because he- he- head bangs, he self-harms, when I come and then he stops... I don't know, I can't describe that feeling I have with me (laughs) you know I just feel like yes, it's working, everything you're doing- can't stop, you have to continue doing it you know' (318-321).	A Felt Sense of Duty	Following Your Heart
2.2	P3	'You get annoyed when you try and give someone a level of support and then they go to another nurse and say that oh I haven't had a level of support- I want a one-on-one with a specific staff member and you feel... not hurt but you think well actually I tried really hard today' (200-202).	Emotional Rollercoaster	
2.3	P2	'I'm telling you he'd be shouting and say 'I will smash you and I'll break all your teeth' oh my God I remember one incident where we had to hide in another patient's um uh bedroom that's how that's the only way you could do it you- people were so frightened' (453-455).	Managing Uncertainty, What Will We Have to Face Next?	It's Really Tough – You Have to be Strong
2.4	P6	'It puts pressure and other staff members because if we attend and then four people cannot work with him and then he- he- he- I don't get exhausted with him, I don't get burned out with him but other people do because his needs are quite... they're demanding' (454-457)	Managing Uncertainty, What Will We Have to Face Next?	
2.5	P5	'If new staff come in and they haven't read the care plan quickly or in detail then they'll just do anything for an easy shift but that doesn't always work because like it might be easy for that that short period of time but then when the next person comes in and does it the way it's meant to be done, yeah then it becomes a challenge then' (80-83).	Tired of Having to Compensate	
2.6	P6	'If I have a staff member just... standing there doing nothing when a patient needs help, I'm gonna have a chat with them, sometimes I'll not do it- I don't do it quite well because sometimes you need to bring them aside and maybe provide and say *come on guys*' (participant's emphasis) (108-110)	Tired of Having to Compensate	

2.7	P3	'I think it's very tempting to- on a really busy day just to not take your break and just get everything done with, but I think if you know that you're gonna finish the day about an hour late you choose to not take your break and I think that impacts you and I think people don't realise as well, they're like 'I don't think I need a break' and you think in your head 'ooh I think you might' (laughs) you're going a bit too fast' (51-55).	There Just Isn't Time	Just out of Reach – the Small Things That Make a Big Difference
2.8	P6	'I was brought in, I was the only a person that works direct with them, senior nurses, managers, I was the only person which I'd consider as the low- lowest person in terms of position but I I did have- put a lot of feedback because we spend more time with the patients' (359-361).	Wanting Small Recognition of all the Hard Work	
2.9	P2	'I think if it becomes like a mandatory training where it- it will give us that same knowledge and will be at- at least the same level we've got, we have the same language, and when I say PBS people can have rough idea of what I mean' (578-579).	Delicate but Determined Seeds of Hope	
2.10	P3	'If we can magically have more staff I think it'd be good because we'd be able to talk to more about [patients'] hygiene and just those things which you might think are smaller but actually make a big difference' (303-304)	Delicate but Determined Seeds of Hope	

Theme One: Following Your Heart

This theme relates to participant narratives about emotional ties to patients which can offer reward and motivation in their roles.

A Felt Sense of Duty

All participants asserted the importance of prioritising patients. P1 shared: 'they're the heart of our service the patients' (763-764). Participants appeared to see privilege in offering support, such as P3 explaining: 'it's trying to explain to your friends "oh we had a good day because someone's blood glucose level is within the normal range" (laughing)' (37-38). This statement playfully shows how patient wellbeing is held dutifully, further evident in P3 suspecting that others could not do what they do. P5 also spoke of commitment: 'I'm not saying he never has a go at me or never- or when he's really struggling hit out at me because he has, but I know- I've heard him sometimes shout he'll need me and that- so I'll go' (223-224). Such is the readiness to answer the call that it connotes being pulled towards the work. This was echoed by P6 (see *Table 2, quote 2.1*). The perceived ability to deliver something unique and uphold individual support ideals seemed to motivate the participants to continue their efforts for patients.

Emotional Rollercoaster

All participants spoke fondly about patients. This came through explicit statements where the conviction in participants' voices was palpable, as per P1: 'I *love* that they're happy to see you' (116-117) (participant's emphasis). There was also warmth conveyed through stories, such as P2 reminiscing: 'you know

it just melts your heart and you think... huh that's all, you miss him…(sighs)' (116-117). In the pauses, the sigh and the use of the phrase 'melts your heart', there is a tone of affection and closeness. While this notion of a heartfelt connection to patients was seen as a positive experience, what seemed more powerful was how having this connection also conjured negative emotions. As P4 explained: 'then [patients are] upset and then obviously it makes us upset' (23-24). That staff feelings are so tightly bound up in patients' experiences is unquestionable for P4.

Others explained how changes in one's own relationship closeness and comparison to that of other staff members could lead to frustration (P3, quote *2.2*), demonstrating that putting in more emotional effort could threaten as well as sustain staff experience. Perhaps where the "emotional rollercoaster" became most hard-hitting was when participants spoke about patients leaving the service. As P5 described: 'what're we going to do when he goes because we've all worked with him for such a long time... so… it's a… it's one of my favourite relationships' (194-195). Having just spoken about joyous shared experiences with the same patient, the pauses and solemnity of tone encapsulate powerful emotionality in their work.

Helping Helps Me

Most participants also spoke of mutual benefit to care offered. P5 shared: 'he'll just chat and he's just so funny, he loves football I love football it's just like... it doesn't feel like work (laughs)' (214-215). Mutual enjoyment transformed support tasks into rewarding experiences. Crucial to this seemed to be that staff

efforts are recognised by the patients. Recognition could be direct, as per P2 recalling: ‘we were happy- and such little things like that and the effort that we put, [patients] see’ (322-323). Alternatively, P1 described feeling gratitude indirectly: ‘[patients] say “oh I missed you [P1]”, “I’m fine”- it’s really nice to think “oh I make a difference”’ (119-120). In this way, participants that could recognise motivational transactions between staff and patients could then appreciate powerful personal rewards for their work, further supporting their commitment in turn.

Summary

Participants felt a strong dedication to patient care, taking personal pride and enjoyment from positive moments. The depth of emotional connection to the patients also appeared to provide meaning in participants’ roles. Powerful bonds also resulted in a heavy emotional impact on participants when they did not believe their support was improving a situation, or when patient connections are lost. Through this spectrum of emotional experiences, these participants seemed to rely on personalised principles of caring to guide their continued service.

Theme Two: It’s Really Tough – You Have to be Strong

The second theme focusses on challenges faced by staff and how these are responded to.

Managing Uncertainty, What Will We Have to Face Next?

All participants characterised their roles as demanding, necessitating adaptation to the unexpected. P3 called for: ‘a proper plan, but I think also… I don’t know it’s hard to tell, there’s a lot of unpredictable things happen’ (41-42). A ‘proper plan’ was deemed essential, yet unachievable. P2 described an atmosphere of tension and needing to tread cautiously to avoid angering patients (quote *2.3*). This illustrates how frightening this risk scenario felt for P2. Taken together, P2’s descriptions invoke a sense of the team wondering “when rather than if” an incident will occur, which in itself may be fear-inducing.

What also came across was ambiguity in how to proceed after risk had peaked. P6 asserted their resilience and elsewhere spoke confidently about responding to risk, yet they hesitated in considering how the team will continue to offer support with additional limitations (quote *2.4*). P4 captures how uncertainty was experienced; ‘sometimes you don’t even get time to deal with your emotions, you’re sort of just thrown into the deep end’ (220-222). It seemed that discomfort in unresolved dilemmas has a cumulative effect due to unremitting challenges.

Tired of Having to Compensate

While all participants mentioned positive aspects of teamwork, division in approaches was named explicitly by most or alluded to through narratives of disagreements. P5 shared: ‘I’ve been able to walk down the corridor with him and people have been really really cross because it’s took three or four people to hold him’ (204-206). Participants described a “right” way of supporting

patients, informed by notions about positive risk-taking, and a “wrong” way that they saw as overly-focussed on risk-related restrictions. P5 explained how competing ideas could lead to some staff having to apply extra effort to re-establish plans (quote *2.5*). P2 spoke of feeling deflated in such situations: ‘sometimes even when you talk PBS-language approach you know nobody really understands you- you’re actually sort of like dividing the team’ (502-503). This suggests that those promoting PBS can feel misunderstood and isolated when colleagues persevere with incompatible approaches and may be deterred from challenging peers.

Colleagues not adhering to set practices seemed to be a source of frustration, such as P4 explaining: ‘[patients] have like whether they’d like their blind open or their lights on or off but some staff will still go and turn the light on even though the individual would like it off’ (351-353). It might be that participants perceived that such actions violated their own values around commitment to patients. This is supported by a quote from P6 (quote *2.6*), where consternation is captured in the emphasis of ‘*come on*’. Participants spoke of resulting additional workload. P4 explained: ‘we’re just not working together and it’s just- it’s already hard as it is you know so it makes it even harder’ (35-36). Feeling obligated to work even harder to compensate for others therefore seemed to leave participants feeling fed up.

Having the Will to Fight

Despite this, most participants maintained a commitment to championing their viewpoints and meeting the challenges of risk scenarios. Participants frequently

used combative language to describe disagreements, but also to capture a willingness to advocate their ideas, as per P1 saying: ‘I’m fighting for the kitchen door to be open’ (516-517). As per P2’s defiantly-delivered assertion: ‘being gentle and kind does not mean that you are not doing your job properly’ (211-212), there were multiple examples of participants retaining a drive to push the agenda of person-centred attitudes, epitomised in P2 declaring: ‘you have to *be* PBS’ (561, participant’s emphasis).

Similarly, there were resolute responses to managing BtC, as P5 described: ‘if it’s been a really tough day but it’s gone really well I then go out with that buzz’ (93-94). Several participants shared this notion that overcoming challenges uniquely energised them. Resilience was illustrated starkly by P4 who said: ‘there’s been a lot of… racial- like abusive comments’ (209), ‘but then you obviously go back into work the next day and you have a great shift so it’s very up and down’ (219-220). Even in response to direct and personal abuse, they showed a desire to rise to this challenge and emerge stronger.

Summary

Participants readily described how intensely demanding their jobs are in managing risk and navigating disagreements between staff members about how to do so. This could introduce an atmosphere of tension, feeling frustrated with colleagues who seem not to share the same professional values. In response, some participants seemed even more motivated to show colleagues the merits of their approach to promoting patient wellbeing. Some participants even

appeared to relish the prospect of new challenges as opportunities to prove their abilities or champion what they see as best for patients.

Theme Three: Just out of Reach – the Small Things That Make a Big Difference

The final theme addresses how participants reflected on progress and wished for greater recognition and more time for PBS initiatives.

There Just Isn't Time

The accounts emphasised a sense of urgency at work. P4 explained: 'you'll be on a like 14-hour shift and you forget to drink water, it's so bad (laughs)' (83-84), showing resignation to acute time pressure. As well as practical limitations, participants also discussed cultural implications. P3 (quote *2.7*) implied that in not taking breaks there is a risk of staff unintentionally jeopardising their own efforts. P5 wistfully remarked: 'we tell [colleagues] what [PBS] means and try and break it down as much as we want but actually- and then you hear them say "oh but there's no consequence"- I just wish there was more time to explain' (442-443). Similarly, P6 said: 'I want to be able to have the time to spend with staff, I know most staff have spent a year or two with him but I don't think they know him enough and that's why they're having incidents with him' (281-283). Despite the recurrence of incidents, and P6's own eagerness to offer peer support, opportunities to share learning have not been forthcoming across two years, highlighting a sense of "stuck-ness".

Wanting Small Recognition of all the Hard Work

In this context of fast-paced work, participants considered how appreciated they felt. P3 asserted: 'just we need more staff and a better pay (289)'. Seeking

greater remuneration seemed related to workload and time-pressure issues, but also to how participants' work felt valued by others. All participants praised their direct managers, however, some participants remarked on a sense of distance between them and more senior managers. It was remarkable for P6 that such interactions occurred only when frontline workers were 'brought in' (quote *2.8*) and relative levels of knowledge about the patient stirred critical curiosity about the regularity that voices from the ward are sought. Direct statements about feeling undervalued were most prominent in P1's account, for example sharing: 'it just seems like you're a number or you're a name on their list and you're not recognised for what you are on the ward' (155-157). Perceived depersonalisation is contrasted with the value P1 attached to what they *are* on the ward, even above what they do. This is further elaborated in an expressed wish that senior managers: 'be more PBS themselves' (756-757), suggesting that staff facilitation of PBS should be supported through the most senior stakeholders modelling and embodying equivalent values, and that this is not currently perceived.

Delicate but Determined Seeds of Hope

This final sub-theme speaks to how participants discussed ideas about future progression. P2 suggested that training might provide a common language for articulating PBS ideas (quote *2.9*). In a 'rough idea', P2 conveys cautiousness about how comprehensively such training would transform staff practices, but also shows how modest change would help them feel more understood. P3 also spoke about small change having great potential (quote *2.10*), although the word 'magically' indicates scepticism. Conceptualisations of progress tended to

be pensive in nature and symptomatic of a sense that goals are, exasperatingly, just out of reach. For example, P4 reflected: ‘it’s a work in progress um but it’s taking every day at a time because- it’s just time and yeah... yeah it’s been tricky yeah…’ (214-215). This statement recognises forward momentum yet highlights the fragility of their hopefulness in how the conversation stops, starts and trails off. A final reflection comes from P6 who suggested that with greater collective empathy: ‘we’d have low incidents, we would leave here like a family where nobody has any problems’ (471). The implication is that the team encounters problems that are not being resolved, however, the analogy of the family gives an impression of being inextricably bound together and hope that there is the possibility of leaving shifts feeling connected and carefree.

Summary

There was a sense that participants’ hopes for the ward were tantalisingly close to fruition, but still unobtainable. Just a little additional time to dedicate to specific projects would make a big difference, but time slips away. In particular, PBS training and mentoring colleagues was seen as having great potential, but currently is not able to be prioritised. There is a desire to feel that staff efforts are valued by senior management, but this has not yet occurred in a way that resonates with the participants.

Discussion

The three superordinate themes capture an array of challenges and benefits experienced by these nurses and HCAs. Ideas about patient support were readily associated with PBS and the themes had apparent links to what might help and hinder effective PBS. Theme one: 'Following Your Heart' recognises how participants' emotional connections with patients fostered more meaningful engagement with their work and rewarded dutiful efforts with playful and warm moments. Simultaneously, the stronger the bond, the more upsetting it could be for staff when setbacks are experienced. Theme two: 'It's Really Tough – You Have to be Strong' addresses participants' efforts to convey the enormity of managing dynamic clinical risk with a sub-optimal sense of cohesion within the team. Nevertheless, meeting challenges head-on could be motivating for some participants and offer a heightened sense of accomplishment. Theme three: 'Just out of Reach – the Small Things that Make a Big Difference' encapsulates participants' awareness of the preciousness of time and how the prospect of improving team practices could be achieved in relatively little time but which seemingly cannot be provided. Despite some participants alluding to a perceived gulf between their work and senior stakeholders, at ward level there was cautious optimism for the future.

Reciprocal relationships with patients have been suggested previously as helpful and valued by frontline workers (Hutchison & Kroese, 2016). While reflected in the current SIP, the findings also highlight a need for staff to feel emotionally supported when closeness to patients attenuates negative emotional costs. Hutchison and Kroese (2016) also reported that staff were

motivated by and better enjoyed their work when they perceived it to be important. Pleasure in spending time with patients and discussion of personal value systems regarding care was prominent in participants' accounts, notably for staff members that were newer to the service than those in the Hutchison and Kroese (2016) study.

While participants recognised support from colleagues, they also framed differences in staff approaches as negatively impacting on morale and productivity. When conflict goes unresolved, some staff members may take on additional workload. Even when feeling compelled to compensate for colleagues, personal accomplishment appeared to be a key protective factor in staff motivation, as reported by Smyth et al. (2015) and Finkelstein et al. (2018). Resistance to adopting PBS as a new way of working might be considered an understandable response if it is not seen to be advantageous and the person has justifications for their current stance (Ntinas, 2022). Hayward et al. (2021) have highlighted the need to provide meaningful evidence that investing in a PBS-informed approach will be worthwhile, while discrediting theoretically incompatible approaches. Ntinas (2022) also advocates understanding resistance, warning that reactive challenging of peers might risk alienation from sub-groups in a staff team. Tension in how to challenge peers, and avoiding challenging, was discussed, however, most participants alluded to protecting patient agency as warranting advocation, even in open opposition of others' views.

Hutchison and Kroese (2016) found that staff felt isolated by comments from managers that devalued contributions made by ward staff. Praise for direct

managers should be noted, but the findings of this SIP raised similar ideas around feeling distanced from and undervalued by more senior stakeholders. Deveau and McGill (2016) evaluated a practice leadership intervention and suggested that senior leaders' increased visibility on the ward positively influenced staff confidence, providing a possible mechanism to redress the notion of distance. Finally, in relation to how staff reflected on developments at the service, Oliver et al. (2019) found that hope for positive patient and staff outcomes was crucial to life satisfaction for staff working in ID services as a moderator of other protective factors, such as high levels of conscientiousness and self-care. Further research might consider the ambiguous nature of hope identified in the current SIP and seek to identify strategies for protecting and fostering hope. IPA research by Whittington and Burns (2005) focussed on the idea of dilemmas for staff. Nearly 20 years on, 'dilemmas' remains a useful term, with uncertainty appearing to persist for staff working in ID services.

We know that PBS holds promise, but effective deployment must address local ideological perspectives (Hayward et al., 2021) and resource limitations (Hassiotis et al., 2018). In delivering recommendations for enhancing PBS practice that have been generated from the ground up, connected to the everyday experiences of frontline staff, it is hoped that this SIP offers the local service paths beyond identified dilemmas, provided below in *Table 3*.

Table 3: Recommendations for Consideration by the Service SLT

Related Superordinate Themes	**Recommendation**	**Related Literature from Discussion**
Following Your Heart It's Really Tough – You Have to be Strong Just out of Reach – the Small Things That Make a Big Difference	Recruitment of a dedicated PBS Lead responsible for implementing, monitoring and evaluating PBS, in accordance with recent evidence.	PBS Framework (PBS Coalition UK, 2015)
Following Your Heart	Continuing efforts to seek and maximise the value of opportunities for patients to provide feedback on and contribute to PBS processes. This is supported by recent PBS guidance and likely to resonate with the values of the participants in this SIP.	(Gore et al., 2022)
Following Your Heart	Ensuring that staff member's emotional responses to developing relationships with patients are on the agenda in relevant forums, e.g. supervision and team meetings. Discussion facilitators should focus on eliciting and valuing open and honest feedback about emotional responses triggered in staff by perceived closeness with or rejections from patients.	(Hutchison & Kroese, 2016)
It's Really Tough – You Have to be Strong	Identify and target efforts to increase PBS knowledge and buy-in towards team members with low affiliation or motivation to adopt PBS. Recognise and formulate resistance to adopting PBS. Increasing the knowledge and skills of such team members will likely indirectly support team members who are more familiar and supportive of PBS and foster group affiliations to the PBS approach.	(Hayward et al., 2021; Ntinas, 2022)

It's Really Tough – You Have to be Strong	Address differences of approaches adopted across members of ward team by promoting tangible benefits of PBS and pointing out unproductive consequences of theoretically incompatible practices. This should be supported by the use of objective measures that connect meaningfully with team members demonstrating resistance. Measures should also connect to shared goals that foster a teamwide unity of purpose.	See recommendations in article by Ntinas (2022)
Just out of Reach – the Small Things That Make a Big Difference	SLT to act as a bridge to provide opportunities to increase visibility and mutual understanding between members of the ward team and leadership figures beyond the direct ward management team. This may be achieved through enabling greater representation of ward team members at relevant meetings and drawing from research and guidelines regarding practice leadership.	(Deveau & McGill, 2016)
Just out of Reach – the Small Things That Make a Big Difference	Identify and ringfence time resource for ward-based staff to engage in discussion and innovation regarding PBS. There is likely value in using existing knowledge within the team to offer peer-learning and coaching, under appropriate supervision. This may be achieved through the commissioning of additional resource, informed by emerging practice-based evidence regarding PBS, and/or through redeployment of existing staff resource. For example, there may be opportunities to maximise existing staff resource through creative matching of tasks that relate to personal professional values and/or dynamically matching	(Gore et al., 2022; PBS Coalition UK, 2015)

	patient and staff personalities and interests.	
Just out of Reach – the Small Things That Make a Big Difference	Engaging with national and international initiatives related to the procurement and retention of ward-based staff.	(Gore et al., 2022)

Limitations

Although representing a substantial proportion of eligible staff, difficulty in recruitment should be noted. Using opportunity sampling likely introduced bias in who chose to participate in interviews at the time of contacting the ward out of the rostered shift. While there was a range of lengths of experience at the service it would have been useful to have heard from staff members who were newer to the service and agency workers completing regular shift work could also have been considered. Lastly, it is recognised that in implementing suggested recommendations, consideration must be given to the dynamic nature of ward issues, particularly in relation to patient and staff turnover. It is possible that responses to interview questions disproportionately captured issues related to a specific shift or which have since evolved.

Conclusion

This SIP evaluated the perceived effectiveness and acceptability of PBS at a medium-secure ID service through frontline staff members' everyday experiences of supporting patients. PBS was a salient topic for these nurses and HCAs who discussed various barriers and facilitators that influence the potential of PBS to improve patients' quality of life. In relation to the three experiential superordinate themes generated, recommendations for how to

improve staff confidence and investment in PBS have been made to the service.

Service Feedback and Response

Feedback was provided to the service in the form of a patient easy-read document (see *Appendix H*), a slideshow presentation recorded via Microsoft Teams for the SLT and wider staff team, and an executive summary report (see *Appendix I*).

Approximately one year on from disseminating the findings, attempts to implement recommendations have been reported by the service. These include introducing a weekly PBS learning and reflection meeting, where frontline staff are encouraged to review data relating to patient progress, identify how recent work has exemplified PBS values, and consider how to improve consistency in approach between team members. The project findings have been referenced by the SLT in ongoing liaison with commissioners regarding additional recruitment incentives for the still vacant PBS Lead role.

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Theoretically Driven Research Project Paper

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Title of the report: “Not my Mess”?: How do Supporters of Individuals with Hoarding Difficulties Rate the Quality of the Support they Offer?

Word count: 5498 words (excluding titles, references & appendices)

Date of the report: 16/05/2024

Internal supervisor: Professor Paul Salkovskis

External / field supervisor: Dr Kate Rosen

Proposed journal: British Journal of Clinical Psychology

Journal choice rationale: Submission to a journal with a wide scope of topic coverage has been chosen in line with a desire to bring hoarding research more into the ‘mainstream’ of mental health research.

Abstract

Hoarding difficulties (HD) affect many people and can cause upset and danger for the person, as well as friends and family, who themselves may experience distress and stigma as a result of clutter. Previous research found that people with HD feel less adequately socially supported compared to individuals with Obsessive Compulsive Disorder (OCD). To evaluate whether people with HD see their support differently, or there is a gap in support quality compared to those with OCD, this study presents the perspectives of 116 people offering support (POS) to people with these conditions (PWC). The research had a two-tailed hypothesis: a) that POS(HD) would not differ on support ratings compared to POS(OCD), or b) that POS(HD) would report comparatively lower ratings across support components. Support quality was measured using an adapted proxy version of the Revised Norbeck Social Support Questionnaire which focusses on the perspective of the supporter. Additional hypotheses predicted that HD would be the more stigmatised condition and that the POS(HD) group would report higher levels of associative stigma (internalised stigma by virtue of having a connection to a stigmatised individual). The design was cross sectional, comparing those supporting OCD with those supporting HD. POS(HD) rated both their wish to support and the perceived success in terms of the PWC's response as significantly lower, but did not differ in rating the impact support has on themselves. Public stigma was rated more highly by POS(HD) relative to POS(OCD) and associative stigma felt more acutely by POS(HD). Further research involving POS and PWC dyads is needed to investigate what

is causing this shortfall in support. Clinical research for HD interventions should also examine how involving POS could enhance treatment outcomes.

Keywords: *Hoarding; OCD; Social Support; Stigma; Associative Stigma.*

Conflicts of Interest: none

Introduction

Clinically significant Hoarding Difficulties (HD) were previously thought to be a symptom of Obsessive Compulsive Disorder (OCD) or Obsessive Compulsive Personality Disorder (OCPD) (Gordon et al., 2013) and efforts to delineate HD from OCD continue. HD refers to:

> Persistent difficulty discarding or parting with possessions, regardless of their actual value […] accompanied by an excessive acquisition of items that are not needed or for which there is no available space (APA, 2013, p.247).

Accumulated items include food waste, packaging, newspapers, animals, etc. resulting in obtrusive clutter (see Pertusa et al., 2019). The lifetime population prevalence of HD has been estimated at 2.6% from meta-analysis, although this may be an underestimation due to barriers in seeking and accessing professional support (Postlethwaite et al., 2019).

Hoarding also impacts people who offer social support. Disruption and danger caused by clutter can become a burden for families, and can result in the development of interpersonal conflict and even hostility (Tolin et al., 2008). Qualitative research conducted in the US (Sampson, 2013) and the UK (Wilbram et al., 2008) has offered insight into carers' guilt in light of their own problems understanding HD, feelings of hopelessness in the context of ineffective or absent professional support, and resentment at themselves becoming increasingly socially isolated as a result of support efforts. Sharing a home with a person that hoards can prompt family members to seek to escape

the clutter, avoid the people-with-the-conditions' (PWC) domestic space and, over time, become alienated from that relationship (Garrett, 2020). Relationships between people offering support (POS) and PWC appear to be most under threat when there is disagreement as to whether the PWC recognises the clutter as a problem (Büscher et al., 2014). Alternatively, supporters may become overwhelmed by carer burden; a self-perceived chronic and multifaceted strain on one's ability to provide support, arising from competing responsibility demands and exhausting emotional and material resources, resulting in decreased care provision and quality-of-life in the POS (Liu et al., 2020). Estrangement from POS may have catastrophic consequences as a lack of supportive relationships has been associated with overall poorer outcomes for the PWC (Chen et al., 2022).

POS to people with OCD are also noted to experience hopelessness, reduced quality-of-life, burden and depressive symptoms (Cicek et al., 2013; Geffken et al., 2006). OCD social support research has tended to focus on the concept of accommodation, whereby family members of individuals with OCD perform well-intentioned actions to alleviate distress through offering reassurance and/or facilitating rituals, but which are associated with increased OCD severity (La Buissonnière-Ariza et al., 2022). Research by Kobori et al. (2017) found that specific forms of response to rituals may be difficult to maintain consistently, resulting in anxiety and frustration in the PWC. However, POS are often invited to offer reassurance in subtle ways, and which are responded to gratefully by the PWC, establishing a predictable and expected helping role (Kobori et al., 2017). Research examining family support for 151 adults with OCD found that

accommodation occurred at least weekly for 87% (La Buissonnière-Ariza et al., 2022). In this context, family-inclusive treatments for adults with OCD are emerging, with early indication that family involvement may produce better outcomes than individual Cognitive Behavioural Therapy (CBT) (Stewart et al., 2020). Accommodation is less well studied in HD populations; however, it is thought to occur at a similar rate to that of OCD (Drury et al., 2014; Vorstenbosch et al., 2015). Despite this, HD treatments involving POS are rare and have focussed on the POS's experience, rather than enhancing outcomes for the PWC (Thompson et al., 2017).

Maintaining supportive connections may be further adversely impacted by prevalent stigmatised attitudes towards individuals who hoard (Chasson et al., 2018), with emerging evidence of family members internalising stigma through their association to the PWC (Prosser et al., 2024). Associative stigma – also referred to as courtesy stigma or affiliate stigma – was originally defined by Goffman (1963) and subsequent research has applied this concept to mental health stigma and investigated mediating factors, including cohabiting as a factor increasing internalised associative stigma (van der Sanden et al., 2015), as well as considering how POS might recognise and fight against stigma (Angermeyer et al., 2003). It is important to understand the extent to which such factors are specific to POS for HD.

It has been suggested that pre-occupation with objects is a form of behavioural avoidance of navigating unpredictable early relationships and that attachment holds the key to improving HD treatment effectiveness (David et al., 2021; Kyrios et al., 2018; Medard & Kellett, 2014). Attachment problems have,

however, been shown to be relevant but not specific to HD, relative to OCD. Barton et al. (2021) found that people with HD and people with OCD did not differ on measures of interpersonal attachment and relational needs, and these clinical groups had comparably smaller social networks than community controls. However, those with HD perceived comparatively less support from that network (Barton et al., 2021). Edwards et al. (2023) replicated this finding with a more rigorous measure, and PWC(HD) were again found to have similarly small social networks and rated the quality of support they received as significantly worse than the OCD and community control groups.

It could be simply a matter of *perception*; that is, those with HD have similar interactions with POS, but do not believe themselves to be supported. Alternatively, it could be that POS are actually responding more negatively to those with HD, due for example to particular attitudes and beliefs about hoarding, or how they view their own role as a supporter. To investigate the question of perception versus inadequate support, this study examines how POS perceive their efforts to support and how it is received.

Hypotheses

The present research hypothesises that the perceived poorer support in PWC could arise from two possible sources:

a. Those with HD have similarly supportive interactions with POS, relative to PWC(OCD), but appraise the support they receive to be poorer.

- If this is the case, we would expect that POS(HD) will not differ in terms of their expressed wish to provide support and will report less successful support, compared to POS(OCD).

Or:

b. POS are responding more negatively to those with HD, relative to OCD, being ambivalent about or disengaged from offering support.
    - If this is the case, we would expect that POS(HD) will report a lower expressed wish to offer support and find their efforts to be less successful.

In both instances, the expectation is that POS(HD) will experience lower satisfaction in offering support, relative to POS(OCD). In line with literature describing estrangement, it is predicted that carer burden would be higher in the HD group, relative to POS(OCD), indicating increased risk of POS becoming unable to continue support.

Secondary hypotheses were considered in relation to the impact stigma has on supportive interactions. It was hypothesised that HD would be rated as a more stigmatised condition compared to OCD and that public stigma presence would translate into internalised associative stigma, which would be reported more intensely by the POS(HD) group versus OCD counterparts. If POS(HD) did report more associative stigma, this would justify exploratory analysis of associations with self-rated support quality, with the expectation that greater associative stigma would negatively impact support quality.

Method

Overview

POS were sought via advertising on social media and sharing adverts via national OCD and HD charities and local support groups (materials in *Appendix K* and *Appendix L*). Participants completed an online survey eliciting the frequency and types of support being offered, the experience of offering support and its perceived effectiveness. No financial incentive was provided.

A power calculation using G*power (Faul et al., 2007), based on a mixed model ANOVA for the primary analysis, indicated a required sample size of 84. This was based on a type 2 error probability rate of 0.2 and an effect size of 0.25. In the absence of any similar previous studies, the effect size was conservatively estimated based on subscale differences of the Revised Norbeck Social Support Questionnaire (NSSQ-R) between HD and OCD groups observed in the Edwards et al. (2023) study.

Ethical approval was granted by the University of Oxford Medical Sciences Interdivisional Research Ethics Committee, ref: R86617/RE001 (see *Appendix M*).

Participants

The concept of POS was operationalised by potential supporters endorsing that there was a person “that you have a personal connection to, e.g. a family member or friend you have known for a number of years, that you offer some

form of support to". The PWC was specified as having to be experiencing OCD or hoarding difficulties. To be eligible, POS and the PWC, were: 30+ years-old and living in the UK. This age limit was selected to mitigate potential difference between the condition groups, with HD typically reaching clinically significant levels later in life (Zaboski II et al., 2019). A formal diagnosis was not required. Validity checks were used to confirm a clinically significant level of impact on the PWCs' functioning. The Work and Social Adjustment Scale (WSAS) has been validated for use with OCD and depression and found to have good-to-excellent internal consistency (Mundt et al., 2002) and was adapted for POS proxy reporting. The Clutter Images Rating Scale (CIR) (Frost et al., 2008) was used to validate HD symptomology in the HD group. The CIR asks respondents to select images that best resemble the level of clutter in a person's home. The measure has good convergence with other measures of HD symptom severity and excellent inter-rater reliability (Frost et al., 2008).

Given that OCD traits are exhibited by many people with HD, with diagnosable comorbidity understood to be around 18% (Pertusa et al., 2019), group designation for POS to individuals believed to have both OCD *and* HD was determined by POS identifying which they perceived to be the PWC's 'main problem'.

Measures

The full survey is included in *Appendix N*. Demographic information was recorded as per potential relevance to the research hypotheses, e.g. previous research has found consistent associations between age and HD prevalence (Postlethwaite et al., 2019).

Social Support Quality and Experience

As no existing scale was identified, to measure POS's self-rating of support quality a novel proxy scale was developed by inverting items from the NSSQ-R (Norbeck et al., 1981), as well as developing additional items relevant to offering rather than receiving support. This proxy scale (P-NSSQ-R) offered a means of assessing differences on three subscales: wish to support, perceived support success and impact of support on the POS. Existing items from the NSSQ-R were transformed into two variants to distinguish between the POS's view of the level of effort they put into supportive actions and the perceived success of these efforts with regard to the observed PWC's response. Whereas an original NSSQ-R item asked 'how much do they make you feel liked or loved', the wish to support subscale included items targeting intention and preparedness to support, such as "how much do you *try* to make the person feel liked or loved?". Perceived support success assessed indicators of effectiveness of the support, such as "how much do you *actually* make this person feel liked or loved?". Additional items were created following consultation with experts-by-experience with HD to aid construct validity by including ideas regarding conflict, frustration and sense of purpose. For example, the P-NSSQ-R asks 'does the person reject your help and support?'. Impact of support on the POS examined responses to and satisfaction taken from offering support, including "do you find helping and supporting the person rewarding?".

Higher P-NSSQ-R scores indicate more positive outcomes, i.e. higher motivation to support, greater sense of the support helping the PWC and less

negative personal consequences experienced from offering support. As existing literature describes PWC(HD) reporting shame about others entering their home (Prosser et al., 2024), it was also deemed important to check for group differences in contact frequency across forms of contact. To aid reliability, internal consistency was measured at a pilot stage and checked again for the complete dataset. Full items and scoring information for the P-NSSQ-R measure is included in *Appendix O*.

16 items from the Burden Scale for Family Caregivers (BSFC) (Grau et al., 2015) were included to support validity of the impact on supporter P-NSSQ-R subscale and to measure burden in a broader sense, acknowledging supporters' resources and other responsibilities. The higher the total score, the greater presence of carer burden and increased likelihood of the caregiver developing mental health distress. A subset of the full 28-item BSFC has been found to have good construct validity in that it showed higher burden in supporters with less access to support resource and predicted future inpatient admission of the PWC on follow-up (Graessel et al. 2020).

Stigma

For the secondary analysis, the measurement of both public stigma attitudes and associative stigma was necessary to delineate between POS's agreement with stigmatised ideas towards people with HD and OCD and the degree to which POS recognise themselves as a target of stigma by virtue of their connection to the stigmatised individual. Ten items from the Community

Attitudes Toward the Mentally Ill Scale (CAMI) (Taylor & Dear, 1981) were used to assess the POS's general attitudes towards individuals with both OCD and HD. The CAMI is regularly used in research investigating prejudicial public attitudes and has been found to have well-validated psychometric properties (Fox et al., 2018). A subset of the original 40 items was selected to avoid respondent fatigue. Items were purposefully selected for conceptual relevance to OCD and HD stigma as well as ensuring representation of items from component subscales. A 10-item version of the CAMI was evaluated demonstrating good test-retest reliability (Sanabria-Mazo et al., 2023), indicating appropriateness in using the scale for two separate targets of stigma consecutively. For this scale, higher scores indicated a higher overall presence of mental health stigma towards OCD and HD separately.

The 22-item Affiliate Stigma Scale (ASS) (Mak & Cheung, 2008) measures the extent of self-stigmatisation of those who are associates of individuals with a mental illness. Three subscales are used to assess associative stigma within affective, behavioural and cognitive domains: the felt sense of stigma; attempts to distance oneself from the stigmatised individual; and beliefs about them and their condition. The validity of the ASS has been supported by consistently high internal consistency as well as total scale and item unidimensionality being supported by Rasch analysis (Chang et al., 2015). Higher scores on the ASS indicate a higher level of associative stigma.

Analysis

The main analysis used a mixed model ANOVA assessing for significant difference between the HD and OCD groups using sub-scale scores on the P-NSSQ-R. For other variables, mixed model ANOVAs were used to compare groups on descriptive variables. Chi Square analyses were used for categorical variables and Independent- or Paired-Samples T-Tests were used for follow-up comparisons where main effects were identified via ANOVAs. Checks for normality of data were completed and test assumptions were met other than where specified. Where data were skewed, Mann-Whitney U tests were used for comparing mean differences in scale data. In line with the main hypothesis, 2-sided *p* values were used.

Results

Internal consistency of the P-NSSQ-R subscales and CAMI and BSFC measures were checked, with acceptable to excellent ratings (see Appendix Q).

116 POS to somebody with OCD and/or hoarding difficulties completed the survey. Five cases from the HD group were removed as scores on the CIR did not indicate a clinically significant hoarding problem, leaving a final total of **111** cases. The HD group contained responses from **69** POS, with 19 of these PWC believed to have comorbid OCD. The OCD group contained responses from **42** POS, with 18 of these PWC believed to have comorbid HD. Of the PWC in the HD group, 29 (42.0%) were thought by the POS to self-identity as having that condition, compared to 39 (92.9%) in the OCD group.

Demographic information is shown in *Table 1* (additional detail is available in Supplementary Information *S2.1*). Group differences were assessed using Chi square tests; where significant, partitioned Chi-Square tests were used. The frequency of the PWC being family members versus friends, neighbours or other types of relationship was not significantly different between the groups, X^2 (1, N=80)=.042, p=.838. However, the OCD group had significantly more spouses or significant others versus family members compared to the HD group X^2 (1, N = 80)=6.0, p=.014, and more spouses or significant others than friends and other types of relationships X^2 (1, N=80)=5.2, p=.023.

Table 1

Demographic Information

	PWC			**POS**		
	HD (*N*=69)	OCD (*N*=42)	Total (*N*=111)	HD (*N*=69)	OCD (*N*=42)	Total (*N*=111)
Age	*M*=63.0, *SD*=12.9	*M*=41.2, *SD*=10.7	*M*=54.8, *SD*=16.1	*M*=52.2, *SD*=13.4	*M*=47.6, *SD*=14.6	*M*=50.4, *SD*=14.0
Gender identity						
Woman	39 (56.5%)	21 (50.0%)	60 (54.1%)	59 (85.5%)	28 (66.7%)	87 (78.4%)
Man	28 (40.6%)	19 (45.2%)	47 (42.3%)	6 (8.7%)	12 (28.6%)	18 (16.2%)
Trans-gender	2 (2.9%)	-	2 (1.8%)	3 (4.3%)	1 (2.4%)	4 (3.6%)
Non-binary	-	2 (4.8%)	2 (1.8%)	-	-	-
Prefer not to say	-	-	-	1 (1.4%)	1 (2.4%)	2 (1.8%)
Ethnicity						
White British	59 (85.5%)	35 (83.3%)	94 (84.7%)	60 (87.0%)	33 (78.6%)	93 (83.8%)
Minority Ethnic Identity	10 (14.5%)	7 (16.7%)	17 (15.3%)	9 (13.0%)	9 (21.4%)	18 (16.2%)
Marital status						
Married or in a civil partnership	18 (26.1)	11 (26.2%)	29 (26.1%)	30 (43.5%)	18 (42.9%)	48 (43.2%)
Cohabiting	7 (10.1%)	8 (19.0%)	15 (13.5%)	15 (21.7%)	11 (26.2%)	26 (23.4%)
Divorced or separated	12 (17.4%)	1 (2.4%)	13 (11.7%)	8 (11.6%)	2 (4.8%)	10 (9.0%)
Widowed	7 (10.1%)	1 (2.4%)	8 (7.2%)	-	3 (7.1%)	3 (2.7%)
Single	25 (36.2%)	21 (50.0%)	46 (41.4%)	16 (23.2%)	8 (19.0%)	24 (21.6%)
Employment status						
Currently employed	22 (31.9%)	21 (50.0%)	43 (38.7%)	44 (63.8%)	27 (64.3%)	46 (41.4%)
Not currently employed	47 (68.1%)	21 (50.0%)	68 (61.3%)	25 (36.2%)	15 (35.7%)	8 (7.2%)

	HD (*N*=69)	OCD (*N*=42)	Total (*N*=111)
Does the PWC have formal diagnoses?			
HD	6 (8.7%)	-	6 (5.4%)
OCD	3 (4.3%)	29 (69.0%)	32 (28.8%)
HD and OCD	-	1 (2.4%)	1 (.9%)
Neither HD nor OCD	60 (87.0%)	12 (28.6%)	72 (64.9%)
Has the PWC sought help for their condition?			
Yes	18 (26.1%)	31 (73.8%)	49 (44.1%)
No	51 (73.9%)	11 (26.2 %)	62 (55.9%)
Years since onset of PWC's condition	*M*=25.6,*SD*=13.7	*M*=22.2,*SD*=11.9	*M*=24.3,*SD*=13.1
Relationship type to PWC			
Spouse or partner	8 (11.6%)	16 (38.1%)	24 (21.6%)
Significant other	5 (7.2%)	2 (4.8%)	7 (6.3%)
Family member or relative	36 (52.2)	16 (38.1%)	52 (46.8%)
Neighbour	1 (1.4%)	-	1 (.9%)
Friend	18 (26.1%)	5 (11.9%)	23 (20.7%)
Work associate	-	1 (2.4%)	1 (.9%)
Other	1 (1.4%)	2 (4.8%)	3 (2.7%)
Years known	*M*=32.4, *SD*=17.4	*M*=22.5, *SD*=16.4	*M*=28.7, *SD*=17.1
Does the POS live with the PWC?			
Yes	20 (29.0%)	25 (59.5%)	45 (40.5%)
No	49 (71.0%)	17 (40.5%)	66 (59.5%)
WSAS scaled total score[a]	*M*=5.1, *SD*=1.9	*M*=4.8, *SD*=2.0	*M*=5.0, *SD*=1.9
CIR total score	*M*=16.1, *SD*=4.9	*M*=7.8, *SD*=4.9	*M*=12.9, *SD*=6.3

[a]WSAS scores divided by applicable items after considering if PWC is unemployed or retired for reasons other than their condition.

In the OCD group, PWC age data were skewed, so a Mann-Whitney U test was selected. PWC were significantly older in the HD group (U=298, p<.001) and had known the POS for longer $t_{(109)}$=3.0, p=.003. PWC more commonly had a formal diagnosis in the OCD group, X^2 (1, N=111)=39.1, p<.001, and were more likely to have sought help for their condition, X^2 (1, N=111)=24.1, p<.001. There were no significant differences for PWC between male and female gender identity, X^2 (1, N=107)=.33, p=.565, nor White British versus minority ethnicity, X^2 (1, N=111)=.10, p=.758. Similarly, there were not significant differences between groups when comparing whether PWC were currently in a relationship, X^2 (1, N=111)=.89, p=.347, or were currently in paid employment versus not employed, X^2 (1, N=111)=3.6, p=.057.

POS's age in the OCD group were also skewed at the lower range. POS did not significantly differ in age between groups (U=1143.5, p=.063). No significant differences were observed for POS's ethnicity X^2 (1, N=111)=1.4, p=.254, relationship status X^2 (1, N=111)=1.7, p=.678, or employment status X^2 (1, N=111)=.003, p=.956. However, more POS in the OCD group were male X^2 (1, N=105)=7.5, p=.006. There was a significant difference in dyads living together more frequently in the OCD group, both historically (X^2 (1, N=111)=10.1, p=.001) and currently (X^2 (1, N = 111)=4.3, p=.039).

Severity of functional impairment for PWC was not significantly different between OCD and HD groups, as assessed by comparing WSAS scores with an Independent-Samples T-test, $t_{(109)}$=.84, p=.404.

Primary analysis

The primary analysis used a 2x3 mixed model ANOVA with condition as the grouping variable and the within-subject variable being sub-scales of the P-NSSQ-R: (wish to support; perceived support success; and impact of support on the POS). The main effect of subscale was significant, $F_{(2,218)}$=77.0, p<.001, as was the main effect of group, $F_{(1,109)}$=16.2, p<.001. These effects were modified by a significant interaction effect, $F_{(2,218)}$=4.7, p=.01 (see *Figure 1*).

Figure 1: P-NSSQ-R Sub-Scale Score by Group

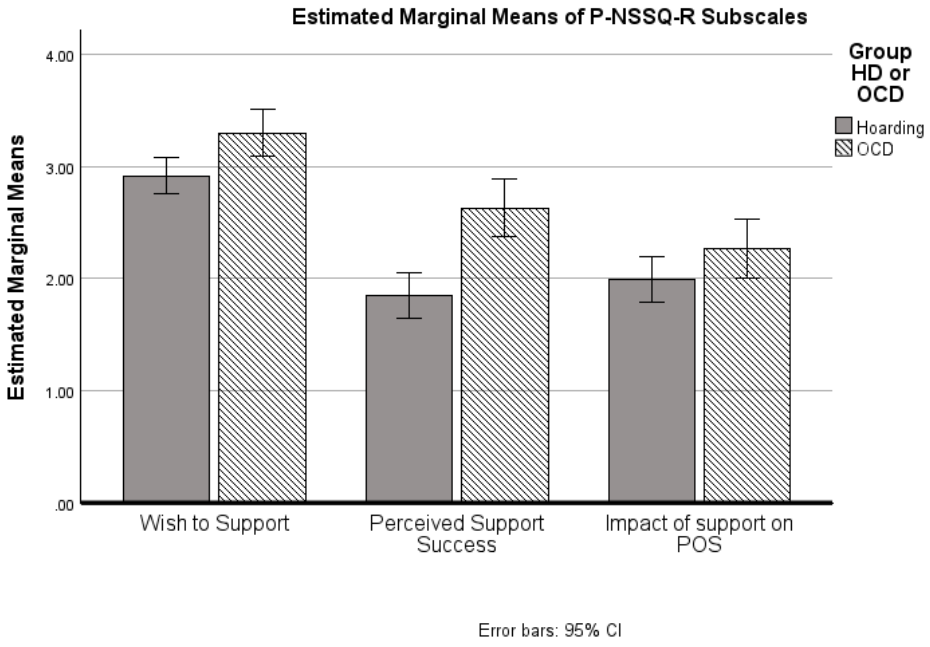


Table 2

Between Groups Scores on P-NSSQ-R Subscales and BSFC (primary analysis) with multiple comparisons

	Group				Between-Groups Comparison	
	HD (*n*=69)		OCD (*n*=42)			
	M	*SD*	*M*	*SD*	*t*	*p*
1 - Wish to Support Subscale[b]	2.9	.74	3.3	.54	-.2.9	.005*
2 - Perceived support success[b]	1.9	.90	2.6	.74	-4.7	<.001*
3 - Impact of support on POS[b]	2.0	.87	2.3	.82	-1.7	.098
Reciprocity subscale[b]	1.9	1.1	2.6	1.0	-3.5	<.001*
Contact subscale[bc]	2.9	.80	3.4	.80	2098.5	<.001*
BSFC total score[d]	24.8	15.0	26.2	9.4	.84	.465
	Matched Pair		Group	*df*	*t*	*p*
Within groups comparison	1 vs 2		HD (*n*=69)	68	9.7	<.001*
			OCD (*n*=42)	41	6.2	<.001*
	1 vs 3		HD (*n*=69)	68	8.7	<.001*
			OCD (*n*=42)	41	6.7	<.001*
	2 vs 3		HD (*n*=69)	68	-1.5	.141
			OCD (*n*=42)	41	2.3	.027*

[b]P-NSSQ-R subscales divided by number of items for comparison.

[c]Contact subscale data not normally distributed in OCD group, Mann-Whitney test used.

[d]BSFC completed by 101 POS, (HD group *n*=59, OCD group *n*=42)

**significant at .05 level*

Multiple comparisons revealed that the POS(HD) reported both significantly lower wish to support ($t_{(109)}$=-2.9, p=.005) and lower perceived support success ($t_{(109)}$=-4.7, p<001) relative to POS(OCD). There was no difference between groups in rating the impact of support on the POS ($t_{(109)}$=-1.7, p=.098). POS also reported similar levels of burden as rated on the BSFC, $t_{(99)}$=.84, p=.465.

Paired-Samples T-Tests revealed that within both groups POS reported higher wish to support versus perceived support success (HD: $t_{(68)}$=9.7, p <.001, OCD: $t_{(41)}$=6.2, p<.001), and versus impact of support on the POS (HD: $t_{(68)}$=8.7, p <.001, OCD: $t_{(41)}$=6.7, p<.001).

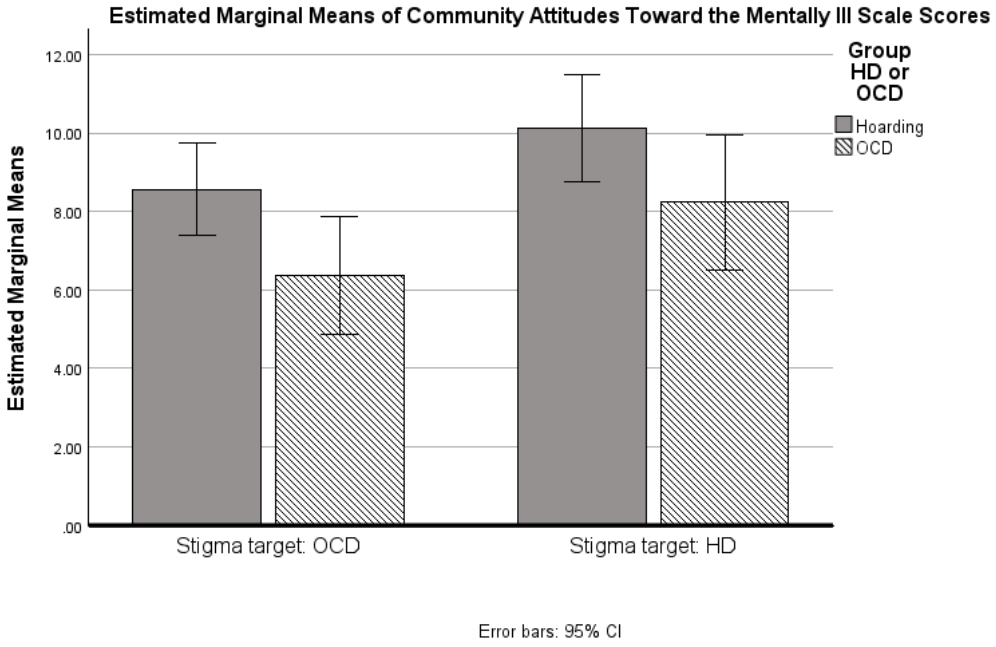
The P-NSSQ-R contact subscale data were skewed at the upper limit in the OCD group. A Mann-Whitney U test found that POS(OCD) reported a higher frequency of contact with the PWC compared to the HD group (U=2098.5, p>.001). Follow-up partitioned Chi Square tests were used to investigate differences in individual items. All but one contact subscale items showed no significant between-groups difference. For frequency of face-to-face contact occurring in PWC homes, weekly in-home contact was significantly less frequently reported in the HD group X^2 (1, N=111)=7.2, p=.007. An Independent-Samples t-test comparing total scores on the P-NSSQ-R reciprocity subscale showed a significant difference, with POS in the OCD group rating greater support available in turn from the PWC, $t_{(109)}$=-3.5, p>.001. Individual item mean scores for the P-NSSQ-R are provided in Supplementary Information (*S2.2*).

Overall, these results indicate that people supporting in the HD group rated both the wish to support and its perceived success as significantly lower than those supporting people with OCD. These groups did not differ in terms of the perceived impact of providing such support. The validity of this finding was aided by the groups not differing significantly on a measure of caregiver burden.

Secondary analysis

Public stigma (CAMI): The extent to which the POS separately stigmatised OCD and HD was analysed using a mixed model ANOVA. The main effect of stigma target was significant, $F_{(1,107)}$=15.9, p<.001, as was the main effect of group, $F_{(1,107)}$=4.6, p=.034. The interaction was not significant, $F_{(1,107)}$=.13, p=.722. The group difference indicated that POS in the HD group reported higher perceived stigma overall for both diagnoses, with both groups ratings HD more negatively. Surprisingly, there was no evidence that being a supporter to somebody with either condition modified these ratings.

Figure 2: CAMI Scores by Group for Public Stigma Attitudes Toward Individuals with OCD versus HD.



Associative Stigma (ASS): A mixed model ANOVA on the extent to which the POS feel themselves to be stigmatised by their association with the person (group x ASS sub-scales (affective, behavioural, cognitive)) found a significant main effect of subscale ($F_{(2,210)}$=41.4, p<.001) and of group ($F_{(1,105)}$=9.6, p=.003). The interaction effect was not significant, $F_{(2,218)}$=2.2, p=.111. Significantly greater levels of associative stigma were reported by POS(HD).

Table 3

Between Groups Scores on Additional Self-Report Measures (secondary analysis)

	Group						**Between-Groups Comparison**	
	HD (*n*=67)		OCD (*n*=42)		Total (*n*=109)			
	M	*SD*	*M*	*SD*	*M*	*SD*	*t*	*p*
CAMI								
Stigma target was OCD[e]	8.6	5.5	6.4	3.9	7.7	5.0	2.4	.016*
Stigma target was HD	10.1	5.8	8.2	5.3	9.4	5.7	1.7	.092
	HD (*n*=65)		OCD (*n*=42)		Total (*n*=107)			
ASS								
ASS total score[e]	18.9	15.0	10.5	11.1	15.6	14.1	3.3	.001*
Affect[e]	7.6	5.5	4.4	4.4	6.3	5.3	3.4	<.001*
Behaviour[ef]	5.1	4.7	2.6	3.2	4.1	4.3	3.2	.002*
Cognition[e]	5.5	4.9	3.2	3.5	4.6	4.5	2.8	.006*

[e]Adjusted for unequal variances

[f]Behaviour ASS subscale transformed for comparison.

**significant at .05 level*

Exploratory analysis

Due to a comorbidity rate of 33.3% in the total sample, the primary and secondary analyses were re-run, omitting cases where POS identified the PWC as having comorbid OCD or HD (filtered group sizes HD *n*=50, OCD *n*=24, see Supplementary Information *S2.3*). Similar main and interaction effects were found as per the whole sample grouping, other than that the main effect of group in the public stigma model was no longer significant $F_{(1,70)}$=3.6, *p*=.062,

likely due to the decreased power. This analysis indicates that comorbidity was unlikely to have overestimated or underestimated any differences in the primary analysis.

A hierarchical regression model investigated relationships between group and associative stigma (total ASS score) on the dependent variables of subscales of the P-NSSQ-R, when controlling first for PWC age. The model for wish to support was significant ($F_{(3,106)}$=4.6, p=.005) with age accounting for 4.2% of the variance (R^2 change=.042, p=.033), associative stigma an additional 5.0% (R^2 change=.33, p=.018) and group an additional 2.5% (R^2 change=.025, p=.091). The model for Perceived support success was significant ($F_{(3,106)}$=11.8, p<.001) with age accounting for 13.5% of the variance (R^2 change=.135, p>.001), associative stigma an additional 6.8% (R^2 change=.068, p=.003) and group an additional 5.3% (R^2 change=.053, p=.008). The model for impact of support on the POS was significant ($F_{(3,106)}$=19.0, p<.001) with age accounting for 2.3% of the variance (R^2 change=.023, p=.12), associative stigma an additional 33.0% (R^2 change=.33, p<.001) and group an additional .40% (R^2 change=.004, p=.45).

Discussion

Based on previous findings that people with HD rated their social support as less adequate than OCD controls, this study used the perspectives of those providing such support to evaluate the two factors which could explain that finding. Specifically, how much the POS *wishes* to offer support, and how *successful* they perceive that support to be. Both factors were expected to be associated with the degree of satisfaction in providing support. Results suggest that both factors differentiate between diagnosis. Those supporting people with HD reported a lower wish to support relative to POS in the OCD group, suggesting that support is being offered less willingly. Those supporting people with HD also viewed their support as less successful relative to OCD group counterparts, consistent with findings of lower ratings of “being supported” by people with HD (Barton et al., 2021; Edwards et al., 2023). Interestingly, the hypothesis that POS(HD) would also report a more negative impact on them from offering support was not supported, with support experience not differing on the P-NSSQ-R subscale nor as measured more globally via burden. Note that samples were comparable in terms of levels of functional impairment due to their condition. The differences found in associative stigma and its relationship to wish to support and its success suggest that this could be a possible mechanism.

Previous literature finding poorer perceived support for individuals with HD (Barton et al., 2021; Edwards et al., 2023) can now be understood, at least in part, in relation to shortcomings in available support availability and provision. Another relevant factor was PWC age, which was associated with lower

perceived success of support. Previous research has found associations between age and hoarding severity, noting uncertainty as to whether there are indeed differentiating age-related factors or if cumulative accumulation of clutter over time is the primary cause (Drury et al., 2014). There is no comparative evidence to suggest that offering support to someone with HD would be a more difficult or burdensome experience than offering support to an individual with OCD, but this was tentatively considered in the context of HD carer research focusing on social isolation and carer frustration (Sampson, 2013; Wilbram et al., 2008). The findings did not indicate that these POS(HD) are at increased risk of withdrawing support due to carer burden, relative to OCD. We can tentatively consider that estrangement in HD more likely occurs through POS choosing to increase distance from the PWC, rather than reaching a point of overwhelm whilst maintaining their best efforts to continue to help.

Previous research has suggested how an inability to visit a person's home might lead to ambiguous loss of that relationship and associated gradual dwindling of support efforts (Sampson, 2013). Alternatively, it might be the case that the negative effects of accommodating hoarding symptoms are more salient to these POS and there is less motivation to add fuel to the fire through perceived collusion or unwanted actions, such as covert house clearances (Büscher et al., 2014). Where with OCD there might be an idea that POS accommodating symptoms is "better than doing nothing" (Kobori et al., 2017), could it be that for HD POS begin to believe that reducing support is best? This aligns with Mayes et al. (2024) finding that with increased clutter, relatives experienced less benefit from offering support and less certainty that the PWC

was getting the right help. It would also appear that PWC's age plays a role in POS's perception of support success; possibly the longer that clutter remains the less hopeful and involved a supporter might become.

Those supporting PWC(HD) in this sample were also found to experience more associative stigma (supporters' own sense of stigma due to their connection to the stigmatised individual), and to have more negative attitudes towards both OCD and HD, relative to POS(OCD). Note that POS in both the HD and OCD groups rated HD as a more stigmatised condition on a measure of public stigma, as found in a previous comparison of HD and OCD public stigma (Chasson et al., 2018). Previous research found that proximity reduced a sense of difference to individuals with HD but not disdain or blame toward them (Chasson et al., 2018). An unexpected finding was that POS in the HD group also rated OCD as more stigmatised, relative to peers. Higher mental health stigma regarding HD could be being generalised to another condition, though this warrants further investigation. Research has already established that relatives of a person with HD may become socially isolated themselves (Sampson, 2013; Wilbram et al., 2008). The present findings suggest that associative stigma from internalising persecutory ideas about mental health conditions is significantly elevated in POS to those with HD.

Limitations

The findings of this study have been used to infer what might be happening between POS-PWC dyads in the context of HD. Having established a deficit in support quality, further research involving dyads of supporter and supported is needed to investigate causal factors and clinical interventions which increase

support quality. It is also recognised that the primary analysis was based on adaptation of the NSSQ-R beyond its originally intended use, to the point of developing a novel scale. While this poses a challenge to the validity of the findings, the scale was adapted with reference to existing literature and what PWC, from clinical experience, report to be key aspects of offering support and measuring support quality in the absence of a readily available alternative measure. Nonetheless, future research involving dyads could aid construct validity by testing the P-NSSQ-R's correlation with existing validated measures for related concepts, such as familial rejection (Tolin et al., 2008).

There was also an acceptable but lower-than-expected internal consistency found for the CAMI when OCD was the stigma target. Greater reliability may have been achieved had the full scale been administered. Dyads more commonly lived together in the OCD group and it could be that lower associative stigma and enhanced support were attributable to proximity. Higher rates of PWCs having a diagnosis, having sought professional help and having more frequent contact in the PWC's home were expected for the OCD group, in line with previous literature describing barriers in these factors for individuals with HD. However, future research could seek to recruit matched samples to increase confidence in the specificity of findings.

This study recruited via social media and advertising through relevant charities which may have introduced a sampling bias. It is unlikely that this recruitment method would have appealed to POS who were actively choosing not to engage in support activities, or who were estranged from the PWC that they had a connection to, supported by the high frequency of ongoing contact with the

PWC reported in this sample. Future research could seek a broader range of engagement in current support activity. Also related to recruitment is the high level of comorbidity, although this was mitigated by repeating the main analysis with smaller but more specific groups.

Study Implications

Across both OCD and HD groups, these POS reported a higher wish to support than the perceived level of success they believe to be achieving. This demonstrates the potential usefulness of involving partners and family members in psychological therapy and POS learning alternative strategies to accommodating symptoms. While this is becoming better recognised in OCD treatment, family-integrated CBT for HD is lagging behind. Involving POS may hold specific value for HD treatment, addressing hopelessness before POS are no longer prepared to offer help. Clinicians should also consider that, with HD, POS may have particular vulnerability to associative stigma and help POS acknowledge and resist stigma.

Further research should involve POS and PWC to understand *why* support for HD seems to be relatively less well delivered and received. Recruiting dyads would add reliability to future studies and provide a means of experimentally investigating interpersonal factors, such as warmth, trust and stigma-related concepts, such as disdain (Chasson et al., 2018). Longitudinal research could chart the provision and quality of support for PWC with HD over time, helping to identify factors associated with estrangement and with the maintenance of long-term supportive relationships.

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Executive summary document for TDRP

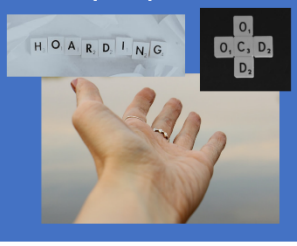
Poster and text only versions are provided below

Oxford Institute of Clinical Psychology Training and Research
Research team: James Dennis, Trainee Clinical Psychologist (james.dennis@stx.ox.ac.uk), Professor Paul Salkovskis, Dr Kate Rosen

Holding on to Support

Research study investigating differences in social support for people with hoarding difficulties and people with Obsessive Compulsive Disorder (OCD)

Offering support to someone with a mental health condition can be difficult and people might not always know the best way to help. Research into hoarding suggests there is a particular risk of the condition getting worse when the person does not have support from people that know them. Unfortunately, people with hoarding difficulties often become disconnected from family and friends.



What we aimed to do: Previous research found that people with hoarding difficulties feel less supported than those with OCD. We wanted to explore if this is because people with hoarding difficulties are actually getting less support, or if they are getting similar support to those with OCD but view the support more negatively. We also wanted to see if having more stigmatised ideas about the conditions affected support and if supporters felt stigmatised because of their connection to the person with the condition.

What we did: We asked people to answer a survey about the support they offer to people with these conditions. We statistically compared the responses to look for differences between the conditions.

What we found: People who offered support to those with OCD rated their wish to support as higher than how successful they thought their support actually was. In comparison to OCD supporters, people offering support to those with hoarding difficulties saw their support as even less successful and had a lower wish to support. This was the case even though people's conditions were rated as similarly disruptive to their lives. The supporters to people with hoarding difficulties also had more stigmatised ideas about these mental health conditions and felt more stigmatised themselves because of their connection to the person with the condition.

What does this mean for people with **hoarding difficulties** and those who support them?

- Offering support had a similar impact and burden on supporters of people with hoarding difficulties to people supporting OCD. This was surprising as the OCD supporters felt their support was more successful.
- One explanation links to previous hoarding difficulties research where supporters felt hopeless about giving the right support. These supporters might need more help to stay motivated and engaged in helping the person.
- Age was also important. The older the person with hoarding difficulties was, the less successful the supporter felt their help was. We don't know if there are other things to do with being older that mean this is the case or if this is due to more clutter over time being the cause.
- Knowing someone with hoarding difficulties did not impact the level of stigma supporters rated toward the condition. The supporters themselves also felt stigmatised through their connection to the person with hoarding difficulties.

What does this mean for people with **OCD** and those who support them?

- Evidence is starting to show that involving family in psychological treatments works better than individual therapy.
- Our findings suggest that support could be optimised by involving supporters in treatments for OCD.

What should happen next?

More research is needed to find out *why* support for people with hoarding difficulties is less forthcoming and less successful. More research should involve both the individual with hoarding difficulties and those who offer support. We need to develop treatments that involve supporters to better help them and the person with hoarding difficulties.

Thank you to everybody who took part in and supported this study!

Holding on to Support – Research study investigating differences in social support for people with hoarding difficulties and people with Obsessive Compulsive Disorder (OCD)

Background

Offering support to someone with a mental health condition can be difficult and people might not always know the best way to help.

Research into hoarding suggests there is a particular risk of the condition getting worse when the person does not have support from people that know them. Unfortunately, people with hoarding difficulties often become disconnected from family and friends.

What we aimed to do

Previous research found that people with hoarding difficulties feel less supported than those with OCD. We wanted to explore if this is because people with hoarding difficulties are actually getting less support, or if they are getting similar support to those with OCD but view the support more negatively. We also wanted to see if having more stigmatised ideas about the conditions affected support and if supporters felt stigmatised because of their connection to the person with the condition.

What we did

We asked people to answer a survey about the support they offer to people with these conditions. We statistically compared the responses to look for differences between the conditions.

What we found

People who offered support to those with OCD rated their wish to support as higher than how successful they thought their support actually was. In comparison to OCD supporters, people offering support to those with hoarding difficulties saw their support as even less successful and had a lower wish to support. This was the case even though people's conditions were rated as similarly disruptive to their lives. The supporters to people with hoarding difficulties also had more stigmatised ideas about these mental health conditions and felt more stigmatised themselves because of their connection to the person with the condition.

What does this mean for people with hoarding difficulties and those who support them?

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Knowing someone with hoarding difficulties did not impact the level of stigma supporters rated toward the condition. The supporters themselves also felt stigmatised through their connection to the person with hoarding difficulties.

What does this mean for people with OCD and those who support them?

Evidence is starting to show that involving family in psychological treatments works better than individual therapy.

Our findings suggest that support could be optimised by involving supporters in treatments for OCD.

What should happen next?

More research is needed to find out why support for people with hoarding difficulties is less forthcoming and less successful. More research should involve both the individual with hoarding difficulties and those who offer support. We need to develop treatments that involve supporters to better help them and the person with hoarding difficulties.

Thank you to everybody who took part in and supported this study!

Connecting Narrative

On my application form for the DClin, I specified that I was interested in pursuing a portfolio career, incorporating research and clinical roles. Prior to re-training in psychology, I was working in the technology sector and I had admired how research projects seemed to have greater potential to benefit a wider number of people as opposed to commercial projects. Starting my DClin training, I often found myself reflecting on the statement I had written on my application. I thought about how this likely supported my selection, given the emphasis of the Oxford course on research excellence and viewing excellent clinical practice as combining clinical art and clinical science. Another recurring idea concerned the moral issue of how the wider psychological profession takes a balanced approach in reactively offering treatments for those in distress and in proactively identifying and alleviating sources of distress. I appreciate both perspectives, that working with distressed individuals is vital, and that failing to try to influence systemic factors causing mental health distress risks waiting list perpetually outgrowing provision.

Despite early training experiences validating my ideal to straddle clinical and research work in the future, my experience of completing these research projects has left me questioning the feasibility of a split role. Perhaps working with a high level of risk acuity in a Crisis Resolution and Home Treatment Team has influenced my perspective, but in producing this integrated thesis, I have struggled to see how I could commit to both streams simultaneously. My difficulty has come in managing the ebb and flow of research alongside clinical work, with inevitable delays and periods where there is a need to wait for

relevant approvals before a string of much tighter deadlines. Clinical work has been at a consistently busy and hectic level across my placements. However, at times when these research projects have required a faster pace of completion, or more complex thought, I have noticed in myself that the right word at the right time in a therapeutic scenario becomes just that bit more elusive.

Most notably, this has been the case while on placement alongside the recruitment and data analysis phases of my TDRP. Interestingly, hoarding was extremely infrequently a factor of clinical work, however, without an apparent prompt, I would find myself writing a session note or driving between appointments with my head filled with ideas about boosting recruitment or relating findings to the wider research context. There may have been a subtler connection between crisis work and the TDRP concerning people in a position to offer support, with home visits often involving liaison or direct support for family members. Nonetheless, the clear boundary of research versus placement days became permeable in my own mind and the more there seemed to be a barrier in understanding something in either stream, the more I struggled to prevent thought cycles of solution-focussed ideas about how I could approach the other. While I am sure there was benefit in actively practicing alongside conducting this research project, and vice versa, I was left feeling that I could do a better job of both if I was able to focus on these roles sequentially, rather than simultaneously.

With my SRL, split working did make more sense in that my original inspiration for the project came from a particular piece of client work. This placement case taught me the value in how clinical psychologists can have a luxury in more

face-to-face contact time with individuals, relative to other professionals. My sense was that efforts to understand how this client interacted with professional services were hampered by seeing their behaviour in isolation from their day-to-day experience. With the SRL, I saw an opportunity to examine psychosocial wellbeing for autistic older adults from a more holistic perspective and believed that contributing a published research paper would likely have a greater influence on the local service than me offering a re-formulation of a single case, and through training I could do both. This added evidence of the value of combining practice and research, however, my sense remains that taking a break from clinical work to further investigate anecdotal observations could be a more satisfying experience than balancing these activities.

By its nature, the project that appeared to lend itself best to integrating clinical and research work was the SIP. There is less scope to generalise findings, but I do still believe that case studies and SIPs can offer a great deal to wider improvement efforts. However, my SIP was not conducted at my placement service. This meant that coordinating time to meet with members of that team was trickier and resulted in bottlenecks of research activity. Again, I questioned the significance of this SIP being conducted alongside clinical practice versus in between periods of clinical practice. Later on in my training, I completed a consultancy project, giving me a flavour of what it might be like to complete a SIP at one's home service. With the consultancy project, it did feel like being embedded in the service gave me knowledge of contexts that aided the specificity of the recommendations. There was also a sense of the timeliness of the project extracting greater value. Delivering that report within a matter of

weeks seemed to offer unique positive local outcomes, with my other projects able to be written up within the same year without there seeming to be a risk of a lost opportunity for action.

This gives me confidence that I can follow the Oxford course mantra of being a consumer and producer of high-quality research. In addition, I see a further learning phase, considering how I resolve the dilemma of allowing research with a wider lens to seem less urgent, when I cannot consciously endorse this idea which sits so uncomfortably. Of course, there are limits to what any Clinical Psychologist can do in terms of clinical and research productivity, but there might be other ways to build flexibility into these limits that I have yet to discover. I hope that this is the case.

Acknowledgments

I would like to thank all of my placement supervisors for their support in producing this research alongside challenging and rewarding clinical work. Your kindness and encouragement have been sustaining and kept me aware of how important our colleagues are in this industry.

For her excellent and swift collaboration on my SRL, thank you to Rachel ‘future-professor’ Prosser.

For expert advice, thoughtful consideration and constructive feedback I would like to thank all of my brilliant research supervisors.

Thank you to my course tutor Craig Steel for helping me hold the big picture in mind.

Without my wonderful cohort of fellow trainees, I would not have been able to complete this training programme. For always knowing what to say and how to say it, my heartfelt thanks. You will all make sublime Clinical Psychologists.

As always, you inspire and motivate me in everything we do. Thank you to my fiancée Joanna, a colossal star.

Appendices

SRL

- Appendix A: Position Statement Regarding the PTMF
- Appendix B: SRL Search Strategy
- Appendix C: Quality Appraisal
- Appendix D: Coding of Extracted Data
- Appendix E: Instructions to authors (Journal of Autism and Developmental Disorders)

SIP

- Appendix F: Interview Schedule
- Appendix G: Bracketing Interview Reflexive Summary
- Appendix H: Easy-Read Project Feedback for Patients
- Appendix I: Executive Summary Report for SLT
- Appendix J: Instructions to authors (Journal of Applied Research in Intellectual Disabilities)

TDRP

- Appendix K: Study recruitment poster
- Appendix L: Study information sheet
- Appendix M: Ethical approval
- Appendix N: Paper Survey Form
- Appendix O: P-NSSQ-R Items and Scoring Guide

- Appendix P: Instructions to authors (British Journal of Clinical Psychology)

For supplementary information, please refer to:

Supplementary Information S1 (Service Improvement Project)

- S1.1 – Procedure for Analysis
- S1.2 – Visual Process of Developing Superordinate Themes
- S1.3 – Full Themes Overview and Transcript Data

Supplementary Information S2 (Theoretically Driven Research Project)

- S2.1 – Full demographics table
- S2.2 – Adapted Norbeck Full Scores
- S2.3 – Full description of supplementary analysis with grouping excluding comorbid OCD and HD

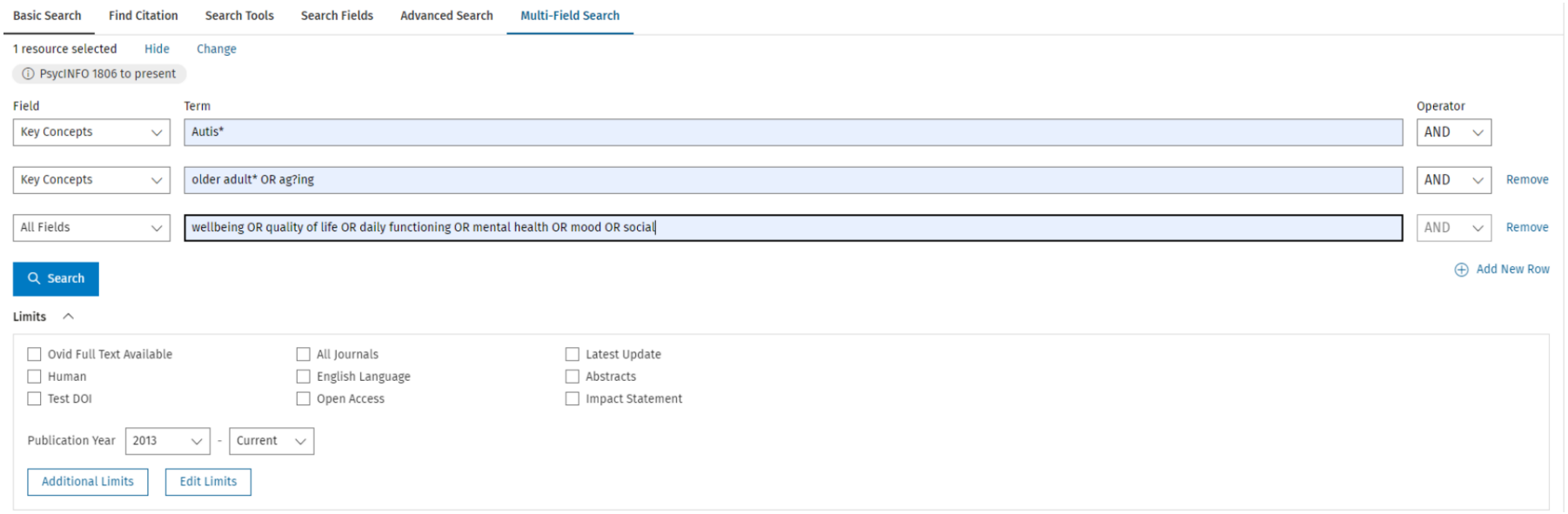
Appendix A: Position Statement Regarding the PTMF

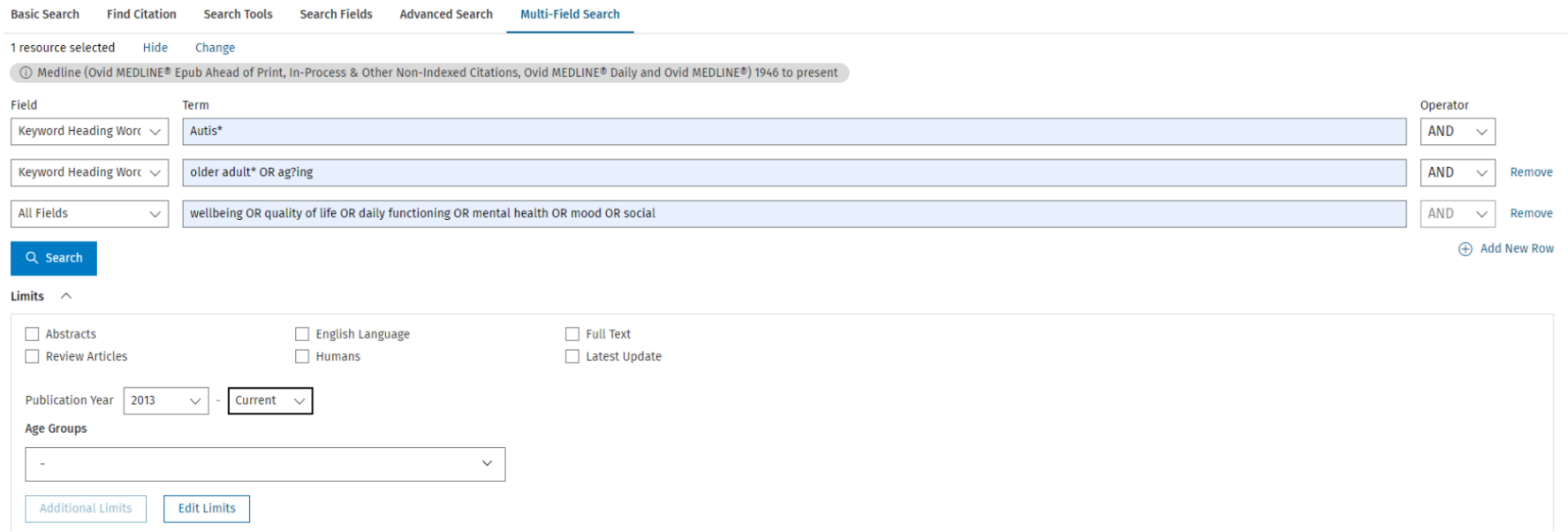
As outlined in the PTMF document (Johnstone et al., 2018), the focus of the initiative is to provide an alternative to the traditional diagnostic approach, informed by the 'medical model'. Certainly, the notion of placing discourses around social inequality more centrally in therapeutic practice and psychological service provision planning is one that the lead reviewer endorses. However, it is recognised that concerns have been raised about the 'anti-positivist' agenda of the PTMF and the true innovativeness versus re-purposing of existing ideas has been critiqued, citing a risk of 'throwing the baby out with the bathwater' (Salkovskis & Edge, 2018). This reviewer is hesitant to reject an initiative reflecting wider efforts in the industry to adapt to changing expectations from clients, reduce stigma and take a more active stance against social injustice. Perhaps it is felt though that the 'moving towards' part of the PTMF handbook title should be kept more at the fore of the debate and that overall merit in the framework has been limited thus far by an absence of constructive debate directly between those who are promoting and those who are sceptical of the PTMF.

As outlined in the handbook (Johnstone et al., 2018), the PTMF is primarily speaking to issues relating to clinical practice, whereas the proposed review applies the framework to a research context. Again, there are issues with the extent to which the PTMF is moving beyond or simply updating an existing system of classification. However, when it comes to producing a literature review, the framework's emphasis on understanding peoples' stories, and recognising the function of ascribing of meaning and threat response as socially

constructed, may enable previous findings to be understood in a way that better serves the population in question. Given that autistic older adults appear to be a marginalised group, the PTMF was employed with the intention of avoiding recreating ‘discourses of deficit’ and minimising the role of socio-political factors by revising experiences down to aspects of biology (Boyle, 2022).

Appendix B: SRL Search Strategy

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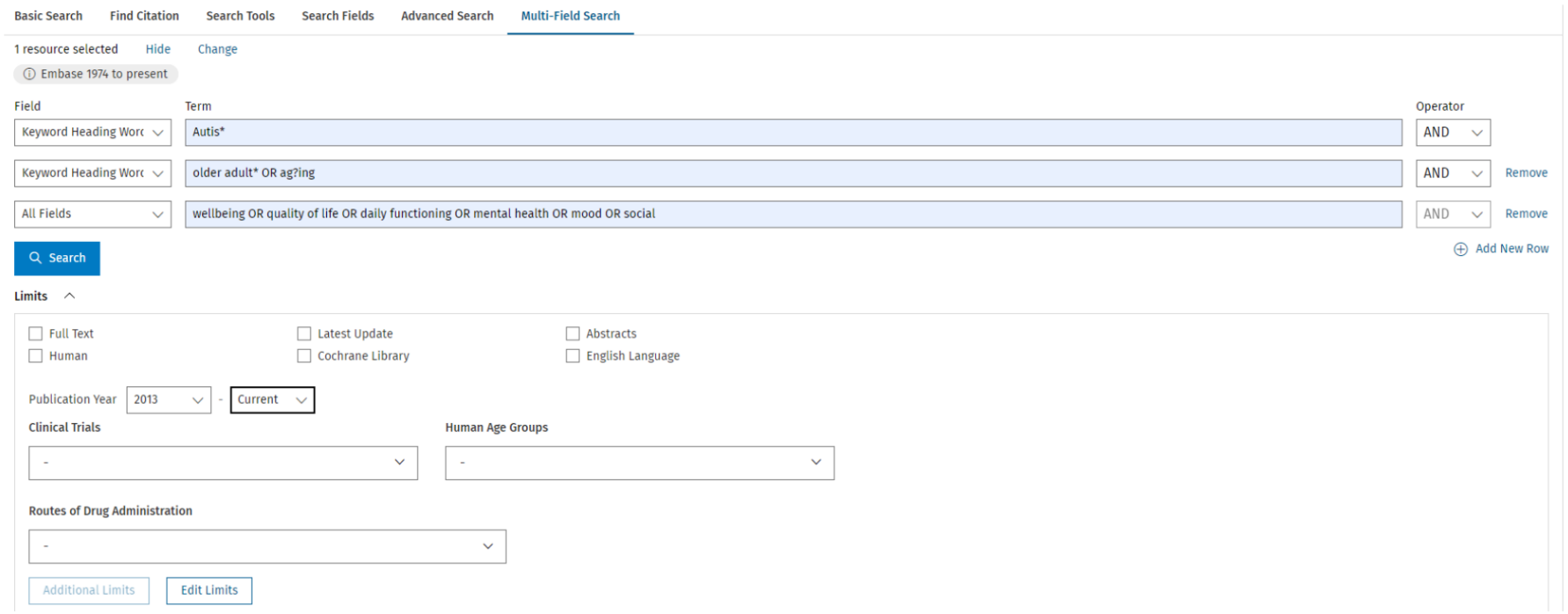
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Appendix C: Quality Appraisal

Y= yes, P = partial, N = no

Quantitative

Rated in duplicate	Author	Did the study address a clearly focused issue?	Was the cohort recruited in an acceptable way?	Was the exposure accurately measured to minimise bias?	Have the authors identified all important confounding factors?	Have they taken account of the confounding factors in the design and/or analysis?	Was the follow up of subjects complete enough?	Was the follow up of subjects long enough?	Do you believe the results?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?	What are the implications of this study for practice?
Y	Charlton et al	Y	Y	Y	Y	Y	N/A	N/A	Y	P	Y	Y
N	Lever and Geurts 2016	Y	Y	Y	Y	Y	N/A	N/A	Y	Y	Y	Y
N	Lever and Geurts 2018	Y	Y	Y	Y	Y	N/A	N/A	Y	Y	Y	Y
N	Mason et al	Y	Y	Y	Y	Y	N/A	N/A	Y	Y	Y	Y
Y	Nylander et al	Y	P	P	N	P	N/A	N/A	P	P	P	Y
Y	Roestorf et al	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Y	Uljarevic	Y	P	Y	P	Y	N/A	N/A	Y	Y	Y	Y
N	Van Heijst and Geurts	Y	P	Y	P	Y	N/A	N/A	Y	Y	Y	P
N	Zivrali-Yarar et al 2020	Y	Y	Y	Y	Y	N/A	N/A	Y	Y	Y	Y
Y	Zivrali-Yarar et al 2022	Y	Y	Y	Y	P	N/A	N/A	Y	Y	Y	Y

Qualitative

Rated in duplicate	Author	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
N	Barber	Y	Y	Y	N	Y	Y	Y	Y	Y
N	Brady et al	Y	Y	Y	P	Y	Y	Y	Y	Y
Y	Elichaoff	Y	Y	Y	N	Y	P	Y	Y	P
Y	Hickey et al	Y	Y	Y	Y	Y	P	Y	Y	Y
N	Hwang 2023	Y	Y	Y	Y	Y	Y	Y	Y	Y
Y	Hwang 2017	Y	Y	Y	Y	Y	P	Y	Y	Y
N	Mason et al	Y	Y	Y	Y	Y	Y	Y	Y	Y
Y	Moseley et al	Y	Y	Y	Y	Y	Y	Y	P	Y
Y	Stagg and Belcher	Y	Y	Y	Y	P	Y	Y	Y	Y
N	Waldron	Y	Y	Y	Y	Y	P	Y	P	Y
N	Zheng et al	Y	Y	Y	Y	Y	Y	Y	Y	Y

Appendix D: Coding of Extracted Data

Qualitative

		Superordinate themes		
Living well as an autistic older adult	Gradually figuring things out	Legacy of exclusion	Familiar unremitting challenges	Experiences of diagnosis
		Sub-themes		
Preparation and fitting things around autism and therefore around the individual	Getting older, getting easier	Autism being 'treated' as anxiety/depression by increased use of medication	Financial limitations	Keenness to engage with autistic community and support others
Managing the right level of independence	Acceptance of old age	Experiencing others as treating us inappropriately	Harder for us to fill gaps in fulfilment, seeming destined to remain	Diagnosis as unlocking past and present understanding
Social interaction wanted on my terms	Compassionate realism in navigating the social world	Having educational accreditation but not able to apply qualifications. Not allowed career prospects.	Sensory challenges always there	Journey of integrating new label
Gratitude for support	Making good use of time - feeling good or doing good	Lots of professional contact but lacking in knowledge and expertise	Cognitive decline as adding to complexity of tasks	Intentions not able to be conveyed in communication resulting in feeling 'wrong'
Heterogeneity of autistic lives	Following an alternative life trajectory	Seeking understanding from others, calling for	Lack of support systems	Vindication - diagnosis as taking away blame for 'faults'

	others to make effort to understand		
	Pressure to fit in	Unravelling of protective layers when facing new stressors and confusion	Diagnosis coming too late
	High incidence of mental health difficulties		
	Pain of not being accepted		

Quantitative

Codes	**Corresponding data items**
Autism traits	11
Gender differences	3
Limitations of findings *(reported in relation to study quality)*	4
Mental health	32
Overall quality of life	20
Physical health *(inclusive but not specific to older autistic adults)*	2
Social experience	10
Social Support	6

Appendix E: Instructions to authors (Journal of Autism and Developmental Disorders)

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.

APA Style

APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.

The anonymized manuscripts containing no author information (no name, no affiliation, and so forth).

Back to top

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

*JADD is no longer accepting manuscripts with only one participant or group studies without an appropriate comparison group.

The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.

A Brief Report: A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. Must meet the demands of scientific rigor required of a JADD article but can be preliminary findings.

A Letter to the Editor/Commentary is 6 or less double spaced pages with shorter references, tables and figures.

Style sheet for Letter to the Editor:

A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information

The anonymized manuscripts containing no author information (no name, no affiliation, and so forth):-

- 6 or less double spaced pages with shorter references, tables and figures

- Line 1: “Letter to the Editor”

- Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

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Review your manuscript for these elements

Order of manuscript pages:

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Anonymized Abstract, manuscripts and References without contact information

Appendix

Figure Caption Sheet

Figures

Tables

JADD submissions should include:

A structured abstract with the Purpose, Methods, Results, and Conclusion.

COI and other author statements placed on the title page.

No more than 40 double-spaced pages, including double-spaced references (with hanging indents), tables, and figures.

Tables and Figures placed at the end of the manuscript with callouts in the text.

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Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly

– at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Suggestions for Inclusive Language in JADD Submissions

JADD Inclusive Language Guide (Download pdf, 134 kB)

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Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

The name(s) of the author(s)

The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country

A clear indication and an active e-mail address of the corresponding author

If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

Purpose (stating the main purposes and research question)

Methods

Results

Conclusion

For life science journals only (when applicable)

Trial registration number and date of registration for prospectively registered trials

Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

Competing Interests: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

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Text

Text Formatting

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Back to top

Body

The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

Introduction (The introduction has no label.)

Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)

Results (Center the heading.)

Discussion (Center the heading.)

Back to top

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

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Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

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Terminology

Please always use internationally accepted signs and symbols for units (SI units).

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Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.:Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

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References

Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson, 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the

first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

Journal article 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/ppm0000185

Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435

Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.

Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.

Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

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Tables

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within

the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

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Artwork and Illustrations Guidelines

Electronic Figure Submission

Supply all figures electronically.

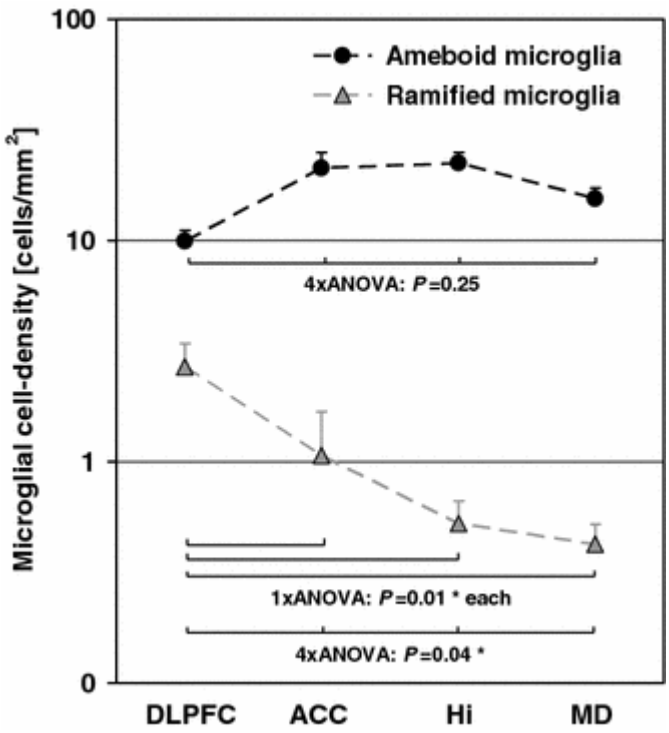
Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



Definition: Black and white graphic with no shading.

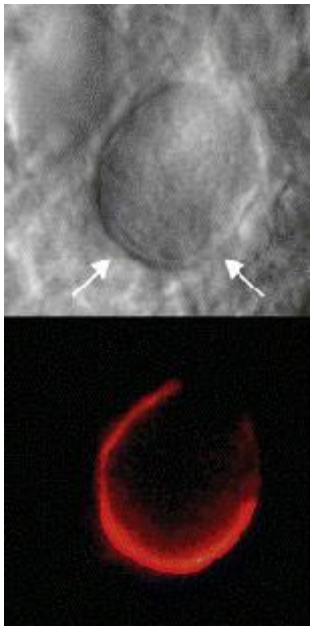
Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.

All lines should be at least 0.1 mm (0.3 pt) wide.

Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.

Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art

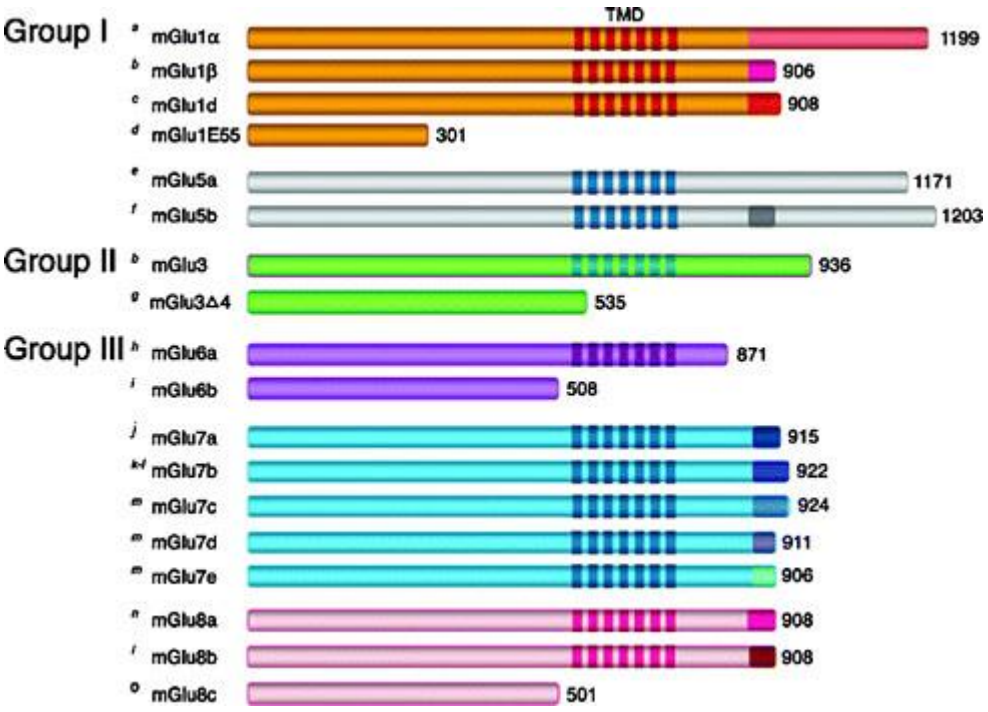


Definition: Photographs, drawings, or paintings with fine shading, etc.

If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.

Halftones should have a minimum resolution of 300 dpi.

Combination Art



Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.

Combination artwork should have a minimum resolution of 600 dpi.

Color Art

Color art is free of charge for online publication.

If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.

If the figures will be printed in black and white, do not refer to color in the captions.

Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

To add lettering, it is best to use Helvetica or Arial (sans serif fonts).

Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).

Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.

Avoid effects such as shading, outline letters, etc.

Do not include titles or captions within your illustrations.

Figure Numbering

All figures are to be numbered using Arabic numerals.

Figures should always be cited in text in consecutive numerical order.

Figure parts should be denoted by lowercase letters (a, b, c, etc.).

If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.

Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.

No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.

Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.

Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.

When preparing your figures, size figures to fit in the column width.

For large-sized journals the figures should be 84 mm (for double-column text areas), or 174 mm (for single-column text areas) wide and not higher than 234 mm.

For small-sized journals, the figures should be 119 mm wide and not higher than 195 mm.

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If you include figures that have already been published elsewhere, you must obtain permission from the copyright owner(s) for both the print and online format. Please be aware that some publishers do not grant electronic rights for free and that Springer will not be able to refund any costs that may have occurred to receive these permissions. In such cases, material from other sources should be used.

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In order to give people of all abilities and disabilities access to the content of your figures, please make sure that

All figures have descriptive captions (blind users could then use a text-to-speech software or a text-to-Braille hardware)

Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)

Any figure lettering has a contrast ratio of at least 4.5:1

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Please check Springer's policy on generative AI images and make sure your work adheres to the principles described therein.

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Figure caption sheet

The figure caption sheet contains a list of only the captions for all figures used. Center the label "Figure Captions" in uppercase and lowercase letters at the top of the page. Begin each caption entry flush left, and type the word "Figure", followed by the appropriate number and a period, all in italics. In the text of the caption (not italicized), capitalize only the first word and any proper nouns. Table notes: Copyright permission footnotes for figures are typed as part of the figure caption.

Each figure should appear on a separate page. The page where the figure is found should have the figure number and the word "top"[ie, Figure 1 top] typed above the figure. Figures or illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Figures may be embedded in the text of a Word document. Electronic artwork may be in the TIFF, EPS or Powerpoint format (best is 1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color

space. *** After first mention in the body of the manuscript, a call-out for the correct placement of each figure should be included in brackets on a separate line within the text.

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Supplementary Information (SI)

Springer accepts electronic multimedia files (animations, movies, audio, etc.) and other supplementary files to be published online along with an article or a book chapter. This feature can add dimension to the author's article, as certain information cannot be printed or is more convenient in electronic form.

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Submission

Supply all supplementary material in standard file formats.

Please include in each file the following information: article title, journal name, author names; affiliation and e-mail address of the corresponding author.

To accommodate user downloads, please keep in mind that larger-sized files may require very long download times and that some users may experience other problems during downloading.

High resolution (streamable quality) videos can be submitted up to a maximum of 25GB; low resolution videos should not be larger than 5GB.

Audio, Video, and Animations

Aspect ratio: 16:9 or 4:3

Maximum file size: 25 GB for high resolution files; 5 GB for low resolution files

Minimum video duration: 1 sec

Supported file formats: avi, wmv, mp4, mov, m2p, mp2, mpg, mpeg, flv, mxf, mts, m4v, 3gp

Text and Presentations

Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.

A collection of figures may also be combined in a PDF file.

Spreadsheets

Spreadsheets should be submitted as .csv or .xlsx files (MS Excel).

Specialized Formats

Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

Collecting Multiple Files

It is possible to collect multiple files in a .zip or .gz file.

Numbering

If supplying any supplementary material, the text must make specific mention of the material as a citation, similar to that of figures and tables.

Refer to the supplementary files as “Online Resource”, e.g., "... as shown in the animation (Online Resource 3)", “... additional data are given in Online Resource 4”.

Name the files consecutively, e.g. “ESM_3.mpg”, “ESM_4.pdf”.

Captions

For each supplementary material, please supply a concise caption describing the content of the file.

Processing of supplementary files

Supplementary Information (SI) will be published as received from the author without any conversion, editing, or reformatting.

Accessibility

In order to give people of all abilities and disabilities access to the content of your supplementary files, please make sure that

The manuscript contains a descriptive caption for each supplementary material

Video files do not contain anything that flashes more than three times per second (so that users prone to seizures caused by such effects are not put at risk)

Generative AI Images

Please check Springer’s policy on generative AI images and make sure your work adheres to the principles described therein.

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Ethical Responsibilities of Authors

This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct.

Authors should refrain from misrepresenting research results which could damage the trust in the journal, the professionalism of scientific authorship, and ultimately the entire scientific endeavour. Maintaining integrity of the research and its presentation is helped by following the rules of good scientific practice, which include*:

The manuscript should not be submitted to more than one journal for simultaneous consideration.

The submitted work should be original and should not have been published elsewhere in any form or language (partially or in full), unless the new work concerns an expansion of previous work. (Please provide transparency on the re-use of material to avoid the concerns about text-recycling (‘self-plagiarism’).

A single study should not be split up into several parts to increase the quantity of submissions and submitted to various journals or to one journal over time (i.e. ‘salami-slicing/publishing’).

Concurrent or secondary publication is sometimes justifiable, provided certain conditions are met. Examples include: translations or a manuscript that is intended for a different group of readers.

Results should be presented clearly, honestly, and without fabrication, falsification or inappropriate data manipulation (including image based manipulation). Authors should adhere to discipline-specific rules for acquiring, selecting and processing data.

No data, text, or theories by others are presented as if they were the author’s own (‘plagiarism’). Proper acknowledgements to other works must be given (this includes material that is closely copied (near verbatim), summarized and/or paraphrased), quotation marks (to indicate words taken from another source) are used for verbatim copying of material, and permissions secured for material that is copyrighted.

Important note: the journal may use software to screen for plagiarism.

Authors should make sure they have permissions for the use of software, questionnaires/(web) surveys and scales in their studies (if appropriate).

Research articles and non-research articles (e.g. Opinion, Review, and Commentary articles) must cite appropriate and relevant literature in support of the claims made. Excessive and inappropriate self-citation or coordinated efforts among several authors to collectively self-cite is strongly discouraged.

Authors should avoid untrue statements about an entity (who can be an individual person or a company) or descriptions of their behavior or actions that could potentially be seen as personal attacks or allegations about that person.

Research that may be misapplied to pose a threat to public health or national security should be clearly identified in the manuscript (e.g. dual use of research). Examples include creation of harmful consequences of biological agents or toxins, disruption of immunity of vaccines, unusual hazards in the use of chemicals, weaponization of research/technology (amongst others).

Authors are strongly advised to ensure the author group, the Corresponding Author, and the order of authors are all correct at submission. Adding and/or deleting authors during the revision stages is generally not permitted, but in some cases may be warranted. Reasons for changes in authorship should be explained in detail. Please note that changes to authorship cannot be made after acceptance of a manuscript.

*All of the above are guidelines and authors need to make sure to respect third parties rights such as copyright and/or moral rights.

Upon request authors should be prepared to send relevant documentation or data in order to verify the validity of the results presented. This could be in the form of raw data, samples, records, etc. Sensitive information in the form of confidential or proprietary data is excluded.

If there is suspicion of misbehavior or alleged fraud the Journal and/or Publisher will carry out an investigation following COPE guidelines. If, after investigation, there are valid concerns, the author(s) concerned will be contacted under their given e-mail address and given an opportunity

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If the article has already been published online, depending on the nature and severity of the infraction:

- an erratum/correction may be placed with the article

- an expression of concern may be placed with the article

- or in severe cases retraction of the article may occur.

The reason will be given in the published erratum/correction, expression of concern or retraction note. Please note that retraction means that the article is maintained on the platform, watermarked "retracted" and the explanation for the retraction is provided in a note linked to the watermarked article.

The author's institution may be informed

A notice of suspected transgression of ethical standards in the peer review system may be included as part of the author's and article's bibliographic record.

Fundamental errors

Authors have an obligation to correct mistakes once they discover a significant error or inaccuracy in their published article. The author(s) is/are requested to contact the journal and explain in what sense the error is impacting the article. A decision on how to correct the literature will depend on the nature of the error. This may be a correction or retraction. The retraction note should provide transparency which parts of the article are impacted by the error.

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Authors are welcome to suggest suitable reviewers and/or request the exclusion of certain individuals when they submit their manuscripts. When suggesting reviewers, authors should make sure they are totally independent and not connected to the work in any way. It is strongly recommended to suggest a mix of reviewers from different countries and different institutions. When suggesting reviewers, the Corresponding Author must provide an institutional email address for each suggested reviewer, or, if this is not possible to include other means of verifying the identity such as a link to a personal homepage, a link to the publication record or a researcher or author ID in the submission letter. Please note that the Journal may not use the suggestions, but suggestions are appreciated and may help facilitate the peer review process.

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Authorship principles

These guidelines describe authorship principles and good authorship practices to which prospective authors should adhere to.

Authorship clarified

The Journal and Publisher assume all authors agreed with the content and that all gave explicit consent to submit and that they obtained consent from the responsible authorities at the institute/organization where the work has been carried out, before the work is submitted.

The Publisher does not prescribe the kinds of contributions that warrant authorship. It is recommended that authors adhere to the guidelines for authorship that are applicable in their specific research field. In absence of specific guidelines it is recommended to adhere to the following guidelines*:

All authors whose names appear on the submission

1) made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data; or the creation of new software used in the work;

2) drafted the work or revised it critically for important intellectual content;

3) approved the version to be published; and

4) agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

* Based on/adapted from:

ICMJE, Defining the Role of Authors and Contributors,

Transparency in authors' contributions and responsibilities to promote integrity in scientific publication, McNutt at all, PNAS February 27, 2018

Disclosures and declarations

All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate).

The decision whether such information should be included is not only dependent on the scope of the journal, but also the scope of the article. Work submitted for publication may have implications for public health or general welfare and in those cases it is the responsibility of all authors to include the appropriate disclosures and declarations.

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All authors are requested to make sure that all data and materials as well as software application or custom code support their published claims and comply with field standards. Please note that journals may have individual policies on (sharing) research data in concordance with disciplinary norms and expectations.

Role of the Corresponding Author

One author is assigned as Corresponding Author and acts on behalf of all co-authors and ensures that questions related to the accuracy or integrity of any part of the work are appropriately addressed.

The Corresponding Author is responsible for the following requirements:

ensuring that all listed authors have approved the manuscript before submission, including the names and order of authors;

managing all communication between the Journal and all co-authors, before and after publication;*

providing transparency on re-use of material and mention any unpublished material (for example manuscripts in press) included in the manuscript in a cover letter to the Editor;

making sure disclosures, declarations and transparency on data statements from all authors are included in the manuscript as appropriate (see above).

* The requirement of managing all communication between the journal and all co-authors during submission and proofing may be delegated to a Contact or Submitting Author. In this case please make sure the Corresponding Author is clearly indicated in the manuscript.

Author contributions

In absence of specific instructions and in research fields where it is possible to describe discrete efforts, the Publisher recommends authors to include contribution statements in the work that specifies the contribution of every author in order to promote transparency. These contributions should be listed at the separate title page.

Examples of such statement(s) are shown below:

• Free text:

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Example: CRediT taxonomy:

• Conceptualization: [full name], …; Methodology: [full name], …; Formal analysis and investigation: [full name], …; Writing - original draft preparation: [full name, …]; Writing - review and editing: [full name], …; Funding acquisition: [full name], …; Resources: [full name], …; Supervision: [full name],….

For review articles where discrete statements are less applicable a statement should be included who had the idea for the article, who performed the literature search and data analysis, and who drafted and/or critically revised the work.

For articles that are based primarily on the student's dissertation or thesis, it is recommended that the student is usually listed as principal author:

A Graduate Student's Guide to Determining Authorship Credit and Authorship Order, APA Science Student Council 2006

Affiliation

The primary affiliation for each author should be the institution where the majority of their work was done. If an author has subsequently moved, the current address may additionally be stated. Addresses will not be updated or changed after publication of the article.

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Authors are strongly advised to ensure the correct author group, the Corresponding Author, and the order of authors at submission. Changes of authorship by adding or deleting authors, and/or changes in Corresponding Author, and/or changes in the sequence of authors are not accepted after acceptance of a manuscript.

Please note that author names will be published exactly as they appear on the accepted submission!

Please make sure that the names of all authors are present and correctly spelled, and that addresses and affiliations are current.

Adding and/or deleting authors at revision stage are generally not permitted, but in some cases it may be warranted. Reasons for these changes in authorship should be explained. Approval of the change during revision is at the discretion of the Editor-in-Chief. Please note that journals may have individual policies on adding and/or deleting authors during revision stage.

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For cases in which a co-author dies or is incapacitated during the writing, submission, or peer-review process, and the co-authors feel it is appropriate to include the author, co-authors should obtain approval from a (legal) representative which could be a direct relative.

Authorship issues or disputes

In the case of an authorship dispute during peer review or after acceptance and publication, the Journal will not be in a position to investigate or adjudicate. Authors will be asked to resolve the dispute themselves. If they are unable the Journal reserves the right to withdraw a manuscript from the editorial process or in case of a published paper raise the issue with the authors' institution(s) and abide by its guidelines.

Confidentiality

Authors should treat all communication with the Journal as confidential which includes correspondence with direct representatives from the Journal such as Editors-in-Chief and/or Handling Editors and reviewers' reports unless explicit consent has been received to share information.

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Compliance with Ethical Standards

To ensure objectivity and transparency in research and to ensure that accepted principles of ethical and professional conduct have been followed, authors should include information regarding sources of funding, potential conflicts of interest (financial or non-financial), informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals.

Authors should include the following statements (if applicable) in a separate section entitled "Compliance with Ethical Standards" when submitting a paper:

Disclosure of potential conflicts of interest

Research involving Human Participants and/or Animals

Informed consent

Please note that standards could vary slightly per journal dependent on their peer review policies (i.e. single or double blind peer review) as well as per journal subject discipline. Before submitting your article check the instructions following this section carefully.

The corresponding author should be prepared to collect documentation of compliance with ethical standards and send if requested during peer review or after publication.

The Editors reserve the right to reject manuscripts that do not comply with the above-mentioned guidelines. The author will be held responsible for false statements or failure to fulfill the above-mentioned guidelines.

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Competing Interests

Authors are requested to disclose interests that are directly or indirectly related to the work submitted for publication. Interests within the last 3 years of beginning the work (conducting the research and preparing the work for submission) should be reported. Interests outside the 3-year time frame must be disclosed if they could reasonably be perceived as influencing the submitted work. Disclosure of interests provides a complete and transparent process and helps readers form their own judgments of potential bias. This is not meant to imply that a financial relationship with an organization that sponsored the research or compensation received for consultancy work is inappropriate.

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Financial interests: Stocks or shares in companies (including holdings of spouse and/or children) that may gain or lose financially through publication of this manuscript; consultation fees or other forms of remuneration from organizations that may gain or lose financially; patents or patent applications whose value may be affected by publication of this manuscript.

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Please note that, in addition to the above requirements, funding information (given that funding is a potential competing interest (as mentioned above)) needs to be disclosed upon submission of the manuscript in the peer review system. This information will automatically be added to the Record of CrossMark, however it is not added to the manuscript itself. Under ‘summary of requirements’ (see below) funding information should be included in the ‘Declarations’ section.

Summary of requirements

The above should be summarized in a statement and included on a title page that is separate from the manuscript with a section entitled “Declarations” when submitting a paper. Having all statements in one place allows for a consistent and unified review of the information by the Editor-in-Chief and/or peer reviewers and may speed up the handling of the paper. Declarations include Funding, Competing interests, Ethics approval, Consent, Data, Materials and/or Code availability and Authors’ contribution statements. Please use the title page for providing the statements.

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Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

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Partial financial support was received from [...]

The research leading to these results received funding from […] under Grant Agreement No[…].

This study was funded by […]

This work was supported by […] (Grant numbers […] and […]

Examples of statements to be used when there is no funding:

The authors did not receive support from any organization for the submitted work.

No funding was received to assist with the preparation of this manuscript.

No funding was received for conducting this study.

No funds, grants, or other support was received.

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Financial interests: Author A has received research support from Company A. Author B has received a speaker honorarium from Company W and owns stock in Company X. Author C is consultant to company Y.

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Non-financial interests: none.

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Non-financial interests: Author D has served on advisory boards for Company M, Company N and Company O.

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The authors have no relevant financial or non-financial interests to disclose.

The authors have no competing interests to declare that are relevant to the content of this article.

All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

The authors have no financial or proprietary interests in any material discussed in this article.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

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Vested Interest in Intervention Evaluation

If this is not an independent evaluation of an intervention it should be stated in the COI that the study is an evaluation of an intervention developed by the author(s).

Please add any steps taken to reduce risk of bias in the Methods, such as independence from data collection and analysis, masking procedures, etc.

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Research involving human participants, their data or biological material

Ethics approval

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

Retrospective ethics approval

If a study has not been granted ethics committee approval prior to commencing, retrospective ethics approval usually cannot be obtained and it may not be possible to consider the manuscript for peer review. The decision on whether to proceed to peer review in such cases is at the Editor's discretion.

Ethics approval for retrospective studies

Although retrospective studies are conducted on already available data or biological material (for which formal consent may not be needed or is difficult to obtain) ethics approval may be required dependent on the law and the national ethical guidelines of a country. Authors should check with their institution to make sure they are complying with the specific requirements of their country.

Ethics approval for case studies

Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on Informed Consent.

Cell lines

If human cells are used, authors must declare in the manuscript: what cell lines were used by describing the source of the cell line, including when and from where it was obtained, whether the cell line has recently been authenticated and by what method. If cells were bought from a life science company the following need to be given in the manuscript: name of company (that provided the cells), cell type, number of cell line, and batch of cells.

It is recommended that authors check the NCBI database for misidentification and contamination of human cell lines. This step will alert authors to possible problems with the cell line and may save considerable time and effort.

Further information is available from the International Cell Line Authentication Committee (ICLAC).

Authors should include a statement that confirms that an institutional or independent ethics committee (including the name of the ethics committee) approved the study and that informed consent was obtained from the donor or next of kin.

Research Resource Identifiers (RRID)

Research Resource Identifiers (RRID) are persistent unique identifiers (effectively similar to a DOI) for research resources. This journal encourages authors to adopt RRIDs when reporting key biological resources (antibodies, cell lines, model organisms and tools) in their manuscripts.

Examples:

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Plasmid: mRuby3 plasmid RRID:Addgene_104005

Software: ImageJ Version 1.2.4 RRID:SCR_003070

RRIDs are provided by the Resource Identification Portal. Many commonly used research resources already have designated RRIDs. The portal also provides authors links so that they can quickly register a new resource and obtain an RRID.

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The World Health Organization (WHO) definition of a clinical trial is "any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes". The WHO defines health interventions as “A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions” and a health-related outcome is generally defined as a change in the health of a person or population as a result of an intervention.

To ensure the integrity of the reporting of patient-centered trials, authors must register prospective clinical trials (phase II to IV trials) in suitable publicly available repositories. For example www.clinicaltrials.gov or any of the primary registries that participate in the WHO International Clinical Trials Registry Platform.

The trial registration number (TRN) and date of registration should be included as the last line of the manuscript abstract.

For clinical trials that have not been registered prospectively, authors are encouraged to register retrospectively to ensure the complete publication of all results. The trial registration number (TRN), date of registration and the words 'retrospectively registered' should be included as the last line of the manuscript abstract.

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Springer Nature advocates complete and transparent reporting of biomedical and biological research and research with biological applications. Authors are recommended to adhere to the minimum reporting guidelines hosted by the EQUATOR Network when preparing their manuscript.

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Checklists are available for a number of study designs, including:

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Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Ethics approval'.

Examples of statements to be used when ethics approval has been obtained:

• All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

• Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

• This research study was conducted retrospectively from data obtained for clinical purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

• This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of University B approved this study.

Examples of statements to be used when no ethical approval is required/exemption granted:

• This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required.

• The data reproduced from Article X utilized human tissue that was procured via our Biobank AB, which provides de-identified samples. This study was reviewed and deemed exempt by our XYZ Institutional Review Board. The BioBank protocols are in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

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Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images.

Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their

identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person.

Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.

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• Images such as x rays, laparoscopic images, ultrasound images, brain scans, pathology slides unless there is a concern about identifying information in which case, authors should ensure that consent is obtained.

• Reuse of images: If images are being reused from prior publications, the Publisher will assume that the prior publication obtained the relevant information regarding consent. Authors should provide the appropriate attribution for republished images.

Consent and already available data and/or biologic material

Regardless of whether material is collected from living or dead patients, they (family or guardian if the deceased has not made a pre-mortem decision) must have given prior written consent. The aspect of confidentiality as well as any wishes from the deceased should be respected.

Data protection, confidentiality and privacy

When biological material is donated for or data is generated as part of a research project authors should ensure, as part of the informed consent procedure, that the participants are made aware what kind of (personal) data will be processed, how it will be used and for what purpose. In case of data acquired via a biobank/biorepository, it is possible they apply a broad consent which allows research participants to consent to a broad range of uses of their data and samples which is regarded by research ethics committees as specific enough to be considered “informed”. However, authors should always check the specific biobank/biorepository policies or any other type of data provider policies (in case of non-bio research) to be sure that this is the case.

Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not have been fully informed, extra care will be taken by the editor and may be referred to the Springer Nature Research Integrity Group.

Consent to Publish

Individuals may consent to participate in a study, but object to having their data published in a journal article. Authors should make sure to also seek consent from individuals to publish their data prior to submitting their paper to a journal. This is in particular applicable to case studies. A consent to publish form can be found

here. (Download docx, 36 kB)

Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Consent to participate’ and/or ‘Consent to publish’. Other declarations include Funding, Competing interests, Ethics approval, Consent, Data and/or Code availability and Authors’ contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for "Consent to participate":

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

Sample statements for “Consent to publish”:

The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

Sample statements if identifying information about participants is available in the article:

Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

Images will be removed from publication if authors have not obtained informed consent or the paper may be removed and replaced with a notice explaining the reason for removal.

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Appendix F: SIP Interview Schedule

1. Can you tell me what you do in your work here at [ward name]?
    a. What does a typical shift involve for you?
    b. What tasks do you do?

2. What is different between a good day and a bad day at work?
    a. What has helped (make it good)?
    b. What has not helped?

3. Are there things that help you manage your wellbeing at work?
    a. Do you do anything to manage stress at work?
    b. Is there something that you can turn to at work that makes you feel better?

4. Have you received any feedback about your work?
    a. From fellow HCAs/nurses? From others?
    b. What was it like to hear that?

5. How have you gone about building relationships with patients?
    a. What did you do to get to know each other?
    b. What helped you to become more familiar?

6. Can you tell me about your relationship with a particular patient?
    a. How do you work together with them?
    b. What has been memorable about this?
    c. How successful has this been?

7. And can you tell me about a relationship with a patient that has felt harder/easier to develop?
    a. What have been the challenges/helpful things?
    b. What has been different to the other relationship you talked about?
    c. What has enabled this/got in the way?

8. What has been your experience of Positive Behaviour Support (PBS) at [ward name]?
    a. What experiences come to mind?
    b. What did you do in your PBS training?

9. Can you think of a time when you have used a PBS approach?
    a. Can you think of a time when you have seen PBS be used?
    b. How did this go?

10. What would you change to improve things for patients and staff?

a. Can you think of a time when this would have led to better results?
b. What would be different with that change in place?

Appendix G: Bracketing Interview Reflexive Summary

"Reflecting on my year of working in a secure ID hospital as a support worker and subsequent two years working at the same site as an Assistant Psychologist, I noticed that I had developed a simplified perspective on the application of PBS in practice. In transitioning roles within one service, I felt that I was considerate to multiple perspectives that tended to be described by individuals at different levels of the service hierarchy, but perhaps less aware of being pulled towards viewing PBS as 'working' or 'not working' at various moments. Noticing binary evaluations of PBS might have been hindered by an ever-present sense of urgency in needing to act and re-consider approaches in response to constant changes in a patient's need. 'Working' was more associated with ideals about patients having the means to thrive, brought to bear in times when patients had provided positive feedback or shown happiness at an outcome. 'Not working' tended to relate to feeling that plans were destined to fall by the wayside due to the staff team's ability to fully appreciate the underlying purpose and practical steps being overly impacted by perceived imbalance of patient need and staff numbers provision. Related to this is a recurring personal discomfort with holding that working as a support worker has been the hardest work I have done to date, whilst offering comparatively lower financial reward. In arriving at this SIP, my overriding feeling is hopefulness that it will be possible to present participant accounts sensitively and in a way that captures a spectrum of perspectives about PBS and work in this context more broadly.

My intention in recognising this is to be observant to uncover potential subtlety in participants experiencing PBS as being partially realised, looking to ground any notion of this in the data, being curious as to whether these participants might see a dichotomy in PBS effectiveness as I did, and to ensure that my own interpretations around this are done so intentionally and traceably."

Appendix H: Easy-Read Project Feedback for Patients

[ward name] and PBS

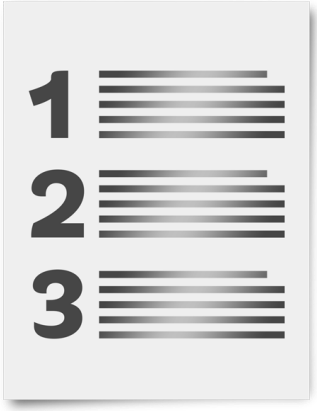
Easy read summary for the PBS project.

- What the project did
- What the project found out
- What will happen next

This is James. James works for the NHS. James is training to be a psychologist.	
James has been doing a project at [ward name]. The project wanted to find out ways to make things better for staff and patients. The project is now finished.	[ward photo]

James spoke with staff about their job. James met with staff one to one to ask about how they support patients.	
Staff enjoy doing activities with patients. Staff told James that they felt happy when patients were happy.	
And staff felt sad when patients get sad. This is because they care about patients.	
Sometimes staff wanted to work together more as a team.	

Sometimes teamwork is hard because staff have different ideas about how to help patients.	
Staff said that they wanted to help patients learn new skills	
Staff wish there was more time to spend on little things that make a big difference.	

James has given a list of suggestions to the senior team. These are ideas to help staff carry on what is working well. And some changes that could make things better.	
The senior team will think about how to keep making things better. Patients will be invited to say what they think. This helps to make things better for everyone!	

Appendix I: Executive Summary Report for SLT

Oxford Institute of Clinical Psychology Training and Research
Report by James Dennis, Trainee Clinical Psychologist.
Supervised by Dr Matthew Knight (Senior Admissions Tutor, Clinical Tutor, & Consultant Clinical Psychologist) and Julia Kelly (Principal Forensic Psychologist, [redacted]).

"Being PBS"

Staff Experiences of Positive Behaviour Support

Previous research tells us that doing a job supporting people with an Intellectual Disability (ID) can be positive in lots of ways, but that there are often challenges. Many nurses and health care assistants (HCAs) work with patient behaviours that are dangerous or where it is difficult to know how to help the person who is upset.

Positive Behaviour Support (PBS) is a set of ideas that guides nurses, HCAs, therapists and managers to help patients to feel happier and improve their quality of life. Unfortunately, there are often things which get in the way of PBS being successful in these aims.

This project used interviews with nurses and HCAs to find out what it is like to support patients day-to-day. A useful way of understanding the six people's responses, called Interpretative Phenomenological Analysis, was used, which led to three main ideas:

1. Staff liking patients and wanting the best for them helped staff to enjoy their jobs more. They also felt sad when patients felt sad.

2. Staff talked about times when their job was frustrating or scary. At those times it gets harder to work as a team. Some staff liked that they could do a good job and turn things around, even when things had been difficult.

3. Staff wished they had more time to do extra little things that make a big difference. Sometimes staff wanted other people to notice all their hard work more. Most staff felt that PBS could work more successfully with continued effort and teamwork.

A list of suggestions was made for how to address these findings and to make improvements to help staff and patients. The list will be shared with the ward leadership team so that they can talk about the suggestions and make a plan for making changes. This project shows that it is important to see how things are for staff on the ward so that PBS can work well for staff and patients.

"Then [patients are] upset and then obviously it makes us upset."

"I love that they're happy to see you."

"They're the heart of our service the patients."

Following Your Heart

"I can see him- because he- he- head bangs, he self-harms, when I come and then he stops... I don't know, I can't describe that feeling I have with me (laughs) you know I just feel like yes, it's working, everything you're doing- can't stop, you have to continue doing it you know."

"What're we going to do when he goes because we've all worked with him for such a long time..."

"Being gentle and kind does not mean that you are not doing your job properly."

"You have to *be* PBS."

"We're just not working together and it's just- it's already hard as it is you know so it makes it even harder."

"Sometimes you don't even get time to deal with your emotions, you're sort of just thrown into the deep end."

It's Really Tough – You Have to be Strong

"Sometimes even when you talk PBS-language approach you know nobody really understands you- you're actually sort of like dividing the team."

"If new staff come in and they haven't read the care plan quickly or in detail then they'll just do anything for an easy shift but that doesn't always work because like it might be easy for that that short period of time but then when the next person comes in and does it the way it's meant to be done, yeah then it becomes a challenge then."

"If it's been a really tough day but it's gone really well I then go out with that buzz."

"We tell [colleagues] what [PBS] means and try and break it down as much as we want but actually- and then you hear them say "oh but there's no consequence"- I just wish there was more time to explain."

"I was brought in, I was the only a person that works direct with them, senior nurses, managers, I was the only person which I'd consider as the low- lowest person in terms of position but I I did have- put a lot of feedback because we spend more time with the patients."

Just out of Reach –Small Things That Make a Big Difference.

"We'd be able to talk to more about [patients'] hygiene and just those things which you might think are smaller but actually make a big difference."

"It just seems like you're a number or you're a name on their list and you're not recognised for what you are on the ward."

"You'll be on a like 14-hour shift and you forget to drink water, it's so bad (laughs)."

"It's a work in progress um but it's taking every day at a time because- it's just time and yeah... yeah it's been tricky yeah…."

The three superordinate themes capture an array of challenges and benefits experienced by these nurses and HCAs. Ideas about patient support were readily associated with PBS and the themes had apparent links to what might help and hinder effective PBS.

Theme one: 'Following Your Heart' recognises how participants' emotional connections with patients fostered more meaningful engagement with their work and rewarded dutiful efforts with playful and warm moments. Simultaneously, the stronger the bond, the more upsetting it could be for staff when setbacks are experienced.

Theme two: 'It's Really Tough – You Have to be Strong' addresses participants' efforts to convey the enormity of managing dynamic clinical risk with a sub-optimal sense of cohesion within the team. Nevertheless, meeting challenges head-on could be motivating for some participants and offer a heightened sense of accomplishment.

Theme three: 'Just out of Reach – the Small Things that Make a Big Difference' encapsulates participants' awareness of the preciousness of time and how the prospect of improving team practices could be achieved in relatively little time but which seemingly cannot be provided. Despite some participants alluding to a perceived gulf between their work and senior stakeholders, at ward level there was cautious optimism for the future.

PBS was a salient topic for these nurses and HCAs who discussed various barriers and facilitators that influence the potential of PBS to improve patients' quality of life. In relation to the three experiential superordinate themes generated, the following recommendations are made to improve staff confidence and investment in PBS:

Related Themes	**Recommendations**
All themes	Recruitment of a dedicated PBS Lead responsible for implementing, monitoring and evaluating PBS, in accordance with recent evidence.
Following Your Heart	Continuing efforts to seek and maximise the value of opportunities for patients to provide feedback on and contribute to PBS processes. This is supported by recent PBS guidance and likely to resonate with the values of the participants in this SIP.

Following Your Heart	Ensuring that staff emotional responses to developing relationships with patients are on the agenda in relevant forums, e.g., supervision and team meetings. Discussion facilitators should focus on eliciting and valuing open and honest feedback about emotional responses triggered in staff by perceived closeness with or rejections from patients.
It's Really Tough – You Have to be Strong	Identify and target efforts to increase PBS knowledge and buy-in towards team members with low affiliation or motivation to adopt PBS. Recognise and formulate resistance to adopting PBS. Increasing the knowledge and skills of such team members will likely indirectly support team members who are more familiar and supportive of PBS and foster group affiliations to the PBS approach.
It's Really Tough – You Have to be Strong	Address differences of approaches adopted across members of ward team by promoting tangible benefits of PBS and pointing out unproductive consequences of theoretically incompatible practices. This should be supported by the use of objective measures that connect meaningfully with team members demonstrating resistance. Measures should also connect to shared goals that foster a teamwide unity of purpose.
Just out of Reach – the Small Things That Make a Big Difference	SLT to act as a bridge to provide opportunities to increase visibility and mutual understanding between members of the ward team and leadership figures beyond the direct ward management team. This may be achieved through enabling greater representation of ward team members at relevant meetings and drawing from research and guidelines regarding practice leadership.
Just out of Reach – the Small Things That Make a Big Difference	Identify and ringfence time resource for ward-based staff to engage in discussion and innovation regarding PBS. There is likely value in using existing knowledge within the team to offer peer-learning and coaching, under appropriate supervision. This may be achieved through the commissioning of additional resource, informed by emerging practice-based evidence regarding PBS, and/or through redeployment of existing staff resource. For example, there may be opportunities to maximise existing staff resource through creative matching of tasks that relate to personal professional values and/or dynamically matching patient and staff personalities and interests.
Just out of Reach – the Small Things That Make a Big Difference	Engaging with national and international initiatives related to the procurement and retention of ward-based staff.

Further information about the project methodology and discussion of the findings in relation to existing literature can be found in the full report which has been shared with Julia Kelly.

Approval for this service improvement project was granted at the [redacted] Forensic & Specialist Clinical Governance Meeting, August 2022.

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Thank you very much to all of the staff who took part in or helped with completing this project.

Appendix J: Instructions to authors (Journal of Applied Research in Intellectual Disabilities)

JARID Author Guidelines

Sections

1. Submission
2. Aims and Scope
3. Manuscript Categories and Requirements
4. Preparing the Submission
5. Editorial Policies and Ethical Considerations
6. Author Licensing
7. Publication Process After Acceptance
8. Post Publication
9. Editorial Office Contact Details

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In order for a paper to be considered for publication, it must be about people with intellectual disabilities. Manuscripts which focus upon autism will be considered only when the focus is also upon intellectual disabilities. Papers which focus upon autism and exclude people with intellectual disabilities will not be considered.

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Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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We have consulted with over 40 self-advocates through Learning Disability England which included the North West Self-Advocacy Group, as well as Self-Advocacy Together and asked them what language we should use when writing about people with intellectual disabilities.

People with intellectual disabilities said that they do not like to be referred to by acronyms or abbreviations. Authors must therefore not use an abbreviation to describe intellectual disabilities such as “ID” or “LD”. Instead, use person-first language such as children, teenagers, adults, or people with intellectual disabilities, avoiding acronyms or abbreviations.

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All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. We kindly request that authors place the abstract and title at the beginning of the main manuscript document.

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Been involved in drafting the manuscript or revising it critically for important intellectual content; and

Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; and

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Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section (for example, to recognize contributions from people who provided technical help, collation of data, writing assistance, acquisition of funding, or a department chairperson who provided general support). Prior to submitting the article all authors should agree on the order in which their names will be listed in the manuscript.

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• The corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

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9. EDITORIAL OFFICE CONTACT DETAILS

For queries about submissions, please contact the *JARID* Editorial Office.
jarid.office@wiley.com

Author Guidelines Updated January 2024

Appendix K: Study recruitment poster

Oxford Institute of Clinical Psychology Training and Research
Primary Researcher: James Dennis, Trainee Clinical Psychologist
james.dennis@stx.ox.ac.uk

Holding on to Support

Ethics Approval Reference: R86617/RE001

Do you offer support to someone with OCD or hoarding difficulties?
Can you support this research study?



We are looking for volunteers, aged 30+ years old, to answer a survey about offering support to individuals with Obsessive Compulsive Disorder (OCD) and/or hoarding difficulties.

The person being offered support does not need to have a formal diagnosis of OCD and/or hoarding difficulties. The person may be accepting the support you are offering or not.

To take part, you must know the person with OCD and/or hoarding difficulties well, e.g., a family member or friend you have known for a number of years. The person must also be aged 30+ years old. You and the person being offered support must live in the UK.

Learning more about offering support to these individuals will help mental health services to plan more effective treatments and consider how best to involve those who support them.

You are invited to participate in an online study. The questions will take about 30 minutes of your time.

If you are interested and would like more information, please contact James Dennis at the Oxford Institute of Clinical Psychology Training and Research by email: james.dennis@stx.ac.ox.uk. There is no obligation to take part.

To take part , **click the link in the caption**: (https://oxicptr.web.ox.ac.uk/help-our-research)

Thank you!

Poster advert, version 1.2, July 2023

Appendix L: Study information sheet

Oxford Institute of Clinical Psychology Training and Research
Principal Investigator (Project supervisor): Paul Salkovskis, Professor of Clinical Psychology, Department of Experimental Psychology, University of Oxford paul.salkovskis@hmc.ox.ac.uk

Primary Researcher: James Dennis, Trainee Clinical Psychologist
james.dennis@stx.ox.ac.uk

Holding on to Support

CUREC Approval Reference: R86617/RE001

General Information

Hoarding difficulties and Obsessive Compulsive Disorder (OCD) affect many people and can cause upset and danger for the person. Research suggests that people with these problems are also at risk of becoming disconnected from their friends and family.

This study will survey people who offer support to people with hoarding difficulties and OCD. The questions will ask about the help and support they give, or try to give. This will help us to understand any differences in how people with hoarding difficulties and OCD are offered support. Knowing this will help plan more effective treatments and how best to involve those who support them.

We appreciate your interest in participating in this questionnaire. You have been invited to participate as you are 30 years of age or above and you offer support to somebody with hoarding difficulties and/or OCD that you have a personal connection to (e.g., a family member or friend you have known for a number of years?). The person with hoarding difficulties and/or OCD should also be 30 years of age or above.

Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

You may ask any questions before deciding to take part by contacting the researcher (details below).

The Primary Researcher is James Dennis (Trainee Clinical Psychologist, The Oxford Institute of Clinical Psychology Training and Research). This project is being completed under the supervision of Prof Paul Salkovskis (Professor of Clinical Psychology, Department of Experimental Psychology), and Dr Kate Rosen (Consultant Clinical Psychologist, Oxford Cognitive Therapy Centre and OHSPIC).

You will be asked to respond to a number of questions, most of which have multiple options. It is important that you try to answer all of the questions. This should take about 30 minutes. No specialist background knowledge is required.

Do I have to take part?

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button/ closing the browser.

How will my data be used?

We will not collect any data that could directly identify you. Your IP address will not be stored.

The responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications, conference presentations, reports for external organisations, websites, videos. Research data will be stored for three years after publication or public release of the work of the research.

The results will be written up for a DClin Psych degree.

Who has reviewed this study?

This project has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee [R86617/RE001].

Who do I contact if I have a concern or I wish to complain?

If you have a concern about any aspect of this study, please speak to James Dennis (james.dennis@stx.ox.ac.uk) or their supervisor Paul Salkovskis, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

Please note that you may only participate in this survey if:

- You are 30 years of age or over.
- You live in the UK.
- You offer support to somebody with hoarding difficulties and/or OCD that you have a personal connection to, e.g., a family member or friend you have known for a number of years.
- The person you offer support to is 30 years of age or over.
- The person you offer support to lives in the UK.
- You agree: to take part in this study; to your responses being included in a dataset that shall be analysed and written up as part of a doctoral thesis; and academic journal publication.

If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please click the link to start. <link>

Appendix M: Ethical approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Professor Paul Salkovskis & James Dennis
Oxford Institute for Clinical Psychology Training
(OxICPTR)
Isis Education Centre
Warneford Hospital
Oxford

4 July 2023

Dear Professor Salkovskis and James,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R86617/RE001

Study title: "It's not my Mess": How do Supporters of Individuals with Hoarding Difficulties Rate the Quality of the Support they Offer?

Short title: Holding on to Support

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 5th July 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 N: Paper Survey Form

Please note: The paper form was not requested for use by any respondents. The items are equivalent to those included in the online Qualtrics survey.

Oxford Institute of Clinical Psychology Training and Research
Principal Investigator (Project supervisor): Paul Salkovskis, Professor of Clinical Psychology, Department of Experimental Psychology, University of Oxford

Primary Researcher: James Dennis, Trainee Clinical Psychologist
james.dennis@stx.ox.ac.uk

Holding on to Support

CUREC Approval Reference: R86617/RE001

Please note that you may only participate in this survey if:

- You are 30 years of age or over.
- You live in the UK.
- You offer support to somebody with hoarding difficulties and/or OCD that you have a personal connection to, e.g., a family member or friend you have known for a number of years.
- The person you offer support to is 30 years of age or over.
- The person you offer support to lives in the UK.
- You agree: to take part in this study; to your responses being included in a dataset that shall be analysed and written up as part of a doctoral thesis; and academic journal publication.

If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please tick the box below to start.

☐Yes, I have read the criteria and information sheet and I wish to take part

☐No, I do not wish to take part

Demographics

The following questions relate to **the person that you offer support to**

- Can you confirm that the person lives in the UK?
  - ☐ Yes

- Obsessive compulsive disorder (OCD) is a mental health condition where a person has obsessive thoughts and compulsive behaviours.

  Obsessive compulsive disorder (OCD) affects people differently, but usually causes a particular pattern of thoughts and behaviours.

  An obsession is an unwanted and unpleasant thought, image or urge that repeatedly enters your mind, causing feelings of anxiety, disgust or unease. A compulsion is a repetitive behaviour or mental act that you feel you need to do to temporarily relieve the unpleasant feelings brought on by the obsessive thought.

  NHS (2023) *Obsessive compulsive disorder (OCD)* (https://www.nhs.uk/mental-health/conditions/obsessive-compulsive-disorder-ocd/)

  Does the person you offer support to have OCD?
  - ☐ Yes
  - ☐ No

- A hoarding disorder is where someone acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter. The items can be of little or no monetary value.

  Hoarding is considered a significant problem if: the amount of clutter interferes with everyday living – for example, the person is unable to use their kitchen or bathroom and cannot access rooms the clutter is causing significant distress or negatively affecting the quality of life of the person or their family – for example, they become upset if someone tries to clear the clutter and their relationship suffers

  NHS (2022) *Hoarding Disorder* (https://www.nhs.uk/mental-health/conditions/hoarding-disorder/)

  Does the person you offer support to have hoarding disorder?
  - ☐ Yes
  - ☐ No

- If the person has both OCD and hoarding disorder, which condition would you consider to be their main 'problem'?
  - ☐ Hoarding Disorder
  - ☐ Obsessive Compulsive Disorder

- As far as you can tell, does the person you offer support to consider *themselves* to have any of these conditions?
  - ☐ Hoarding Disorder
  - ☐ Obsessive Compulsive Disorder
  - ☐ Does not consider themselves to have either condition

- If the person you offer support to considers themselves to have both OCD and hoarding disorder, which condition do *they* consider to be their main 'problem'?
  - ☐ Hoarding Disorder
  - ☐ Obsessive Compulsive Disorder

- Does the person have a formal diagnosis?
  - ☐ Hoarding Disorder
  - ☐ Obsessive Compulsive Disorder
  - ☐ Hoarding Disorder and OCD
  - ☐ No formal diagnosis of Hoarding Disorder nor Obsessive Compulsive Disorder

- How many years ago did the person first have symptoms of OCD and/or hoarding difficulties?

  - ☐ ……

- To the best of your knowledge, has the person ever sought help for their condition?
  - ☐ Yes
  - ☐ No

- What is their age? (in years)

  - ☐ ……

- What is their gender identity?
  - ☐ Woman
  - ☐ Man
  - ☐ Non-binary
  - ☐ Transgender
  - ☐ Other
  - ☐ Prefer not to say

- What is their ethnicity?
  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 Background:

- What is the person's marital status?
  - ☐ Single
  - ☐ Married or in a civil partnership
  - ☐ Cohabiting
  - ☐ Divorced or separated
  - ☐ Widowed

- What is the person's employment status?
  - ☐ Employed full-time
  - ☐ Employed part-time
  - ☐ Unemployed
  - ☐ Retired
  - ☐ Volunteering

- What is their highest level of formal education?
  - ☐ No formal Qualification
  - ☐ GCSEs/GNVQs/Scottish Standard
  - ☐ A-Levels/BTEC/Scottish Higher
  - ☐ Apprenticeship
  - ☐ Graduate Degree (e.g. BA, BSc)
  - ☐ Higher Degree (e.g. MA, MSc, PGCE)
  - ☐ Doctorate (e.g. PhD, EdD)
  - ☐ Prefer not to say

The following questions are about **you**

- Can you confirm that you live in the UK?
  - ☐ Yes

- What is your age? (in years)

  - ☐ ……

- What is your gender identity?
  - ☐ Woman
  - ☐ Man
  - ☐ Non-binary
  - ☐ Transgender
  - ☐ Other
  - ☐ Prefer not to say

- What is your ethnicity?
  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 Background:

- What is your marital status?
  - ☐ Single
  - ☐ Married or in a civil partnership
  - ☐ Cohabiting
  - ☐ Divorced or separated
  - ☐ Widowed

- What is your employment status?
  - ☐ Employed full-time
  - ☐ Employed part-time
  - ☐ Unemployed
  - ☐ Retired
  - ☐ Volunteering

- What is your highest level of formal education?
  - ☐ No formal Qualification
  - ☐ GCSEs/GNVQs/Scottish Standard
  - ☐ A-Levels/BTEC/Scottish Higher
  - ☐ Apprenticeship
  - ☐ Graduate Degree (e.g. BA, BSc)
  - ☐ Higher Degree (e.g. MA, MSc, PGCE)
  - ☐ Doctorate (e.g. PhD, EdD)
  - ☐ Prefer not to say

- What is your relationship to the person you offer support?
  - ☐ Spouse or partner
  - ☐ Significant other
  - ☐ Family member or relative
  - ☐ Neighbour
  - ☐ Friend
  - ☐ Work associate
  - ☐ Health care provider
  - ☐ Counsellor or therapist
  - ☐ Minister/Priest/Rabbi/Imam
  - ☐ Other

- If 'other', please specify your relationship with the person you offer support.

  ☐ …….

- Have you, or are you currently, living with the person with OCD and/or hoarding difficulties?
  - ☐ Currently, for more than 10 years
  - ☐ Currently, for less than 10 years
  - ☐ Previously, for more than 10 years
  - ☐ Previously, for less than 10 years
  - ☐ Never lived together

Measures

Adapted Work and Social Adjustment Scale

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives.

To rate the impact of the person's problem (hoarding difficulties OR OCD) look at each section and determine on the scale provided how much the problem impairs their ability to carry out the activity.

Please rate the responses on behalf of the person that you offer support to.

1) Because of their problem their ability to work is impaired. '0' means 'not at all impaired' and '8' means very severely impaired to the point they can't work. If the person is retired or chooses not to have a job for reasons unrelated to their problem, do not select an option below, and tick here: ☐

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

2) Because of their problem their home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

3) Because of their problem their social leisure activities (with other people e.g. parties, bars, clubs, outings, visits, dating, home entertaining) are impaired.

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

4) Because of their problem, their private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

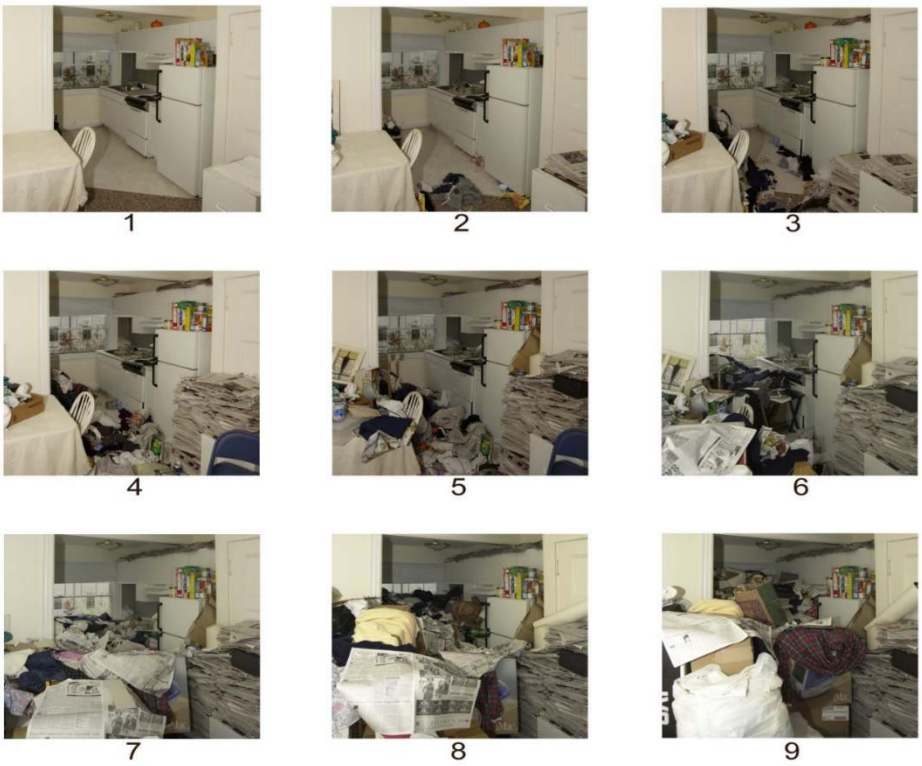
5) Because of their problem, their ability to form and maintain close relationships with others, including those they live with, is impaired.

0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

Clutter Images Rating Scale

Kitchen

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



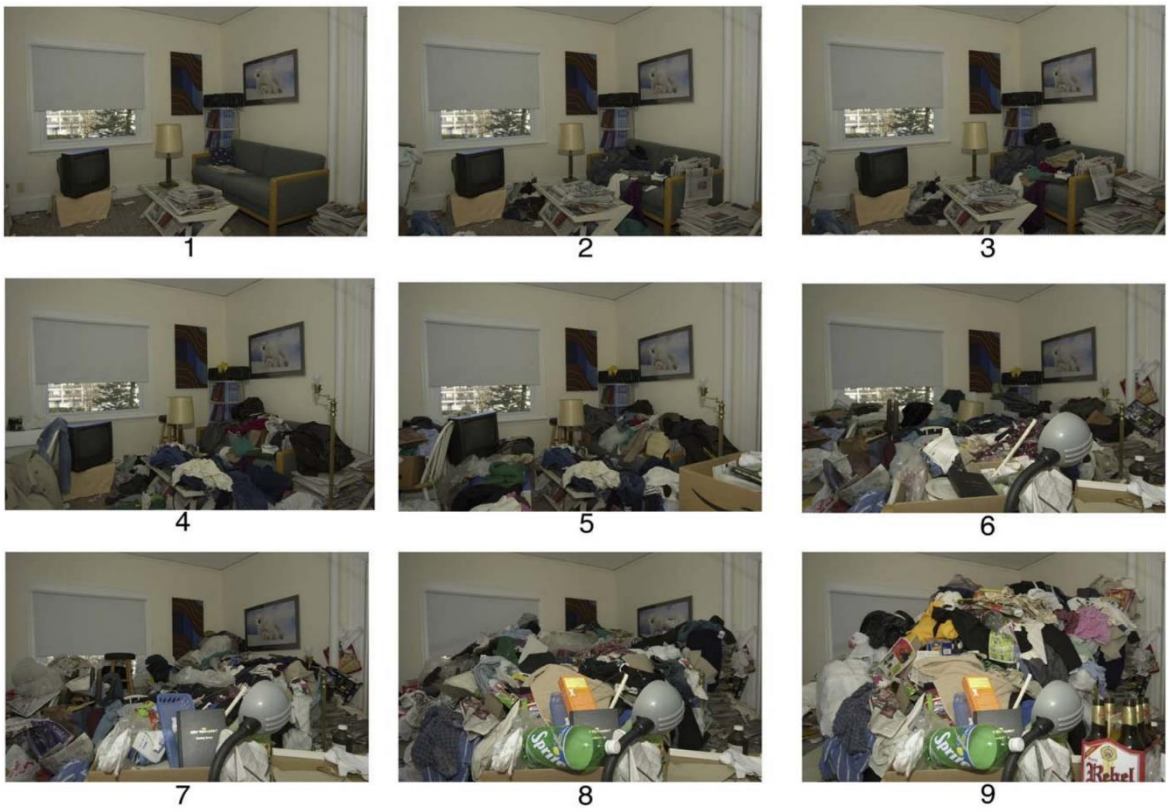
Bedroom

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



Living room

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



Proxy Revised Norbeck Social Support Questionnaire

- In years, how long have you known this person?

  ☐ ……

- How frequently do you usually attempt to make contact with this person via phone call/letter/email/social media?
  - ☐ Daily
  - ☐ Weekly
  - ☐ Monthly
  - ☐ A few times a year
  - ☐ Once a year or less

- How often does the person usually respond?
  - ☐ Every time
  - ☐ Most of the time
  - ☐ Half the time or more
  - ☐ Less than half the time
  - ☐ Rarely or never

- How frequently does the person usually attempt to make contact with you via phone call/letter/email/social media?
  - ☐ Daily
  - ☐ Weekly
  - ☐ Monthly
  - ☐ A few times a year
  - ☐ Once a year or less

- How often do you usually respond?
  - ☐ Every time
  - ☐ Most of the time
  - ☐ Half the time or more
  - ☐ Less than half the time
  - ☐ Rarely or never

- How frequently do you usually see this person face-to-face at your home or in a public place?
  - ☐ Daily
  - ☐ Weekly
  - ☐ Monthly
  - ☐ A few times a year
  - ☐ Once a year or less

- How frequently do you usually see this person in their home?
  - ☐ Daily
  - ☐ Weekly
  - ☐ Monthly
  - ☐ A few times a year
  - ☐ Once a year or less

- When was your most recent contact with this person?
  - ☐ Yesterday
  - ☐ Last week
  - ☐ Last month
  - ☐ In the last year
  - ☐ More than a year ago

	Not at all	**A little**	**Moderately**	**Quite a bit**	**A great deal**
How much do you try to make the person feel liked or loved?					
How much do you actually make this person feel liked or loved?					
How much do you try to make this person feel respected or admired?					
How much do you actually make this person feel respected or admired?					
How open are you to this person confiding in you?					
How much does the person confide in you?					
How much do you agree with or support this person's actions or thoughts regarding over acquiring and keeping possessions and/or obsessional and compulsive problems?					
How much do you agree with or support this person's actions or thoughts (other than matters regarding over acquiring and keeping possessions					

and/or obsessional and compulsive problems)?					

	Not at all	**A little**	**Moderately**	**Quite a bit**	**A great deal**
How available are you to help and support the person to do what they need to do?					
How much does the person accept help and support from you with doing what they need to do?					
How available are you to help and support the person meet their basic needs?					
How much does the person accept help and support from you with meeting their basic needs?					
If the person needed help and support for several weeks, how available could you be to help this person?					
How much would the person accept help and support from you if you offered this for several weeks?					
If the person needed help and support in an emergency, how available could you usually be?					
How much would the person accept help and support from you in an emergency?					

	Not at all	**A little**	**Moderately**	**Quite a bit**	**A great deal**
How warmly does the person respond to your efforts to help and support them?					
Is the person grateful of your efforts to help and support them?					
Does the person recognise the effort you put into helping and supporting them?					
Is the person welcoming of your help and support?					
Does the person reject your help and support?					
How pointless does it feel to offer help and support to the person?					
How confident are you that you are offering the right kind of help and support to the person?					
Does the help and support you offer to the person make a difference?					

	Not at all	**A little**	**Moderately**	**Quite a bit**	**A great deal**
How frustrated do you feel when offering help and support to the person?					
How often do you snap at the person when offering help and support?					
How satisfied are you that you do your best to help and support to the person?					
Do you feel hopeless about offering help and support to the person?					
Do you get angry with the person when offering help and support?					
Do you find helping and supporting the person rewarding?					
Do you feel resentful towards the person that you help and support?					
Do you feel guilty about not offering enough help and support to the person?					

	Not at all	**A little**	**Moderately**	**Quite a bit**	**A great deal**
How much does this person make you feel liked or loved?					
How much does this person make you feel respected or admired?					
How much can you confide in this person?					
How much does this person agree with or support your actions or thoughts (other than matters regarding over acquiring and keeping possessions and/or obsessional and compulsive problems)?					
If you needed immediate help, how much could this person usually help?					
If you needed help for several weeks, how much could this person help you?					

Community Attitudes Toward the Mentally Ill Scale

The following statements express various opinions about **Obsessive Compulsive Disorder** and the people who have this condition.

Please indicate the response which most accurately describes your reaction to each statement. It's your first reaction which is important. Don't be concerned if some statements seem similar to ones you have previously answered. Please be sure to answer all statements.

	Agree Strongly	**Agree Slightly**	**Neither Agree nor disagree**	**Disagree Slightly**	**Disagree Strongly**
One of the main causes of OCD is a lack of self- discipline and will-power					
Virtually anyone can develop OCD					
People with OCD have for too long been the subject of ridicule					
We need to adopt a far more tolerant attitude toward people with OCD in our society					
We have a responsibility to provide the best possible care for people with OCD					
People with OCD don't deserve our sympathy					
There are sufficient existing services for people with OCD					
I would not want to live next door to someone who has OCD					
No-one has the right to exclude people with OCD from their neighbourhood					
The best therapy for many people with OCD is to be part of a normal community					

Community Attitudes Toward the Mentally Ill Scale

The following statements express various opinions about **hoarding difficulties** and the people who have this condition.

Please indicate the response which most accurately describes your reaction to each statement. It's your first reaction which is important. Don't be concerned if some statements seem similar to ones you have previously answered. Please be sure to answer all statements.

	Agree Strongly	**Agree Slightly**	**Neither Agree nor disagree**	**Disagree Slightly**	**Disagree Strongly**
One of the main causes of hoarding difficulties is a lack of self- discipline and will-power					
Virtually anyone can develop hoarding difficulties					
People with hoarding difficulties have for too long been the subject of ridicule					
We need to adopt a far more tolerant attitude toward people with hoarding difficulties in our society					
We have a responsibility to provide the best possible care for people with hoarding difficulties					
People with hoarding difficulties don't deserve our sympathy					
There are sufficient existing services for people with hoarding difficulties					
I would not want to live next door to someone who has hoarding difficulties					
No-one has the right to exclude people with hoarding difficulties from their neighbourhood					
The best therapy for many people with hoarding difficulties is to be part of a normal community					

Affiliate Stigma Scale

Below are some sentences related to your own experience of having a close personal connection to somebody with OCD/Hoarding difficulties. We are asking how your being connected to the person you offer support to impacts you. There are no right or wrong answers. Please read each sentence carefully then choose the option which best represents your opinion.

	Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
I feel inferior because I have a close personal connection to them.	①	②	③	④
I avoid communicating with them.	①	②	③	④
Other people would discriminate against me if I was with them.	①	②	③	④
I feel emotionally disturbed because I have a close personal connection to them.	①	②	③	④
I do not dare to tell others that I have a close personal connection to them.	①	②	③	④
My reputation is damaged because I have a close personal connection to them.	①	②	③	④
Their behaviour is embarrassing.	①	②	③	④
I avoid going out with them.	①	②	③	④
People's attitudes towards me are negative when I am with them.	①	②	③	④
I feel helpless about having a close personal connection to them.	①	②	③	④
I reduce contact with my friends and relatives because I have a close personal connection to them.	①	②	③	④
Having a close personal connection to them has a negative impact on me.	①	②	③	④
I feel sad because I have a close personal connection to them.	①	②	③	④

	Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
When I am with them, I keep a relatively low profile.	①	②	③	④
Having a close personal connection to them makes me think that I am incompetent compared to other people.	①	②	③	④
I worry that other people will find out I have a close personal connection to them.	①	②	③	④
I reduce interacting with them.	①	②	③	④
Having a close personal connection to them makes me think that I am less than others.	①	②	③	④
I feel that I am under great pressure because I have a close personal connection to them.	①	②	③	④
I do not dare to participate in activities related to mental health lest other people suspect I have a close personal connection to them.	①	②	③	④
Having close personal connection to them makes me lose face.	①	②	③	④
I reduce contact with my neighbours because I have a close personal connection to them.	①	②	③	④

Burden Scale for Family Caregivers

We are asking you for information about times when you are offering support to your family member or friend or close personal connection. The following statements often refer to the type of your assistance. Please indicate the best description for how things are when you are offering support.

	Strongly agree	**Agree**	**Disagree**	**Strongly disagree**
My life satisfaction has suffered because of offering support.				
From time to time I wish I could "run away" from the situation I am in.				
Sometimes I feel that the person I am offering support to is using me.				
It's easy for me offering support.				
The support I offer is acknowledged by the person I support.				
The support I offer is acknowledged by others.				
I feel like I am being forced into offering support.				
The wishes of the person I am offering support to are reasonable in my opinion.				
I have had to give up plans because of offering support.				
Offering support takes a lot of my own strength.				
I feel torn between the demands of my environment (such as family) and the demands of offering support.				
I feel I have a good relationship with the person I am offering support to.				

I have problems with other family members due to offering support.				
I am worried about my future because of the support I offer.				
I feel sad because of the fate of the person I am offering support to.				
I can take care of other daily obligations to my satisfaction in addition to offering support.				

Free text

Would you like to write anything about your experience of offering support to somebody with OCD and/or hoarding difficulties? Please ensure your answer fits into the box below. If you do not wish to write anything, please enter 'N/a'.

We thank you for your time spent taking this survey.

This study aims to better understand the support that is being offered to people with hoarding difficulties and OCD. Finding out more about this will help plan more effective treatments and how best to involve those who support them.

We know that it can be difficult to offer support to somebody with these conditions.

If you would like to find out more information about OCD, please see this helpful website: https://ocdaction.org.uk/ OCD Action also offer group support sessions via Zoom for parents or partners of people with OCD, more details about this can be found on the website.

If you would like to find out more information about hoarding difficulties, please see this helpful website: https://hoardinguk.org/ Hoarding UK also provides information about support groups for people with hoarding difficulties and some tips for how family members can support them, more details about this can be found on the website.

Once the study has been completed, information about the findings will be made available via the OXICPTR website.

Appendix O: P-NSSQ-R Items and Scoring Guide

Adapting Norbeck for carer self-report

- Relationship
    - What is your relationship to the person?
        1. Spouse or partner
        2. Significant other
        3. Family member or relative
        4. Neighbour
        5. Friend
        6. Work associate
        7. Health care provider
        8. Counsellor or therapist
        9. Minister/Priest/Rabbi/Imam
        10. Other (please specify…)
    - How long have you known this person (remove Likert, use full range)

- Contact items (**all are reverse coded**)
    - 1) How frequently do you usually attempt to make contact with this person via phone call/letter/email/social media? (4 = daily/3 = weekly/2 = monthly/1 = A few times a year/0 = once a year or less)
    - 2) How often does the person usually respond? (4 = every time/3 = most of the time/2 = half the time or more/1 = less than half the time/0 = rarely or never)
    - 3) How frequently does the person usually attempt to make contact with you via phone call/letter/email/social media? (4 = daily/3 = weekly/2 = monthly/1 = A few times a year/0 = once a year or less)
    - 4) How often do you usually respond? (4 = every time/3 = most of the time/2 = half the time or more/1 = less than half the time/0 = rarely or never)
    - 5) How frequently do you usually see this person face-to-face at your home or in a public place? (4 = daily/3 = weekly/2 = monthly/1 = A few times a year/0 = once a year or less)
    - 6) How frequently do you usually see this person in their home? (4 = daily/3 = weekly/2 = monthly/1 = A few times a year/0 = once a year or less)
    - 7) When was your most recent contact with this person? (4 = yesterday/3 = last week/2 = last month/1 = A few times a year/0 = once a year or less)

Following items 5-point Likert: 0 = not at all/1 = a little/2 = moderately/3 = quite a bit/4 = a great deal

Reversed items in **bold**

- Emotional support

    - Affect
        - How much do you try to make the person feel liked or loved?
        - How much do you actually make this person feel liked or loved?
        - How much do you try to make this person feel respected or admired?
        - How much do you actually make this person feel respected or admired?
    - Affirmation
        5. How open are you to this person confiding in you?
        6. How much does the person confide in you?
        7. **How much do you agree with or support this person's actions or thoughts regarding over acquiring and keeping possessions and/or obsessional and compulsive problems?**
        8. How much do you agree with or support this person's actions or thoughts (other than matters regarding over acquiring and keeping possessions and/or obsessional and compulsive problems)?

- Tangible support
    - Routine support
        - How available are you to help and support the person to do what they need to do?
        - How much does the person accept help and support from you with doing what they need to do?
        - How available are you to help and support the person meet their basic needs?
        - How much does the person accept help and support from you with meeting their basic needs?
    - Additional support
        5. If the person needed help and support for several weeks, how available could you be to help this person?
        6. How much would the person accept help and support from you if you offered this for several weeks?
        7. If the person needed help and support in an emergency, how available could you usually be?
        8. How much would the person accept help and support from you in an emergency?

- Perceived effectiveness
    - PWC response
        - How warmly does the person respond to your efforts to help and support them?
        - Is the person grateful of your efforts to help and support them?
        - Does the person recognise the effort you put into helping and supporting them?
        - Is the person welcoming of your help and support?
        - **Does the person reject your help and support?**

        - **How pointless does it feel to offer help and support to the person?**
        - How confident are you that you are offering the right kind of help and support to the person?
        - Does the help and support you offer to the person make a difference?
    - POS response
        9. **How frustrated do you feel when offering help and support to the person?**
        10. **How often do you snap at the person when offering help and support?**
        11. How satisfied are you that you do your best to help and support to the person?
        12. **Do you feel hopeless about offering help and support to the person?**
        13. **Do you get angry with the person when offering help and support?**
        14. Do you find helping and supporting the person rewarding?
        15. **Do you feel resentful towards the person that you help and support?**
        16. **Do you feel guilty about not offering enough help and support to the person?**

- Reciprocity (POS rating of support from PWC in turn)
    - Emotional support
        1. How much does this person make you feel liked or loved?
        2. How much does this person make you feel respected or admired?
        3. How much can you confide in this person?
        4. How much does this person agree with or support your actions or thoughts (other than matters regarding over acquiring and keeping possessions and/or obsessional and compulsive problems)?
    - Tangible support
        5. If you needed immediate help, how much could this person usually help?
        6. If you needed help for several weeks, how much could this person help you?

<u>Calculating subscales</u>

Wish to support = sum of 8 items:

- Emotional support items 1, 3, 5
- Tangible support items 1, 3, 5, 7
- Perceived effectiveness item 11

Perceived success of support = sum of 13 items:

- Emotional support items 2, 4, 6

- Tangible support items 2, 4, 6, 8
- Perceived effectiveness items 1-5, 8

Impact of support on POS = sum of 9 items:

- Perceived effectiveness items 6, 7, 9, 10, 12-16

Contact = sum of 7 contact items

Reciprocity = sum of 6 reciprocity items

Appendix P: Instructions to Authors (British Journal of Clinical Psychology)

AUTHOR GUIDELINES

Sections

Submission

Aims and Scope

Manuscript Categories and Requirements

Preparing the Submission

Editorial Policies and Ethical Considerations

Author Licensing

Publication Process After Acceptance

Post Publication

Editorial Office Contact Details

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

New submissions should be made via the Research Exchange submission portal. You may check the status of your submission at any time by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

All papers published in the *British Journal of Clinical Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

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.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The *British Journal of Clinical Psychology* publishes original research, both empirical and theoretical, on all aspects of clinical psychology:

clinical and abnormal psychology featuring descriptive or experimental studies

aetiology, assessment and treatment of the whole range of psychological disorders irrespective of age group and setting

biological influences on individual behaviour

studies of psychological interventions and treatment on individuals, dyads, families and groups

For specific submission requirements, read the Author Guidelines.

The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

The following types of paper are invited:

papers reporting original empirical investigations;

theoretical papers, provided that these are sufficiently related to empirical data;

review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;

Brief Reports and Comments.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Papers describing quantitative research should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.

In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

Refer to the separate guidelines for Registered Reports.

All systematic reviews must be pre-registered and an anonymous link to the pre-registration must be provided in the main document, so that it is available to reviewers. Systematic reviews without pre-registration details will be returned to the authors at submission.

4. PREPARING THE SUBMISSION

Free Format Submission

British Journal of Clinical Psychology now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer (If you do submit separate files, we encourage you to also include your figures within the main document to make it easier for editors and reviewers to read your manuscript, but this is not compulsory). All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.

The title page of the manuscript, including a data availability statement and your co-author details with affiliations. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)* You may like to use this template for your title page.

Important: the journal operates a double-anonymous peer review policy. Anonymise your manuscript and prepare a separate title page containing author details. *(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)*

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.)*

To submit, login at https://wiley.atyponrex.com/journal/BJC and create a new submission. Follow the submission steps as required and submit the manuscript.

If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page

You may like to use this template for your title page. The title page should contain:

A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);

A short running title of less than 40 characters;

The full names of the authors;

The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Abstract;

Keywords

Data availability statement (see Data Sharing and Data Accessibility Policy);

Acknowledgments.

Author Contributions

For all articles, the journal mandates the CRediT (Contribution Roles Taxonomy)—more information is available on our Author Services site.

Abstract

Please provide a structured abstract under the headings: Objectives, Methods, Results, Conclusions. For Articles, the abstract should not exceed 250 words. For Brief Reports, abstracts should not exceed 120 words.

Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

Keywords

Provide appropriate keywords.

Acknowledgments

Contributions from anyone who does 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.

Practitioner Points

All articles must include Practitioner Points – these are 2-4 bullet points, following the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.

Main Text File

As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors.
Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTex (.tex) format.

If submitting your manuscript file in LaTex format via Research Exchange, select the file designation "Main Document – LaTeX .tex File" on upload. When submitting a LaTex Main Document, you must also provide a PDF version of the manuscript for Peer Review. Please upload this file as "Main Document - LaTeX PDF." All supporting files that are referred to in the LaTex Main Document should be uploaded as a "LaTeX Supplementary File."

LaTex Guidelines for Post-Acceptance:

Please check that you have supplied the following files for typesetting post-acceptance:

PDF of the finalized source manuscript files compiled without any errors.

The LaTeX source code files (text, figure captions, and tables, preferably in a single file), BibTex files (if used), any associated packages/files along with all other files needed for compiling without any errors. This is particularly important if authors have used any LaTeX style or class files, bibliography files (.bbl, .bst. .blg) or packages apart from those used in the NJD LaTex Template class file.

Electronic graphics files for the illustrations in Encapsulated PostScript (EPS), PDF or TIFF format. Authors are requested not to create figures using LaTeX codes.

Your main document file should include:

A short informative title containing the major key words. The title should not contain abbreviations;

Abstract structured (objectives/methods/results/conclusions);

Up to seven keywords;

Practitioner Points: Authors will need to provide no more than 2-4 bullet points, written with the practitioner in mind, that summarize the key messages of their paper to be published with their article;

Main body: formatted as introduction, materials & methods, results, discussion, conclusion;

References;

Tables (each table complete with title and footnotes);

Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below).

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors. Do not mention the authors' names or affiliations and always refer to any previous work in the third person.

The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

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.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, 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. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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.

Basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

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.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association. The following points provide general advice on formatting and style.

Language: Authors must avoid the use of sexist or any other discriminatory language.

Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Units of measurement: Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.

Effect size: In normal circumstances, effect size should be incorporated.

Numbers: numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available here. In particular, we encourage authors to consult Wiley's best practice tips on Writing for Search Engine Optimization.

Article Preparation Support: Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence.

Also, check out our resources for Preparing Your Article for general guidance and the BPS Publish with Impact infographic for advice on optimizing your article for search engines.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

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Except where otherwise stated, the journal operates a policy of anonymous (double-anonymous) peer review. Please ensure that any information which may reveal author identity is anonymized in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, read the terms and conditions of submission and the declaration of competing interests.

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Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards.

We also encourage authors to refer to and follow guidelines from:

Future of Research Communications and e-Scholarship (FORCE11)

The Gold Standard Publication Checklist from Hooijmans and colleagues

FAIRsharing website

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The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: https://www.crossref.org/services/funder-registry/

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Appendix Q: P-NSSQ-R pilot and reliability analysis

Internal consistency of the P-NSSQ-R subscales related to the main hypothesis was checked at an initial pilot phase. Seven responses from POS(OCD) and five from POS(HD) were analysed and Cronbach's alpha ranged from good to excellent, with the removal of any single item not producing an improved rating for any of the scales (wish to support α=.73, perceived support success α=.90, impact of support on POS α=.84). These respondents were invited to provide feedback on the survey and consequently two standard inverted NSSQ items were omitted from subsequent analyses on the basis that multiple respondents found the items confusing ('how much do you agree with or support this person's actions or thoughts regarding over acquiring and keeping possessions and/or obsessional and compulsive problems?' and 'how much do you agree with or support this person's actions or thoughts (other than matters regarding over acquiring and keeping possessions and/or obsessional and compulsive problems)?'). Internal consistency was re-checked and was maintained or improved in the full sample (wish to support α=.83, perceived support success α=.94, impact of support on POS α=.83).

Due to using abridged versions for the original scales, the internal consistency was also checked for the CAMI (OCD α=.66, HD α=.71) and BSFC (α=.89), indicating acceptable to good reliability. Internal consistency for the ASS was rated as excellent (α=.95).