



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Quality Of Life In Older Autistic Adults: A Scoping Review; 2) Exploring the efficacy of a UK university-based counselling service using CORE-OM outcome data and service-user feedback; 3) "I feel like pieces of me are missing now": An Exploration into Experiences of Non-Diagnosis of Autism using Interpretative Phenomenological Analysis.

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Research Portfolio

Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

Literature Review: Quality Of Life In Older Autistic Adults: A Scoping Review

Service-related Project: Exploring the efficacy of a UK university-based counselling service using CORE-OM outcome data and service-user feedback.

Main Research Project: "I feel like pieces of me are missing now": An Exploration into Experiences of Non-Diagnosis of Autism using Interpretative Phenomenological Analysis.

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May 2024

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Candidate's
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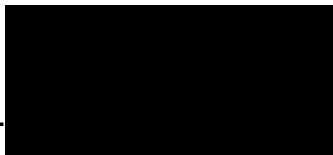


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Declaration of authorship

I am the author of this portfolio, and the work described therein was carried out by myself personally, with oversight and support from Dr Cathy Randle-Phillips.

Candidate's
signature.....



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Literature review: 6,643

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Abstracts

Literature Review:

Quality Of Life In Older Autistic Adults: A Scoping Review

Background

Consistent research has shown that autistic individuals have lower quality of life (QoL) when compared to neurotypical people. Studies involving older autistic adults are known to be very limited, and existing reviews have not exclusively focused on papers including only the oldest groups. This has made it difficult to know what factors influence the QoL of older autistic people.

Methods

By systematically searching the existing literature on a number of databases including published and grey literature, this scoping review aimed to summarise the current evidence base on the QoL of older autistic people, scoping the current knowledge and gaps in literature. After systematic screening by two researchers, eleven studies were included in the final review. Data was extracted and charted. A numerical description of the studies is provided, followed by a descriptive account of the main findings. Quality appraisal of the included studies was also undertaken.

Results

Consistently, older autistic people are shown to have lower quality of life than neurotypical people. Additionally, this review found that older autistics appear to have higher QoL than younger autistic people, especially in social domains. Research on the predictors of QoL in older people is very limited, as many studies include broader aged samples rather than stratification. However, this review found that comorbid mental health and perceived stress are predictors of QoL in older autistic adults.

Conclusion

Future research should include longitudinal methods to gain a more nuanced understanding of the age-related changes which influence fluctuating QoL in autism over the lifespan. Further qualitative research exploring the meaning and definition of QoL for older autistic people would also be of value. Future research should also investigate the impact of intersectionality on QoL for autistic older people, such as gender and ethnicity.

Service-Related Project:**Exploring the efficacy of a UK university-based counselling service using CORE-OM outcome data and service-user feedback.**

Mental health problems in students are becoming more prevalent, creating increased demand on university counselling services. COVID-19 may have contributed to this rise, whilst also placing universities in financial insecurity. Therefore, it is an important time to review the efficacy of mental health services with university settings, in line with guidance from university regulators. This study used routinely collected pre and post therapy CORE-OM scores, as well as routinely collected service user feedback from students who had completed therapy with an in-house university counselling service. Approximately 50% of the sample achieved reliable improvement in CORE-OM scores, which is consistent with similar research, and meets the key performance indicators which guide NHS improving access to psychological therapies services. Feedback from students highlighted how valued in-house counselling services are, and that overwhelmingly, students desired more sessions with their therapists. This study provides evidence of the effectiveness and value of university-based counselling services.

Keywords: Student mental health, therapy outcomes, student feedback, university mental health services.

Main Research Project:**"I feel like pieces of me are missing now": An Exploration into Experiences of Non-Diagnosis of Autism using Interpretative Phenomenological Analysis.**

Receiving a diagnosis of autism in adulthood can be a positive experience, validating previous concerns, and providing an improved sense of self-understanding. We do not currently have a sufficient understanding of the experience of having an autism assessment and being told you do not meet diagnostic criteria. This project explored 10 adults' experience of non-diagnosis of autism. Interpretative phenomenological analysis was used to gain an in-depth understanding of the participants' experience. Four overarching themes with 10 sub themes were identified: pre-diagnostic experiences and beliefs, experiences of assessment, impact, and influences on self-concept. Results suggest that non-diagnosis of autism can be a distressing, invalidating and destabilising experience for someone who has built autism into their personal identity and

views the diagnosis positively. For others who have not integrated it into their identity, and may view autism more negatively, it can be validating to not receive the diagnosis. This study replicated previous research about impact of diagnosis and late diagnosis. The specific contribution of this study is explored, alongside future recommendations for research and clinical implications.

Keywords: Autism, Diagnosis, Non-Diagnosis, Self-Identity, Social-Identity

Literature Review

Quality Of Life In Older Autistic Adults: A Scoping Review

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May 2024

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The target journal for my literature review project was Autism in Adulthood The guidance on journal formatting requirements is here:

<https://home.liebertpub.com/publications/autism-in-adulthood/646/for-authors>

This journal is chosen as it aims to publish academic literature focused on autism in adulthood and later life, including systematic scoping reviews. The editorial board includes autistic people, who are involved in the peer review process.

Background

Quality of life (QoL) is a term employed in scientific literature which describes a person's satisfaction with life (Van Heijst and Geurts (2015). Assessing QoL involves consideration of a broad and complex range of life circumstances and environmental factors, which can be difficult to define. It is therefore unsurprising that multiple conceptualisations of QoL have been used in the literature (Theofilou, 2013). Commonly, QoL is used interchangeably with subjective wellbeing and life satisfaction, often with overlapping or encompassing definitions (Theofilou, 2013). It has been proposed that wellbeing involves objective life conditions that can apply to a population more generally, whereas QoL involves the subjective cognitive and affective assessment of these life conditions (Diener et al., 1999). These definitions were defined some time ago (Smith, 1973), and more recent calls have been made to return to these definitions, or reach a consensus in the literature. In this review, our understanding of QoL is in line with the suggestion from Smith (1973) and based upon the World Health Organizations (WHO) definition of QoL; 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (WHO, 1998).

Autism is a neurodevelopmental disorder which is widely accepted as a heterogeneous condition (Masi et al., 2017). Since its original conception by Kanner (1943), there have been multiple iterations of diagnostic definition. Research has shown multiple aetiologies and developmental trajectories leading to wide acceptance of the term autism spectrum disorder (ASD). In the latest version of the international classification of diseases (ICD-11), ASD is classified by persistent difficulties with social interaction and communication, with restricted, repetitive and inflexible behaviours, interests and activities (World Health Organization, 2022). These factors often become evident and are diagnosed in childhood when typical developmental milestones are late (Brett et al., 2016). Increasingly, people are diagnosed later in adult life due to improved public awareness of autism and service availability (De Broize et al., 2022). In a population based cohort study, there was a 787% increase in autism prevalence between 1998 to 2018, with the greatest rise in incidence among adults (Russell et al., 2022), and yet as of 2016, only 2%-10% of all funding for priority research areas (in US, UK, Canada and Australia) was focused on lifespan issues in autism (Office of Autism Research Coordination. et al., 2016). Historically, autism was thought to be more prevalent in males (Baron-Cohen, 2002), however with

improved understanding of the female autistic phenotype (Cruz et al., 2024) increasing numbers of adult women are being diagnosed (Cook et al., 2024).

Older autistic adults are frequently defined as those over 50 years of age in the literature (Mason, Stewart, et al., 2022; Tse et al., 2022). Research about the QoL of older OAA is vital for driving interventions and services (Mason et al., 2018). However the research is yet to catch up to need, and to the authors knowledge there have been no reviews of QoL in OAA. There is also a dearth of literature regarding OAA more generally (Mason, Stewart, et al., 2022). The term 'lost generation' (Lai & Baron-Cohen, 2015) has been applied to a generation of adults who grew up before the growth in research and public awareness of autism.

Autistic adults aged eighteen to eighty-three report lower than average QoL when compared to neurotypical samples (Ayres et al., 2018; Mason et al., 2018). Social functioning appears to be the most impacted domain of QoL (Van Heijst & Geurts, 2015), and autistic people (aged 9-40) were found to report fewer friends and lower QoL with regard to relationships when compared to neurotypical controls. This may be unsurprising given the diagnostic criteria. However, in a validation study of a well-used QoL measure, Mason, Rodgers, et al. (2022) found that some of the social items were interpreted differently by autistic adults (aged 18-80 years), for example when asked about satisfaction with support from friends, autistic people said that 'support' is not a function they value or would request from a friend. Therefore QoL measures had poor psychometric properties in the social domain.

Due to these differences in interpretation McConachie et al. (2018) developed a 9-item autism specific add-on to the measure, the ASQoL to be used alongside the 13-item disability module of the World Health Organisation QoL scale brief version (WHOQOL-BREF). This was developed through a Delphi survey and cognitive interviews with autistic people. It was found that existing measures did not include aspects such as sensory difficulties. The agreed items relate to sensory overload, friendships, barriers to service access and autistic identity. Another measure, the Patient-Reported Outcomes Measurement Information System Global-10 (PROMIS global-10) has been validated for use with autistic adults, and normed data is available based upon a validation study with 901 autistic adults (Williams et al., 2023). This measure includes items assessing health, general QoL, physical health, mental health, social functioning, emotional distress, fatigue and pain. Which measures are being applied to OAA is unknown.

Autistic adults are at increased risk of mental health difficulties (Croen et al., 2015), including anxiety and depression (Lai et al., 2019), are less likely to be in paid employment (Bush & Tassé, 2017), experience barriers in healthcare (Sidhu & Greene, 2023) alongside increased risk of adverse health outcomes (Croen et al., 2015) and premature mortality (Hirvikoski et al., 2016). The National Institute for Health and Care Excellence (NICE) guidelines indicate that interventions for behaviours that challenge should aim to improve QoL (National Institute for Health and Care Excellence, 2014). Whilst QoL is clearly an overall goal of the interventions, this recommendation does not speak to the societal level disparities which may impact the QoL of autistic people. Botha and Frost (2020) explored minority stressors which contribute to health disparities, and their impact on mental health. Minority stressors can be defined as life experiences of a group by means of their minority status, such as discrimination, internalized stigma, and concealment. These minority stressors were found to significantly predict poorer mental health in autistic adults (mean age of 35). It is therefore likely that minority stressors also predict poorer QoL in autism as they are shown to have an additive negative impact on health (Botha & Frost, 2020).

Some predictors of QoL have been explored in autistic adults. A UK based study including 370 autistic adults with a mean age of forty-one found that being employed, receiving support and being in a relationship were positively correlated with QoL (Mason et al., 2018). Poorer quality of life was associated with having a mental health condition and higher social communication difficulties. In terms of the influence of age, a meta-analysis found no relationship between age and QoL in autistic samples, but reviewers commented that this is likely due to a lack of representation from older individuals (Van Heijst & Geurts, 2015). There was a maximum mean age of 40 in the studies included in the review. This indicates a stark lack of understanding of QoL in OAA who are more likely to be exposed to some of the predictors identified by Mason et al. (2018).

International empirical studies have shown a curvilinear relationship between age and wellbeing in non-autistic samples, with highest scores at a younger age, moving into the lowest scores around 40 years of age, rising again into later life. It has also been suggested that this rise peaks in the late sixties, and declines thereafter (Layte et al., 2013). This curvilinear relationship is likely influenced by multiple overlapping factors, such as changes in employment status, marital status, wealth and health status accompanied by life transitions such as retirement (Layte et al., 2013; Webb et al., 2011). As already discussed, there is not one single predictor of QoL, and for the general population, research

has suggested that marital status, social contact, relationships, socioeconomic status and health all influence QoL at older ages (Webb et al., 2011). There are issues related to the measurement of QoL for older non-autistic people, with some arguing that traditional measures of QoL overestimate the impact of poor health and underestimate the positive aspects of ageing (Wiggins et al., 2004). Specific QoL measures have been developed for older people (Netuveli et al., 2006), but it is unclear whether these have been applied to autistic populations.

In 2012, a review concluded that ageing-related outcomes for autistic individuals were largely unknown (Perkins & Berkman, 2012). A narrative review on ageing in autism in 2020 also highlighted the lack of studies specifically focused on the older population. Although many of the samples included OAA, they remained under-represented (Wise, 2020). An even more recent review found that only 0.4% of all published autism research in the past decade has focused on the older adult population (Mason, Stewart, et al., 2022).

The most recent systematic review by Tse et al. (2022) looked at literature regarding characteristics of OAA across six domains, including QoL. This study included papers up to May 2020 which focused on autism, and where participants were 50 years or above, or when age was used as a predictor of the outcome. A limitation of this review is that there may have been very few participants over 50, and authors comment that this was not always transparent in the included papers, making it hard to understand the importance of their findings for OAA specifically.

The current review aimed to explore QoL in OAA. This review expanded its search beyond the Tse et al. (2022) review to include additional databases and grey literature. With an ageing population (Jarman, 2022) this review was deemed timely and aimed to map and synthesize current evidence. The main aims of the research are as follows:

1. What does the research tell us about QoL for OAA (50+)? How does this compare to QoL for typically developing older adults?
2. Which measures of QoL are being used with OAA?

Additionally, the research aims to summarise any known predictors of QoL for OAA where this information is available, as well as highlighting key gaps in the current evidence base for QoL in OAA.

Methods

The scoping review was based upon the aforementioned research questions, and followed guidance from the framework for scoping reviews (Arksey & O'Malley, 2005), the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) (appendix D) (Tricco et al., 2018) and the Joanna Briggs Institute (JBI) Reviewer's Manual (Peters et al., 2020). The protocol was initially registered on PROSPERO (CRD42023408728) as a systematic review protocol, however, when the authors familiarised themselves with the breadth and scope of the literature, scoping review methodology was deemed more appropriate.

Eligibility criteria

The review included both published and grey literature due to the limited scope of current literature. The following criteria were used:

1. Studies including autistic participants over the age of 50 (or studies which include participants from age 18+ who have stratified their results to show outcomes for those over 50 years of age).
2. Studies which have included a quantitative measure of QoL (including self-report, informant, observation)
3. Studies which are published or available in English language.

Articles were excluded if they focused on the QoL of children or adolescents, were review articles or where the full text was not available.

Defining older age and aging within autism literature has been a topic of discussion, and agreements from the International Society for Autism Research (INSAR) were summarised by Roestorf et al. (2019). It was suggested that research on aging in autism should focus on individuals over 50 years of age due to research on premature death in ASD, co-occurring medical conditions and cognitive ageing being evident from around 50 years of age. Additionally, as discussed by Sonido et al. (2020), the World Health Organisation (WHO) defines an older person as those who have lived beyond their median life expectancy at birth, and the median life expectancy for autistic people (as per the most robust current evidence) was 55 years of age, and for low functioning autism, 40, and 63 for high functioning autism (Hirvikoski et al., 2016). Further, previous meta-analyses have used a cut off score of 50, as longitudinal studies of autism in

adulthood have an upper age limit of 50 (Tse et al., 2022; Van Heijst & Geurts, 2015). The age cut off of 50 was therefore agreed.

Search Strategy

A search strategy was developed based upon the research question and familiarisation with the existing literature, as recommended by (Arksey & O'Malley, 2005). As authors were aware that research would be limited, publication year was not restricted. Published literature was searched for with the following databases: PsycINFO, PsycARTICLES, PubMed, Web of Science core collection, Embase and CINAHL. Grey literature was sourced from EThOS and APA PsycExtra. Search strategies were developed in consultation with librarians with specialist knowledge on each database. The search strategies employed Boolean operators and truncation such as 'Autis*' and 'AND' to combine key criteria for the review. Relevant terms for ASD included 'autis*', 'asperger*', 'neurodevelopmental disorder'. QoL terms included 'QoL', 'life quality' and 'QoL'. Finally, to search for older age research, the following terms were applied, 'elder' 'older', 'later life', 'ageing'. We searched within the title, abstract and keywords on each of the databases (full searches for each database in appendix A.), with the exception of CINAHL where only abstracts were able to be searched.

Study Selection

Articles were reviewed using Covidence which is a web-based collaboration software platform that streamlines the production of reviews (Veritas Health Innovation, n.d.). Articles from each database were imported into Covidence, and duplicates removed automatically. Two reviewers completed a title and abstract screening of all papers to remove ineligible results as per eligibility criteria. Agreement rate on titles and abstracts was 91%, Cohen's Kappa 0.58, which can be described as moderate. During a consensus process, many of these disagreements were in relation to establishing if the papers had stratified their outcomes by age. Reviewers decided to include all articles which focused on QoL in autistic adults where it was not clear if the results had been stratified by age, as to not erroneously exclude relevant papers. The main author also went back through all abstracts to ensure no papers were erroneously included or excluded on this basis. The full texts were then reviewed by two reviewers, and discrepancies were resolved on a consensus basis. All of the articles were reviewed in full to establish whether there were QoL findings which had been stratified by age group. Where this was not the case, or where this was

unclear from the article, these articles were excluded. Full text agreement was 80% (Cohen's Kappa 0.50, moderate), and all disagreements were discussed in a consensus process and successfully resolved.

Data Extraction

Data from the included studies was then extracted by one reviewer and checked by a second reviewer (Robson et al., 2019). A data charting form was developed by authors based upon the research question (appendix B), as recommended by (Arksey & O'Malley, 2005). The first author charted the following data presented in table 1.

Table 1.

Charted Data

Item	Information Extracted
1	Key information about the paper; reference, title, journal, year, authors, country.
2	Aims and research questions.
3	Sample information and demographics (setting, presence of control group, diagnostic confirmation methods for ASD and whether comorbidity was considered)
5	Method (including design, procedure, recruitment, analysis methods)
6	QoL measure employed by the research (self-report or informant)
7	Key findings related to QoL and predictors of QoL (if available) and author interpretations.
8	Limitations suggested by study authors.

Critical Appraisal

Formal appraisal of studies is not typical within scoping reviews (Arksey & O'Malley, 2005). However, it was deemed important to summarise the methodological drawbacks of the current research base in order to inform future research. The Mixed Methods Appraisal Tool (Hong et al., 2019; Pluye et al., 2011) (appendix C) was chosen as it is designed for the appraisal stage of reviews which include studies a wide variety of methodological approaches. The tool includes questions enabling authors to review the quality of randomised-

controlled trials, non-randomised studies, quantitative descriptive studies, qualitative studies, and mixed methods studies. All studies were appraised by the author and a second reviewer. No studies were excluded from the review based on the appraisal.

Data Analysis

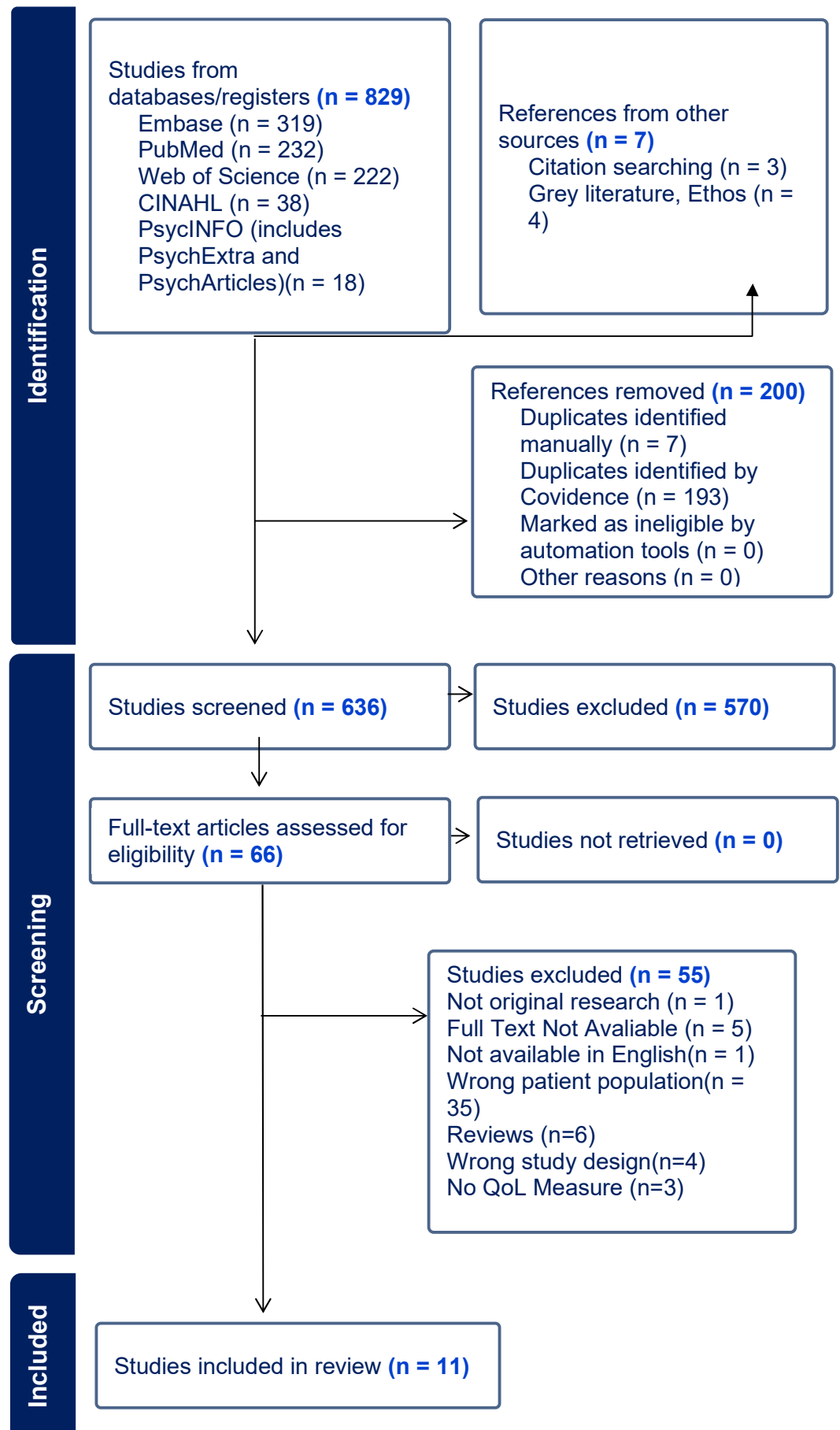
In line with the guidance for scoping reviews, the characteristics of the data are described. This focused on summarising the themes from the research on QoL in OAA, in line with the study aims. Authors firstly present a descriptive numerical summary of the included studies (Arksey & O'Malley, 2005) from the data charting process, followed by a descriptive account of the main findings of the studies and the quality appraisal.

Researcher Positionality

The main researcher identifies as white-British, cis-gendered, female and neurotypical. The researcher has developed a strong interest in the lived experiences of autistic adults which has developed throughout their career in both academia and clinical practice. The interest in the intersection of autism and older age developed whilst working in older adult and learning disability settings and noticing a stark lack of clinical guidance for working with older autistic people.

Figure 1.

PRISMA flowchart showing selection of studies for scoping review.



Results

Descriptive Numerical Summary

In total, 11 of the 829 studies identified by the searches fulfilled the study criteria (see figure 1.) Table 2 presents the key characteristic of the included studies, which were published between 2010 and 2023. 9 studies were cross sectional designs which looked at QoL in OAA at a specific time point. One study was longitudinal as it included a two-year follow-up period (Roestorf, 2018). Another study was a case report of a group intervention (Groenendijk et al., 2023). Sample sizes (including only the participants over 50) ranged from 9 (Groenendijk et al., 2023) to 282 (Totsika et al., 2010), making a combined sample size of 860. Only three of the studies included participants over 50 exclusively (Groenendijk et al., 2023; Mason et al., 2019; Van Heijst & Geurts, 2015), with the remainder including all adult samples from ages 18 to 90. The mean age of samples ranged from 30 (Khanna et al., 2014) to 65 (Groenendijk et al., 2023). For studies which reported stratified older age groups, the mean age ranged from 54 (Charlton et al., 2022) to 66 (Charlton et al., 2022). As expected, there was a predominance of male participants.

Only three of the eleven studies reported the ethnicity of their samples (Charlton et al., 2022; Khanna et al., 2014; McQuaid et al., 2022), which happened to be the studies generated in the USA which had predominantly white samples, for example 83.7% (McQuaid et al., 2022) and 80.1% (Khanna et al., 2014) The remainder of the papers were based in the UK (Mason et al., 2019; Mason et al., 2018; Roestorf, 2018; Roestorf et al., 2022; Totsika et al., 2010; Van Heijst & Geurts, 2015; Yarar et al., 2022) and one in the Netherlands (Groenendijk et al., 2023).

Predominantly studies included participants with higher intellectual level. Of the studies which reported intelligence quotient scores (Roestorf, 2018; Roestorf et al., 2022; Van Heijst & Geurts, 2015; Yarar et al., 2022), intellectual level ranged from average to above average. Seven of the studies did not include people with Intellectual Disabilities (ID) (Charlton et al., 2022; Khanna et al., 2014; McQuaid et al., 2022; Roestorf, 2018; Roestorf et al., 2022; Van Heijst & Geurts, 2015; Yarar et al., 2022), and one had a specific criteria for an intelligence quotient of over 70 (Yarar et al., 2022). Two studies did not report whether they had anyone with ID included in the study (Groenendijk et al., 2023; Mason et al., 2018), although Mason et al. (2018) reported their sample was unlikely to include people with lower intellectual ability as the sample was able to self-report. One paper included just one participant with ID (Mason et al., 2019).

Finally, one study was entirely based upon people with ID and autism (Totsika et al., 2010).

Most of the studies relied on existing clinical diagnoses of autism, which was self-reported in four studies (Charlton et al., 2022; Mason et al., 2019; Mason et al., 2018; McQuaid et al., 2022), or confirmed by diagnostic reports in two (Roestorf, 2018; Roestorf et al., 2022). In three studies, the autism quotient (AQ-28) or Social Responsiveness Scale (SRS) was used to confirm autism (Charlton et al., 2022; Mason et al., 2018; Van Heijst & Geurts, 2015). Two studies relied upon self-reported diagnoses but used additional measures to rate the severity of autism symptoms (Khanna et al., 2014; Yazar et al., 2022). Groenendijk et al. (2023) reported that their sample had a diagnosis from a specialist team, with no further details provided. In the sample of people with ID, the disability assessment schedule (DAS) was used to confirm problems with the triad of impairments (as diagnostic criteria was at the time) (Totsika et al., 2010).

Quality of life measures

Eight studies used the WHOQOL-BREF, which has been shown to have good reliability and validity with autistic people (Charlton et al., 2022; Groenendijk et al., 2023; Mason et al., 2019; Mason et al., 2018; McQuaid et al., 2022; Roestorf, 2018; Roestorf et al., 2022; Yazar et al., 2022). Two of these studies used the autism addition to the disability module (Charlton et al., 2022; McQuaid et al., 2022), the ASQoL (McConachie et al., 2018). One study used the ASQoL without the disability module of the WHOQOL (Charlton et al., 2022), which is not the recommended administration of the measure (McConachie et al., 2018).

Some studies utilised measures which have not been validated for autistic people. For example, the Personal Wellbeing Index (PWI) was used alongside the WHOQOL-BREF (Roestorf et al., 2022). Totsika et al. (2010) used measures validated only for people with intellectual disability including the Index of Participation in Domestic Life (IDPL) and the Index of Community Activities (ICI), as well as observational assessments of levels of activity engagement and levels of staff attention in a two hour period (Totsika et al., 2010). The RAND-36 is a health-related QoL measure used by (Van Heijst & Geurts, 2015), which has not been validated in autistic samples.

Table 2*Characteristics of the included studies (n=11)*

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
Khanna et al. (2014)	USA	Cross sectional	White - 233 (80.1) Other - 58 (19.9)	Whole Sample : 61% Male, 39.2% Female	No	18-68 (30.76)	HRQOL	No significant difference in MCS score was observed between the autism without comorbid mental health group and US population norms.	Significant difference between mental component score of the HRQOL between the study sample and US population norms in age group 55-64, but not between the physical component scores. No other differences observed.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
Groene ndijk et al. (2023)	The Netherlands	Case Series	NR	Whole Sample	Yes	56-73 (65)	WHOQoL-BREF	NA	Study did not find evidence of efficacy of the psychoeducational group. QoL included as an outcome measure. Reliable change indicators showed that improvements in environmental QoL were found in 5/9 participants, social QoL improved for 3/9, psychological QoL 2/9 and 0/9 improvement for Physical QoL.
Roestorf et al. (2022)	UK	Longitudinal	NR	T1 Older Group,	No	19-80 (44.1)	WHOQoL-BREF (T1 and T2) & PWI	NS	The sample were below average population means on the PWI and WHOQL. Overall QoL was significantly higher in the older group in this study. Indicating better QoL for OAA compared to

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
				22.6% Female)		age = 58.6			<p>younger. Psychological and social QoL was higher for the older group.</p> <p>PWI: subjective wellbeing higher in the older group</p> <p>Both younger and older groups reported low degree of support received for the everyday needs. Indicators of SWB were related to lack of personal relationships, feeling isolated, lack of achievement and concerns about health and future.</p> <p>Standard of living and feeling safe (safety) were amongst the highest SWB indicators.</p>
(Charlton et al)	USA	cross sectional	Latinx 26 Not Latinx - 356 Unknown 6	Total sample: 388	No	40-83 Groups :	WHOQoL-BREF and the ASQOL	NS	Age correlated significantly with Psychological and Environmental QoL

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
al., 2022)				(41.5% male, 71.4% female)		50-59 (54.33)			with better QoL being associated with older age:
				**		60+ group (66.47)			A significant age-group difference was observed only for the mean score for the Psychological WHOQOL-BREF subscale, with the older (60+ group scoring significantly higher than the 40-49 group).
				Age Group: 43.2% male, 56.8% female					Social support was significantly associated with each aspect of QoL when age was controlled for, meaning that this is the same effect in older adults.
						60+ Group:			

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
				53.7% male, 46.3% female.					
(Mason et al., 2018)	UK	cross sectional	NR	Whole sample: 53.8% Male, 42.7% Female , Other/r ather not	No	17-78 (41.681)	WHOQo L-BREF	Predictors were not stratified	Physical QoL does not appear to differ across all the age groups. Marginal differences found here. Psychological QoL does not appear to change significantly. Social QoL appears to decline with increasing age and is lowest for the 61+ group.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
					say/not reported, 3.5%.				Environmental appears to drop at the mid and increase (inverted U shape). The older group did not have significantly different QoL scores, in any domain, to any of the other groups in the study (17-25, 26.40, 41-60)
(Mason et al., 2019)	UK	cross sectional	NR	Whole Sample	Yes	NR (61.5)	WHOQoL-BREF	QoL scores higher, across all domains for those in normal range for anxiety and depression, apart from social domain	The majority of the sample scored 1 SD below the norm group on Physical (56.5%) , Psychological (75.4%) and Social QoL (62.3%), but most scored within one SD on environmental QoL (56.5%). Significant overall effect of depression and anxiety on QoL.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
								where there were no group (clinical caseness vs normal range) differences. Those who met caseness for both and anxiety and depression had significantly lower QoL scores than	Significant effect of depression on each domain of QoL. Significant effect of anxiety on physical, psychological, and environmental domains. QoL scores were not significantly different according to participation in normative outcomes.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
								those who met caseness for anxiety or depression.	
(Totsika et al., 2010)	UK	cross sectional	NR	Whole Sample : 52.7% Male, 47.3% Female	No, younger matched comparison group	18-90 (44.5) Over 50 group (59.1)	IPDL, ICI, Activity Engagement, Staff Attention	Higher adaptive functioning explained the differences between the QoL measures in the ASD group and the ASD absent group. Would suggest that	The variance in QoL measures were explained by adaptive skills, rather than presence or absence of ASD in over 50s. When comparing the older ASD group to the younger ASD group, there was no difference in the QoL measures, apart from the younger group receiving more staff attention.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
				Male, 43.7% Female				those with higher adaptive functioning had better QoL scores	No significant differences in the QoL measures between the younger and older groups, apart from more behaviour problems in the younger group, higher clinical caseness in the younger group and the younger group
(McQuaid et al., 2022)	USA	cross sectional	Latinx 63 (8.9%) Not Latinx 634 (89.5%) Unknown 11 (1.6%) Race: Asian: 9 (1.3%)	Whole Sample : 40.7% Male, 59.3% female	No	18.17-83.33 (38.47)	WHOQoL-BREF and the ASQOL	Perceived Stress was higher in the 55-64 and 65+ groups., and across all ages.	Higher perceived stress was linked with lower QoL across all domains.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
			Black/African-American: 15 (2.1%) More than one race: 70 (9.8%) Native American/Alaska Native: 8 (1.1%) White: 594 (83.7%) Other: 14 (2.0%)						
(Van Heijst & Geurts,	The Netherlands	cross sectional	NR	Whole Sample	Yes : 79.2%	53-83 (63.7)	RAND-36	Age, IQ, and symptom	Autism group had lower QoL than TD group. No effect of increasing age found. Appears to be about individual factors.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
2015) (Study 2)		w control group.		Male, 20.8% Female					severity did not predict QoL.
(Yarar et al., 2022)	UK	cross sectional w control group.	NR	Whole Sample : NR Older autism group: 41 (78% male, 22% female)	No	21-71 (44.96) Older Group: 50-71 (57.88)	WHOQoL-BREF	No difference in the proportions of younger and older autistic groups meeting cut off for mental health problems. Older groups reported	All mean scores on the WHOQOL are higher in the ASD older group compared to the younger ASD group, but overall lower than the control group. In the autism group, older adults reported significantly better social QoL than younger autism group.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
								significantly less anxiety and somatoform disorders. No difference in depression or alcohol abuse.	
(Roestorf, 2018)	UK	Cross-sectional w control group.	NR	Younger	No	23-80 (47.34)	WHOQoL-BREF	For oASD adults, none of the self-reported or objective measures of PM were predictors of	Regarding QoL, there were no age-related differences on QoL domains within each Diagnostic Group, except for Social-QoL which was significantly better for oASD compared to yASD, but significantly poorer for oTA compared to yTA adults.

Author and Year	Country	Design	Ethnicity	Gender	Sample 50+ (Y/N)	Age Range (mean)	QoL Tool Used	Relationship between predictors and QoL	Main Findings related to 50+
								Older Group: 76.5% male, 23.5% female.	either Overall QoL. PM did not predict QoL in the same way in ageing and ASD as it did in typical ageing. Poorer QoL for ASD compared to TA adults.

Note: PCS , physical component score; MCS, mental component score; NR, not reported; NS, Not Stratified by Age; TD, Typically Developing; PM, Prospective Memory

HRQOL: Health related QoL / WHOQOL-BREF: World health organisation QoL measure brief version.

PWI : personal wellbeing Index

IDPI: Index of participation in Domestic Life

ICI: Index of Community Activities

SWB: Subjective Wellbeing Being

*Approximate scores as data only available from a graph

** As reported

QoL of OAA compared to neurotypical older adults.

Overall, the studies found that QoL was consistently lower in OAA compared to older non-autistic people. Health related QoL was lower in people with ASD compared to US national norms of the same age group, but only on the mental component of the HRQoL, not the physical component (Khanna et al., 2014). Similarly, health related QoL was lower in OAA compared to matched controls as measured by the RAND-36 (Van Heijst & Geurts, 2015). In studies which used the WHOQOL-BREF, a consistent finding was that OAA had lower QoL scores when compared to population norms (Mason et al., 2019; Roestorf et al., 2022), and when compared to neurotypical matched controls (Roestorf, 2018; Yarar et al., 2022). Some domains appeared to differ more with Mason et al. (2019) finding that autistic people scored one standard deviation (SD) below the normative values on the on physical, psychological and social domains, but within one SD on the environmental domain (Mason et al., 2019).

QoL For Older Autistic Adults Compared To Autistic Younger Adults

Studies also compared QoL in OAA with younger autistic adults. Roestorf et al. (2022) found that the older group in their study had significantly higher overall QoL scores on the WHOQOL, and for the subscale scores both psychological and social QoL was significantly higher for the older group. They used another measure of wellbeing, the Personal Wellbeing Index (Khor et al., 2020), which similarly demonstrated higher subjective wellbeing in the older group, but no difference in global life satisfaction. Similarly, Yarar et al. (2022) found no significant difference in overall QoL scores, but the older group scored significantly higher on the social relationship domain compared to younger autistic adults, whereas controls showed no effect of age on this domain. No other domains showed effects of age. This same finding was replicated by Roestorf (2018) who found social QoL was significantly higher for the older group, compared to the younger group, which was the opposite correlation in typically developing adults in the study. They did not find any other differences in age groups on other domains of the WHOQOL (Roestorf, 2018). Mason et al. (2018) found no significant differences in any of the WHOQOL-BREF domains between the older group (60+) and any of the younger age groups.

Another study only found a significant effect of age in the psychological domain of the WHOQOL-BREF when comparing 60+, to the 40-49 group (Charlton et al., 2022). This would suggest that differences in QoL between

younger and OAA may be domain specific, rather than global, often with older adults having better perceived social relationships and psychological QoL.

In a sample of people with ID and autism traits, Totsika et al. (2010) found no difference in QoL measures between older and younger groups in their research, apart from the younger group receiving more staff attention during a period of observation. Their results indicated that clinical caseness was higher in the younger group (18-49) compared to the older group (50+), which may have skewed the QoL scores, although statistical analysis to explore the mediating role of clinical caseness was not completed.

Predictors Of QoL In OAA

Six of the studies which included broader age ranges did not stratify their samples when looking at predictor variables, most likely due to small sample size and lack of statistical power. Five of the included studies looked at predictors in older groups, and a number of predictors were explored; comorbid mental health conditions (Khanna et al., 2014; Mason et al., 2019), social support (Charlton et al., 2022; Roestorf et al., 2022), prospective memory (PM) (Roestorf, 2018) perceived stress (McQuaid et al., 2022) and IQ, symptom severity, cognitive problems and psychological problems (Van Heijst & Geurts, 2015). Interestingly, increasing age was not found to be significantly related to QoL (Van Heijst & Geurts, 2015).

Several studies explored the impact of ethnicity and gender, but not specifically for older adults (Charlton et al., 2022; Khanna et al., 2014; Mason et al., 2018; McQuaid et al., 2022). None of the studies with stratification or older samples explored the impact of these demographic variables. Intellectual ability was not found to be a significant predictor of QoL in a non-intellectual disability sample (Van Heijst & Geurts, 2015), but in an intellectual disability sample adaptive skills were predictive of QoL, rather than autism (Totsika et al., 2010).

When exploring the impact of age and comorbid mental health on HRQOL in autistic people compared to the general population, Khanna et al. (2014) found no significant differences between people with ASD without any comorbidity across all ages, and the general population, which indicated that the overall differences they had observed between ASD and US norm groups may have been explained by comorbid mental health, rather than autism, suggesting that poorer mental health negatively impacted health related QoL. Similarly, Mason et al. (2019) found that OAA with anxiety and depression scored lower on all

WHOQOL domains, in comparison to those who did not have anxiety or depression. Additionally, those who met caseness for both anxiety and depression had significantly lower physical and psychological QoL compared to those who only met caseness for anxiety or depression. This suggests that having anxiety and depression was associated with lower QoL in autistic OAA, and this relationship was more pronounced when the individual has both anxiety and depression. However, causal conclusions cannot be drawn due to cross-sectional data and exploratory comparisons with normative data (Mason et al., 2019).

When looking at the impact of social support on QoL, Charlton et al. (2022) found little evidence of age related differences in social support and QoL in their sample. However, Roestorf et al. (2022) found that both younger and older groups reported having a lower degree of social support, and they found that subjective wellbeing was related to a lack of personal relationships, feeling isolated, lack of achievement, concerns about healthcare, standard of living and feeling safe. When exploring perceived stress, McQuaid et al. (2022) found this to be linked with lower QoL across all domains. Lastly, Van Heijst and Geurts (2015) found that autism symptom severity, IQ, cognitive problems and psychological problems did not significantly predict QoL in OAA. Cognitive problems were further explored by Roestorf (2018) and none of the self-reported or objective measures of PM were predictors of QoL in OAA.

Methodological Quality of the Included Studies

All studies were quality assessed using the MMAT (Hong et al., 2019; Pluye et al., 2011). In using the tool, authors firstly chose the relevant methodology, and then answer five questions with 'yes', 'no', or 'can't tell' (see table 3.). All of the studies had clear aims and collected data which enabled them to answer their research questions. Although the study by Mason et al. (2019) used mixed methodology, this was not the predominant focus of the research and so using the MMAT gave it a disproportionately low score. Therefore this study was appraised as a quantitative nonrandomized study. One study was found to have poor methodological quality (Groenendijk et al., 2023) as it was a smaller scale project looking at the efficacy of a group psycho-educational intervention and did not report average QoL scores.

Table 3*Quality Appraisal of the included studies*

Study ID	Are there clear research questions?	Do the collected data allow to address the research questions?	MMAT Appraisal Questions					
			Quantitative Descriptive Studies	Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Groenendijk 2023	Yes	Yes		Yes	No	No	No	No
Khanna 2014	Yes	Yes		Yes	Yes	Yes	Can't Tell	Yes
Charlton 2023	Yes	Yes		Yes	Yes	Yes	Can't Tell	Yes
Mason 2018	Yes	Yes		Yes	Yes	Yes	Yes	Yes
Totsika 2010 McQuaid 2022	Yes yes	Can't tell yes		Yes Yes	Can't Tell Yes	No Yes	Can't tell Yes	Yes Yes
			Quantitative nonrandomized studies	3.1. Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure

					and intervention (or exposure)?			occurred) as intended?
Roestorf 2022	yes	yes		Yes	Yes	No	Yes	Yes
vanHeijst 2015	Yes	Yes		Yes	Yes	Yes	Yes	Yes
Yarar 2022	Yes	Yes		Yes	Yes	Yes	Yes	Yes
Roestorf 2018	Yes	Yes		Yes	Yes	Yes	Yes	Yes
Mason 2019	Yes	yes		Yes	Yes	Yes	No	Yes

Discussion

This review aimed to scope the current evidence base regarding QoL in OAA. Unlike previous reviews, only studies with samples aged 50 and above, or studies with stratified results were included.

It would appear that across adulthood, autistic people have lower QoL. Consistent with research for younger autistic adults (Ayres et al., 2018; Mason et al., 2018), this review consistently found that QoL was lower for OAA compared to older neurotypical adults. Secondly, this review found that OAA reported higher QoL when compared to autistic adults. Within the general population, as described, there is a curvilinear relationship between QoL and age, with QoL dipping in late adulthood, and gradually rising to late sixties, before dropping again into later life (Layte et al., 2013). If this is a similar pattern in autistic people, it would be unsurprising that older groups in this review had higher QoL as there was maximum age of 66 in the included studies. The identified predictors for QoL in neurotypical older age (e.g marital status, social contact, mental health, physical health) are not well researched enough with OAA at this stage to draw clear conclusions about mediating variables for this observation, however differences in domain scores may give some indication.

Younger and OAA score differently on different domains of QoL and social QoL was often reported to be higher among OAA. This contradicts research with broader aged autistic samples which have shown decreasing social QoL with increasing age (Mason et al., 2018). It was suggested that autistic people may be more able to cope with social isolation in older age due to having more solitary hobbies and interests, as well as possibly never having had extended social networks (Happé & Charlton, 2012). Previous research has also shown that being in a relationship and receiving support is a positive predictor of social QoL, and with this review including the younger spectrum of OAA these supports may still be in place (Mason et al., 2018). It is possible that OAA may be more accepting of their social situation than their younger counterparts who may feel they are striving to be more like the norm group, but there is currently limited evidence to support this. Psychological QoL was found to be higher for the older group, although not as consistently. This is another difference which warrants further investigation. Papers included in the review indicated that gender predicts QoL, specifically males reported higher physical QoL than females, and females higher social QoL than males (Mason et al., 2018)

This review highlighted the lack of representation of the oldest groups who may be more impacted by factors such as loss of supportive loved ones and death of family members, which are shown to be predictors of lower QoL (Mason et al., 2018). However, this review did not find conclusive evidence regarding the role of social support in QoL for OAA. Significant predictors of lower QoL were found to be increased mental health difficulties and higher perceived stress. Intellectual ability was not a predictor QoL, however adaptive ability was and those with lower adaptive functioning scored lower on measures of QoL. Additionally autism symptom severity, cognitive problems, prospective memory, and psychological problems were not predictive of QoL. This is not to say these factors are unrelated to QoL, as some of these findings are likely to be influenced by methodological bias or a lack of statistical power.

Gaps in Literature

Demographic information was under-reported in the included papers. A limited number of the papers considered the intersectionality of autism and gender or ethnicity, and none of them considered this in older adults specifically. The intersection between ethnicity and autism is not yet well understood. Recent research has demonstrated that African American and Black autistic young adults had differing experiences of discrimination, but many reported discriminatory experiences related to race and disability (Davis et al., 2022). Discrimination has been shown to be linked with poor physical and mental health (Bergeron et al., 2020; Botha & Frost, 2020), so understanding the intersection and possible cumulative impact on QoL is vital in providing effective services and support for autistic people from marginalised groups.

The intersection of older age and ethnicity has been explored in relation to QoL. Bajekal et al. (2004) found that different ethnicity groups scored differently across aspects of QoL, e.g. the white group scored highest on material circumstances, health, participation in formal social networks and quality of physical environment, whereas the Pakistani group scored higher on factors capturing frequency of family contact and desirability of the neighbourhood. This study demonstrated that global measures of QoL might diminish these variations making it difficult to ascertain what is important for different groups. The consideration of different factors which contribute to improved QoL for OAA from different cultural backgrounds would further advance the evidence base.

Very few studies included participants with intellectual disability, often having average to above average intelligence participants. Validated measures of

QoL may be inaccessible to people with a lower intellectual level. Only one included study focused on both intellectual disability and autism in later life, and found that lower adaptive functioning was associated with lower QoL, rather than the presence or absence of autism (Totsika et al., 2010). This requires replication and further QoL research inclusive of people with lower intellectual ability and autism should be conducted. This is particularly important as these groups are highly vulnerable to discrimination (Scior & Werner, 2015).

Thus far, predictors of QoL have only been explored specifically in discreet older age samples (as opposed to stratified statistical analysis) in one study included in this review. This adds to findings from a previous review by Tse et al. (2022) who noted the dearth of literature, including QoL studies, with autistic samples over the age of 50. It would appear that two years on, the evidence base has not grown substantially, and it remains a challenge to ascertain how important certain factors are in the QoL of OAA. This is an important finding from this review, which should generate motivation for further research attention to this area.

Future recommendations

Whilst the majority of the studies used measures of QoL which have been validated for use with autistic people, a much smaller minority made use of autism specific QoL measures such as the ASQoL add on to the WHOQoL-BREF (McConachie et al., 2018), or administered them against the recommendations from the original validation studies. Future studies should consider using the autism-specific tools with this population, including a more recent measure with good psychometric properties (Williams et al., 2023).

New measures which include items considering the intersectionality of age and autism are required. As discussed, the validity of existing QoL measures for older people has been questioned (Wiggins et al., 2004). Therefore, there is a strong need for the development of measures with stronger ecological validity. Such measures should be sensitive to cultural background and ethnicity which are shown to have additional implications for health and wellbeing of autistic people (Botha & Frost, 2020). Qualitative research could inform this process by providing in-depth exploration of the intersection of autism in later life, age at diagnosis, cultural considerations, ethnicity, and migrant status. This research may also help to identify explanations for higher social and psychological QoL in OAA compared to younger autistic adults.

To date, the research has been predominantly cross-sectional and only included younger cohorts of OAA. Longitudinal research would also help in understanding the changing influences and predictors of QoL with ageing.

Clinical Implications

Overall, it is clear that the QoL of autistic people is lower than the general population. In clinical practice, awareness that both younger and older autistic people are likely to have lower QoL than neurotypical people is important, leading to more clinical focus on the areas of life which may be particularly impacted in these groups. For OAA, there should be consideration of diminishing social, physical and psychological health with ageing. Although this review would indicate these aspects appear to improve with age, they remain lower than the general population and thus still require clinical attention. Additionally, the evidence base thus far does not include OAA into their late sixties, seventies or eighties, where QoL may be further impacted. Services may focus on priority areas, for example routinely assessing mental health which appears to be the most well evidenced predictor of lower QoL in OAA. This may be even more pronounced for younger autistic adults, who appear to have lower scores across these domains compared to OAA. As such, services for adults, including autism specialities, should remain conscious that autistic adults may be even further impacted in terms of their psychological health and social lives and develop pathways for assessment of needs. Research indicates that a focus on employment, social support, relationships and mental health would be salient (Mason et al., 2018).

The timing of autism diagnosis may also be impactful. In a sample of autistic adults aged eighteen to sixty-three, correlational analysis showed that later diagnosis was associated with lower QoL across all domains (Atherton et al., 2022) and increasing age of diagnosis was associated with increased social anxiety, social avoidance and a lack of support. This may suggest that late diagnosis, as opposed to age may influence QoL outcomes. However, the study did not demonstrate the temporal association between timing of diagnosis and QoL outcomes. Their findings did not differentiate between those who may have received their diagnosis recently, and those who received this many years prior, nor how this may then also be influenced by age. This nuance should be further explored in the literature for clear conclusions to be drawn. Despite these drawbacks of the evidence base, the findings from the current study and previous research are indicative of the need for thorough and effective autism

assessments across the lifespan, and consideration of QoL issues at each life stage. In particular for autistic women who are at higher risk of late and missed diagnosis (Gesi et al., 2021; Loomes et al., 2017).

Limitations of the review

Grey literature was searched in order to lower the risk of publication bias. However, a large amount of grey literature was excluded from the review as the full text was not available. Therefore the review may still be influenced by publication bias. Additionally, the authors acknowledge that this review has included QoL within a narrower framework. As discussed, different terminology is often used within the literature, such as subjective wellbeing (SWB). Not including research which used SWB may have limited the amount of available literature concerning OAA. Future reviews could consider including not only QoL, but SWB and other synonyms for life satisfaction.

Conclusions

To conclude, this review has helped to draw further attention to the lack of published literature about the QoL for OAA. Overall, the results have indicated that OAA have lower QoL than their neurotypical counterparts, and only few predictors of this have been explored in detail and with insufficient evidence to inform clinical practice. Recommendations have been made for future research to fill in the gaps in current knowledge.

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Service-Related Project

Exploring the efficacy of a UK university-based counselling service using CORE-OM outcome data and service-user feedback.

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Target Journal: British Journal of Guidance & Counselling.

This journal was chosen as it has published a number of similar papers focused on student counselling services. It also has a focus on career counselling, so is relevant to considering the unique position of services within academic settings, rather than health settings.

The guidance on journal formatting requirements is here:

<https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=cbjg20>

Introduction

The need for universities to support the mental wellbeing of the student population is well evidenced and in 2018, a government initiative established the University Mental Health Charter (Student Minds, 2018). The Mental Health Charter provides universities with a reference point for how to implement a whole university approach to improving the mental health of students, which involves the consideration of genetic, environmental, and learning factors. Aligning policies and practices with the charter, means that steps must be taken to ensure the quality, safety, and effectiveness of the service through the use of triangulated data; clinical data, outcome data and student feedback (Student Minds, 2018). This includes reviewing the effectiveness of the counselling services within universities (Student Minds, 2018). Such services have been a core part of the university offer since the 1950s (Hughes & Spanner, 2019). In the UK, university counselling services are variable, but often include one to one support, guided self-help, peer support or online therapies (Zuroff & Blatt, 2006). The need for such support in university settings has been well evidenced.

Commencing university represents a period of significant change and development for young adults. Often, going to university is a time of psychosocial change including separation from childhood homes, family, friendships and starting to develop life as an independent adult (Lenz, 2001). Alongside this, the brain is undergoing significant change and maturation at this time (Baker et al., 2015). Students are faced with the normalisation of alcohol (Gambles et al., 2022) and drug use (Scott & Oliver, 2022) as a means of assimilation into new friendship groups. Exposure to lifestyle health risk factors such as tobacco smoking, physical inactivity, alcohol consumption, illicit drug use, unhealthy nutrition, and inadequate sleep (El Ansari et al., 2018) is often by means of social pressure. It is therefore unsurprising that population cohort studies have demonstrated high prevalence rates of mental health difficulties in the student population.

It has been suggested that almost half of all adult mental health problems begin in adolescent years (Jones, 2013). The evidence available makes a case for the importance of early identification of mental health problems within the student population, as prevention and early intervention is known to improve outcomes (Mazurek Melnyk et al., 2016). Studies have found high prevalence rates of mental health diagnoses among students, for example a meta-analysis by Sheldon et al. (2021) found a prevalence rate of 25% for depression and suicide-related outcomes at 14% (suicidal ideation, suicidal thoughts, behaviours

and completed suicides were included). Another worldwide meta-analysis found similar results of a depression prevalence rate of 21.6%, anxiety at 24.5% and 18.8% for suicidal ideation (de Paula et al., 2020). The diversity of the student population has also been changing, and individuals from less advantaged backgrounds are now 49% more likely to apply to university, compared to a decade ago, and 19% of the student population are international students (Universities UK, 2018). Further statistical analysis from Advance Higher Education (HE, 2022) has shown that the proportion of Black, Asian and minority ethnic students has risen from 14.9% in 2003/04 to 26.2% in 2020/21. This is an important consideration as we know from general population research, that both migrant populations and ethnic minorities are at a disproportionate risk of mental health diagnoses and health inequalities (Grey et al., 2013). This places a unique pressure on universities who are required to have skills to respond to a range of needs from an increasingly diverse and transient population.

There has been increasing demand on mental health services within university settings, and an increase in the severity of mental health problems reported by students (RCPsych, 2021). Hughes and Spanner (2019) found that the number of students declaring a pre-existing mental illness upon admission has doubled since 2014/15, which has been reflected in the number of students accessing mental health support. According to Duffy et al. (2019) the increase in demand for such services has exceeded the increase in enrolment. This appears to have also been impacted by the COVID-19 pandemic as YoungMinds (2020) found that 83% of the students reported a worsening of pre-existing mental health conditions due to the pandemic. Cao et al. (2020) explored some of the mediating factors which included academic delays, financial difficulties due to the pandemic and changes to daily life.

Internal counselling services make up a small but important part of the overall wellbeing services within universities. Previous research which looked at multiple university-based counselling services in the UK, prior to the COVID-19 pandemic, found that short-term counselling was effective, with 56% of students achieving reliable and clinical improvement on clinical outcomes in routine evaluation (CORE-OM) scores (Connell et al., 2008). Effective university counselling has also shown to improve academic performance (McKenzie et al., 2015) and retention (Wallace, 2012). It has been argued that community-based care is not designed to meet the needs of students, who are often transient and experiencing these unique stressors but falling short of high thresholds for local services (Duffy et al., 2019). On the development of the mental health charter,

student panels recommended that universities work on increasing access points and removing barriers. This involved additional funding for services and practitioners in-house, including counselling and psychological therapies. This was seen as important in supporting the diverse range of needs within the student population, and reports included that students felt better understood by someone who works within the university (Priestley et al., 2022).

Aims of the study

In the context of the presented challenges and pressures on universities, the current study aimed to zoom into the efficacy of a counselling service within one UK based university. The aim was to evaluate the service in line with the Mental Health Charter (2018) and guidance from the British association for counselling psychologists (BACP), that being by reviewing clinical data, outcome data and student feedback.

The BACP recommend that university counselling services monitor their outcomes using service user feedback and the CORE-OM (Butlin et al., 2017). The project aims to achieve this this by conducting statistical analysis on the pre and post CORE-OM scores for all students who had engaged with the counselling service since the beginning of the 2021/22 academic year. The study also aimed to qualitatively analyse feedback data which had been collected, highlighting key themes and areas for service development as identified by students. Service improvement recommendations are made.

Methods

Service context

This project focused on a university-based counselling service who adopt a 'stepped care model' much like the Improving access to psychological therapies (IAPT) model (England, 2021). After an initial consultation, students are signposted to therapeutic groups, self-help resources, low-cost counselling, external therapy providers, mental health advisors and the internal counselling service, depending on the level of intervention required. This model is typical of other universities in the UK (Zuroff & Blatt, 2006).

The current study focused on analysing data for students treated at step three of the model. These included students experiencing moderate to severe depression and anxiety, trauma, emotional dysregulation, psychosis, bipolar disorder, eating disorders and personality disorders. To reach threshold for step three interventions, there must also be a presence of risk which requires ongoing monitoring, as well as a severe impact on day-to-day functioning.

At step three, students are seen by therapists employed by the university counselling service. The service employs therapists from a range of backgrounds who have experience working with student populations. They are able to offer short-term episodes of therapy to students (6 sessions), in a range of psychological approaches including Counselling, Cognitive Behavioural Therapy (CBT), Eye Movement Desensitisation and Reprocessing (EMDR), Solution Focused Therapy and Compassion Focused Therapy.

Design

The current study used secondary data analysis. It utilised existing and routinely collected data gathered between September 2021 and March 2022. Variables were extracted from the electronic recording system (ERS), and demographic variables were pulled from additional databases held by the university. The data was extracted by the Data and Insight Lead for Student services who is familiar with processes involved in gathering data from the systems. Once extracted, the data was cleaned to remove duplicate and incomplete data.

Sample

All students who engaged with the internal counselling service and completed their course of therapy between September 2021 and March 2022 were included in the study. Students were deemed to have completed their course of therapy if both pre and post outcome measures were recorded, and the case was marked as 'completed' on the ERS. Students who engaged with

external therapy providers via the university were excluded from the current data set due to incomplete outcome data.

Measures

Pre and Post Therapy Scores were measured using the CORE-OM (Evans et al., 2002). The CORE-OM is a 34-item scale with four domains including subjective wellbeing, problems and symptoms, life functioning and risk. Items are rated based on the last week and scored from 0 (not at all) to 4 (most or all the time). The measure has been well validated for use within counselling settings, with high validity and reliability (Connell et al., 2007; Evans et al., 2002). Test-retest stability was between 0.87-0.91 on all subscales, apart from risk which was lower at 0.64. Overall there is excellent stability, and it is unsurprising that the risk subscale has higher mean change, as these items consider highly changeable and often reactive experiences, as discussed by authors (Evans et al., 2002).

There are different cut-off for the CORE-OM used in the literature, depending on the sample. The original cut off scores were developed using a large student sample reported by Evans et al. (2002), and adopted in previous studies looking at outcomes as measured by CORE-OM in the student population (Connell et al., 2007). These are 11.9 for males and 12.9 for females. A cut-off score of 10 has been indicated from general population studies (Connell et al., 2007). Both cut-off scores will be shown for reference. A cut-off score of 25 is also used to indicate severe impairment, as also adopted by Connell et al. (2007) and suggested by Barkham et al. (2001).

Feedback Data

The feedback data was collected anonymously, so it was not possible to match the feedback data to the demographic information or CORE-OM outcomes. Therefore, the 59 students who had completed the feedback questionnaire between September 2021 and March 2022, may be a different sample to those included in the quantitative analysis. The feedback is collected through an online questionnaire with qualitative and Likert scale data. The questionnaire was developed in service and has three free text questions and nine Likert scale questions relating to experience and outcomes from the episode of therapy. The 9 Likert scale questions are scored from 1 (strongly agree) to 5 (strongly disagree), with a Cronbach's Alpha of .91 with the current sample. These questionnaires were sent to students by the practitioner following

completion of therapy and filled-out via an online form. Feedback data for 59 students was available at the time of data extraction.

Free text questions:

1. What was the most valuable part of the work you did with the practitioner?
2. How could the work you did with the practitioner have been more helpful to you?
3. Is there any aspect of the overall service you received from Counselling and Mental Health that we could improve?

Likert questions:

1. I felt safe and able to talk freely to the practitioner.
2. I felt understood by the practitioner.
3. I felt confident in the practitioners ability to help me.
4. The Counselling or Mental Health advice I received helped me achieve the goals discussed with the practitioner at the start.
5. I understand myself better.
6. I can cope better with my feelings and problems.
7. My relationships and/or social life have improved.
8. I am managing better in my studies.
9. I am happier and enjoy life more.

Data Collection

Students were asked to complete the CORE-OM before they commence treatment with the counselling service. This request was usually sent via email, and students completed the questionnaire online. They were asked to complete this again once they have completed their course of therapy. It was not possible to extract the date and time of completion of the CORE-OM from the ERS. Demographic information about students was held within multiple electronic systems managed by the university. Variables of interest were extracted from a number of different systems. Data was anonymised by the data and insight lead before it was made available to researchers.

Data Analysis

The data was analysed using SPSS statistical software package. Data was explored for reliable as significant change and presented as the percentage of the sample whose scores met reliable and significant change indices as reported by Connell et al. (2007). A binary logistic regression was used to explore whether age, gender, number of sessions attended, and pre-therapy CORE-OM

score had an influence on the likelihood of a clinically significant improvement in CORE-OM scores. For the feedback data, the Likert scale data is presented graphically. Qualitative data from the free-text questions were analysed using content analysis (Elo & Kyngäs, 2008). Codes were derived using an inductive process, allowing ideas to emerge from the data. These codes were then organised into overarching themes, which are reported. This method was chosen as it is intended to identify perspectives of a topic, experience or phenomenon and can be used inductively to look for patterns in data (Elo & Kyngäs, 2008). In this study, it was important to stick closely to content of the feedback and summarise this, as opposed to being more interpretative.

Results

Data from 65 students was extracted from the ERS. The mean age of the students was 21 and the range from 18 to 43. There was a higher proportion of females in the study compared to males. There were no students who identified as non-binary or transgender in the sample. The sample was predominantly white British. A further breakdown of the descriptive statistics is provided in Tables 1 and 2.

Table 1

Age distribution of sample

N	Mean Age	Age Range
65	21.43	18-43

Table 2

Gender, Nationality and Ethnicity of the sample

Category	N	%
Gender		
Female	41	63.1
Male	24	36.9
Nationality		
British Nationality	55	84.6%
Asian		
Indian	1	1.5%
Singaporean	1	1.5%
African		
Sudanese	1	1.5%
European		
Austrian	1	1.5%

Category	N	%
Hungarian	1	1.5%
Italian	1	1.5%
Romanian	1	1.5%
Swedish	1	1.5%
Polish	1	1.5%
Spanish	1	1.5%
Ethnicity		
White	54	83.1
Arab	1	1.5
Chinese	2	3.1
Asian or Asian	1	1.5
British - Indian		
Asian/Asian British	2	3.1
Mixed - Black African and White	2	3.1
Mixed - Asian and White	1	1.5
Black or Black British - African	1	1.5
Mixed/multiple	1	1.5

When students enrol with the university, they are asked to declare any existing disabilities. This data is shown below. The majority (70.8%) of the sample declared no disability, and the second most common disability reported was mental health conditions followed by specific learning difficulties.

Table 4

Disability status of sample (as declared by student upon registration with the university)

Disability	N	%
No disability	46	70.8
Mental health condition (eg depression)	8	12.3
Specific learning difficulty (eg dyslexia, ADHD)	5	7.7
Long illness (eg cancer, HIV, diabetes)	2	3.1
Multiple disabilities	2	3.1
Blind or a serious visual impairment	1	1.5

Disability	N	%
Social or Communication impair (eg Asperger's)	1	1.5

Data pertaining to the level of study was extracted from the ERS and is shown in Table 5. A high proportion of the sample were undergraduate students (81.5%).

Table 5

Level of Study

Level of Study	N	%
Post Graduate Research	6	9.2
Taught Masters	6	9.2
Undergraduate	53	81.5

Descriptive statistics relating to counselling intervention.

The model of the counselling service is to offer six therapy sessions. Data indicates that 52.3% of the sample attended this number of sessions, whilst 23% attended less than 6. The minimum number of sessions attended was three, and this was only one student. 36.9% of students attended more than six sessions with the service. Around half of the sample were seen face to face for therapy, with the other half seen online only, and a small percentage seen both face to face and online.

Table 6

Number of sessions attended

Mode: 6

No. of sessions attended	N	%
3	1	1.54
4	3	4.62
5	3	4.62
6	34	52.31
7	12	18.46
8	6	9.23
9	2	3.08
10	1	1.54
11	1	1.54
12	2	3.08

Feedback Data from Students

Feedback data was received from 59 students. Around half of the students were seen face to face, and the other half either totally online or a mixture (see table 7.) Waiting time data was pertained via the feedback questionnaire and is shown in Table 8.

Table 7

Treatment modality

Modality	N	%
Face to face	30	50.8
Both online and face to face	4	6.8
Online only	25	42.4

Table 8

Waiting times as reported by students

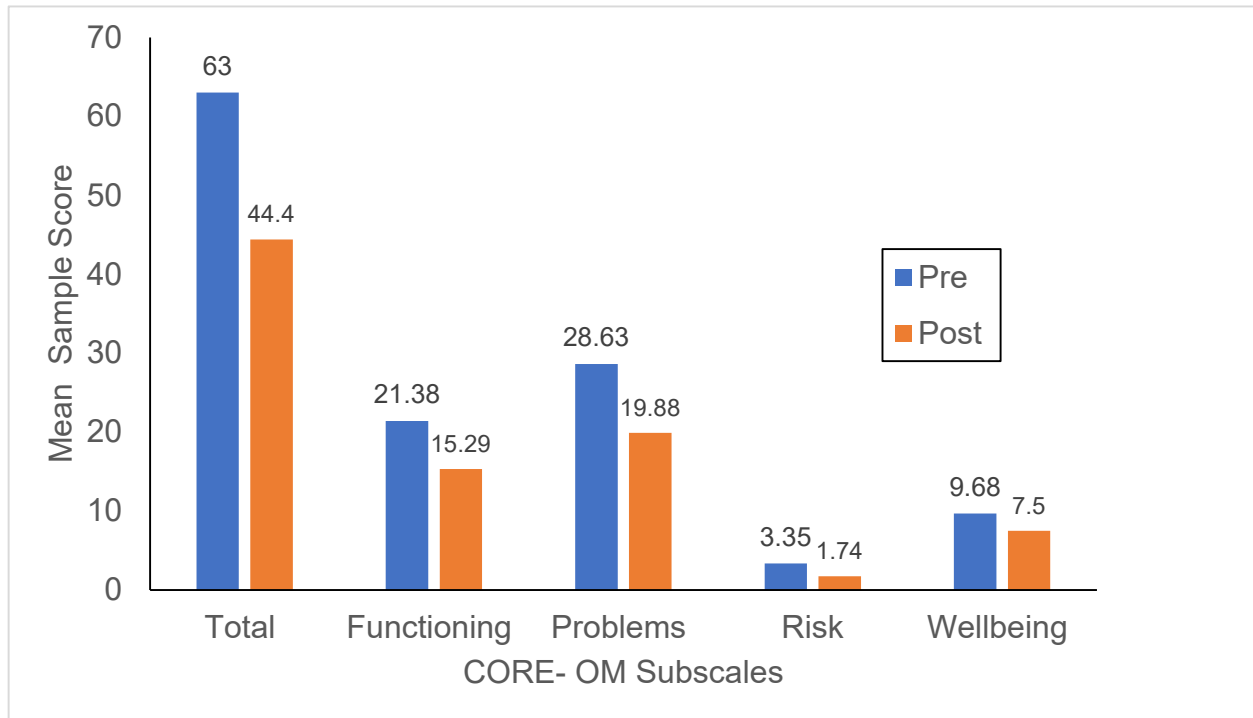
Time frame	N	%
Within a week	8	13.6
1-2 weeks	13	22
3-4 weeks	22	37.3
1-3 months	14	23.7
3 months +	2	3.4

CORE-OM outcomes

Figure 1 shows the mean pre and post therapy CORE-OM scores. Mean total and subscale scores reduced from pre-treatment to post-treatment overall.

Figure 1

Mean pre and post-therapy CORE-OM total and subscale scores.



Reliable and Clinical Significance

Table 9 shows the percentage of the sample showing reliable and significant improvements in CORE-OM scores at outcome. For reference, general population and student sample norms are shown. Reliable and clinically significant differences are shown together, as clinically significant improvement cannot be achieved without meeting reliable improvement.

When using student normative data, 39.6% of the sample who could achieve clinically significant improvement (starting with a score over the clinical cut off), met reliable and clinically significant improvement indices, and a further 16.9% of the overall sample achieved reliable improvement only. There was no reliable improvement in 50.8% of the sample and 0% reliable deterioration.

When using data from general population means, 29.5% of the sample met reliable and clinically significant improvement indices. 21.5% of the sample met reliable change only. 50.7% experienced no reliable change. Again, 0% of the sample experienced a reliable deterioration.

When using general population means, the threshold for a clinical score is lower, therefore we can see a higher number of students scoring above clinical cut off pre-therapy. This indicates that using general population cut-offs might overestimate the prevalence of difficulties in this sample. Additionally, this may also explain why when using population means, fewer students achieve clinically significant improvement (as it is more difficult to get a score lower than 10,

compared to lower than 11.9 or 12.9). The higher cut-off scores from student normative data may lead to an overestimation of clinically significant change due to the higher cut-off scores, however, the normative data from students is felt to be more valid for the current sample.

Table 9.

Reliable and clinically significant improvement percentages using student and general population norms.

	Cut-off 11.9/12.9 (student norms)				Cut-off 10 (general population norms)			
	All clients (n=65)		Clients above cut off only (n=53)		All clients (n=65)		Clients above cut off only (n=61)	
	N	%	N	%	N	%	N	%
1. Reliable and clinically significant improvement	21	32.3	21	39.6	18	27.7	18	29.5
2. Reliable improvement only	11	16.9	7	13.2	14	21.5	13	21.3
3. No reliable change	33	50.8	25	47.2	33	50.7	30	49.2
4. Reliable Deterioration	0	0	0	0	0	0	0	0

Relationship between clinically significant change and other variables.

Results from a logistic regression are shown below in Table 10. None of the variables were shown to have a significant relationship with the occurrence of clinically significant change in CORE-OM scores.

Table 10.

Logistic regression predicting clinically significant change associated with counselling intervention

Variable	B	SE	P
Age	-.11	.11	.3
Gender	.22	.57	.7
Pre CORE-OM score	-.00	.02	.97
No of sessions attended	.08	.16	.61
Engaged with additional services	-.65	.56	.27

Student Feedback Data

Results from the feedback questionnaire are now presented. Responses to the nine likert scale questions are shown below in figures 2, 3 and 4. As can be seen in figure 2, large proportions of the sample reported strongly agreeing that they felt safe and able to talk to the practitioner, felt understood by the practitioner and confident in the practitioners ability to help them.

As indicated in figure 3, a large proportion of the sample strongly agreed, or agreed that the support they received helped them to achieve their goals, understand themselves better and cope better with their feelings and problems.

As indicated in figure 4, approximately 70% of the sample said they strongly agreed or agreed that their relationships and social life had improved, however 30% that they neither agreed or disagreed with this. When asked if they felt they were managing better in their studies, the largest proportion reported they neither agreed or disagreed with this, with smaller proportions reporting they strongly agreed and agreed with this. Lastly, roughly 70% agreed or strongly agreed that they felt happier and were enjoying life more.

Figure 2.

Likert Scale Responses to Questions 1 to 3.

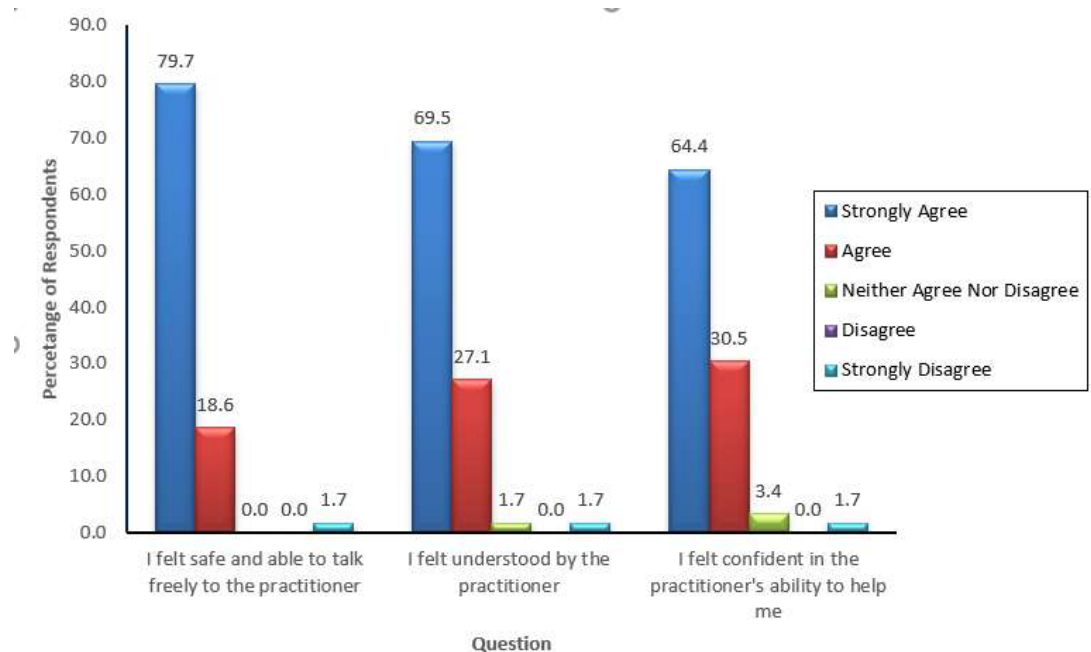


Figure 3.

Likert Scale Responses to Questions 4 to 6.

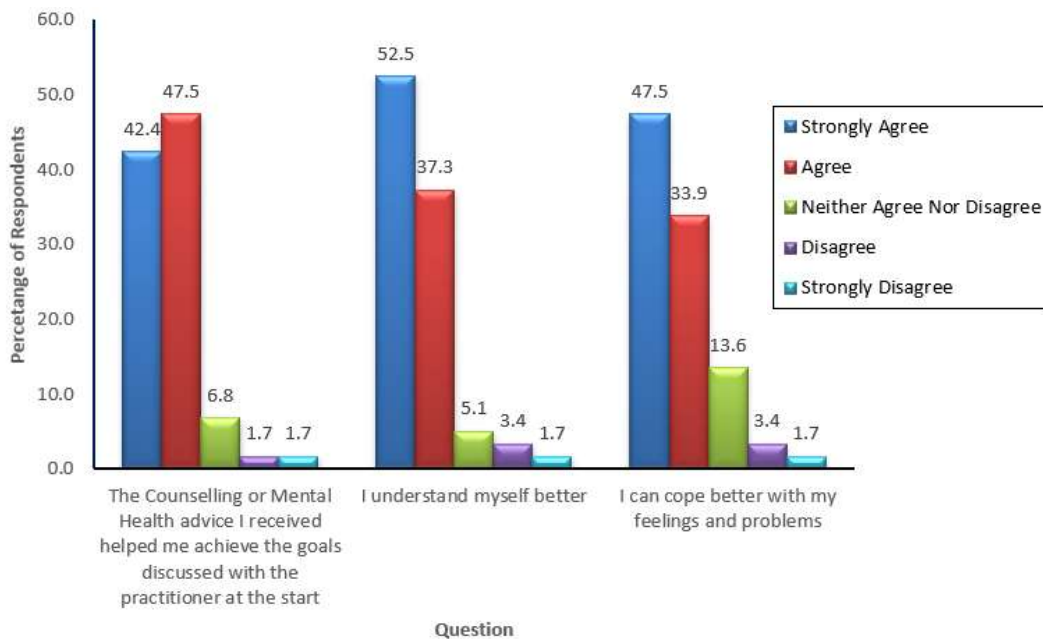
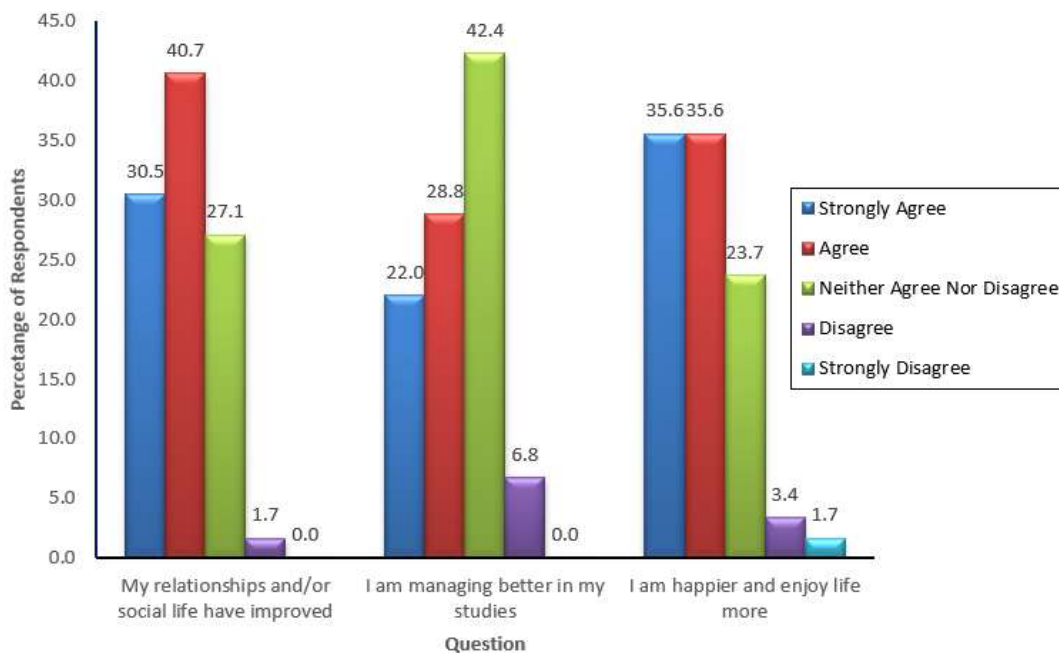


Figure 4.

Likert Scale Responses to Questions 4 to 6.



Content Analysis of free-text feedback

Emergent themes from the content analysis of free text questionnaire feedback data are now described. These are presented in relation to the three questions. See table 11 for a full breakdown of the themes. It is worth noting that a high

percentage of respondents expressed satisfaction with the service or had no specific feedback they wished to provide in relation to the three questions. It was deemed important to have all views reflected in the feedback, even if only from a very small proportion of the sample, as such frequency and percentages of students reporting the specific themes are shown.

Question 1. What was the most valuable part of the work you did with the practitioner?

The main themes emerging included aspects related to the therapeutic relationship and therapy process. Many students valued having a space where they felt listened to and understood by the practitioner. Having a safe space, free from judgement was also highly valued. Many students acknowledged specific characteristics of the therapist which were important to them and valued having someone to be able to contact when they required support with their mental health.

In terms of therapy process, the most commonly fed back aspect was around learning new techniques and skills to manage their mental health needs, as well as feeling as though they were able to understand themselves better after therapy. Additionally, having skills and expertise from a therapist was helpful. Other factors included normalising experiences, being able to process things from the past. Some students also mentioned the specific modality being used as a helpful aspect of their therapy.

Question 2. How could the work you did with the practitioner have been more helpful to you?

Many students reported they were satisfied with the service they received or did not feedback any specific ways in which the work could have been more helpful. The most common feedback was to be able to access more sessions from the service. Several students also mentioned how specific therapeutic aspects may have improved their experience, such as the use of homework or activities to complete outside of the sessions. Aspects related to initial engagement were discussed by a small number of students, which included preferring to meet face to face, understanding how to make use of the sessions and setting goals.

Question 3. Is there any aspect of the overall service you received from Counselling and Mental Health that we could improve?

Feedback for question three was broken down into four main themes; accessibility, availability, confidentiality and beginnings and endings. 40% of respondents fed back that they had a positive experience or had made no specific comments regarding improvements for the service. Feedback regarding accessibility related to the experience of finding the communication with the

service quite formal, feeling there was a lack of integration with local services and initially feeling unsure about where to get help from. Students commented upon the availability of the service, with the most commonly reported improvement suggested around waiting times before assessment, and between assessment and starting therapy. Again, the number of sessions available was raised as an improvement. Other suggestions included a desire for an outreach style of work and regular, informal check-ins. Some students commented on improvements related to their privacy and confidentiality, for example having to wait in busy areas of the university and feeling unsure about how their information is shared. Beginnings and endings of therapy was also significant, with students reflecting on some invalidating experiences of seeking help from the services, which impacted on further help-seeking behaviours.

Table 11

Emergent themes from free text feedback questionnaire.

Question 1. What was the most valuable part of the work you did with the practitioner?	
	N (%)
Therapeutic Relationship	
Being listened to and understood	14 (23.7)
Characteristics of the therapist	5 (8.5)
Safe, non-judgemental space	15 (25.4)
Having someone to contact for support	5 (8.5)
Therapy Process	
External and expert perspective and knowledge	8 (13.6)
Learning new techniques and skills	18 (30.5)
Normalising	4 (6.8)
Processing the past	8 (13.6)
Specific Modalities	5 (8.5)
Understanding myself better	26 (44)
Question 2. How could the work you did with the practitioner have been more helpful to you?	
Satisfied with service/unsure	14 (23.7)
Not sure	7 (11.9)
Being able to access more sessions	16 (27.1)
Engagement	
Modality – preferring face to face	4 (6.7)

Initial engagement difficulties e.g knowing how to use the sessions	3 (5)
Reviewing the focus of work and goals	3 (5)
Therapy Content and Style	
More practical advice	1 (1.7)
Therapeutic style – different preferences	2 (3.4)
Use of specific therapeutic techniques e.g homework, diaries, activities	10 (16.9)
Question 3. Is there any aspect of the overall service you received from Counselling and Mental Health that we could improve?	
Positive experience reported or no improvement suggested	23 (40%)
Accessibility	
Overly formal	1 (1.7)
More integration with local services	1 (1.7)
Knowing where to go for help	2 (3.4)
Availability of the service	
Contact during waiting time	2 (3.4)
Placements and accessing therapy	1 (1.7)
Knowing what services are available	1 (1.7)
Desire for outreach work/check-ins	4 (6.7)
More sessions	8 (13.6)
Waiting times	14 (23.7)
Confidentiality	
Privacy of appointments	3 (5)
Sharing of information	5 (8.5)
Beginnings and endings	
Invalidating experiences	5 (8.5)
Previous negative experience impacting future help seeking	4 (6.7)
Knowing what to do next	1 (1.7)

Discussion

The current study aimed to explore the efficacy of a university-based counselling service. In line with recommendations, it used both quantitative and qualitative data consisting of routinely collected outcome measures and service user feedback. The key findings will be discussed, followed by limitations and recommendations. This study has demonstrated the breadth and severity of difficulties experienced by the student population, as anticipated. It is unsurprising that a large proportion of the current sample were undergraduate students; as these students represent a large majority of university cohorts and this group appear at a higher risk of the difficulties which may contribute to poorer mental health at a time of individuating and separation from family (El Ansari et al., 2018; Lenz, 2001).

A large proportion of students were seen within four weeks of requesting counselling from the university. Key performance indicators (KPIs) for the IAPT programme include waiting time standards which indicate that 75% of people referred to IAPT should start treatment within 6 weeks of referral and 95% should start within 18 weeks (NHS England, n.d). The university counselling service appears to be outperforming these KPIs with 96.6% of the sample being seen within 12 weeks. However, this data is self-reported by students, rather than recorded based on data from the ERS, so this should be interpreted with caution due to recall bias.

Approximately 50% of the sample achieved a reliable improvement in CORE-OM scores post therapy. This includes 39.9% of the sample who met clinically significant change, and a further 16.9% who met reliable improvement only. This is consistent with previous research using CORE-OM to measure efficacy of university-based counselling services (Bani et al., 2020; Murray et al., 2016). Rates of reliable improvement are lower than slightly older rates of 70% reported by Connell et al. (2008). However, we have seen a worsening and higher prevalence of mental health problems in the student population over this time (Duffy et al., 2019; Tabor et al., 2021), alongside cuts and austerity (Thompson et al., 2022), all of which may be contributing to lower rates of reliable improvement due to more limited services and higher complexity. Although, students had attended comparable numbers of sessions in the data reported by Connell et al. (2007).

Using NHS IAPT recovery rates as a comparison, the aim is for 50% of those in treatment to reliably improve (Department of Health, 2014). These rates have been achieved in this sample, and as explained by Connell et al. (2008) the

use of reliable and clinically significant change reflects that the change is not only significant but is shown to make a meaningful difference in the day to day lives of individuals. They also explain that these criteria are much more stringent, compared to statistical criteria (Connell et al., 2008). The current study has therefore provided evidence of the efficacy of university-based counselling services.

It is interesting to note that the service adopts a six session model, which appears typical for in-house student counselling services in the UK (Connell et al., 2008). However, 36.9% of the sample were offered more than 6 sessions. The reason for this is not explained in the data, however, it may indicate that the complexity of difficulties being treated within the service is contributing to practitioners extending the number of sessions. Compounding this, a consistent report from the students in this sample was that they desired more sessions. The authors acknowledge that it is a challenging time for universities from a financial perspective due to the reduction in international students who previously brought in a substantial proportion of income, as reported by the government in 2021 (Bolton & Hubble, 2021).

Systematically analysing the feedback data generated several important themes from the student perspective. Likert scale questions revealed that students felt positively about their practitioners and that therapy had a positive impact on their lives, in terms of understanding themselves better, meeting their goals and coping with difficulties more effectively. One area where students were less confident was in feeling they were managing better in their studies, a large proportion (42.4%) reported that they neither agreed or disagreed with this. Thompson et al. (2022) gathered data from professionals in higher education, finding evidence for a culture which fosters academic competition and pressure on students, which was suggested as one of the possible drivers for higher rates of distress. The research by Thompson et al. (2022) also highlighted that interpersonal constructs including self-efficacy and academic confidence were correlates of student stress and adjustment to university. Therefore, it appears unsurprising that the majority of this sample were ambivalent about feeling better able to manage their studies more effectively, as this may be driven not only by common interpersonal constructs held by students, but by wider cultural and systemic factors within university settings.

Another consistent finding was that students desired more sessions and time with their practitioner, and it was clear that many aspects of the therapy were helpful including feeling heard and understood, having experiences

validated as well as learning new skills and finding ways to cope with their difficulties. It is clear that students felt as though the practitioners understood them and their needs, which provides a strong justification for the continued funding of internal counselling services for students. However, due to the pressure on university mental health services, alongside austerity, covid-19 and inflation, many universities have moved to outsourcing providers of mental health services as a cheaper alternative. Broglia et al. (2017) argued that universities should provide specialist counselling services to students, as they are a unique population with different needs compared to the general population. They argue that students require a unique in-house service which is flexible to needs such as their age, transient living, reliance on digital technology and financial constraints. This study provides further evidence that practitioners who understand the strains and challenges faced by students is valued by this cohort and equally effective as comparable NHS services.

Limitations and recommendations

A key limitation of this research is that it only analysed data from students who had completed the post-therapy measures, excluding those with incomplete data. Additionally, the study did not include data pertaining to planned and unplanned endings. Time restraints prevented researchers from gathering this data, as it would have required manual exploration of individual student files on the ERS. This data would have enabled researchers to explore the representativeness of the sample. As such, there may be unknown systematic differences between the students who complete the post-therapy outcome measures, and those who did not. To illustrate this, previous research with very similar methodology and sampling (Connell et al., 2008) found that those who completed the post-therapy outcome data had attended more sessions, were less likely to be from an ethnic minority and had higher pre-therapy anxiety scores compared to those who did not complete post-therapy measures. Age, gender and CORE-OM pre-therapy scores were not found to be significantly different. As such, there may be confounding variables which influence the rates of reliable and clinically significant improvement found in this study, such as number of sessions attended, pre-therapy scores, ethnicity. There may also be a bias towards reporting successful outcomes. Based on previous evidence (Connell et al., 2008), it is more likely that exclusion of those who did not complete their post-therapy measures may lead to an overestimation of efficacy.

Additionally, the study did not include a control group which means it cannot rule out additional confounding variables, such as time. The time point for completion of measures may have differed depending on the practitioner and the referral process. This may have an impact on both the pre-therapy and post-therapy scores, as measures completed during a final session might be different to those completed two weeks post-therapy, for example. Follow-up data was also not available.

A large proportion of the current sample were white British (84.6%). The most recent data available from the university indicates that 66% of core students were white British and 32% were Asian, Black, Mixed and other ethnic groups. This data only includes students who were actively studying on the census date (1st December 2021) and core students (not those who are visiting from other institutions) (The University of Bath Academic Registry, 2021). This would suggest that students from minoritised backgrounds are under-represented in the study which may be explained by the use of external therapy providers.

The service works with external agencies who offer therapy to students who speak languages other than English or would prefer to speak to a therapist of the same ethnicity. Unfortunately, pre and post outcome measures for these groups had not been made available to the service so these groups are not represented in the current study. It is vital that services ensure they can effectively monitor outcomes for all groups, as this could further marginalise individuals from minoritised and non-English-speaking backgrounds. Therefore, a key recommendation is to ensure that universities work collaboratively with external therapy providers to ensure all outcome measures are completed and returned for monitoring purposes. This is an important recommendation from the Mental Health Charter (Hughes & Spanner, 2019) and the BACP (Butlin et al., 2017) around ensuring equitable services.

Another explanation for the under-representation of students from minoritised backgrounds may be that these students are not accessing services as readily. Since data was not available on the number of students accessing external therapy providers, a key limitation of this study is that we are unable to say with certainty if this is the case. Therefore, a key recommendation for future research and service level audits, is to include all internal and external services accessed by students. It is also vital for services to explore the perceptions and accessibility of counselling services to non-native students to enable appropriate promotion of services to these groups. As discussed, the student population is becoming more diverse, and the prevalence of mental health difficulties reported

by students increasing. There is a noticeable gap in the literature looking into the intersectionality of ethnicity and mental health in the student population. This is a recommendation for future research.

It is clear from these limitations that data recording systems can present a barrier to audit and research processes. Therefore, a key recommendation to university-based counselling services is to ensure their recording processes are optimised for data extraction. As discussed, data pertinent to therapy endings and outcomes was not easily extracted from the ESR. Additionally, the current study was unable to look in detail at types of therapy offered to students, as this information was not routinely recorded. Additionally, it was not possible to look at therapy outcomes for specific problem types, for example depression or relationship difficulties. Often there were more than one presenting problem recorded for each student and some missing data. The authors acknowledge that students often present to services with multiple difficulties, and practitioners are often working trans-diagnostically, therefore the way the data is currently recorded is more reflective of real-world practice. However, for auditing purposes, it is beneficial to streamline ERS to enable the service to conduct time efficient audits of the service, focusing on important outcomes for students.

It is also worth considering the process of diagnosis within university-based counselling services. Whilst practitioners are experienced and knowledgeable in the assessment and treatment of a variety of mental health problems, they are not providing diagnostic assessments. Therefore, the data pertaining to presenting problems in this study should not be viewed as diagnostic.

Dissemination to service and responses

Researchers met with key service stakeholders to discuss the outcomes of the service project. This occurred at a time when a restructure of the university wellbeing services was being considered. The service adopted several recommendations from the project, which were discussed with panels of students with personal experience of using the counselling services. Changes included working with external therapy providers to ensure complete outcome data was returned. The service also came to agreement, through consultation with stakeholders, on the categories to be used to describe problem types. It is hoped that these changes will enable future audits to ensure all students are represented, and to look more closely at the outcomes for different problem types.

Conclusions

Unlike specialist NHS services, universities face a unique challenge whereby they are required to meet the needs of a transient population, at a time where exposures to risk factors for mental health difficulties are highly prevalent. This study has added to a body of evidence which suggests that internal counselling services within universities are able to provide an efficacious service to students which is comparable to the equivalent NHS services. In particular, it has highlighted the experience of service users, demonstrating that internal counselling services are highly valued by students and there is a strong desire for increasing support and funding. Future and continuous replication of service evaluation, incorporating feedback and consultation with students, is vital in the continual development of university-based counselling services which enables them to be responsive to the societal pressures which impact the student population.

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Main Research Project

“I feel like pieces of me are missing now”: An Exploration into Experiences of Non-Diagnosis of Autism using Interpretative Phenomenological Analysis.

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The target journal for my main research project was Advances in Neurodevelopmental Disorders. This journal was chosen as it publishes research on neurodevelopmental disorders, including papers focusing on diagnosis. It also has a longer manuscript length which is more appropriate for qualitative research. The guidance on journal formatting requirements is here:

[https://link.springer.com/journal/41252/submission-guidelines#Instructions%20for%20Authors%20Manuscript%20Submission.](https://link.springer.com/journal/41252/submission-guidelines#Instructions%20for%20Authors%20Manuscript%20Submission)

Introduction

Labelling theory is rooted in sociology and considers the way in which labels influence the formation of identity and self-perception (O'Leary, 2007). A scoping review by Sims et al. (2021) collated research exploring consequences of physical and psychological diagnostic labels, including autism, from the perspective of diagnosed individuals, families and community. Their thematic framework suggested both positive and negative implications of diagnostic labelling, including adaptations required by individuals in response to their label, changes to self, social stigma, medicalisation of their experience, implications on support systems, issues related to disclosure of their diagnosis, and considerations around future life planning (Sims et al., 2021).

The application of diagnostic labels has not only become a way in which we understand and treat disorders, but a lens by which individuals and society understand themselves, as described by Brinkmann and his work on 'diagnostic cultures' (Brinkmann, 2016, 2017). Therefore, when considering the personal impact of an autism diagnosis, one must consider the evolution of autism as a label. As described by Botha et al. (2022) autism has historically been pathologized as a disease or disorder of the mind, often with dehumanising, negative media portrayals. Autism was initially considered a psychiatric disorder or mental illness, as described by non-autistic researchers and medics. Over time, autism has evolved from being considered a mental illness to a cognitive condition, and autistic people are more likely to identify with the concept of neurodiversity, as opposed to deficiency (Botha et al., 2022).

Autism is classified by the International Statistical Classification of Diseases and Related Health Problems (ICD-11) (World Health Organization, 2022) as a neurodevelopmental disorder characterised by impairments in cognition, social communication and interaction, alongside restricted, repetitive and inflexible behaviours, interests and activities. Globally it is estimated that 1 in 100 people are autistic (Zeidan et al., 2022). Autism is typically diagnosed in childhood when developmental milestones are not met as anticipated (Brett et al., 2016). There has been an exponential increase in the number of adults receiving a diagnosis from 1998 to 2018 (Russell et al., 2022). This cohort study found a 787% increase in autism prevalence over the 20 year period, likely due to increased reporting and application of the diagnosis (Russell et al., 2022). Despite this, recent estimations suggest that as of 2018, 0.77%-2.12% of the English population may be undiagnosed (O'Nions et al., 2023).

The lived experience of autism diagnosis in adulthood has been well explored within recent years (Bargiela et al., 2016; de Broize et al., 2022; Huang et al., 2020, 2022; Jones et al., 2014; Leedham et al., 2020; Lewis, 2016b; Lupindo et al., 2023). Responses to diagnosis vary considerably and depend upon individual circumstances, and predictions regarding assessment outcome (Jones et al., 2014). Positive responses to diagnosis are frequently reported, including relief and validation (Jones et al., 2014; Lewis, 2016b; Punshon et al., 2009). Benefits of diagnosis include improved self-understanding and feeling able to progress in life (Lewis, 2016b). Diagnosis has been shown to reduce self-blame about difficult experiences, such as bullying (Punshon et al., 2009). This is not universal, as some negative responses including anxiety, anger and confusion are evident (Huang et al., 2020). Disappointment and beliefs that an earlier diagnosis would have positively impacted life is common in late diagnosed adults (Jones et al., 2014). For many, the hope of gaining access to support is linked with the positive response to diagnosis.

Significant delays in the diagnostic pathways and the increasing waiting lists (Lewis, 2016a) has meant that many people are applying the label of autism to themselves without formal diagnosis (Lewis, 2017), often following periods of familiarisation with the diagnosis through the internet, social media and literature (Lewis, 2016a). The Westminster Commission on Autism (Smith et al., 2021) recommend that services are made available to those with a formal diagnosis, those who are waiting for diagnosis, those who do not wish to be diagnosed, and those who did not meet criteria for autism against their expectation (i.e inclusive of people who self-identify as autistic). This recommendation was based upon consultations with autistic people who by means of social support, felt less ostracized. As well as the frequently reported issues with accessing diagnosis, and gaining appropriate support post-diagnosis, stigmatisation of people with autism remains a concern of individuals and their families.

Despite the many positive associations autistic people feel with their diagnosis, empirical evidence highlights that Autism remains a diagnosis which is stigmatised in the United Kingdom (UK) with both individuals (MacLeod et al., 2013), and families (Mitter et al., 2019) reporting experiences of stigma. Autistic people report feeling they are perceived in line with negative stereotypes which misrepresent their identity (MacLeod et al., 2013). A more recent study replicates some of these earlier findings and autistic people reported feeling as though autism was considered a 'bad thing' by society, with sensationalistic journalism perpetuating narratives about violence by autistic people. Additionally, people

reported that when they did not fit into the typical stereotype (white, CIS-gendered, heterosexual, non-verbal) this presented a barrier to diagnosis and potential dismissal by services (Botha et al., 2022). Stigmatisation of autism is known to vary between ethnic and cultural groups (Kandeh et al., 2020).

Whilst negative narratives of autism persist and are feared by some, a societal shift towards more acknowledgement of positive attributes and skills of autistic people is evident (Kenny et al., 2016). Autistic people are shown to report many positive attributes, which is predictive of collective self-esteem (Cooper et al., 2021) due to a strong affiliation with autistic identity. Consistent with social identity theory (SIT) (Tajfel & Turner, 1979), which postulates a perception of belonging to a group we perceive positively is a source of pride and self-esteem and linked with improved psychological wellbeing, autism identification has been shown to be linked with personal self-esteem. This was mediated by collective self-esteem and in turn, improved depression and anxiety (Cooper et al., 2017).

If autism diagnosis can contribute to improved mental health and wellbeing by enhancing collective self-esteem, we must consider the implications for people who experience non-diagnosis against their expectation, a gap in current literature. A mixed-methods study (Powell & Acker, 2016) involving 74 autistic individuals including those with a subclinical threshold diagnosis, found that people who received a full diagnosis felt relieved and reported improved self-esteem, as is replicated in more recent research (de Broize et al., 2022; Huang et al., 2020; Lupindo et al., 2023). However, people with a subclinical threshold diagnosis expressed confusion and disappointment as a result of being neither autistic nor non-autistic, posing a challenge given autistic tendencies towards black and white thinking (Geurts et al., 2009). The current study aims to explore these themes further, by focusing on non-diagnosis specifically.

Research has examined the experience of parents whose children did not receive a diagnosis (Bendik & Spicer-White, 2021). Interviews with six parents of children between the ages of four and fifteen revealed several themes. Parents acknowledged their child as different but lacked a way to describe this without a label. Parents felt alone and judged within the assessment process, paired with pressure to perform and to advocate for their child. Although some were left with a sense of relief following non-diagnosis, others lacked closure and an understanding of their child's needs (Bendik & Spicer-White, 2021).

The current study aims to explore the lived experience of non-diagnosis in adults, from a first-hand perspective. The study aims to understand the

implications of non-diagnosis on an individual's self and social identity, functioning and access to support. To the researcher's knowledge, there is no existing research in this area.

Method

Researchers and positionality

The first author identifies as a neurotypical, CIS-gendered, white-British female with an interest in the lived experiences of autistic people and is undertaking this research within clinical psychology training. The second author is a clinical psychologist and academic with an interest in learning disabilities and autism. Autistic people were consulted throughout the project and supported in the development of the materials and content of the semi-structured interview. Autistic people consulted researchers on adapting the interviews and recruitment processes. In line with the preference of autistic people, the article will use identity first language and refer to autistic people, instead of people with autism (Kapp et al., 2013).

Methodological approach

This cross-sectional study used semi-structured interviews analysed using interpretative phenomenological analysis (IPA). IPA has been developed as a method to explore the lived experience of individuals, it is ideographic in the sense that it aims to elicit the meaning people make of significant life events (Smith et al., 2022). The hermeneutic cycle (Smith et al., 2022) describes the double layer of meaning making, as the researcher aims to interpret the meaning participants make of their own experience. IPA studies involve small, homogenous samples of people with similar experiences. Keeping a reflexive diary is an important part of the research process.

IPA is an important tool in autism research due to its focus on lived experience and meaning making (Howard et al., 2019; MacLeod, 2019). IPA was chosen for this particular research question, over other qualitative methodologies, due to its idiographic nature, ability to consider people within their own context and its focus on the meaning people make from their lived experience. Additionally, IPA insists upon recognition and reflection on the double hermeneutic cycle, which feels particularly relevant as the authors are neurotypical individuals, attempting to interpret the meaning of people who may identify themselves as neurodiverse.

Participants

A homogenous sample of 10 adults aged 25 to 50 (6 females, 3 males and 1 non-binary) were recruited who had been through a diagnostic assessment for autism and not received a diagnosis. One participant had later gone on to receive a diagnosis and was included as they felt they could consider their experience of non-diagnosis retrospectively as it had been highly memorable and impactful. One participant was diagnosed with a learning disability, but questioned the validity of this diagnosis and felt he was autistic. Most participants had been assessed by the national health service (NHS), but some were assessed in private practice. Participants were all fluent in English as either a first or second language.

Participants were recruited through an online mental health research participation platform (MQ Participate) (N=7), via social media (n=1) and through charitable organisations (n=2). Table 1 presents the demographics of the sample.

Table 1

Participant Demographics

Participant Pseudonym	Ethnicity	Age at assessment
Shona	White British	Adulthood
Theresa	White British	Adulthood
Alan	White British	Adulthood
Chen	Chinese	Adulthood
George	Other White	Adulthood
Sarah	White and Asian	Adulthood
Mary	White British	Adulthood
Emily	White British	Adulthood
Lauren	White British/American	Adulthood
Henry	White and Black African	Childhood

Procedure

The study was approved by the University of Bath Psychology Research Ethics Committee (23015) (see appendix I). Participants recruited via social media or charities firstly contacted the researcher by email to express their interest in taking part in the study. If the person had signed up via MQ participate, the researcher was automatically notified and sent their details. At this point, the

researcher sent the information sheet (appendix J) and consent form (appendix K) over to the participant. Interviews were scheduled once informed consent had been provided.

The interviews lasted 1.5 hours and took place on a video conferencing platform. Participants were given the option to have their camera off if this was more comfortable for them. At the beginning of the interview, the researcher explained the process of the interview. None of the interviewees requested any adjustments apart from having their cameras off (n=4).

In line with IPA methodology, open questions were asked, and participants were prompted to provide further information on topics relevant to the research question. A semi-structured interview schedule was utilised, but there was flexibility to explore interesting lines of enquiry within this (see appendix H for semi-structured interview questions). All of the interviews were suitable to be included in the final sample, however some interviews were richer than others due to language differences and self-reported difficulties with communication. One participant had their autism diagnosis in an atypical scenario through involvement in a research study. Their interview was included as it reflected the diversity of experiences of non-diagnosis.

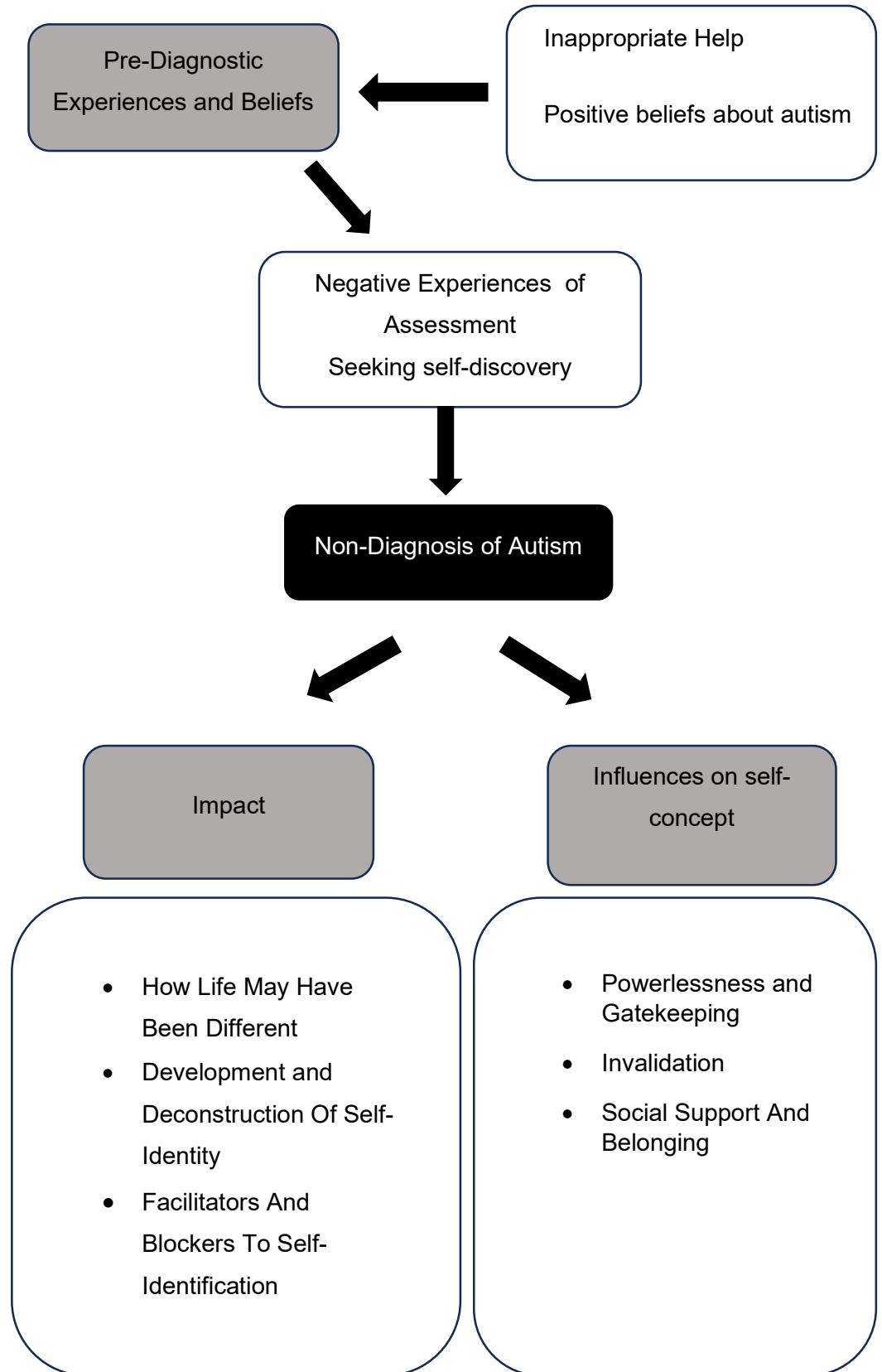
Participants received a £15 voucher for their time. Debriefing information (appendix L), contact details for the researcher and signposting for local organisations was provided. The interviews were automatically transcribed but checked for accuracy by the main researcher and research apprentice.

Analysis

Each interview was initially analysed individually. Firstly, each transcript was read and re-read to enable the researcher to become immersed and familiar with the data. This was followed by developing exploratory notes, where the researcher makes note of anything they notice within the data. Then, a more interpretative stance is taken to developing a set of personal experiential statements based upon the transcript and the exploratory notes (see appendix F for illustrative example). After this, the researcher developed personal experiential themes by looking for patterns within the experiential statements (appendix G for illustrative example). This enables each participant to be considered on their own, and their individual experience interpreted, before moving into developing larger group level themes which are presented in the results.

Figure 2

Diagrammatic presentation of study themes (grey boxes) and subthemes (white boxes) with black arrows and boxes to demonstrate the processes and events.



Results

See figure 1 for a diagrammatic presentation of study themes and table 2 for the full table of group themes and subthemes.

Table 2

Summary of Group Experiential Themes and Subthemes

Group Experiential Theme	Subthemes
Pre-Diagnostic Experiences And Beliefs	Inappropriate Help Positive beliefs about autism
Experiences of Assessment	Negative Experiences Of Assessment Seeking self-discovery
Impact	How Life May Have Been Different Development And Deconstruction Of Self-Identity Facilitators And Blockers To Self-Identification
Influences on self-concept	Powerlessness and Gatekeeping Invalidation Social Support And Belonging

Pre-Diagnostic Experiences and Beliefs

Inappropriate Help

This theme describes the common experience of having unmet needs and feeling overlooked prior to assessment. Many participants talked of their emotional struggle or discomfort with the approach being taken to meeting their needs, and there was often a dissonance between the participants' perspective and the focus of the therapeutic support. . Lauren was particularly frustrated by this:

Lauren: Cue more rounds of CBT, CB ***** T, which is helpful, but only if it's there to treat the right problem.

Lauren used expletives as a way to emphasise her frustration of this mismatch of needs and support. She talked about a dehumanising experience, likening herself to a broken object going through a factory process.

Lauren: Where you come in one end as a slightly broken, damaged piece of a thing and they spit you back out of their factory process. Mended.

Except that's not possible when you have complicated stuff going on.

A similar sentiment from Mary

Mary: And the therapy had just taught me how to again, how to say what I should say and how I should say it. Rather than actually me saying what I need to say.

Mary's experience speaks again to the discomfort of the approach often taken to meet her needs. She talks about the overwhelming sense of anxiety she would experience as a result. This account emphasises not only the felt sense of disconnect, but also the worsening of experiences as a result of this disconnect. Many participants had difficult early experiences and had received multiple diagnoses and had repeated experiences of ineffective and unhelpful treatment. A subgroup of the sample talked about the stigma they experienced as a result of different psychiatric labels. Emily talked of receiving a diagnosis of borderline personality disorder and being treated for this, explaining 'when I don't really agree with it, it is really hard'.

Emily: ohh acceptance I suppose... The BPD diagnosis and that has never sat comfortably with me. You know it's it's it's BPD is quite quite difficult diagnosis anyway. Because of stigma and such.

Positive Beliefs About Autism

There was an association between the person's internal model and assumptions of autism, their views of societal beliefs about autism, and their response to non-diagnosis. Two of the participants talked about their strong positive view of autism, for example George said 'I think that it is actually an asset in my field of work' and Alan said 'Autistic people are a bit like the X-Men...they're the best'. As such, an autism diagnosis was frequently discussed as a preferred alternative to what felt like inappropriate, more stigmatising psychiatric diagnoses.

Shona: 'I've already faced a lot of stigma through my mental health diagnosis... And if I was considered more disabled, I'd have access to different services. Um but because it's because they're viewing it as mental health, they just say oh you just gotta practise till it becomes better

for you... Yeah, it's like with autism they accept that you've got stuff that you can't do'

There was a sense that many participants, particularly those who had received inappropriate help, really sought the autism label for themselves.

Emily: he's recently been diagnosed...and sort of has said what a complete difference it's made to his life and how he now understands himself a lot better and... Just like I want to be able to say that, with my heart.

Whilst this was a strong narrative coming through from the participant accounts, it was not shared by all, and some participants had positive reactions to learning they did not receive a diagnosis.

Henry: 'it is strengthened my wellbeing yeah, to find out that I didn't have a such kind of a disorder.'

Experiences Of Assessment

Negative Experiences of Assessment

This theme is broad and encapsulates different aspects of the difficulty participants experiences around their assessment.

Managing the waiting time. Waiting for an autism assessment was frequently discussed as being accompanied by strong emotions, often of anxiety with themes of uncertainty. This was indicative of a sense of importance being placed on the assessment, with the outcome being seen as something with important implications on the life of the individual.

Emily: I don't wanna, I said. Look, don't rush it cause I'm this my pretty much my life hinging on this. The outcome of this.

This often meant that people developed strategies to cope with this period of waiting.

Lauren: I'm gonna just explain that that's painful. Waiting is really painful...I was reaching out to the community, so I found. The X Charity here in X and connected with them a little bit.

Developing an approach to the assessment. With the significance of the assessment, participants reported methods to manage the anticipation and intense emotions which accompanied the assessment, including psychologically preparing themselves for an adverse outcome.

George: I went into the process being quite open minded about this and and realising that you know, maybe I'll get a diagnosis. Maybe I won't. Um

and maybe the maybe some of my my behaviours could be explained one way or another'.

George talks about the importance of approaching the assessment holding a view of the outcome as not guaranteed and preparing oneself for the possibility of not getting the diagnosis. This experience was often shared, with participants placing importance on remaining open to the possibility of not getting the diagnosis.

Invisibility within the assessment. Many participants expected to receive a diagnosis, as they had often spent many years developing a narrative of their lives through this lens. Unsurprisingly, this often meant that when assessments did not have the expected outcome, people felt invisible and unseen, as though parts of their experiences had been missed.

Mary: I feel like they knew nothing about me and my history at all, so I was like a completely, you know, a complete stranger just turning up to this unit...Which made it really difficult to kind of, you know, get everything across.

Mary: And I think that's what I didn't get from the assessment at all, the possibility that going through life as an undiagnosed adult female, um life experiences could have affected my ability to communicate properly and clearly.

Shona and Theresa, with a similar sentiment of not feeling seen or believed:

Shona: I don't know really cause like I said, I know I've got difficulties, but nobody seems to believe I've got these difficulties.

Theresa: And he (assessor) sort of flipped through it (background information about Theresa) within about, I don't know, 10 seconds. Ohh I can see you've got a lot of information here and didn't even read a thing.

Invisibility also related closely to participants lived experience of masking their difficulties throughout their lives. For some, this appeared linked to a sense of being unseen in the assessment, as assessors did not see through this mask.

Mary: My my partner was like now make sure we don't mask and I'm like. I'm at the point where I can't tell whether I am or not. Because it's just automatic. It's just an automatic thing. I will do whatever I can do to get through.

Alan talked of a very similar experience, but one where he felt manipulated into dropping the mask and then felt humiliated and exposed.

Alan: He actually opened up the window. But with the hopes that will put my hands over my ears... I don't see why should have to be humiliated, just it serves some per- serve some alter ego of somebody else.

This theme presents a narrative of assessments as a life changing experience, with strong emotional investment from the participants. This investment as something which needed to be managed by the participants by developing ways to cope with the uncertainty of the wait.

Seeking Self-Discovery

Participants were asked about their hopes going into an autism assessment. Assessments were discussed as a process of developing self-understanding, finding closure, and reducing self-blame. It was often explicit that the label itself was not sought, and self-discovery was placed at a higher importance.

Sarah: I wasn't necessarily seeking a diagnosis, but if that would have helped like, you know, answer like a lot of the concerns and questions that I had...you know why these things were happening or why I was feeling this.

Similarly, Lauren talked about not explicitly wanting the diagnosis, but seeking to understand herself better:

Lauren: I'm not here for the label. I'm here to understand myself better. I'm hoping that with your clinical experience, you can tell me things that I haven't been able to work out for myself or give me strategies that will help me to chart a course for myself.

It appears that participants were seeking a level of self-understanding to aid them in getting the right help, but also being able to find more compassionate views of themselves. For example Alan talked of some shameful social experiences and when talking about his hopes from the assessment, went onto say:

Alan: Um. Closure. From some of the, from. I suppose for example. I suppose just closure of how I was when I was a child, and even partly in my adult life.

As a result of non-diagnosis, many participants weren't able to achieve this level of self-understanding and were left feeling confused such as Sarah who said 'if it's not this, what is it or what has been causing these take things to go wrong with me'.

Lauren also had a significant recollection of being told she did not meet diagnostic criteria for autism. She talks about the assessment 'not covering' her experience, indicating a sense of her difficulties feeling bigger than what was perceived by the assessors.

Lauren: It did not cover it by a long way and I said this isn't good enough. I said this like I've come to you asking you to enlighten me about myself and I feel like you're telling me I'm not the thing that I, that I know, you know, how do you explain these things then?

Impact

How Life Might Have Been Different

A diagnosis of autism was seen as something which may have altered the trajectory of the participants lives, with expressions of loss and missed opportunities as a result of non-diagnosis. This theme echoes previous research about late diagnosis of autism.

Theresa: What comes to mind is lost opportunities. You know, I mean it's I could give you a couple of incidences, but it's full, full of life's incidences. This loss often involved issues surrounding early life, education, employment, and social lives. This was often intertwined with ideas around living undiagnosed throughout life, rather than specifically what opportunities are lost as a result of the non-diagnosis.

Shona: But when I was at university, I struggled a bit at university with my mental health and stuff. So if I'd had the diagnosis and I've had it earlier, I might have been a bit more looked after.

When looking for work, Theresa talked about the implication of decisions which would have been very different if she had more understanding of her own needs:

Theresa: You know, and so I went into it and it was the worst decision of my life. And ended up, having a nervous breakdown, essentially.

This sense of loss extended beyond practical opportunities; it also involved the loss of the psychological impact of a diagnosis. Theresa, for instance, expressed the absence of a more compassionate view of her social skills, and Lauren about how it may have boosted her confidence.

Theresa: And if I'd have had the help even if I wasn't very good at people's skills, at least I'd know why.

Lauren: You know, then then you have got some confidence to go into the world and be yourself.

With supportive contexts surrounding the person, these kinds of experiences were quite different.

George: I count myself as quite lucky for A. working in software engineering and industry where neurodivergence is a lot more prevalent than in general population...and B. having a very understanding uh employer and and management structure. I'm conscious that a lot of

people are not in this position and their employer would all but require a formal diagnosis before offering any kind of adjustment.

Another alternative perspective was seen by Alan, who considered whether having the diagnosis may have led to some loss of opportunity, rather than the other way around. He said 'would I be better off if I didn't have?'. For Alan, his experience of marginalisation from his learning disability diagnosis may have influenced his belief that at times, a diagnosis may contribute to a loss of opportunity and independence.

For two participants involved in the study, complex physical health issues were impacting on their well-being and functioning. This was often linked to the experience of being undiagnosed, and having to work hard to fit within a society which does not understand them.

Lauren: I had suffered what I now understand or or have come to recognise as being an autistic burnout from which I still have not fully recovered, and I don't really think I'm ever going to fully recover now because it it's had physical health knock ons that I'm now living with long term conditions basically from a lifetime of overcompensating.

Development And Deconstruction Of Self-Identity

The participants careful construction of an autistic identity was evident. Life experiences and difficulties were often understood as autistic experiences. An initial sense of relief was often reported when finding information which resonated with the participants. What followed was a lengthy process of gathering evidence, gaining support, and confirmation from social circles. Participants often used language suggesting they felt compelled to justify and legitimise their development of an autistic self-identity, possibly in response to a felt sense of being a 'fraud' for self-identifying as autistic (see facilitators and blockers to self-identity). Following non-diagnosis, a process of deconstructing this self-identity was often fraught with difficult emotions and feelings of rejection and invalidation. Evidence of being autistic was often gathered through family, friends, and information, for example:

Emily: I've got, two nephews that are on the spectrum...So it's kind of ohh, it's like in the family...I picked up this book about autism in women and girls and was reading it... I was like oh my god this is me'.

A process of realisation and connection to material about autism was evident.

Theresa: And realised ohh this empathy thing is different. And ohh I do have lots of difficulty with people...Realised that ohh I didn't I. I had a lot of difficulty with um um yeah, I had a lot of difficulty with people.

Alan talks of the diagnosis 'finding him', the use of such language indicating that it was not something he was necessarily seeking out, implying some shame about intentionally finding evidence for a diagnosis, or having to justify their belief following non-diagnosis.

Alan: But I was exploring my own behaviour. Why I act certain way? Why I act in certain ways I do....I wasn't looking for it at all. It found me, if you like...Because whenever I was looking at my behaviour. Autism came up Following non-diagnosis there appeared to be an undoing of the narrative which had been carefully constructed by the participants. This was talked about as beyond a facet of their lives but an intrinsic shift in self.

Theresa: You know it rocked who I am, as opposed to a thing in my life, which was much, much more.

This 'rock of identity' encompassed many aspects in terms of how people would be viewed and understood by others.

Theresa: Because it is so important to me now being autistic, it's it's it really is who I am. And and I'm sort of trying to still come to terms with other people are not gonna understand me.

For others, the deconstruction of this part of their identity gave rise to some more difficult thoughts and emotions:

Mary: If you're just not trying hard enough, you're just being awkward and all the disabilities are in your head...And it just kind of confirmed it.

Mary: And then when it came up again after the assessment, it was just like yeah, you're just a bad person. Yes, you don't belong.

Understandably, this deconstruction of identity was often expressed with distress. This intense emotional response often prevailed over time.

Emily: I was devastated. Absolutely. I still am....Cause I thought sort put so much into it and was really like I said cause it just made more sense to me. And. But when I didn't get it. It was. Ohh yeah, horrendous. It still it still is.

Theresa: I remember pacing up and down my living room. Just going what? I actually had a meltdown on the phone, and I was crying and crying.

Facilitators And Blockers To Self-Identification

Self-identification was discussed in interviews. Multiple perspectives were held, and specific blockers and facilitators to feeling able to self-identify became evident in the analysis process. For example, having a supportive social context enabled some people to feel able to self-identify as autistic. The use of the word 'tribe' emphasised a sense of belonging and connection to a group of women

with similar experiences which, for Lauren, facilitated a lesser need for a diagnostic label, possibly by means of developing a shared identity.

Lauren: What I did see was that I had things in common with these other women that were consistent, and I said I don't really care what we call it, but whatever it is that they're struggling with, I'm in that tribe.

For others however, the concept of self-identification was blocked by fears of rejection and judgement from autistic communities, strengthened by the knowledge that they were not diagnosed following an assessment. Emily talks of 'jumping on the bandwagon' with regards to how she might be perceived as a self-identified autistic person. This suggests perceived criticism for following a trend or popular belief without a sense of genuineness or authenticity.

Emily: And I I do worry that that you know if, if I did sort of self-identify, the autistic community, whether there would be, if not outwardly, perhaps some another word is some sort of 'well, you're not actually diagnosed as autistic'...I wouldn't like it to be sort of jumping on the bandwagon as well.

Mary had a similar experience and talked of feeling 'like a liar, like a fraud, like a fake' for self-identifying as autistic. She also predicted that others would say 'you don't belong here. You're just doing this to be trendy or something'.

Perhaps in response to this fear of judgement on part of a lack of authenticity, several participants felt that a diagnosis must be confirmed or verified by someone in a position of power, perhaps as a means of proving this authenticity.

Emily: Well, can't really explain it, but it's great that if people are able to think, yeah, this is me and you know, this is what I am when I wanna identify as autistic. Brilliant. But with me it needs confirmation, I suppose.

This same felt sense of being fraudulent came from Theresa too, who talked of self-identification as 'taking somebody else's label that wasn't mine yet'.

For Sarah, the perceived social evaluation was a barrier to self-identification, in that she perceived her social context as one which would not accept her diagnosis, and would be accompanied by negative assumptions of her, which she wished to avoid:

Sarah: Why would I, don't want like to, you know, sort of portray myself to the world that like... And then there's also, like, discrimination that happens in, like, especially if it's like these mental health things because a lot of people think you're using that as an excuse to avoid doing things

Influences on Self-Concept

Powerlessness and Gatekeeping

The role of power was evident within many parts of the participants experience. Having a diagnosis of autism, or using a label often felt empowering, but first this diagnosis had to come from someone holding a position of power.

Lauren: I need something on paper that says I have these difficulties from somebody apart from me because they're not just going to take my word for it.

The lack of power is reflected suggesting that her word is not enough to be believed about the things she finds difficult. This lack of power even led to consideration of extreme ways to get needs met.

Lauren: I was falling between the gaps of provision because I'd never been hospitalised. So it does actually make you slightly motivated to be hospitalised, quite honestly.

She went onto talk about how she can use the diagnosis in certain situations to get her needs met, in so doing, gaining a sense of power and autonomy.

Lauren: So I guess maybe it's a card (saying she is autistic) that I play when I feel the need or I feel that it's helpful.

Similarly, Alan talked about needing the power of a professional making a diagnosis before his needs would be seen within his family context.

Alan: The reason I'm saying my family is because they're relying on that diagnosis...To them, if I if the doctor say I hadn't got it, they won't even entertain the idea.

For some, this lack of power was a struggle and something which they felt they needed to fight against, and use their self-advocacy skills to gain power and be heard. For Chen, however, there was agreement that the professional power is needed.

Chen: but um it's like a um a thing that need doctors to see and solve'.

This sense of powerlessness was related to feeling gatekept from the help which was needed. Participants felt held back from accessing the support they felt they needed, which was often viscerally likened to feeling trapped.

Theresa: So for me, I've got a picture in my head I've just being gaffer taped around my mouth and my hands tied to a chair.

This description highlights the felt sense of forced entrapment for Theresa and may also indicate the power imbalance experienced in relation to gatekeeping processes put in place by services. This eliciting feelings of powerlessness

against a system, which is experienced as threatening. This same sense of feeling trapped was shared among other participants.

Shona: Um (pause) so (pause) I don't, I don't really have anywhere to go in terms of my needs.

Mary: but it's like there's an invisible barrier between me and everyone else

A sense of despondency in response to such barriers is evident in the way Mary talks about her experience, and how Lauren articulated 'turning her back'.

Lauren: So. I kind of. Turned my back on that. And for lots of reasons I thought well. They've got very strong gatekeepers here. It may be that the definitions they have are there for financial reasons.

Invalidation

Experiences of being invalidated appeared to prevail across the lives of many of the participants, and specific incidents had 'cut like a knife' (Theresa). The impact of invalidation was evident, both before their assessment, and in response to non-diagnosis. For some, needing validation was the reason for seeking the assessment.

Theresa: So I couldn't for me. I couldn't self-identify without having that validation. I knew that people did...you don't need to go and get a diagnosis of being gay, do you?...So I do understand you know why people don't bother?...Whereas because of my upbringing and history, I really feel. I do....I wish I didn't, but I do.

Here Theresa is talking about feeling unable to self-identify as autistic but likens it to homosexuality, drawing attention to the view of autism as something intrinsic and associated with a person's identity. For her though, the need to have a diagnosis was driven by a sense of wanting the validation related to her difficult early life experiences:

Theresa: My Mum used to say ohh you're so sensitive. Ohh you wear your heart on your sleeve. Ohh. Stop being so ridiculous. That's not loud. No. And I just the invalidation of like what? It's not just me, is it? Doesn't everyone experience it? You know, just continue if you can. Imagine from birth having your whole life invalidated so.

For Theresa, this sense of being invalidated throughout her life only served to increase the need to get a diagnosis, to finally get the validation she had been seeking. She talked of needing such validation:

Theresa: And not having that validation of that inter that internal. I guess it's like a strong person inside. Yeah, I've yeah, the the parent I never had and trying to be my the parent, I never had to myself. It's very much to self-validate.

Similarly, Mary reflected on how she may have felt had she received a diagnosis and how this invalidation has impacted her self-identity:

Mary: I would have felt validated as a person...Accepted that I had place. That I had other people that were like me. Other people that might like me. Other people that I could try and learn to be myself with and you know and trust and be who I was meant to be. And that's the thing going through when I'm 43 and I'm still struggling to work out who I am.

For some, there were difficult implications of this invalidation, leading to suicidality and worsening of mental health difficulties:

Theresa: I could have well been suicidal again at that point I think, because I was so sure and it would have rocked me so much. That I would have been so confused. And dejected. And confused. Just so confused. I yeah. I think it's to do with not feeling validated. Not feeling understood. And people completely dismissing me. It's just like, what's the point?

Social Support And Belonging

Another theme emerged from the common reflection upon the role and impact of the systems surrounding people, and society. Often, participants reflected on seeking a diagnosis to gain a sense of belonging in their lives. Belonging often being placed in opposition to the idea of facing things alone:

Mary: But I want to know that I'm not alone...That there is a reason for this, not just like, ohh, cause you're weird.

Participants, by means of not finding this sense of belonging were often left with difficult emotional states regarding their experience of the world:

Emily: I just don't. I just don't feel like I fit in this world anywhere... And it's just over the years, it's just become increasingly increasingly difficult to deal with, and I find the world a very painful place to exist in...I have said many times, you know, this world's really painful. I don't really wanna be in it.

A sense of not belonging was often held by this group, for example Alan described being 'part of both, or neither', when reflecting on his position. Lauren articulated the same sentiment about her social self.

Lauren: Is that my my social existence has been very much pushed into the margins of, like the corners of society. I feel very marginalised.

People often used language which evoked a sense of feeling equal and accepted, such as Mary who said, 'finally I can get to a point...where I feel, I get

a place' and Shona 'I felt like I fit in there'. This highlighted the human desire to feel a sense of normalcy and acceptance within our social groups. For those who had not received a diagnosis, there was a longing for support.

Shona: I feel like I want to be part of a community where people help each other and stuff as well, like um I feel like if I went to autism meetings, there's probably people there to help you with different struggles and stuff, and then you can help other people with things and stuff. Um, but there's nothing like that for mental health, really.

Discussion

Participants described a wide breadth of emotional, social, and physical implications of non-diagnosis of autism. Four superordinate themes were identified including pre-diagnostic experiences and beliefs influencing responses to non-diagnosis, experience of assessment, impact of non-diagnosis and the influence on self-concept.

A key theme was the development and deconstruction of an autistic identity. As discussed, participants had carefully gathered evidence and constructed an identity through the lens of autism, which felt validating and was often confirmed by others. Understandably, distress was a product of non-diagnosis, related to the deconstruction of this identity. For some, this confirmed alternative, self-critical beliefs and attributions for their difficulties. This replicates previous research which has found that people who receive a diagnosis are able to disconfirm more self-critical beliefs about their difficulties (Punshon et al., 2009). Non-diagnosis contributed to feelings of confusion, destabilisation and not knowing their place in society, much like the experience of receiving a borderline diagnosis of autism, as explored by Powell and Acker (2016). This experience of confusion is evident in the current study. In line with previous research, (Leedham et al., 2020) self-understanding was a goal for many participants, as opposed to a label. Unfortunately, the opposite was experienced, and participants felt more confused about their identity. This process also appeared to impact upon the participants ability to self-identify as autistic.

Self-identified autistic people who later received a diagnosis have described their reasoning for seeking a formal assessment. This indicated that people sought validation for their experiences, wanted to reduce feelings of being a fraud, and wanted support for their unmet needs (Sandland, 2022). The current study suggests that non-diagnosis might maintain feelings of being a fraud and perceived negative judgement from autistic groups, preventing self-identification. As such, many participants felt unable to engage with support or access help

which they felt may have benefited them. It has also been found that self-identifying as autistic can lead to development of a positive autistic identity (Parsloe, 2015), which has been linked with improved psychological wellbeing (Cooper et al., 2017). Therefore, people experiencing non-diagnosis of autism are likely to remain in an unvalidated position, with unmet needs whilst also feeling unable to access services as a self-identified autistic person. Supportive social systems were important to the participants in this study, in line with previous research about late-diagnosis (Bargiela et al., 2016; Leedham et al., 2020). Social support had enabled some participants to access autism services, contributing to feeling supported, validated, and addressing unmet needs. Sadly, many others had not felt able to do so and reported feelings of marginalisation within society.

Invalidation was pertinent to the experience of non-diagnosis. Participants reported multiple experiences of being invalidated throughout life, including having their difficulties minimised or unseen by others and lacking an appropriate way to describe their needs. Feeling invalidated appeared to strengthen the need for some participants to gain a diagnosis, only to feel invalidated again by non-diagnosis. This theme has been replicated in late-diagnosed women who felt validated by a diagnosis (Leedham et al., 2020). In this study, several participants linked this invalidation with worsening of their mental health. Mental health was shown to improve once people gained validation and appropriate support following diagnosis (Leedham et al., 2020). Unfortunately, non-diagnosis may perpetuate invalidation and impact on mental health.

Women made up the majority of the sample, which is unsurprising given the continued gender disparity in autism diagnoses, which has been suggested as three to one, male to female (Loomes et al., 2017), as well as the evidence that diagnostic tests such as the autism observation schedule (ADOS) and autism diagnostic interview-revised (ADI-R) are not sensitive enough to reliably identify autism in females (Rynkiewicz et al., 2019). The majority of women included in the study reflected upon their experience of mis-labelling, whereas only one of the men included in the research had this experience. This is consistent with previous research which reports that women are more likely than men to be identified late, be mis-diagnosed or not diagnosed at all due to a focus on alternative conditions (Gesi et al., 2021; Loomes et al., 2017). These women in the study had experienced backgrounds of bullying, abuse, and attachment trauma. They linked such experiences with difficulties with interpersonal relationships and mental health. As described in *inappropriate help*, women felt

that because of these experiences, the diagnosis of autism was overlooked and several received diagnoses of borderline personality disorder (BPD), and thus unhelpful treatment options.

Previous research shows that the most common misdiagnosis for autistic women is personality disorder (36.4% of misdiagnoses) (Gesi et al., 2021), which authors suggest is due to high diagnostic overlap. Recent qualitative research (Powell et al., 2024) has explored the experiences of women who were diagnosed with autism, after an initial diagnosis of BPD. The majority of the participants reported that the BPD diagnosis did not fit, much like participants in the current study. Additionally, it was common for undiagnosed autistic women who self-harm to be diagnosed with BPD and receive subsequent treatment which felt inappropriate and unhelpful. The authors provide a useful summary to support clinicians to differentiate between autism and BPD in women. Similar results have been shown with groups of men and women with late diagnoses (Leedham et al., 2020; Lupindo et al., 2023). As such, there is clear evidence that non-diagnosis can contribute to continued inappropriate help, invalidation and possible worsening of mental health symptoms (Kreiser & White, 2014).

Unsurprisingly, individuals not expecting to be diagnosed appeared to accept the non-diagnosis more readily. However, for those who did anticipate a diagnosis, it was much more difficult to make sense of this and deconstruct their autism identity. With the aforementioned issues of mislabelling and inappropriate help being more prevalent in female populations, it is unsurprising that men in the study were, in some cases, more accepting of non-diagnosis. For example, one male-identifying participant was very comfortable with non-diagnosis, despite relating to much of the diagnostic criteria, as their differences were accepted and supported by their system. This difference is likely to be influenced by the social context and expectations of men and women. It is suggested that the same level of autism traits may be more impairing for a women due to the societal expectations (Taylor & DaWalt, 2020), of femininity, appearance, caregiving and sensitivity (Kanfischer et al., 2017; Miller, 2003). Whilst the expression of emotion in males has often been associated with weakness (Pollastri et al., 2018). As such, traits of autism may be more expected and normalised in men, which makes a non-diagnosis of autism easier to accept. Further exploration of these societal influences would be a valuable contribution to the evidence base surrounding non-diagnosis.

Participants spoke of their preference to be labelled with autism over BPD or psychosis. Unfortunately, research continues to demonstrate that public and

professional views of BPD remain stigmatising, often related to people being hard to treat or intentionally manipulative (Ociskova et al., 2023), so it is unsurprising that people may wish for a different diagnosis as a means of feeling less social and self-stigma. Autism may be a more acceptable diagnosis due to the continued shift in societal narratives (Kenny et al., 2016).

Limitations

The sample size is large within the context of IPA research (Smith et al., 2022). As expected with qualitative research, rich, in-depth data is provided but there are limitations to the generalisability of the findings due to smaller samples. Participants in the study were self-selected, and the study may have attracted people who had negative experiences, possibly creating bias towards negative experiences of non-diagnosis. However, the study did include two people who had more positive responses to their non-diagnosis, which is reflected in the results. These narratives are less dominant throughout the research due to them being less frequently reported. In IPA studies with larger groups, a careful balance is struck between holding the experiences of each individual, whilst also being able to describe the experience on behalf of a larger group.

Clinical Implications of the Research

With increased awareness of the emotional and social implications of non-diagnosis of autism, services can develop methods by which to support individuals through this experience. Acknowledgement of prior work and consideration that people will have put into viewing themselves as autistic is likely to support people to feel more validated in their pursuit of a diagnosis, combating feelings of invisibility within assessments which was evident in this research. Additional support to interpret and make sense of assessment outcomes is likely to support individuals who may struggle with the deconstruction of their identity and lack of self-understanding. For people who still feel strongly that they are autistic, support to access the help which they feel they would benefit from, such as individualised signposting and recommendations could be beneficial. This has to be considered at many levels of the care pathways, such as from general practitioners, as well as through specialist autism assessment services.

A theme in the current study was that people sought self-understanding over a label, and often felt confused, uncontained, and distressed following non-diagnosis, with a sense of 'well now what?'. In the UK, the healthcare system functions within silos, and people are referred to specialist teams for autism

assessments. Once this assessment is completed, depending on the outcome, people are likely to be discharged, referred on or given signposting. For those who experience non-diagnosis, this can feel dismissing and uncontainable and not meet their need for self-understanding. This may be where psychological formulation, as a more holistic, person-centred approach may be of benefit (Johnstone, 2018).

This study supports a reshaping of clinical services in the UK, with a move away from diagnostic thresholds and towards a needs-led approach, as has been campaigned for by Johnstone (2018) in her work with the power threat meaning framework. It could be argued the cohort of undiagnosed people have fallen short of the somewhat arbitrary application of a diagnostic threshold. All the while, autism has been largely accepted as a spectrum. The national framework to deliver improved outcomes in all-age autism assessment pathways (England, 2023) only refers to the experience of those who aren't diagnosed once, stating the guidance aims to increase the satisfaction of these groups. Much of the guidance, frameworks and operational policies do not consider the process by which non-diagnosis gatekeeps from the support available following diagnosis. It is our view that this population are disenfranchised; they may meet two of the diagnostic criteria or have significant difficulties in social communication yet will miss out on full funding and support. As an alternative to diagnosis, a working group in Portsmouth, UK have begun trialling a neurodevelopmental profiling system (Dunn, n.d) which recognises that people often fall short of full diagnostic criteria but still experience significant difficulties. The tool has a function of describing observable behaviours to enable interventions or adjustments individuals. This research is in its infancy and not yet trialled with adults, which would be a justifiable next step in clinical practice and research.

This research has shown that self-identification is difficult for people who have experienced non-diagnosis, contributing to feeling blocked from support services. Although services should be available to these groups (Smith et al., 2021), more work may be required to address the fears of negative judgement from autistic peers, possibly by means of developing specific spaces for self-identified people and those who disagree with their assessment outcome. Self-identification can feel validating (Sandland, 2022), and practitioners holding professional power may be able to facilitate conversations around self-identification with non-diagnosed individuals, possibly alleviating some fears. Practitioners may support in developing services for such groups.

Future Research

Future research could focus on how the experience of non-diagnosis is influenced by demographic factors such as age and gender. As discussed, gender may be of particular interest given the aforementioned disproportion of males and females with the diagnosis and how this intersects with responses to non-diagnosis. Future research should address the hypothesis that males are more comfortable and accepting of non-diagnosis as autistic traits are more normalised in society for males compared to females, who are often expected and assumed to be more emotional and social. It would also be important to understand the importance of a diagnosis for women, as this was often identified as a facilitator for social connection which can be associated with improved psychological wellbeing.

Future research should focus on the difference in experience of non-diagnosis for those who self-identify and those who do not. The experience of self-identification should be research more broadly, with an aim to inform how services can implement pathways which support individuals through this experience in the absence of a formal diagnosis.

Additional research into the experience of non-diagnosis from the perspective of families and clinicians would also broaden out the perspectives on the issue, highlighting system level pressures and areas for change.

Conclusion

In conclusion, the experience of non-diagnosis of autism in adults is varied and complex. For those who do not see themselves as autistic, non-diagnosis fits with their view of themselves and appears to validate them. However for others, non-diagnosis can be experienced as a threat to self-identity and contribute to high levels of distress and invalidation, leaving people feeling confused and without access to support. The key themes from this research have been discussed in relation to broader literature on autism diagnosis. The key clinical and research recommendation is a culture shift in service provision, moving away from the black and white thresholds of diagnostic assessments and towards formulation and needs driven assessments for people with sub-threshold difficulties, enabling immediate and detailed recommendations for adjustments and interventions.

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Executive Summary

Scoping Review

Autistic adults report lower quality of life (QoL) than neurotypical adults (Ayres et al., 2018; Mason et al., 2018). The most recent review including QoL literature (Tse et al., 2022) found a paucity of studies including samples over 50 years of age, with a lack of transparency regarding sample age. Consequently, this scoping review aimed to conduct a systematic search of studies exploring QoL in autistic people over the age of 50. It aimed to summarise what we know about QoL in older autistic people compared to neurotypical people. Additionally, it aimed to summarise any known predictors of QoL and measures which have been applied to older groups.

The study systematically searched published and grey literature databases to find relevant research papers. The inclusion criteria were samples over the age of 50, or where the QoL results have been stratified by age group, where a quantitative measure of QoL has been used and published in English language. Abstract and full text screening was completed by two researchers. Data extraction and quality assessment was completed by the main author and then verified by the second reviewer. Disagreements were conferred during a consensus process. 11 papers were included in the final review which had mixed methodological approaches.

The review revealed that there continues to be limited research about QoL in older autistic people. However, it highlighted that QoL was consistently shown to be lower in older autistic people compared to neurotypical older people. Older autistic people are shown to report higher QoL compared to younger, particularly in social and psychological domains. The review overall showed that there is a lack of studies including the oldest old. Additionally, although there are validated tools for assessing QoL in autism, these have not been applied or validated with older samples and are not routinely utilised in the research. Future research recommendations and clinical implications are considered.

Service-Related Project

The rates of mental health difficulties are known to be rising within the student population. The diversity of students in the UK is also expanding, with more international students attending UK universities compared to 20 years ago. Student support services have therefore been faced with rapidly changing demographics. This project aimed to review the efficacy of a UK based university

counselling service in line with recommendations from the British Association of Counselling Psychologists (BACP).

The study analysed secondary data which was routinely collected by the service. Data for all students who completed counselling between September 2021 and March 2022 was included. Outcomes were measured by the Clinical Outcomes in Routine Evaluation-Outcome measure (CORE-OM), and a questionnaire with qualitative and Likert questions. The percentage of students meeting reliable and significant change indices was calculated. Likert data was presented graphically, and qualitative data analysed using content analysis.

The study demonstrated the breadth and severity of mental health difficulties reported by students. The counselling service was outperforming key performance indicators for talking therapies services, with 96.6% of students being seen for therapy within 12 weeks. 50% of the sample achieved a reliable improvement in CORE-OM scores, and 39% achieved reliable and clinically significant change. 36.9% of the sample were being offered more sessions than the service would typically provide (6 session interventions), which might suggest there is a level of need above the current provision. Qualitative analysis revealed largely positive experiences of the service, but highlighted students often wished for more sessions.

This study provides evidence of the efficacy of in-house student counselling services. Support from within the university was valued, from practitioners who understood student needs. Continued and increased funding for these services is vital in the continued provision of this effective support.

Main Research Project

Labels of both physical and mental conditions are shown to have implications on individuals in a number of ways, including having to make adaptations to their life, changing their sense of self and identity, experiencing social stigma, implications on support systems and considerations about life planning. Historically, autism has been considered a disorder and its symptoms often described as deficiencies. However the social construction of autism has been shifting with more acknowledgement of the broad spectrum of neurodiversity and positive assets. Receiving a diagnosis of autism as an adult has been shown to offer a sense of relief, validation, improved self-understanding and feeling able to progress in life. Diagnoses are also shown to reduce self-blame about difficult experiences. It has also been shown that positive

associations of autism can contribute to collective self-esteem which in turn, is shown to contribute to improved depression and anxiety.

In conversations with psychologists working in autism diagnostic services, there appeared to be a gap in the current understanding of the experience of those people who suspect they are autistic but do not get a diagnosis following assessment. This is also a noticeable gap in the academic literature. This study therefore aimed to understand the lived experience of non-diagnosis of autism. Semi-structured interviews were conducted with 10 adults who had been through a diagnostic assessment. The sample included 4 men and 6 women. The main author analysed the data following the step-by-step process, as recommended by Smith et al (2022), starting with exploratory noting and personal experiential statements. Themes were then generated for each participant to understand their experience on an individual level, before moving into more interpretative group themes, which are presented.

Four overarching themes were generated, including pre-diagnostic experiences and beliefs, experiences of assessment, impact of non-diagnosis and influences on self-concept. A key theme included the careful construction of an autistic identity, which is then deconstructed upon non-diagnosis of autism. Additionally, many participants reflected on the invalidation they felt and confirmation of alternative negative beliefs about self. A large sub-group reflected on their experience of receiving multiple diagnoses before their autism assessment, all of which felt like a poor fit and were accompanied by inappropriate treatment or social stigma. Participants frequently reflected on a feeling of 'well now what?' and lack of self-understanding.

Clinical and research implications are discussed, including the need for a reshaping of diagnostic services in the UK, moving away from a diagnostically led system towards needs focused assessments. Such a shift would support people who have not met diagnostic threshold but have differences and needs which require adjustments or possible intervention. It may also facilitate a stronger sense of self-understanding and validation which was so often missing.

Acknowledgements

Without the support of a huge number of people the completion of this portfolio of research would not have been possible. I firstly want to thank Dr Cathy Randle-Phillips for her support with the three research projects presented in this portfolio. Your support in developing skills in qualitative research, experience in learning disability and autism services and connections to professionals has been invaluable. I would also like to thank my two research assistants, Jagriti Jalan and Priscilla Lung, who gave up many hours of their time to support with my main research project and literature review.

Thanks also go to my clinical tutor, Dr Paul Chadwick, for the continued support with my progression through training. I would also like to thank each of my placement supervisors for their commitment to supporting me through each aspect of training. My thanks to Amanda James, Effie Lunn, Dr Kirsty Sherratt, Dr Rachel Barden, Dr Claire Delaney, Hannah Lehrain, Dr Vineeta Gupta and Dr Antonia Reay.

Finally, I want to thank my friends and family for supporting me. My parents supported me immensely in relocating to Bath and finding myself an amazing place to live during my time on training. The friendships I have gained on the course will be friends for life. I want to give particular thanks to Hannah Pendlebury, Holly Mattock and Tamara Smith-Jones for being the best group of cheerleaders and supporters I could have asked for.

Appendices

Appendix A.

LR:Search Strategy for all databases.

Databases	Search terms	Notes
PsychNET (includes PsychINFO, PsychArticle sand APA PsycExtra)	Keywords: autis* <i>OR</i> Keywords: asperger* <i>OR</i> Keywords: pervasive developmental disorder <i>OR</i> Keywords: neurodevelopmental disorder <i>OR</i> Keywords: neurodivergent <i>AND</i> Keywords: “elder*” <i>OR</i> “older” <i>OR</i> “old age” <i>OR</i> “later life” <i>OR</i> “late life” <i>OR</i> “geriatric” <i>OR</i> “aging” <i>OR</i> “ageing” <i>OR</i> “senior” <i>OR</i> ‘middle aged’[MESH] <i>AND</i> Keywords: World Health Organization Quality of Life <i>OR</i> Keywords: Quality of life <i>OR</i> Keywords: life quality <i>OR</i> Keywords: QoL <i>OR</i> Keywords: WHOQOL	Keywords includes title and abstract on this database .
PubMed	((autis*[Title/Abstract] <i>OR</i> asperger*[Title/Abstract] <i>OR</i> pervasive developmental disorder[Title/Abstract] <i>OR</i> neurodevelopmental disorder[Title/Abstract] <i>OR</i> neurodivergent[Title/Abstract]) <i>AND</i> (“elder*” <i>OR</i> “older” <i>OR</i> “old age” <i>OR</i> “later life” <i>OR</i> “late life” <i>OR</i> “geriatric” <i>OR</i> “aging” <i>OR</i> “ageing” <i>OR</i> “senior” <i>OR</i> ‘middle aged’[MESH])) <i>AND</i> (World Health Organization Quality of Life[Title/Abstract] <i>OR</i> Quality of life[Title/Abstract] <i>OR</i> life quality[Title/Abstract] <i>OR</i> QoL[Title/Abstract] <i>OR</i> WHOQOL[Title/Abstract])	Includes Keywords
Web of Science core collection	((TS=(Autis* <i>OR</i> Asperger* “Pervasive Developmental Disorder*” <i>OR</i> “Neurodevelopmental Disorder” <i>OR</i> neurodivergent)) <i>AND</i> TS=(“elder*” <i>OR</i> “older” <i>OR</i> “old age” <i>OR</i> “later life” <i>OR</i> “late life” <i>OR</i> “geriatric” <i>OR</i> “aging” <i>OR</i> “ageing” <i>OR</i> “senior” <i>OR</i> ‘middle aged’[MESH])) <i>AND</i> TS=(Quality of life <i>OR</i> life quality <i>OR</i> QOL <i>OR</i> WHOQOL <i>OR</i> “Quality of Life”[Mesh])	TS searches for title, abstract, author keywords and keywords plus.
Embase and Medline	('autis*':kw,ti,ab <i>OR</i> 'asperger*':kw,ti,ab <i>OR</i> 'pervasive developmental disorder*':kw,ti,ab <i>OR</i> 'neurodevelopmental disorder':kw,ti,ab <i>OR</i> 'neurodivergent':kw,ti,ab) <i>AND</i> ('quality of life':kw,ti,ab <i>OR</i> 'QoL':kw,ti,ab <i>OR</i> 'WHOQOL':kw,ti,ab <i>OR</i> 'world health organization quality of life':kw,ti,ab) <i>AND</i> ('older adults':kw,ti,ab <i>OR</i> 'aged':kw,ti,ab <i>OR</i> 'geriatric':kw,ti,ab <i>OR</i> 'aging':kw,ti,ab <i>OR</i> 'later life':kw,ti,ab <i>OR</i> 'middle aged':kw,ti,ab <i>OR</i> 'late life':kw,ti,ab) <i>AND</i> ([embase]/lim <i>OR</i> [medline]/lim) <i>AND</i> [english]/lim ('autis*':kw,ti,ab <i>OR</i> 'asperger*':kw,ti,ab <i>OR</i> 'pervasive developmental disorder*':kw,ti,ab <i>OR</i> 'neurodevelopmental disorder':kw,ti,ab <i>OR</i>	'kw.ti.ab' indicating searches within keywords , title and abstract.

	'neurodivergent':kw,ti,ab) AND ('quality of life':kw,ti,ab OR 'QoL':kw,ti,ab OR 'WHOQOL':kw,ti,ab OR 'world health organization quality of life':kw,ti,ab) AND ('older adults':kw,ti,ab OR 'aged':kw,ti,ab OR 'geriatric':kw,ti,ab OR 'aging':kw,ti,ab OR 'later life':kw,ti,ab OR 'middle aged':kw,ti,ab OR 'late life':kw,ti,ab) AND ([embase]/lim OR [medline]/lim) AND [english]/lim	
CINAHL	AB (Autis* OR Asperger* OR "Pervasive Developmental Disorder*" OR "Neurodevelopmental Disorder* OR neurodivergent) AND AB ("elder*" OR "older" OR "old age" OR "later life" OR "late life" OR "geriatric" OR "aging" OR "ageing" OR "senior" OR 'middle aged'[MESH]) AND AB (Quality of life OR life quality OR QOL OR WHOQOL OR "Quality of Life"[Mesh])	Unable to search keywords , so used abstract searches .
Ethos	older adult AND quality of life AND autism	Manual exploration of ethos as can't be automatically imported into covidence.

Appendix B.**LR: Full list of Charted Data**

1. Full Reference
2. Title
3. Journal
4. Year
5. Authors
6. Country
7. Aims and Questions
8. Design
9. Sample size
10. Age range
11. Minimum and Maximum Age
12. Gender distribution
13. Nationality
14. Ethnicity
15. Socio-demographic factors
16. Co-morbidity
17. Setting
18. Diagnostic Criteria
19. How were the participants recruited into the study?
20. What were the selection criteria?
21. Did they use a control group, explain it?
22. QoL tool used (Informant or self-report)
23. Validated Tool?
24. Other measures used in the research.
25. Predictors reviewed and how.
26. Statistical Analysis
27. Relationship between QoL and Age
28. Average QoL scores
29. Predictors of QoL explained.
30. Main findings
31. Reported Limitation

Appendix C

LR: Mixed Methods Appraisal Tool (MMAT), version 2018

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses		
		Yes	No	Can't tell Comments
Screening questions (for all types)	S1. Are there clear research questions?			
	S2. Do the collected data allow to address the research questions? <i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>			
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?			
	1.2. Are the qualitative data collection methods adequate to address the research question?			
	1.3. Are the findings adequately derived from the data?			
	1.4. Is the interpretation of results sufficiently substantiated by data?			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?			
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?			
	2.2. Are the groups comparable at baseline?			
	2.3. Are there complete outcome data?			
	2.4. Are outcome assessors blinded to the intervention provided?			
	2.5. Did the participants adhere to the assigned intervention?			
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?			
	3.3. Are there complete outcome data?			
	3.4. Are the confounders accounted for in the design and analysis?			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?			
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?			
	4.2. Is the sample representative of the target population?			
	4.3. Are the measurements appropriate?			
	4.4. Is the risk of nonresponse bias low?			
	4.5. Is the statistical analysis appropriate to answer the research question?			
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?			
	5.2. Are the different components of the study effectively integrated to answer the research question?			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			

Appendix D

LR: PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Click here to enter text.
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Click here to enter text.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Click here to enter text.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Click here to enter text.
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Click here to enter text.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Click here to enter text.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Click here to enter text.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Click here to enter text.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Click here to enter text.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Click here to enter text.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Click here to enter text.

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Click here to enter text.
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Click here to enter text.
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Click here to enter text.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Click here to enter text.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Click here to enter text.
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Click here to enter text.
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

JBIC = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 16 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467-473. doi: 10.7326/M18-0850.

Appendix E

SRP: Ethical Approval

From: psychology-ethics <psychology-ethics@bath.ac.uk>
Sent: 14 March 2022 10:29
To: Ellie Hughes <eh2053@bath.ac.uk>
Cc: psychology-ethics <psychology-ethics@bath.ac.uk>
Subject: FW: PREC 22-024

Hi Ellie,

I am taking Chairs Action to approve the application. Good luck with the research.

Best wishes,
Chris Ashwin
Chair of PREC

From: Ellie Hughes <eh2053@bath.ac.uk>
Sent: 08 March 2022 16:31
To: psychology-ethics <psychology-ethics@bath.ac.uk>
Cc: Cathy Randle-Phillips <cmd46@bath.ac.uk>
Subject: RE: PREC 22-024

Dear PREC,

As per your previous email, I have addressed the following query:

Section 2.3 - You suggest there is no data gatekeeper – does this mean that you have direct access to the proposed data? Please clarify.

In response, this project will in fact have a data gatekeeper. This is the service manager for therapeutic services as well as the data and insight lead for student services. Technically, I do have access to the proposed data as I work clinically within the service using the recording systems, however, I will not be using the systems for the purpose of extracting the proposed data. In this case, the data and insight lead and service manager will be co-operating in the data extraction process.

The updated application is attached with changes highlighted in yellow,

Kind regards,
Ellie Hughes

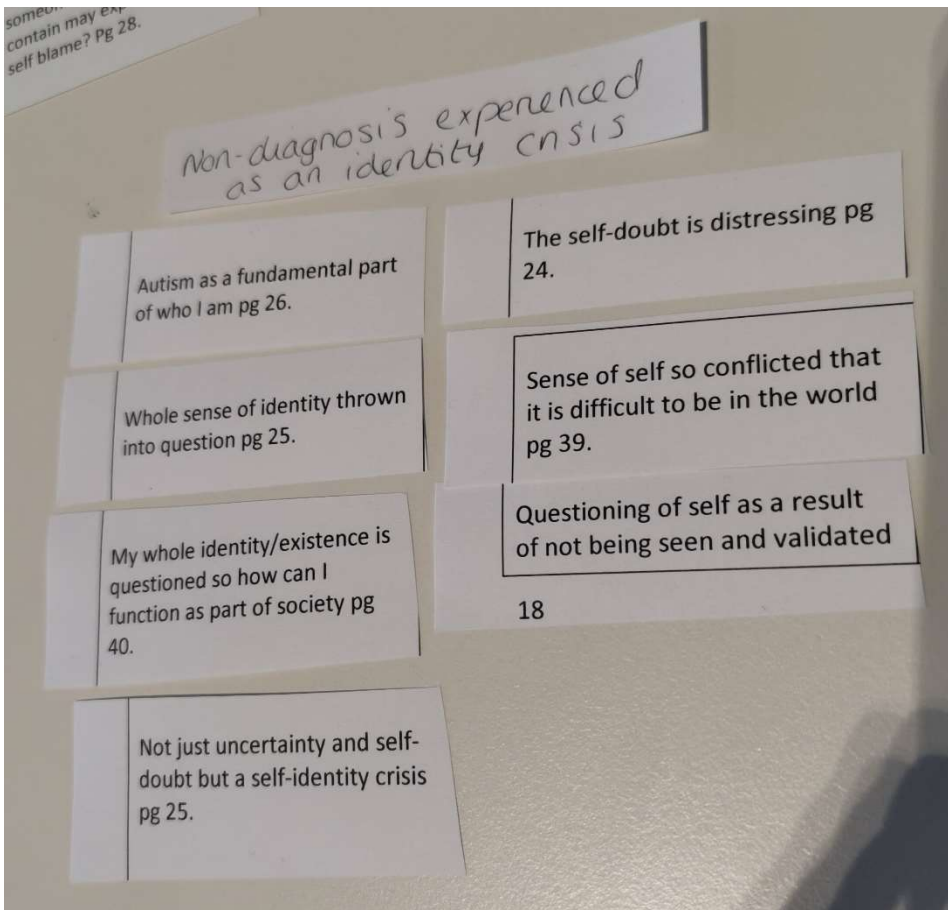
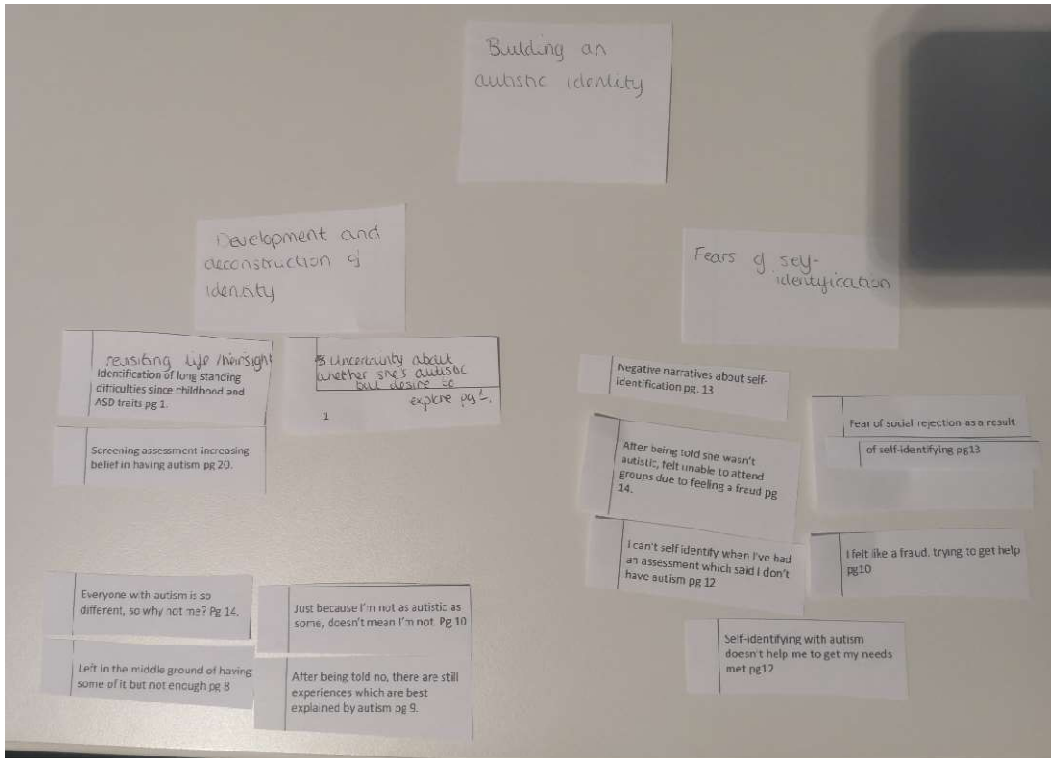
Appendix F

MRP: Illustrative Excerpt of Exploratory Notes and Experiential Statements

Exploratory Notes	Transcript	Experiential Statements
<p>Treacle again – imagining the exhaustion of this, emphasising this Considering whether she might be depressed – being assertive and taking measures to the doctor and asking for help. Trying medication for depression</p> <p>Exacerbation at therapy offered to her – not for the right problem for her</p> <p>It look courage to google this – why courage? Some fear involved in what might be found (negative interpretation of Aspergers due to father??) Sudden understanding of her father’s behaviours – as a result, understanding self better</p> <p>‘made a profession of it’ – something we are successful/advanced at asking questions and being curious</p>	<p>Part: But I was lying on my bed in 2019 in the kind of end of summer autumn of 2019, trying to figure out how do I get through this treacle? Because I'm so worn out I don't like I have the motivation to do things. This is not depression. I've done depression before. This does not feel like depression, but I then went to my doctor later and said no, I've gone to her in May and said I've taken the Beck inventory. I don't think It's depression, but I'm scoring as borderline severe depressed. So what do we do? And she said. All right, well, let's give you some antidepressants to see if we can figure something out.</p> <p>Part: Cue more rounds of CBT, CB ***** CBT, which is helpful, but only if it's there to treat the right problem.</p> <p>Int: Hmm.</p> <p>Part: So. I finally Google. I got the courage up to Google Asperger's and depression.</p> <p>Int: Mm hmm.</p> <p>Int: OK.</p> <p>Part: And that search led me on to a trail of reading that meant that all of a sudden lots of light bulbs went off. I started to understand my father's behaviour better. I started to understand myself better. I started to see myself and of course being, I mean, I I have made a profession since I was five or younger of asking questions. I'm always asking questions, asking questions, asking questions, trying to figure out</p>	<p>Rebecca emphasising the ‘treacle’ she was in, a feeling of stuckness and inability to proceed with life pg 3.</p> <p>Searching for the right label for the ‘problem’ pg 3</p> <p>Rounds of inappropriate treatment were exhausting and frustrating for Rebecca pg 3.</p> <p>Rebecca experiencing trepidation about considering herself as neurodiverse due to familial experience pg 3.</p> <p>‘Light bulbs’ and validation – seeing herself in the information she was reading leading to a sense of understanding self-better pg 3.</p>

Appendix G.

MRP: Pictures illustrating the process of personal experiential theme development.



Appendix H

MRP: Semi-Structured interview questions

1. Can you tell me about the process of seeking an autism assessment?
2. Can you tell me a bit about your expectations and hopes from your autism assessment?
3. And what was your experience of being told you did not meet diagnostic criteria?
 - a. How did it impact you emotionally?
 - b. What were you thinking?
 - c. Did you agree with the outcome or still feel you strongly align yourself with autism?
4. Did not getting the diagnosis change how you see yourself? Did this impact you socially?
5. If you'd have got the diagnosis, how would it have changed how you see yourself?
6. What would having a diagnosis have offered you?
7. Do you self-identify as autistic? If yes, please tell us more about your experiences of self-identified autism. If no, tell us your thoughts about self-identification.
8. Do you relate to and see yourself as belonging to the autistic community? (if not, why not? What prevents this? Would it help in any way?)
9. Have you engaged with any autism organisations, what has this been like as someone without a diagnosis?
10. Have there been any barriers for you as a result of not having an autism diagnosis? E.g in terms of education, employment, support or accessing services which you may find useful?
11. When you were told about not having a diagnosis, is there anything which could have been useful for services to say or recommend?
12. Is there anything else about this experience that you feel is important to share?

Appendix I

MRP: Evidence of Ethical Approval

From: psychology-ethics <psychology-ethics@bath.ac.uk>
Sent: 17 March 2023 13:05
To: Ellie Hughes <eh2053@bath.ac.uk>
Cc: Cathy Randle-Phillips <cmd46@bath.ac.uk>
Subject: 23 015

Dear Ellie

Full title of study: An Exploration into Experiences of The Autism Diagnostic Pathway and Non-Diagnosis of Autism
PREC reference number: 23 015

On behalf of the Committee, I am pleased to confirm that you have received a favourable ethical opinion for the above proposal from the Psychology Research Ethics Committee.

However please be aware that a researcher (or supervisor in the case of UG or Masters students) is responsible for ensuring full data protection compliance. Please seek further advice from dataprotection-queries@lists.bath.ac.uk if you have any concerns.

1

Under current Covid restrictions, if you are proposing lab based or field research involving in-person testing you will also need to get approval from the Psychology Research Restart Group (PRRG) before you can start to gather data. More information can be found here: <https://wiki.bath.ac.uk/display/PC/Psychology+COVID-19+Guidance>

If you intend to display recruitment posters/materials, please ensure you obtain the appropriate permission to do so from those who manage the location(s) you choose.

Please inform PREC about any substantial amendments made to the study if they have ethical implications.

Please make sure you quote your unique PREC reference number in any future correspondence.

Rebecca Wise
On behalf of Psychology Research Ethics Committee

Rebecca Wise
DC Research Ethics

Appendix J

MRP: Information Sheet

Information Sheet

Who am I?

My name is Ellie Hughes. I am a Clinical Psychologist in Training within the Department of Psychology at the University of Bath. I am conducting this study as part of my doctoral training program. The research is being supervised by Dr Cathy Randle-Phillips who is also based at the University of Bath.

What is this study about?

This study is interested to explore the lived experience of people who have been through a diagnostic assessment for autism and been told they do not meet criteria for a diagnosis.

We are interested to learn about what this experience is like for individuals, in particular whether it has an impact on your sense of identity and the social groups you feel connected to.

We are curious to learn about how being told you do not meet criteria influences the connection you may feel to the autistic community, as research has told us that people who identify with many positive aspects of their autism diagnosis, have higher self-esteem and collective self-esteem (i.e being proud of our group memberships).

There is now a movement for people to self-identify as autistic, and services for autistic people should be made available for those people who self-identify. We are also interested to ask about whether not receiving a diagnosis has created any barriers in life, whether that be socially, financially or related to work.

There is currently limited research in this area, and we therefore feel it is important to explore and publish more information about this experience. It is hoped that knowing more about this process can have an influence on how autism services operate and talk about diagnoses with people.

What will I be asked to do?

I would like you to come along to an interview where we would talk about your experience of going through the assessment process and being told you do not meet criteria for a diagnosis of autism:

- I will ask questions such as ‘what were your hopes when seeking an autism assessment?’.
- I will ask approximately 10 questions relating to this topic.
- The interview will be scheduled for no longer than 90 minutes.
- If you would like to take a break, or have two shorter interviews, this can also be arranged.
- There are no right or wrong answers, we are simply curious to learn about yours and other peoples experience of this topic.
- The interviews will be held on Microsoft Teams at a time that suits you. If you would prefer to meet over the telephone, this can also be arranged. The interview will be recorded so that I can catch everything you say, and then listen to it again later. You are welcome to have you camera on or off, and can request for me to have my camera on or off.

After completing the interview you will be given a £10 gift voucher to thank you for taking part.

Do I have to take part?

Taking part in this research is entirely voluntary, and you are free to make your own choice about whether you want to participate. If you agree to take part you can choose not to answer any questions that you do not want to.

If you would like to withdraw before the interview, you can contact me directly via email or telephone and provide a reason for withdrawal. After the interview, there is a two week period where you can withdraw your data from the study. This two week period is to enable the researchers to manage the time scale of the project.

To withdraw after the interview, please also contact me via email or telephone with your reason for withdrawing (this helps us to get an idea of how we can adapt the protocol, if necessary).

What will happen to the information I provide?

Should you decide to take part, the interview will be recorded. The audio file will be saved in an encrypted folder which is only accessed by the researchers. The recording of the interview will be deleted once it has been transcribed into a word document, approximately six weeks after the interview. Any potentially identifying details, including your name, will be removed.

The interview information and recording will not be linked to any contact details that you provide and will be stored separately so you cannot be identified. Once the project is completed, the information you have given to me will be kept safely by the University of Bath.

What will happen to the results of this research?

What you tell me will inform our project on the experience of not receiving a diagnosis of autism. I may use extracts taken from what you have told me, however these would not identify you to anyone. The findings of the research may also be published in research journals or used in presentations. If you would like to be sent a summary of the findings, we can arrange for this.

University of Bath privacy notice

The University of Bath privacy notice can be found here:

<https://www.bath.ac.uk/corporate-information/university-of-bath-privacy-notice-for-research-participants/>.

What do I do if I would like to take part or have any more questions? You can contact me, Ellie Hughes, to arrange a suitable time or to discuss any questions you might have.

Email – eh2053@bath.ac.uk Phone – 01225 384251

You can also speak to the supervisor of the project, Dr Cathy Randle-Phillips

Email – cmd46@bath.ac.uk

If you have any concerns related to your participation in this study please direct them to the Chair of the Department of Psychology Research Ethics Committee, email: psychology-ethics@bath.ac.uk.

Our address is

Department of Psychology

University of Bath

Claverton Down

Bath, BA2 7AY

Many thanks for taking the time to read this. I would be delighted if you would be willing to take part.

Appendix K. MRP: Consent Form

University of Bath Department of
Psychology Ellie Hughes,
Trainee Clinical Psychologist
eh2053@bath.ac.uk



University of Bath Consent Form

An Exploration into Experiences of The Autism Diagnostic Pathway and Non- Diagnosis of Autism.
Please answer the following questions to the best of your knowledge

Do you confirm that you:

Have had an assessment for autism? *

- Yes
 No

Been told by a suitably trained professional that you do not meet diagnostic criteria for Autism?
(DSM-5 or ICD-10 criteria) *

- YES
 NO

Can speak English fluently as either a first language or additional language? *

- Yes
 No

Are not diagnosed with a learning or intellectual disability? *

- Yes
 No

Are over the age of 18? *

- YES
 NO

Have you:

Been given information explaining the study? *

- Yes
 No

Had an opportunity to ask questions about the study? *

- Yes
 No

Received satisfactory answers to all questions you asked? *

- Yes
 No

Received satisfactory answers to any questions you asked: *

- YES
 NO

Received enough information about the study for you to make a decision about your participation?

- YES
 NO

Do you understand:

That you are free to withdraw from the study: Before and during the interview? Within two weeks of completion of the interview? Without having to give a reason for withdrawal? That your interview will be audio recorded and stored for six weeks until it is transcribed. It will then be deleted. *

- Yes
 No

I hereby fully and freely consent to my participation in this study I understand the nature and purpose of the procedures involved in this study. These have been communicated to me on the information sheet accompanying this form. I understand and acknowledge that the investigation is designed to promote scientific knowledge and that the University of Bath will use the data I provide for no purpose other than research. I understand the data I provide will be kept confidential. My name or other identifying information will not be disclosed in any presentation or publication of the research. I understand that the University of Bath may use the data collected for this project in a future research project but that the conditions on this form under which I have provided the data will still apply.

Signature

Date

Month Day Year

Name in BLOCK Letters

University of Bath Department of Psychology Ellie Hughes, Trainee Clinical Psychologist eh2053@bath.ac.uk

Appendix L.

MRP: Debriefing Sheet

Debriefing Information

Thank you for taking part in this project which has been investigating the impact of going through the autism diagnostic process and being told you do not have autism. Your contribution is very much appreciated.

Although this project is not focused on 'problems' related to autism non-diagnosis, we are aware that some of the people who take part in this project may find information about where to get further advice, support and information useful. Below is a list of organisations and websites that may contain information useful to you.

For information, signposting: The National Autistic Society

https://www.autism.org.uk/?gclid=EAlaQobChMInPrtuong_AIVCJ7tCh1neQuKEAAYASAAEgIIM_D_BwE

If you are under 25 and live in south Gloucestershire, Youth Intervention Support Service <http://www.southglos.gov.uk>

If you are under 30, A Different Perspective

<http://www.adifferentperspective.info/>

For any age, AS we are Chippenham (support and social group for adults)

<http://www.autism.org.uk>

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 If you feel you require support with **mental health**, you can also speak to your GP. If you are interested in accessing talking therapies, you can also contact your local talking therapies provider:

For BANES: <https://iapt.awp.nhs.uk/talking-therapies-banes>

For Bristol: <https://www.vitahealthgroup.co.uk/nhs-services/nhs-mental-health/bristol-north-somerset-and-south-gloucestershire-mental-health-services/>

To find local talking therapies services outside of these areas:

<https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service>

.....

 Thank you again for participating. If you would like to speak to us about the project please get in touch.

Email – eh2053@bath.ac.uk **Phone** – 01225 384251 (can take messages only and return your call)

You can also speak to the supervisor of the project, Dr Cathy Randle-Phillips

Email – cmd46@bath.ac.uk

Our address is: Department of Psychology, University of Bath, Claverton Down Bath, BA2 7AY

.....

 I confirm I have received a voucher to the value of £15 for participating in the University of Bath project 'An Exploration into Experiences of The Autism Diagnostic Pathway and Non-Diagnosis of Autism'

Signed.....Date.....

.....

Researcher's
signature.....Date.....
.....

If you have any concerns related to your participation in this study please direct them to the Chair of the Department of Psychology Research Ethics Committee, email: psychology-ethics@bath.a.uk.