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Qualitative Analysis of the Experiences of Autistic People and their Families

by

Sanu Pattni

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Thesis for the degree of Doctorate in Clinical Psychology

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University of Southampton

<u>Abstract</u>

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Systematic Review - Parental experience of autism in India
Research concerning autism in India is a growing, and current literature suggests that the prevalence of autism is increasing year-on-year. However, a relative lack of public spend, and stigma and discrimination associated with disabilities and difference, means that there is a lack of health provision for autistic people and their families, and these families are also subjected to negative judgements from society. The aim of this systematic review was to synthesise qualitative research concerning parental experiences of autism in India, considering the implications for future research, policy and practice. A qualitative systematic review was conducted using thematic synthesis, and analysed six papers with a total of 80 participants. The analysis found that the parental experience of autism in India was made up of four themes: *(1) misunderstanding autism*, *(2) negative attitudes toward autism*, *(3) largely difficult experiences with services*, and *(4) specific challenges parenting an autistic child in India*. This review concluded that there is limited research into autism in India, and as such further research needs to be conducted to consider the culturally-specific presentation of autism in India, services outcomes, and experiences of autistic people, their caregivers, and service providers. It is also noted that India has work to do, both in terms of policy and practice in order to improve understanding of, as well as health provision for autistic people and their families in India.

Empirical Paper - Autistic People's CBT Experiences
CBT is the recommended intervention for autistic people with mental health difficulties. A growing body of research suggests that, because of the specific difficulties faced by autistic people, CBT may be difficult for them to access, and thus to be reasonably adjusted for best engagement and outcomes. However, much of the research does not include autistic people's voices. This study looked to address this gap in the literature. This qualitative research looked to gain insight into the question: "How do autistic people experience CBT?" in the form of semi-structured interviews with five autistic people. Interviews were analysed using Interpretative Phenomenological Analysis (IPA). IPA revealed autistic people's experience of CBT were made up of three superordinate themes (along with 12 subordinate themes): (1) "Useful aspects of CBT"; (2) "CBT not a good fit for autism"; and (3) "Inaccessibility of services". While autistic people noted some benefits of engaging in CBT, such as learning more about themselves, and being better prepared for further therapy, there was an overall feeling that CBT was not a good fit, and was not adapted appropriately for them because of a lack of knowledge, awareness and training with regard to autism within services. It was also noted that they felt services were not able to make the reasonable adjustments necessary for better accessibility. This has important clinical and academic implications, and suggests that the structure of service provision for autistic people needs to be better supported or reconsidered entirely.

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Research Thesis: Declaration of Authorship

Print name: SANU PATTNI

Title of thesis: Qualitative Analysis of the Experiences of Autistic People and their Families

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: .... Date: 18/10/2024 ....

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Chapter 1 Systematic Review

Title Page

Title

Parental Experiences of Raising Autistic Children in India – A Systematic Review

Running Head

Parental experience of autism in India

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Abstract

Purpose – Research concerning autism in India is a growing, and current literature suggests that the prevalence of autism is increasing year-on-year. However, a relative lack of public spend, and stigma and discrimination associated with disabilities and difference, means that there is a lack of health provision for autistic people and their families, and these families are also subjected to negative judgements from society. The aim of this systematic review was to synthesise qualitative research concerning parental experiences of autism in India, considering the implications for future research, policy and practice. ***Methods*** – A qualitative systematic review was conducted using thematic synthesis, and analysed six papers with a total of 80 participants. ***Results*** – The analysis found that the parental experience of autism in India was made up of four themes: *(1) misunderstanding autism*, *(2) negative attitudes toward autism, (3) largely difficult experiences with services*, and *(4) specific challenges parenting an autistic child in India*. ***Conclusions*** – This review concluded that there is limited research into autism in India, and as such further research needs to be conducted to consider the culturally-specific presentation of autism in India, services outcomes, and experiences of autistic people, their caregivers, and service providers. It is also noted that India has work to do, both in terms of policy and practice in order to improve understanding of, as well as health provision for autistic people and their families in India.

Key Words

Autism, India, Parents, Caregivers, Experiences

Parental Experiences of Raising Autistic Children in India – A Systematic Review

Autism Spectrum Disorder (ASD; referred to in this paper as autism henceforth) is a spectrum of neurodevelopmental disorders characterised by difficulties with social communication and interaction, and repetitive, restrictive patterns of behaviour and interests, which are not accounted for by an intellectual disability or physical condition (International Statistical Classification of Diseases and Related Health Problems 11th edition [ICD-11] World Health Organization [WHO], 2019). Zeidan et al.'s (2022) systematic review considering the global prevalence of autism found that about 1 in 100 children have a diagnosis (it should be considered this is likely to be an underestimation of actual prevalence). It is estimated that the prevalence of autism in India is around 0.09-0.11%; India is the second most populated country, with around one sixth of the global population (~1.35 billion people), suggesting that just under 15 million people could be living with autism in India (Chauhan et al., 2019). Chauhan et al. also note that there are few high-quality, population-based studies on autism in India, and so prevalence rates are difficult to estimate, but suggest that for this reason alone, there is an urgent need to conduct research into autism in India to improve understanding of the diagnosis, both in terms of prevalence and impact.

The Constitution of India underlies the Indian healthcare system and obliges the government to ensure the "right to health" for everyone, with each state being required to provide free, universal access to health services (Tikkanen et al., 2020). India's public health spending has ranged from 1.2-1.6% of GDP in recent years (Bhatia & Singh., 2021), and is lower than the global average of 7% (Government of India, 2017). Ahjua (2019) notes that India is hoping to increase public health spending to 2.5%, however it is widely recognised that public health spending in India leaves much to be desired, and as such, the healthcare system is run via a combination of public and private services (Mehta, Thomas & Mathur, 2023). The relative lack of public health spending results in challenges faced by Indian

citizens with regard to the public health system, including: inadequate infrastructure, a shortage of medical practitioners, and urban-rural disparities – as such there is a fragmented healthcare system combined with an inequity in access to care (Kumar, 2023).

Given the relative lack of public health spending, it is reasonable to posit that there will be a chronic lack of spending in specific health areas, such as autism diagnostic and support services, and this is routinely reported in research (Patra & Kar, 2021). This is despite autism being included as one of the 21 recognised disabilities within the Rights of Persons with Disabilities (India) Act 2016, an Act that aims to protect the rights and facilitate the development of services for autistic people, ensuring that they are not deprived or discriminated against because of their diagnosis. While this may be a positive element of Indian policy concerning autism, it should be noted that difference and disability are often viewed negatively in India, and are associated with stigma and discrimination, both in terms of physical differences or disabilities, as well as psychological or intellectual disabilities that is reinforced by a hierarchical social system (Antony, 2013; Kayama, Johnstone & Limaye, 2019; Panicker, 2021). This stigma and discrimination, alongside chronic underfunding in health (resulting in poor infrastructure, and a lack of access to services), means that families may have difficult experiences both within the community, and within the healthcare system. This idea is played out in the evidence, with research suggesting that families of children with autism are often subjected to stigma and discrimination in the form of negative judgements from society (Patra & Patro, 2019), and difficulty accessing services (Gudlavalleti et al., 2014; Patra & Kar, 2021). These families are also shown to have a poorer quality of life than families with neurotypical children (Perumal, Veeraraghavan & Lekhra, 2014). It should be noted, however, that research in the area tends to be survey-based, collecting quantitative data, and so the qualitative experiences of families are often not accounted for.

The aim of this review is to consider research around the experiences of parents of autistic people in India, with a focus on the process of receiving a diagnosis, accessing relevant support services, and also experiences within their communities. The research question is: "What are the experiences for parents bringing up an autistic child in India?" This paper focuses on qualitative research and the experiences reported directly from parents, and the data will be used to make recommendations about the direction of future research, as well as consider how autism services in India could adapt moving forwards.

Method

Design

A systematic review of qualitative literature was conducted using thematic synthesis (TS), (Thomas & Harden, 2008). TS is an adaptation of thematic analysis (Braun & Clark, 2012), a method for analysing multiple qualitative papers to generate analytical themes. TS is an integrative and interpretative approach to reviewing qualitative literature and has been shown to be useful in considering participants' acceptance of, as well as opinions regarding the appropriateness of interventions and healthcare systems (Cherry, Boland & Dickson, 2023). This is an appropriate method of review in relation to our research question, and epistemologically speaking, is grounded in interpretivism, which assumes that reality is socially constructed (Myers, 2019), and therefore our approach subscribed to the notion that there may be more than one truth. Interpretivism favours subjectivity, inductiveness and reflexivity, and these elements were important for us to consider throughout the process of data analysis.

Search Strategy

Studies regarding the experiences of parents of children with autism in India were located by searching major electronic databases and grey literature repositories. For published literature,

MEDLINE, PSYCINFO, CINAHL and Web of Science were searched; for grey literature, ProQuest was searched. Initial search terms were discussed by the research team, and it was agreed that terms related to "Autism", "Experience", "Caregiver" and "India" would be utilised for the search. The databases were searched using the following key words: Autis*, Autism Spectrum Disorder*, ASD, Autism Spectrum Condition*, ASC, Asperger's, Asperger's syndrome, India*, Indian Culture*, Indian Famil*, Experience*, Perception*, View*, Attitude*, Caregiver*, Parent*, Mother*, Father*, and Famil*. The wording of the search terms differed slightly depending on the requirements of the database being searched (Appendix A). A total of 219 papers were found as a result of the search across the five databases. Seventy-four duplicate papers were removed in Endnote 21 (The EndNote Team, 2013), leaving 145 papers to consider for inclusion or exclusion.

Inclusion & Exclusion Criteria

This review included papers whose participants were adults (18+ years old) living in India, who were also parents of children with a diagnosis of autism. Furthermore, the papers needed to present qualitative data concerning the experiences or attitudes of said parents with relation to parenting their child. The full inclusion criteria are outlined in Table 1.

[INSERT TABLE 1 – Inclusion & Exclusion Criteria]

Selection Procedure

Stage 1 of the selection procedure focused on inclusion/exclusion through reading titles only; this was completed by the first author and 59 papers were excluded, leaving 86 papers remaining. Stage 2 involved reading abstracts of the papers only; this was completed by the first author and a research assistant. Cohen's κ was run to determine the level of agreement between the two reviewers' judgements on whether the 87 papers should be "Included", "Excluded", or were "Unsure" about inclusion. There was "none-to-slight" agreement

between the researchers' judgements, κ = .102, 95% CI [-.103, .227], p = .222. The two reviewers met to discuss the discrepancies, and it was found that all discrepancies were a consequence of a misreading of the inclusion criteria from the research assistant – following a discussion, the inclusion criteria were updated to be more explicit, and a unanimous consensus was reached regarding inclusion and exclusion; no discrepancies were present. It was agreed that 75 papers would be excluded based on their abstracts, leaving 11 full text papers to screen. Stage 3 involved screening of 11 full texts, and was completed by the first author. Four papers were excluded for not being relevant, and one paper (a grey literature dissertation) was excluded owing to the fact that it could not be accessed. This left six papers to be included for data extraction and analysis. At each selection stage, the reason for excluding each paper was recorded, and a summary of the screening process (and reasons for exclusion) are shown in the PRISMA flow diagram (Figure 1).

[INSERT FIGURE 1 – PRISMA Diagram]

Data Extraction, Quality Assessment & Data Analysis

Data from the selected studies were extracted following recommendations from Thomas and Harden's (2008). General study characteristics (country, setting, sampling approach, sample size, purpose of study, data collection method, and data analysis method) were extracted from each paper. Furthermore, the entire Results/Findings sections, and aspects of the Abstracts referencing the results were extracted in the form of transcripts. "Findings" in qualitative research are noted to be distinct from, but made up of, the data they are based on, as well as the researchers conclusions and interpretations (Sandelowski & Barroso, 2002). Therefore, we felt that the data to be extracted and analysed for this review needed to include both participant quotes and author interpretations and extracting all text from Abstract related to results, and Results/Finding sections allows for this. This is also in line with Thomas and Harden's (2008) approach to data extraction and analysis.

Quality assessment of the papers and associated data was conducted using the Critical Appraisal Skills Programme (CASP) checklist, which is an appraisal tool for considering the quality of a piece of qualitative research (Long, French & Brooks, 2020) This assessment tool was used for each of the six papers included in the analysis by the first author and a second research assistant. There were disagreements in the answers for some of the questions across the papers (Appendix B), but in a follow-up discussion it was agreed that the included papers generally had a clear statement of aims, utilised appropriate design and methodology, and included sufficiently rigorous data analysis to provide clear and useful findings. It should be noted that it was unanimously agreed that all six papers did not adequately account for the relationship between the researcher and participants, and so it was important to consider the implications of this in our review. Overall, however, it was agreed that each of the included papers were of sufficient quality to provide rich information that would contribute to the analysis in relation to our research question.

Data analysis was conducted through TS, a process which involves three stages (Thomas & Harden, 2008). Stage 1 involves coding text; this was taken using a data-driven approach, going through each transcript line-by-line and highlighting anything noteworthy in relation to the research question, as well as allowing consideration of the translation of concepts between the studies. Each code was noted on the transcripts themselves, and then transferred into an Excel spreadsheet (with a note highlighting the paper and line number). Stage 2 involved developing descriptive themes; similar codes were either merged (if the same words were used) or grouped together (by meaning); these groups of codes would then become initial descriptive themes. Stage 3 involved the generation of analytical themes; the underlying meaning behind each of the themes were considered. It was noted that this process was largely dependent on the judgement, attitudes, and insights from the reviewers, which may lead to some bias in the reporting. The initial coding and generation of themes

was conducted by the first author, and then discussed with the research team at length, to first consider if anything had been missed in the data, and then to discuss generating meaningful analytical themes. All researchers agreed the arrangement of final themes.

The core research team was made up of three members; two male and one female. Two of the research team were White-British, and one was Asian-British (Indian), and all identified as neurotypical, with multiple years' experience working with neurodiverse people. Throughout the process, the researchers were mindful of bringing the conversations back to the data during the discussions, with a careful consideration of their own attitudes and biases towards neurodiversity and geographical location. This was borne out in discussions around the use of appropriate terminology throughout the paper, as well during data analysis, when thinking about the wording of theme names.

Results

Description of included studies

This qualitative systematic review included six studies published between 2012 and 2023. Across the six studies, there were a total of 80 participants; all participants were parents of autistic children. Data collection in the studies occurred via semi-structured interviews and focus groups. There were a range of data analyses across the papers, including thematic analysis, interpretative phenomenological analysis, and framework analysis. Table 2 outlines important descriptive aspects of the included studies.

[INSERT TABLE 2 – Characteristics of the Included Studies]

Results of TS

TS found that the parental experience of parenting an autistic child in India was summarised in four analytical themes: (1) *misunderstanding autism*, (2) *negative attitudes toward autism*, (3) *largely difficult experiences with services*, and (4) *specific challenges parenting an*

autistic child in India. Table 3 outlines the four analytical themes and associated sub-themes. The themes are discussed below with associated quotations and information regarding study identification number and line number in the published transcript (Paper; Line).

[INSERT TABLE 3 – Themes and Subthemes Extracted via TS]

Theme 1: Misunderstanding autism

Parents reported a general lack of awareness and misunderstanding of autism across the population. This was evidenced in multiple ways, including the belief that difficulties shown by the child were temporary, a difficulty in recognising and identifying symptoms accurately, and the contradictory and confusing explanations of their child's behaviours and symptoms.

Subtheme 1.1: General lack of awareness of autism

A general lack of awareness and appreciation of autism as a concept was commonly reported by parents across the studies, which therefore had an impact on their understanding of autism: *"When the term 'autism' was introduced early in this phase, its' meaning for parents remained relatively empty and without significant implications"* (P1; 620); *" 'We have seen this problem for the first time . . . we never heard that children have such problem.' (mother of child with an ASD diagnosis). "* (P4; 5). Parents also highlighted that there was a distinct lack of awareness and understanding of autism among professionals of various disciplines, that impacted on the service they received, and had emotional and financial consequences: *"...professionals from the health, education, and religious sectors have a low awareness of the unique needs of families living with ASD which leads to a considerable economic and emotional burden on families."* (P2; 190).

Parents explained that diagnosis proved to be an important turning-point in promoting their awareness and understanding of their child's difficulties and helped to see autism from a different perspective: *"'Pooja: For me it was complete relief… when I finally got the*

diagnosis it was almost like 'thank God! Now I know what's wrong and now maybe I can do something about it.'" (P3; 224). Along with this, they also highlighted the importance of increasing community awareness and understanding of autism: *"Our findings highlighted a vital need for greater community awareness and recognition of autism in India."* (P4; 1), and emphasised the important role the media had to play in this: *" 'This awareness for autism has been done very well by Shah Rukh Khan [a film actor]… After watching the movie I came to know that there is something called autism..'"* (P2; 196).

Subtheme 1.2: Wide-held belief that difficulties were temporary

Another way in which the misunderstanding of autism played out was that parents and caregivers reported they initially held the belief their child's difficulties were temporary: *"Even as parents' perspectives on their child became increasingly divergent from reassuring others, they continued to believe that the disruptions would eventually pass."* (P1; 620); and they held out hope for their child growing up to be "normal": *"Four families reported that they had the belief that their child will become normal with time and would start interacting late just like one of the distant relative's child in the family."* (P6; 5). There was, however, evidence to suggest that over time parents began to understand their child's difficulties were persistent, and would be present throughout their life: *"Parents accepted and owned their child's limitations as a consequence of seeing that their child remained different from other children in situations essential for becoming a fully functioning adult in the local setting."* (P1; 162).

Subtheme 1.3: Difficulty in initial recognition of symptoms

Parents reported difficulty in the initial recognition of symptoms because there were no obvious or outward signs of difference, or the behaviours simply seemed like extreme examples of "normal" child behaviour:

> *"Caregivers described that they felt that their child was like other children, and this made it difficult to know there were symptoms of autism / developmental disability. 'No one can say by looking at him that he might have any problem.' ..."* (P4; 6).

They noted that medical conditions were easier to spot and respond to, as these were more familiar to them: *"'Autism' and troublesome behaviors beyond the scope of routine parenting had yet to appear. If significant medical problems of the child appeared, courses of action were clear, such as taking the child to a doctor for excessive vomiting."* (P1; 619).

Parents also noted that they were only able to acknowledge that something was 'wrong' or different when people outside of the family (teachers, doctors, and others in the wider community) raised their concerns.

> *"Caregivers in the clinical groups highlighted how important it was for them to have assistance from the wider family, school, as well as experienced childcare support, such as from an employed child-carer or extended family members, e.g., grandparents, in helping to recognise their child's difficulties"* (P4; 6).

Parents explained that while these 'outsider' observations and opinions were important in the recognition of difficulties, family members often dismissed the worries, and this resulted in a delay in help-seeking behaviour: *" 'My mother-in-law repeatedly told me that boys speak late and I should not bother wasting money by consulting doctors.'"* (P5; 123). This led to a feeling of confusion among parents, which made the process of recognising their child's symptoms more difficult: *"Geeta remembers questioning herself about her child's delays in order to try to make sense of them. For this mother, other peoples' assumptions and reassurances (about the problem being simply delayed speech) further added to the confusion."* (P3; 223).

Subtheme 1.4: Varied explanations of autism/behaviours

Parents outlined that there were varied, almost competing explanations of their child's behaviours, which sometimes led to confusion – often autism was not considered as an explanation. *"'No one thought that it could be an autism symptom.'" (mother of child with ASD diagnosis)."* (P4; 6). Once a diagnosis was received, various causes and explanations were given, including genetic explanations, family and wider 'lack of optimal environment' explanations, and medical explanations.

> *"Some general trends of explanation included: (a) genetics or chemical exposure (M1, a PhD scientist); (b) potential links to other children in the family with developmental issues, e.g., a 'spastic' relative (M6); (c) mother not taking required medications while pregnant, or taking too many medications (F3, M10); and (d) stressful experiences during or after pregnancy."* (P1; 623).

> *" 'The environment of the house also makes a difference. Joint family produces more growth, nuclear less.' (mother of child with ASD diagnosis)."* (P4; 6).

Theme 2: Negative attitudes towards autism

The parents explained that there was an overall negative attitude and stigma towards autistic people. This was manifested through discrimination in the form of negative judgements and a lack of acceptance from others within the community.

Subtheme 2.1: Stigma experienced by children and families

Parents reported that it was common for people in Indian society to think negatively about autistic people: *" Smith: 'It's the thought process, like they think negatively. They are labelling these children, one label is they're abnormal. That is the problem here in India….'"* (P3; 226). It was also noted that there was considerable stigma associated with autism, as well as other conditions, disabilities and illnesses: *" 'The problem is with the people. They*

don't know anything about autism … in India, any disability or mental illness is still
considered a stigma.' (Mother)" (P5; 123). Parents also reported that this stigma around their
child's diagnosis of autism seemed to be associated with the child looking or acting
differently to neurotypical children in the community; there was an intolerance of
'difference'. Parents felt that this stigma was associated with a lack of acceptance of autism,
and was often a barrier to acceptance and inclusion within the community.

> *"…it is clear that mothers recognised that stigmatising views were often associated*
> *with their children's deviations away from the expected norms of performing and*
> *confirming in society, which ultimately meant that they were labelled as being*
> *'abnormal or not normal'. Parents attributed stigmatising attitudes to societies' lack*
> *of awareness, lack of education and understanding about autism, which acted as a*
> *barrier to acceptance and inclusion."* (P3; 226).

Subtheme 2.2: Acts of discrimination

Parents described that the stigma and negative attitudes towards autism within society was
shown through discrimination in the form of negative judgements from the community. They
explained that they and their children experienced marginalisation and a lack of acceptance
from those in the wider family and community.

> *" 'I had no support system from the family . . . I mean no one accepts, even your*
> *brothers and sisters.' (mother of a child with an ASD diagnosis). 'In family…. lack*
> *acceptance. They didn't accept. Even when I told my mother.' (mother of a child with*
> *an ASD diagnosis)."* (P4; 9).

Parents also explained that people within the community often made critical
statements about the family: *"Stigma as well as myths and beliefs related to children with*
ASD have to be dealt with by parents on an everyday basis as the critical statements are not

just directed toward the child with ASD, but also toward the parents." (P6; 5). They went on to explain that some in the community used derogatory terms toward both them and their autistic children:

> *" 'He had been called by local harsh words like 'pagla hai, albataha, lahera hai''*
> *(1). 'My child had been called upon by derogatory words like 'gong'' (2) ''loth,*
> *vaheer'' (8) ''gadha, bewakoof, bolta nahi hai'' (13), 'as if he is mad or moron'*
> *(15)."* (P6; 13).

Theme 3: Largely difficult experiences with services

Parents overall reported a mostly difficult experience working with services. It was noted that the disappointment and negative outlook towards services was as much related to the poor infrastructure, poor professional knowledge of autism, and lack of local availability of services, as it was the very high, perhaps unrealistic expectations parents had of the services. Parents sought treatment from a wide variety of sources and professionals, and while experiences were largely negative, there were examples of positive experiences reported.

Subtheme 3.1: High expectations of treatments and services

Parents had very high expectations of services and treatments, with the hopes that intervention or medication would either result in a cure or complete recovery from autism, lead to an improvement in day-to-day functioning, independence and communication that would allow them to secure a job, or untap an underlying genius within the child: *"Some parents continued to hold on to dreams such as the arrival of a medical advancement or cure, the hope of a desirable job in government for the child, or the wish of the child becoming an 'Einstein' or 'Beethoven.'"* (P1; 622). This seemed to be alongside the assumption that their child's difficulties were temporary, and that any difficulties could be cured by medicine: *" 'If we give him some medications, then he will become fine.' (12)."* (P6; 13).

Subtheme 3.2: Wide variety of services sought

There were a wide variety of services sought by parents for their autistic children, involving a combination of both traditional healthcare-based services, as well as alternative methods.

> *"In the current study, diagnoses were elicited from multiple professionals, including neurologist, psychologists, psychiatrists, and pediatricians. Good number of parents also opted for alternative ways of treatment in the form of going to faith healers, tantriks, ojhas, etc. This indicates a fairly high level of help-seeking behavior from both health professionals and faith healers."* (P6; 5).

Aside from the more traditional services and therapies, families often turned to religious or spiritual services for support: *"'I went to Ajmer shareef, Nizamuddin where I performed holy rituals and prayed for my son.' (1). 'I went to balajee and prayed for my son. I will go to vaishno devi for pooja when my child will be able to speak' (2)."* (P6; 13). Others families turned to completing certain prayers and rituals themselves: *"Other common practices included prayers and ceremonies to remove 'bad spirits', consuming blessed foods and holy water, making offerings, tying holy threads, and fasting."* (P2; 196).

Further, Ayurvedic services (an alternative medicine practice, originating in India) were also a popular choice for support sought by many families, despite some reservations.

> *" 'People don't trust Ayurvedic doctors, but I got benefit from the treatment. My son was not giving eye contact, not understanding anything. I started him on Ayurvedic medicine, within a month he started giving eye contact and his progress started. He continues on that medicine.'"* (P2; 197).

Subtheme 3.3: Negative experiences of services and customers

Parents reported a largely negative experience of accessing services, citing initial difficulty in accessing support due to a lack of local availability, particularly in rural areas: *"One parent described her village as 'a place where you don't even have access to good doctors.' She was greatly dissatisfied with the lack of available local support and thus grew accustomed to traveling afar for better care."* (P1; 619). This meant that families would have to travel long distances, or even move home in order to access support: *"Krishna: 'This centre has helped us very much, because nothing like this was available in the areas we were living. So we moved to Delhi just for the sake of the child.' "* (P3; 223).

When services were accessed, parents were forced to engage with multiple professionals often offering inadequate and costly assessments and interventions; as such they were left with a negative impression of services: *"The experience of seeking external help involved multiple consultations in which families did not receive satisfying answers and were confronted with the lack of accessible support and resources when a serious problem was perceived."* (P2; 196). They also explained that the professionals they saw often seemed to lack experience/awareness around autism, which often contributed to this negative impression and poor outcomes: *"Challenges at the level of treatment seeking and dealing with lack of awareness among the medical fraternity despite clear red flag signs of ASD lead to late diagnosis and exhaustion among the parents"* (P6; 5). It was noted that this lack of awareness was compounded by an absence of appropriate training and expertise in relation to autism, which meant that approaches were often not adapted for the child's needs:

> *" '... no one is expert. They are also not concerned with what the child wants, they will teach the activities that they know and not according to the need of the child. Also, very few, only 1-2 specialists who have assistants to perform therapy. These assistants are not qualified much (10).'"* (P6; 13).

Parents called into question the attitude of some professionals, and it was explained that some showed insensitive behaviour towards the families and their children, which impacted on the family's ability to engage: *"[professionals were] generally insensitive to the family's situation, leaving an early negative impression that would later color expectations of various service providers when, with the appearance of ASD, the quality of relationships with service providers became a crucial issue."* (P1; 619). They also noted that there seemed to be a lack of professional integrity among services, in terms of a lack of training and competence, and a tendency for practitioners (both medical and religious) to take advantage of their child's difficulties to their own benefit: *" 'Professionals think that there is lot of money in this profession. Some therapist here doing their job with utmost sincerity, but there are some therapists who fool the Guardian' (7). "* (P6; 13); *"Some parents, however, felt that occasionally, religious practitioners took advantage of the families' misfortunes."* (P2; 196).

Subtheme 3.4: Positive experiences of services and outcomes

Some parents reported positive experiences working with professionals: *"...some parents had positive experiences of mentorship from professionals. Special educators were the main advocates for most of the families providing educational inputs and emotional help. Parents characterized the respective educators as 'inspiring', 'pillars of support', and a 'source of pride.'"* (P2; 196). Parents noted that both the process of engaging with services (either through receiving a diagnosis, and completing parenting skills interventions), helped them to understand and become more aware of their child and autism: *"Caregivers of a child diagnosed with ASD or ID described how their understanding of developmental disorders improved because of their own child's diagnosis. 'Now I understand it better than before …' (mother of a child with an ASD diagnosis)."* (P4; 8). They also noted that intervention improving their feelings of control and confidence in certain situations with their children:

"In a way, the parenting skills provided coping resources. Many of the parents reported feeling more 'confident' in their parenting roles. For example, as Krishna describes above, she was able to draw strength from her improved ability to understand her son, which led to her feeling in control as a parent." (P3; 225).

Parents explained that a positive consequence of being involved with services, was that they were able to make connections with other parents in similar situations, and these parent networks became an important source of support:

"Krishna: 'It's less of an institution for us than a family, because we have been here for a long time. If you're having any difficulty, need any support you can come to the centre and talk to somebody, even the parents, the parents are very supportive.'" (P3; 225).

Theme 4: Specific challenges parenting an autistic child in India

The parents in the studies outlined specific challenges bringing up an autistic child in India, including severe disruption of relationships both within the family and the community, significant changes in many areas of life, experiences of parental blame from multiple sources, and deterioration in their own physical and mental health. This made it a potentially harrowing experience for parents bringing up an autistic child in India.

Subtheme 4.1: Disruption and deterioration of family and social life

Parents highlighted that because of their child's diagnosis, and the pressure of caring for them, their marital relationship had suffered, with an increase in marital conflict, distancing and even breakdown: *"Emotional distancing with spouse was regretfully reported by one mother: 'we used to be so close but now we barely get time to talk and bond, so many tasks need my attention all the time.'"* (P5; 124)*; "'It has not been easy at all. I was kind of single*

mindedly obsessed with bringing him up. I thought my marriage almost broke down because I neglected my husband.'" (P2; 194).

It was also highlighted that relationships between the parent and their autistic child had become more difficult: *"The child's unexpected, discrepant behaviors began affecting the everyday parent–child relationship, leading some parents to ponder their own caregiving efforts."* (P1; 620). The relationship between the parent and other siblings also seemed to suffer: *"Parents reported that other siblings were also affected. A mother reported her older daughter yearning attention that her sibling with ASD received with a plea. 'Mamma you spend so much time with him and don't take me anywhere anymore.'"* (P2; 195).

Parents also noted that there was a disruption in their relationships with extended family; it was emphasised that the greater burden to conform to familial expectations fell on the mother's side, with pressure coming from the paternal side of the family: *"Geeta: 'In my case my in-laws are still forcing me to take my son to some temple. Still! They're still forcing me. Whenever I call, they'll say 'you are not following what we are saying to you''".* (P3; 224). They also explained that many difficulties came from having to make decisions against the expectations of other family members: *"At times, the extended family members disagreed about treatment decisions and forced parents to seek out traditional healers and rely on prayers and religious rituals for miracle cures."* (P5; 124). It was noted that because of this deviation from expectations, there was a considerable lack of support from the extended paternal side of the family, with negative attitudes and views being expressed, *" 'She (Grandmother) would care for other children of our family but when it comes to my child, she would start making excuses that she has now become old and she is tired of taking care of children' (1)."* (P6; 13). Along with negative views and a lack of support, there were also threats of divorce: *"Some mothers reported being threatened with divorce by their husband's extended family as they held them responsible for the child's disability."* (P5; 124).

Away from the family, the parents reported that they and their children experienced social isolation in the community because of the negative views and attitudes held, and because of this, attempted to avoid and hide from members of the community: *"Social isolation was discussed by caregivers in the ASD group, but was not highlighted in the comparison groups. 'You are not able to say anything to anyone. Society isolate(s) you. No one wants to talk to you.'"* (P4; 8).

Subtheme 4.2: Significant life changes

Getting help meant significant life changes in multiple areas, including changes to the parents' work arrangements (including having to stop work for mothers in particular) and their living circumstances to accommodate the need of their autistic child. Both seemed to significantly impact on the families' financial status.

> *"The intensity of their child's needs meant that the professional lives of parents were affected—the mother, as the prime carer, adapted her aspirations and often became homebound. With fathers taking on the financial responsibility of the household, their working hours often increased, and one father relocated his work so as to supervise his son at home."* (P2; 194).

Subtheme 4.3: Parental blame

Parents reported blame towards themselves from multiple sources. There were various examples of parents blaming themselves for the difficulties they were facing because of caring for their autistic child: *" 'I feel guilty that all of this happened because of my job. I left him for 2 years after which all of this started. If I would have been there for him then things would have been different.' (3)"* (P6; 13). Parents also turned to blame each other for such difficulties: *"Partners accused each other of not caring, sharing childcare duties, and even attributed the child's disability to poor parenting"* (P5; 124).

It was noted that this behaviour was not limited to the parents, however, with other members of the family, as well as people in the community (including doctors and teachers) often placing blame on the parents for their children's difficulties:

> " 'The way he disclosed it to me, it came as a total shock to me because he said, 'Oh my God, he will be a vegetable for the rest of his life. What kind of mother are you, you don't know how to take care of a child?' . . . I just did not know what to do. I was just totally in a state of shock.' (M10)" (P1; 621).

Subtheme 4.4: Parental physical and mental health challenges

Finally, parents also noted that they experienced an impact on their own physical health because of the pressure of caring for an autistic child in India, often citing fatigue as a result of a loss of sleep as a major difficulty.

> " 'Till he was 5 years I could not sleep in the night, I used to get black circles around my eyes, since he would run; not sitting in one place. I went through so many difficulties. At times I felt I don't want this child.'" (P2; 194).

This highlights some of the difficult thoughts parents had during the process of caring for their child. In line with this, parents also mentioned struggles with their mental health because of caring for their child, saying that they experienced many negative emotions, including depression, anxiety, and stress, as well as difficult and distressing thoughts and worries around the child's future. *"The immediate impact of an ASD diagnosis for caregivers included feelings of depression, concern for the future, and disbelief. 'I didn't make food for three days [when hearing of diagnosis]' [Mother felt overwhelmed and almost cried]."* (P4; 7). There were also some reports of suicidal ideation: *"'I wonder why am I making such a sacrifice in the life, is it really worth it? why should I suffer?' … 'There are days I feel like committing suicide!' (Mother)"* (P5; 13).

Discussion

The aim of this systematic review was to consider qualitative research concerning the parental experiences of autism in India. The review was conducted using TS, and highlighted four analytical themes from the six included papers. Theme 1 highlighted that parents reported a general misunderstanding of autism, resulting from a lack of awareness across the population. This misunderstanding was evidenced in various ways, in terms of misguided beliefs concerning the life-long persistence of autism, the inconsistency in identification of symptoms, and the varied, confusing, and competing explanations as to the causes of their children's behaviours. Misunderstanding seemed, in part, to be linked with the negative attitudes towards autism in Indian society, highlighted in Theme 2. These negative attitudes were reported to have manifested through stigma and discrimination experienced by autistic children and their families. This misunderstanding of, and therefore negative attitudes towards autism, autistic children, and their families, seems to reflect the general attitudes and beliefs towards difference and disability in India highlighted in previous research (Antony, 2013; Kayama, Johnstone & Limaye, 2019; Panicker, 2021; Patra & Patro, 2019; Gudlavalleti et al., 2014; Patra & Kar, 2021). These attitudes toward disability mean that autistic children and their families, who may present with behaviours and coping strategies that may be outside of the cultural norms, are more likely to be subjected to stigma and discrimination, and therefore likely to be at a significant disadvantage in society than their neurotypical counterparts. This disadvantage played out somewhat in Themes 3 and 4.

Theme 3 represented the difficult experiences expressed by parents in relation to working with services in India. This was in part driven by the high expectations they held of said services to provide a cure, or at least a significant improvement in functioning and independence to the point of better integrating into society – it could be seen that this was perhaps led by the general misunderstanding of autism outlined in Theme 1. It should also be

noted, however, that the negative experience of services was also driven by barriers to accessing services locally, as well as a lack of professional knowledge and training in autism. This reflects the findings in the existing literature that funding and provision for autism services is sparse in India, particularly in rural areas (Patra & Kar, 2021). It is also a surprising departure from the Indian government's stance of both providing adequate care for, and avoiding discrimination against people with disabilities (autism is recognised as a disability under the Right of Persons with Disabilities Act 2016). There is still work to be done in the organisation of services for autistic people and their families in India. However, this problem may not be autism-specific, and it should be acknowledged that healthcare in India is chronically underfunded (Bhatia & Singh., 2021; Ahjua, 2019; Kumar, 2023); this lack of provision for autistic people therefore reflects a wider problem within the Indian healthcare system.

Theme 4 highlighted the specific parenting challenges faced by parents of autistic children in India. It could be argued that the ideas expressed here are a function of the misunderstanding, stigma, and poor health provision described in previous themes. Parents highlighted that there were severe disruptions in many areas of life, including work commitments and family/community life. The process of providing care for an autistic child in India alongside such disruptions was said to take a toll on parents both physically and mentally. It was noted that process of caring for, and adapting to, the needs of an autistic child meant that parents routinely had to go against familial pressures and expectations. India is known to have a collectivist culture, where extended family and the wider community are integral in the child-rearing process (Sharma, 2020), and there are cultural expectations of both how to act in, and raise a child within an Indian family (Verma, 2020). Going against these cultural expectations, it seemed, led to the isolation experienced and reported by the parents, which had an impact on their perceptions of their abilities to cope. While the

collectivist approach to child caring may be important and successful in raising neurotypical children in India, these approaches can be challenging for parents of autistic children.

Overall, the results from this qualitative systematic review suggest the experience of raising and caring for an autistic child in India proves to be challenging for parents due to a misunderstanding of, and therefore negative beliefs towards autism. This is reflected in a lack of service provision for such children, as well as challenges in accessing support from family and the local community. It should be noted, however, that the highlighted challenges may not be specific to the families of autistic children, but may also apply to families of people with any disability or difference. Kasthuri (2018) highlights "The Five A's" (awareness, access, absence of human-power, affordability, & accountability) as the major challenges to healthcare in India. The results of this review echo these sentiments in an autism-specific context, suggesting that there is work be done on understanding and working with autism, but also in the wider disabled population, and healthcare in general in India.

Strengths & Limitations

This review main strength is that it is the first systematic review to consider the provision for autism in India from a parental perspective, and has (1) highlighted important findings that outline the need for more, better quality research to be conducted in the area, and (2) provides results that have the scope to direct both future research, and policy and practice in India. There are, however, certain limitations that need to be considered.

First, the search strategy resulted in a limited sample, with six papers being included in the analysis (a total sample of 80 participants). Searches completed through databases and repositories yielded results including both peer-reviewed and grey literature, in-line with the Centre for Reviews and Dissemination's (2008) recommendations for systematic reviews. However other methods of literature searching (e.g. websites, organisations, and citation

searching; Page et al., 2021), were not within the scope of this particular review. Furthermore, search terms did not include terms related to qualitative methodologies (such as "interviews", "focus groups", "IPA" or "Thematic Analysis") – as such, it could be that some relevant papers were missed in the analysis. Future reviews could consider both the use of other literature searching methods, as well as a wider set of qualitative methodology-based search terms, to perhaps yield a slightly larger sample size to complete the review, although it should be noted that there is no clear and consistent rule on how many papers should be included in a qualitative systematic review. It should be also considered that the limited sample in this review may not be down to the depth of the search alone, and may be down to the fact that qualitative research tends to recruit fewer participants. It also suggests that perhaps there is a lack of qualitative research considering parental experiences of autism in India, with much research on autism focusing on survey-based, quantitative data (Patra & Patro, 2019; Gudlavalleti et al., 2014; Patra & Kar, 2021; Perumal, Veeraraghavan & Lekhra, 2014). This is an important finding in itself and, given the difficult experiences that have been described by the parents in this review, highlights the need for further research to focus on gathering data concerning parental experiences of autism in India in order to get a more rounded and comprehensive view on the matter.

Second, certain aspects of the quality of the included papers should be considered when interpreting the results. The CASP was used to assess quality of the papers; it was noted that none of the papers adequately recognised and accounted for the relationship between the researchers and their participants. This is particularly important in qualitative research, as the formulation of research questions, recruitment, and data collection and analysis relies on judgements and interpretation of the researchers, which, when unaccounted for, can result in potential bias in the results. Further research is needed to address this potential bias in the future, however, it was agreed that, overall, the included papers were of

sufficient quality to provide useful data related to our research question, and be included as part of the analysis.

This lack of reported reflexivity, and potential for bias in the results of the original studies, is an important point to consider further. In line with Thomas and Harden's (2008) protocol, the data included in this review comprised of all text in the Results/Findings sections of the original papers, and so included both participant and author quotations; the analysis, therefore, involved third-hand interpretation of experiences of parents of autistic children in India. A "double hermeneutic" is at play during most qualitative research; researchers are interpreting their participants interpretations of a given experience. This qualitative systematic review, then, attempts to interpret not only the participants' interpretations, but also the original authors' interpretations. The lack of reported reflexivity (and therefore potential for bias) in the included papers, is important to consider as there may be misinterpretations of parents' experiences of raising an autistic child in India – therefore, there is a danger that, by including author quotations in this review, we may be moving away from the participant's own words. The purpose of this review, however, was to synthesise all available findings on the matter, and it is noted that "Findings" in qualitative studies, for the purpose of a qualitative systematic review, incorporate the original data (participant's own words) as well as the authors' interpretations (Thomas & Harden, 2008; Sandelowski & Barroso, 2002). Interpretation is a key aspect of qualitative research, and should not go unaccounted for in the systematic review process. It is also important to consider that the authors of the present review will also bring their own ideas and biases to analysis and interpretation. This was however, considered in-depth during meetings within the research team, the analysis of the data, and in the formation of themes and subthemes, as mentioned in the Method section, and we feel that any issues with potential bias in the included studies, as well as any bias during our synthesis of the data was well accounted for. Even if there was a

certain lack of reported reflexivity in the included papers, the research team did it's best to control for this during the review.

One final limitation could be the paper selection screening process. The research assistant screened only at the "abstract" phase, and did not consider titles or full texts. This may have led to some bias in the inclusion of the final papers for analysis, which may have had an impact on the results and conclusions pulled from the paper. It should be considered that the screening was completed in this way because of time constraints both on the first authors' and the research assistants' side; the research assistant did not have the time to read through the full texts. It should also be considered that the selection process resulted discrepancies between the first author and the research assistant in the application of the inclusion criteria; there was found to be "none-to-slight" agreement across ratings for the abstracts. This would suggest that the criteria were not initially explicit enough to be applied reliably across raters, and this is important for the replicability of the review. Future research should ensure a more robust inclusion criteria, and perhaps consider pilot testing before beginning searches, in order to ensure that the criteria are fit-for-purpose. It should be noted though, that the discrepancies were discussed, and the inclusion criteria were revised to be more explicit in a follow-up meeting. A unanimous consensus reached between the researchers following this.

Implications and recommendations

This review found that parental experiences of autism in India are largely negative, resulting from misunderstanding of autism, as well as stigma and discrimination associated with the diagnosis, however, qualitative data in the area are sparse. De Leeuw, Happe and Hoekstra (2020) outline multiple cultural and contextual factors, including stigma, religion, cultural norms, and access to services (among others), which impact on the "expression, recognition,

identification, interpretation and reporting of autism symptoms". These ideas are in line with the findings of the present review, but are particularly important in light of the fact that the diagnostic criteria are founded on research focusing on a White, Western, high-income population (de Vries, 2016). It is suggested that autism symptom recognition and severity differs significantly between cultures (Matson et al., 2020), and so the difficulties presented in this review may be a result of the fact that the current diagnostic criteria are perhaps not in line with how autism presents in India – it may not be that "one size fits all". This highlights the need for further research into autism in terms of (1) understanding the symptoms and presentation from a culturally-specific perspective, not purely relying on current diagnostic criteria; (2) outcomes research to consider which services and interventions are effective; and (3) qualitative research into the experiences of autistic people, their families, and also practitioners. Research conducted in these areas may help to develop a better understanding of how autism presents and is perceived in India, as well as which services are most likely to be helpful. This information could be used to inform future policy and practice around autism in India, which will ultimately allow for a more culturally-aware and culturally-specific approach to identifying, assessing, and providing appropriate intervention for families of autistic people in India.

The results of this systematic review also provides consideration for the general direction of future policy and practice. Parents highlighted particular issues around barriers to accessing services, and this should be an area for consideration; work needs to be done to ensure better provision for autistic people and their families. However, this is not an autism-specific problem, and it seems that the healthcare system in general needs work – the Indian government are aware of this general lack of provision, and are looking to increase public health spend (Ahjua, 2019). This is, however, way below the global average (Government of India, 2017), and given the difficulties presented by parents in this review, the suggested

increase may not be enough to ensure adequate care across the board. Education concerning autism, either through schools, or the media (something which was noted by parents to be a powerful medium in building understanding of autism) should also be considered to improve public understanding of autism as a whole – this in itself would go some way to address the misunderstanding of autism in society and perhaps lead to better access to community and health service support for families.

Investment into clinical psychology provision in India may be beneficial to meet some of these recommendations. Clinical psychologists are, by nature, scientist-practitioners, and so have the knowledge and skills to be able to conduct the above-suggested research, facilitate training and education for professionals, service-users and the general public, and also provide clinical services (in the form of assessment and intervention) for multiple mental health and neurodiversity presentations. The Indian healthcare system, therefore, may benefit from increasing investment in the training and hiring of clinical psychologists (as has happened in the United Kingdom over the years; Marks, 2022), in order to achieve better outcomes for autistic people and their families in India..

Conclusion

The results of this qualitative systematic review suggest that raising an autistic child in India is a massive challenge for parents, due to the society-wide misunderstanding of, and negative attitudes held in the community towards autistic people. Additionally, poor health provision across the board, means that support is extremely difficult or costly to access for these families. There is evidence to suggest that there is work to be done by the people of power in India to develop their understanding of autism, in order to create a shift in attitudes towards, and provision for families in need of support. It should be noted that these challenges may not be autism-specific, however, and there is evidence in the wider literature to suggest that these

difficulties are present for people with other difficulties or behavioural differences, and that the challenge around healthcare provision across the board needs to be seriously reviewed.

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Chapter 2 Empirical Paper

Title Page

Title

Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis

Running Head

Autistic People's CBT Experiences

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Abstract

Purpose: CBT is the recommended intervention for autistic people with mental health difficulties. A growing body of research suggests that, because of the specific difficulties faced by autistic people, CBT may be difficult for them to access, and thus need to be reasonably adjusted for best engagement and outcomes. However, much of the research does not include autistic people's voices. This study looked to address this gap in the literature.

Methods: This qualitative research looked to gain insight into the question: "How do autistic people experience CBT?" in the form of semi-structured interviews with five autistic people. Interviews were analysed using Interpretative Phenomenological Analysis (IPA). ***Results***: IPA revealed autistic people's experience of CBT were made up of three superordinate themes (along with 12 subordinate themes): (1) "Useful aspects of CBT"; (2) "CBT not a good fit for autism"; and (3) "Inaccessibility of services". ***Conclusion***: While autistic people noted some benefits of engaging in CBT, such as learning more about themselves, and being better prepared for further therapy, there was an overall feeling that CBT was not a good fit, and was not adapted appropriately for them because of a lack of knowledge, awareness and training with regard to autism within services. It was also noted that they felt services were not able to make the reasonable adjustments necessary for better accessibility. This has important clinical and academic implications, and suggests that the structure of service provision for autistic people needs to be better supported or reconsidered entirely.

Keywords

Autism, Adults, CBT, Experiences, Therapy, Adaptation

**Exploring the experiences autistic adults who have had Cognitive Behavioural Therapy:
An Interpretative Phenomenological Analysis**

Autism Spectrum Disorder (ASD; referred to in this paper as autism henceforth) is a spectrum of neurodevelopmental disorders characterised by difficulties with social communication and interaction, and repetitive, restrictive patterns of behaviour and interests, which are not accounted for by an Intellectual Disability or physical condition (International Statistical Classification of Diseases and Related Health Problems 11th edition [ICD-11] World Health Organization [WHO], 2019). It is estimated that the current UK prevalence of autism lies between 1-2% of the general population (NHS Digital, 2021). This is rising year-on-year as awareness and understanding of the condition increases (McConkey, 2020). Lai et al.'s (2019) systematic review and meta-analysis highlights that mental health difficulties (depression, anxiety, obsessive compulsive disorder, bipolar disorder & schizophrenia) are more prevalent in autistic than neurotypical people. As such, it is important to consider the efficacy of therapeutic intervention in the neurodivergent population.

The NICE Guidance is a set of clinical guidelines for treatment and care for people within the NHS in England and Wales, and suggests that when working with coexisting mental health disorders in autistic adults, the offer of psychosocial intervention should be led by the existing NICE guidance for the specific mental health disorder (National Institute for Health and Care Excellence; NICE, 2021). This is commonly Cognitive Behaviour Therapy (CBT) (NICE, 2011). Wang et al. (2021) explain CBT is the evidence-based intervention for working with mental health difficulties in autistic people. CBT is a short-term, present-focused form of psychotherapy, developed by Aaron Beck in the 1960s and 1970s, based on the premise that one's interpretation of events and situations (rather than the nature of the situation itself) impacts their emotional, behavioural and physiological reactions to the situation (Beck, 2020). CBT is designed to challenge and change maladaptive beliefs and

behaviours that are present among various mental health difficulties (Beck, 2020). Various systematic reviews and meta-analyses have highlighted the efficacy of CBT in the context of various mental health presentations, including depression, anxiety disorders and eating disorders (Santoft et al., 2019; Van Dis et al., 2020; Atwood & Friedman, 2020), and as such is the recommended first-line psychotherapeutic approach for many mental health difficulties in the UK (NICE, 2011). Research also highlights certain facilitators to engagement in CBT, including the therapeutic relationship, working towards the ending from the beginning of therapy, and having the opportunity to develop an understanding of their mental health difficulty as well as learn problem-solving skills and strategies to help manage it (Gega, Smith & Reynolds, 2013; Hoskins et al., 2019), and inhibitors to engagement, including perceived lack of support from the therapist, and difficulties adapting to changes in routine (Dryberg, Juel & Kragh, 2021; Hughes et al., 2020). These facilitators and inhibitors to engagement are consistent across different forms of CBT (one-to-one, CBT for specific mental health difficulties, remote, and group-based) (Bryde Christensen et al., 2022; Gericke, Ebert, Breet, Auerbach & Bantjes, 2021; Lloyd, Rimes & Hambrook, 2021; Pugh et al., 2015; Tzavela et al., 2018), and have been shown to be linked with the outcomes of therapy (Dryberg et al., 2021).

Research suggests that difficulties experienced by autistic people may be a barrier to both therapeutic engagement and positive outcomes (Ahlers et al., 2017; Doherty et al., 2022), and as such, the NICE Guidance (NICE, 2021) stipulates that staff delivering these interventions must have an understanding of the core aspects of autism and their impact on the treatment of mental health difficulties, as well as seek advice from specialist autism teams in order to adapt the intervention appropriately for the client. There is a growing evidence-base for the therapeutic adaptation for autistic people, however much research tends not to focus on CBT specifically (the evidence-based psychotherapeutic intervention for this

population), or only focuses on the experiences of therapists and/or caregivers (Conner, DeVries & Reaven, 2018; Cullen & Barlow, 2002; Gaus, 2007; Pattni, Fox & Glorney, 2022; Rogerson et al., 2019; Schweizer, Knorth & Spreen, 2014; Walters, Loades & Russell, 2016). While this information is useful to consider, the voice of autistic people is often lost. There is a growing recognition for patient-involvement in the planning, implementation and delivery of services, as it has been found that focusing on client experiences to consider the facilitators and inhibitors of treatment engagement is key in developing appropriate services and therapeutic interventions (Dyrberg et al., 2021). The Autism Depression Trial (ADEPT; Horwood, Cooper, Harvey, Davies & Russell, 2021) has looked to fill this gap somewhat, by interviewing trial participants regarding behavioural activation for depression adapted for autistic people. They found that participants had a preference for this adapted approach, and concluded that a full scale RCT is needed to consider the effectiveness of the intervention in more detail. It should be noted that it ADEPT is based on low-intensity, CBT informed intervention, not "full" CBT. As such, there is a gap in the literature here to collate and analyse the experiences of autistic people who have had CBT, with a view to using this information to further inform CBT-specific adaptations for this population, and hopefully improve outcomes moving forwards. Therefore, the research question this paper is looking to consider is: "How do autistic people experience CBT interventions?". It is hoped that insight in relation to this question will be obtained through qualitative data analysis of interviews with autistic people, and will help to inform both future research in the area, and also autism-specific CBT adaptations.

Method

Design

This was a qualitative study considering the experiences of adults with autism who have received CBT. A favourable ethical opinion was given by the Research Integrity and Governance team at the University of Southampton, allowing the study to commence (Appendix C). Data were collected in the form of explorative semi-structured interviews, utilising a topic guide co-developed with a local expert-by-experience who has a diagnosis of autism, and had previously worked closely with the University on several similar projects. Qualitative data analysis was completed through the use of Interpretative Phenomenological Analysis (IPA). IPA, epistemologically speaking, is grounded in interpretivism, which assumes that reality is socially constructed (Myers, 2019), and therefore our approach subscribed to the notion that there may be more than one truth. Interpretivism favours subjectivity, inductiveness and reflexivity, and these elements were important for us to consider throughout the process of data analysis.

Participants

The inclusion criteria are in Table 4. Five British participants, recruited via local experts-by experience and social media, met the inclusion criteria to take part in this study. Three identified as female, one male and one as non-binary, and ranged in age from 18 to 42 years. All participants reported that they had received CBT in the last two years (anyone receiving therapy at this point would not be eligible, so as not to interfere with their therapeutic engagement and relationships, and to mitigate any potential risk), and confirmed that they had a diagnosis of autism. Demographic information can be seen in Table 5.

[INSERT TABLE 4: Inclusion criteria]

[INSERT TABLE 5 – Participant demographic information]

Materials

There were certain materials used in the process of recruitment of and communication with the participants, including the Study Advert, Information Sheet, Consent Form, and Debrief Form. These were sent to the participants via email, and can be found in Appendix D. A bespoke Pre-Interview Meeting Questionnaire (Appendix E) was used to collect relevant demographic information about the participant, as well as information relevant to the inclusion criteria; we asked questions concerning their receipt of CBT (e.g. content of sessions covered, techniques used) in order to consider whether or not they had received CBT, and sought confirmation of their autism diagnosis by asking them to share their diagnostic report with us. The Clinical Outcomes in Routine Evaluation-10 (CORE-10; Barkham et al., 2013) was used with participants to measure psychological distress around the time of the interviews. It was scored using the recommended categories and cut-off scores, and any participant scoring 20+ ("moderate-to-severe" psychological distress) was not deemed eligible to participate in the study at this time. The CORE-10 is a widely used measure of psychological distress that Barkham et al. showed to have good validity and internal reliability in primary care settings, and in the general population. A Topic Guide (Appendix F) was used to direct the semi-structured interviews, and included questions focusing on participants' experiences of CBT, what went well and not-so-well, what was helpful or unhelpful, and any techniques or strategies used by the therapist to help meet the participants needs, and feel more or less comfortable. A Risk Assessment and Management Plan (Appendix G) was available to use if any risk presented during the process of recruitment and interviewing; it was non-standardised, but was agreed on by the research team (all Clinical Psychologists or Trainee Clinical Psychologists).

Procedure

The recruitment process involved opportunistic sampling, in which the research team reached out to local experts-by-experience, known to the University of Southampton, and asking them to share the Study Advert with any potential participants, as well as posting the Advert on social media platforms (X, & LinkedIn); the Information Sheet and Consent Form were sent to any responders and an initial meeting was organised. There was no deception involved in the recruitment of participants. Freely-given, informed consent was obtained from all individual participants in the study, regarding participation in the research as well as publication of study results in a journal article.

During the initial meeting, the Pre-Interview Meeting Questionnaire was used to gather relevant demographic information and assess the participant for inclusion; as part of this questionnaire, we asked potential participants to mark off aspects of CBT that they had received (e.g. content of sessions covered, techniques used) in order to consider whether or not they had received CBT; we had to take their answers at face value. The Information Sheet and Consent Form were also discussed; capacity to both understand the purpose of the research, and to consent to their participation in the research was considered. Participants were required to give informed consent (both verbally, and by signing the consent form) at this point for both the sharing of any autism diagnostic reports, as well as the interviews taking place. Participants were asked to share a report confirming their diagnosis of autism either via screen sharing during the meeting, or sent by the participant to a secure email, checked and then deleted. The report was not stored in any way, and the email was also deleted. Once the inclusion criteria were met, and interview date was organised to take place virtually on Microsoft Teams. If the inclusion criteria were not met, the participant was informed that they were not eligible to take part in the study at this time.

One week prior to the interview, the CORE-10 (Barkham et al., 2013) was sent via email to participants; anyone scoring 20+ ("moderate-to-severe" psychological distress) would be not be eligible to take part in the research at this time, and would be signposted to relevant support, after the Risk Assessment and Management Plan was completed. No participants scored above the CORE-10 threshold, and risk did not present at any time.

On the day of the interview capacity to understand and consent to the research taking place were assessed by revisiting the Information Sheet and Consent Form. Once informed consent had been obtained, the semi-structured interview took place, lasting approximately 60 minutes. The interview was audio recorded in Microsoft Teams. Upon completion of the interview, the participant was fully debriefed, using the Debrief Form, and contact details were collected to arrange for compensation for their time (in the form of an e-Voucher).

The audio recording was saved to a password-protected computer and then transcribed verbatim by the first author, before being destroyed. Identifying information (i.e. any mention of services or names) was removed from the transcripts, and each participant was given a pseudonym to maintain confidentiality.

Analysis

Interpretative Phenomenological Analysis (IPA) was the chosen qualitative analysis method, and followed the protocol in Smith and Nizza's (2022) book which outlines four general steps to be completed with each transcript separately: (1) "Reading transcripts and making exploratory notes" (differentiating between descriptive, linguistic and conceptual notes); (2) "Formulating experiential statements" – a summary of what the researcher feels is important in the notes regarding a particular part of the transcript; (3) "Finding connections and clustering experiential statements"; and (4) Compiling the table of personal experiential themes. Each of the tables of experiential themes were compared and contrasted in a fifth

step which involved "Cross-case analysis", and the experiential themes were grouped in terms of relevance; these groups made up the superordinate and subordinate themes discussed in the results section. This five-step process was carried out by the first author, and then discussed with the research team at length, considering both the groupings of the themes, as well as any potential meanings and conclusions that could be drawn from them. All researchers agreed the arrangement of final themes.

The research team was made up of three members; two male and one female. Two of the research team were White-British, and one was Asian-British (Indian), and all identified as neurotypical, with multiple years' experience working with neurodiverse people. Throughout the process, the researchers were mindful of bringing the conversations back to the data during the discussions, with a careful consideration of their own attitudes and biases towards neurodiversity in particular. This was borne out in discussions around the use of appropriate terminology throughout the paper, as well during data analysis, when thinking about the wording of theme names. While a typical reflexive log was not used, notes were kept from each of the meetings to refer back to.

Results

Overall, IPA revealed three superordinate themes: (1) "Useful aspects of CBT"; (2) "CBT not a good fit for autism"; and (3) "Inaccessibility of services". Each theme had subordinate themes outlined in Table 3, and discussed in more detail below.

[INSERT TABLE 6 – Superordinate and subordinate themes from IPA]

Superordinate Theme 1: Useful aspects of CBT

This theme outlines that autistic people interviewed in this study did find aspects of CBT useful; some aspects mentioned were generalisable to other therapeutic approaches, while others were more CBT-specific aspects. Any noted benefits were, however, believed to be "secondary", in that they did not seem to address their main presenting problems, and so they may have left with the feeling of unfulfillment and wanting more.

Subordinate Theme 1.1: A neutral space to explore difficulties

All participants were able to identify helpful aspects of their CBT sessions, however, for the most part, they first mentioned aspects of the sessions that were non-CBT-specific. Four participants highlighted that the therapy environment was a useful, consistent space in which to talk to someone about, as well as process, their difficulties and problems: *"I enjoyed having, like a structured place where I could go and talk to someone…. I would know it was the same therapist every week and it was usually in the same room and I, I know what we'll be talking about."* (Emma); *"… it's, it's good to, to, to have someone who you can sit and talk to for that time, even if it's a bit brief to, to help you process things that are happening."* (Frank). They were able to do so in a way they could not do with other people, which may have typically been challenging for them. This suggests that the therapeutic relationship may be one of the more important factors in CBT, however, they acknowledged this experience may be common or "standard" among talking therapies, and so was not specific to CBT:

> *"I suppose getting to see, like, a random person you knew nothing about me, like, outside of my circle against felt refreshing and forced me out of my comfort zone. Umm, because I guess with the autism I find it difficult to talk to new people."* (Jade).

Subordinate Theme 1.2: Improved understanding of symptoms

CBT-specific aspects of sessions were also discussed by four participants. They highlighted that CBT helped them improve their understanding of the interplay between cognitions, emotions and behaviours, through the use of visual formulation models and cycles; *"… it explained to me a bit about how the, the mind works, which I found very helpful, sort of the whole getting stuck in cycles of thinking and that did help me understand myself."* (Rachel)*; "… there was a lot of physical note taking which was helpful more so than just regular talking therapies… I can visually see how I'm feeling or how I react to certain things. It helped with understanding myself more."* (Emma)*.*

It was also noted that the process of CBT improved their emotional literacy, an aspect that autistic people can find extremely challenging. CBT helped them recognise and identify their emotions better through conversations about emotions, and the use of feelings wheels: *"So sometimes saying: 'That must make you feel angry' can be helpful for people like that, who can't put a word on it…. you can get those feeling wheels that can help.* (Ellie).

Subordinate Theme 1.3: Benefits were deemed secondary

Any benefits, or useful aspects to their CBT sessions were described to be "secondary" in that they did not seem to help with their autism-related presenting problems. It was argued that the process of CBT opened them up to talking about their difficulties with other people because of it's consistent, structured approach, but it was felt that this did not necessarily help them to deal with their autism-related difficulties any better. It seemed that CBT helped the participants to drop their defences; Frank noted that it prepared, or "softened" him up, to engage in future, perhaps more in-depth and difficult therapeutic work:

> *"…it prepared me for being able to do those more intricate, in depth, invasive*
>
> *therapies … maybe I wouldn't have been able to do those if I hadn't been softened up*

by the CBT… the openness and the lack of shame with which I can now talk about myself…. I think probably a lot of the work was done in those in those sessions." (Frank).

Participants also described wanting or needing more from CBT, however, it was unclear exactly what content was needed from the sessions: *"It's like it wasn't as intense (?) or, like, as thorough as I kind of hoped it would be... it was more than a regular [therapy]… there was a bit more, structured work. But I… kind of wanted more."* (Emma).

Superordinate Theme 2: CBT not a good fit for autism

Despite the benefits of CBT being highlighted in Theme 1 (providing a neutral space to talk about difficulties, and helping them to improve their understanding of their symptoms), Theme 2 highlights that participants also felt that CBT was not a good fit for them as autistic people. This was very much in-line with the idea of benefits to CBT being secondary for autistic people. Examples of CBT perhaps not being a good fit included the focus of the modality, the content, and communication style employed by the therapists. It was noted that adapting for autistic people's needs would have helped with engagement, and examples of these adaptations were expressed, but it was also explained that they felt this adaptation process required specific knowledge of and experience working with autism, which was often felt to be lacking.

Subordinate theme 2.1: Attempting to fix something that can't be fixed

The overall feeling was that perhaps CBT was not helpful in meeting perceived therapeutic needs and expectations, and so was not the right therapeutic approach for autistic people. It seemed that they had been referred to CBT services for on the basis of difficulties related to autism, but these difficulties had been mistaken for mental health problems. As such, it felt like CBT was being used to "fix" something you cannot fix, and was being applied in a

context for which it was not designed: *"I've often felt…. Like it, I was doing something that would be helpful to someone else but wasn't for me. Um like … I was being given a, a fantastic medical treatment, but for something I didn't have."* (Frank)*; "So I think sort of fundamentally that's why it didn't work for me… the problem with CBT is it's trying to fix something, whereas autism can't be fixed."* (Rachel). This suggests that perhaps CBT-based services are not appropriate to help autistic people deal with autism-specific problems.

Subordinate Theme 2.2: Content felt neither important nor meaningful

It was discussed in more detail which aspects of CBT were not such a good fit for autistic people. Ellie's use of the phrase "wishy washy" suggested that CBT utilised approaches that were focused on areas that were neither meaningful nor useful to autistic people, such as focusing on "surface-based" or perhaps present-moment elements (without considering and addressing longitudinal elements of their difficulties): *"I didn't like how… The root causes of things weren't addressed. It was quite… surface based, a bit wishy washy, kind of like it's … a tool to use in therapy but it shouldn't be the entire therapy."* (Ellie). This lack of meaningfulness resulted in client disengagement.

Subordinate Theme 2.3: Content not explained in an autism-friendly way

It was also explained that certain CBT ideas and resources were often not explained in an autism-friendly way (i.e. being clear, specific, and unambiguous), and were not followed-up adequately in future sessions: *"Because one week we'd seemed to be … going through worksheets and filling them out … And then the next week, we just suddenly jumped to something completely different and we'd never use the sheet again."* (Jade). This meant that the content of the sessions were often either misunderstood, or taken literally and overgeneralised (e.g. using strategies like a "life manual"), and thus was difficult to follow and apply outside of sessions appropriately:

"I was told: 'if this happens try this technique… if this happens, try this technique' … I went and used them and they didn't work the way I was expecting them to work … in retrospect, what I realize is that I wasn't being handed a user manual for dealing with other people, because such a thing doesn't exist." (Frank).

It was noted that a useful adaptation in this area would have been to provide more explicit explanations of the purpose of the strategies and techniques, while also giving some clarity around the idea that these techniques were not likely to work in all situations, and so was not a "user manual" for working and dealing with social situations: *"…it would have been really helpful to have been foregrounded as saying: 'this technique … sometimes it will work and sometimes it won't work', umm, and then maybe discuss with me the reasons it might be worthwhile doing it anyway."* (Frank).

Subordinate Theme 2.4: Social communication differences not accounted for

There also seemed to be a mismatch in communication styles between the therapists and their autistic clients. Socratic, open, non-directive questions championed by the CBT method proved to be difficult for autistic people to engage with because of their social communication difficulties, and this negatively impacted on their ability to understand the stance of the question and provide answers that were meaningful in the context.

"… because of broad questions like "how was the last week been?"… I found it difficult to, sort of, tell what he wanted me to say in terms of, did he want just sort of like a fleeting answer … Or did he want a breakdown, of sort of how each day was like? It was difficult to tell how, how in depth he wanted the answer to be." (Jade).

Jade went on to explain that adapting communication by either providing some scaffolding and examples of answers, or asking questions along with a choice of relevant answers, would help autistic people engage better with the therapeutic process: *"… if you can*

see someone is struggling and they're telling you that they can't come up with examples,

maybe it would help by coming up with an example yourself and then they can adapt it."

(Jade)*;* this is somewhat at odds with the idea that many therapists may not want to lead their

clients towards certain answers.

Jade also suggested that CBT's outcomes focus, and the communication around this,

was ambiguous and difficult to quantify and understand for autistic people, which meant that

responding and engaging appropriately in sessions became a challenge: *"Literally, I'm not*

even joking, he would ask, like: 'how we how are we gonna move forward?'… and then he'd

just, like, stare at me and then I'd be like: 'I don't know what you want me to say'. {laughs}."

(Jade). This may be because of the difficulty that autistic people have with abstract concepts

and imagination, which impacts on their ability to communicate appropriately; Jade here

struggled to imagine how she would move forwards in therapy, and so could not provide an

answer in the context of this conversation. To this point, Emma noted that the therapist

putting their agenda (around progress and outcomes) to one side and focusing on patient

comfort, was a more useful approach to ensuring better communication and engagement in a

given session, but also to ensure that they would continue to come back:

> *"Just prioritising… making me feel comfortable, over constantly needing to be*
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> *progressing … I had some instances where I came in quite upset, and instead of trying*
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> *to hurry me along and try to make me feel better, she allowed me to … have a calmer*
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> *and slower session, and make a little bit less progress, um, until I was back to a*
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> *position where I felt more comfortable."* (Emma).

Subordinate Theme 2.5: Lack of knowledge of autism resulted in poor adaptation

This "poor fit" and lack of adaptation for autistic people's needs was said to be related to

therapists' limited experience with and understanding of autism. There was explained to be a

marked problem in identifying "autistic" strengths and difficulties. This misidentifying of difficulties often led to the misinterpretation of their presentation as being uncooperative, which fed into that idea of "poor fit":

> *"I might well say 'I can't do that because in the future, Y is gonna happen if I do' ... that can be written off as ... doom-laden thinking and paranoia ... but sometimes it isn't ... that was almost taken as me being uncooperative."* (Frank).

The onus, therefore, seemed to fall on the client to bring up and explain autism-related difficulties, however, there was a feeling that these difficulties were not being taken at face value, and, as Jade mentions below, felt the therapists thought they may be lying, which may perhaps have influenced their confidence and engagement in the therapeutic process:

> *"I don't think he really understood what masking was, and he didn't even understand that I was like not, not lying, but I guess fabricating my answers ... I explained how a lot of my social difficulties and anxieties around social situations is because of my autism... but I was kind of having to explain why that is."* (Jade).

Even when these autism-related difficulties were acknowledged by the therapist, they still seemed to find it difficult to use that knowledge to adapt the therapy appropriately: *"... there wasn't really much action in terms of adapting, but I could see he was, he was... at least taking it into account, but, but then didn't know what to do with it."* (Jade). This could be down to lack of service provision, training and resources.

Emma left with a general positive experience of CBT being a good fit for her needs - it was noted she felt therapy was adapted appropriately for her, in terms of communication, because the therapist had good knowledge of autism-related difficulties. As such, Emma felt she was able to engage well with therapy. *"... she would ask me questions ... Like ... if I'm*

upset and I'm crying… What do I want her to do? … questions to really understand … how

she can make me the most comfortable, which was really nice." (Emma).

Superordinate Theme 3: Inaccessibility of services

In Themes 1 and 2, participants spoke of the benefits of CBT, as well as it's lack of fit with

autistic people, with the balance tipping towards the idea of CBT being less useful for autistic

people than they anticipated. This may in some part be linked with the idea that the services

providing them CBT were somewhat inaccessible, which may have impacted on their ability

to engage with CBT appropriately, as highlighted by the third superordinate theme. Theme 3

represents four participants' expressed feelings that the services providing them CBT were

structured in a way that was not designed nor adapted for autistic people. Key issues

included session structure, the physical therapeutic environment, and communication

methods employed by services. Thus, the services felt inaccessible and, ultimately, unhelpful,

and it was difficult for autistic people to raise concerns related to this.

Subordinate Theme 3.1: Insufficient session length & number

Three participants noted an issue with both session number and length (which are often pre-

determined by service provision and commissioning). The issue was primarily related to the

idea that a short session length, or small number of sessions allowed for less processing time,

which proved difficult for autistic people in the context of the slower processing speed they

typically present with: *"I think from an autistic perspective... Because you tend to talk about*

something more, uh, and infodump a bit, that, having a 50-minute session is a bit difficult and

an hour and a half one would be a lot better." (Ellie). This issue adversely impacted on

therapeutic engagement, and it was noted that reasonable adjustments allowing for more

processing time would be better for engagement: *"When you process things in a different way*

and in a slower way ... I wonder if, you know, you would in, in most reasonable adjustments for autism {allow} extra processing time." (Frank).

Furthermore, the act of outlining the finite nature, and limited number of the sessions was said to put pressure the patient to 'do well'. They interpreted this deadline in a way that a neurotypical person might not, as a time by which they should be "better" or "cured", which in turn led to feelings of "failure": *"As an autistic person, you tend to see things black and white, so if I'm not better in six weeks, I failed ... somebody else would be able to rationalize it ... setting deadlines like that doesn't help"* (Rachel). Rachel also explained that this negatively impacted on the autistic person's ability to engage with therapy, and was described as being "scary", suggesting that by setting a deadline without adequately explaining it may result in feelings of anxiety. This highlighted the importance of appropriately working towards the ending from the beginning:

> *"...this person thinks that I only need 12 weeks to get better, so I only need 12 weeks to get better, so... why is this not working?... what happens after 12 weeks? That's just a complete blank, black ... that's really scary ... Will I just fail. Will I succeed?"* (Rachel).

Subordinate Theme 3.2: Uncomfortable, anxiety-provoking therapeutic settings

The therapeutic setting itself was also seen as a barrier to accessibility. Three participants highlighted that the therapy rooms either made them feel uncomfortable, or were at inconsistent locations, meaning that the process of therapy was harder to engage with due to intolerance of change, or certain sensory difficulties: *"he was like 'is there something wrong with this room?' And I went ... 'It's quite bright in here... and we weren't sat at the table, we were just sat ... in floor space ... apart from each other and that I found awkward'"* (Jade); *"... that was difficult to have a different place to go to a different room, to find a different place ... the time it takes you to kind of settle down before you can get into the therapy is*

longer…." (Ellie). It was also noted that even when these challenges were brought up with the therapist, there was little scope for adapting these aspects of the environment, or allowing for consistency (perhaps due to lack of service provision), which made therapeutic engagement more challenging: *"… 'cause I've never experienced that sort of scenario before, but I just found it awkward…. Um, and yeah, so I would mention that to him, but just we went into the same room every single week."* (Jade).

Subordinate Theme 3.3: Unhelpful communication methods from services

Another barrier to accessing services was the chosen methods for communication; there was explained to be a reliance on online video or telephone communication, meaning that services that were designed to support people with anxiety, were difficult to access for autistic people due to being anxiety-provoking, or simply difficult to understand: *"… autistic people find it difficult to use the phone, and people don't give out email-addresses… I have been trying to make an appointment with these people who are only contactable on the phone and … it's taken me six weeks."* (Ellie). To compound the issue, this difficulty in communicating via telephone was explained to be misinterpreted as disengagement, which ultimately resulted in premature discharge from services. As such, services were inaccessible, and autistic people were not getting the support they needed. It was noted communication via text or email would have been preferrable:

> *"I actually got discharged because I hadn't been to appointments, but the reason I hadn't been to appointments was because, at that point I just couldn't … cope with phoning. I mean emails and texts are great because, they're, you can reply to them in your own time."* (Rachel).

Subordinate Theme 3.4: Difficulty in raising service-based concerns

To exacerbate these difficulties, it was discussed by four participants that autistic people may be less likely than neurotypical people to raise any concerns with their therapy/therapist. It was explained that the participants felt pressure to continue with therapy and not raise concerns, in fear of coming across as uncooperative. It was noted that there were fears that, if they were labelled uncooperative, they may be discharged from the service (as alluded to above), or lose access to support in the future: *"As soon as you stop doing it, then you're … labelled as uncooperative, refusing treatment. So you kind of have to go through these treatments in order to get bumped up to the next one."* (Frank). This may relate to the idea that services and therapists were seen as an expert, in a position of power, providing "lessons", and so there seemed to be an element of trust in the services, but also a reluctance to come across as critical:

> *"… I don't know that I did [bring up these issues], just 'cause I didn't want to seem like I was being critical… So I felt like maybe I just needed to give it a try and it would work eventually."* (Emma).

Finally, it was noted that due to the social communication difficulties, and the tendency to for autistic people to be non-confrontational and "people pleasers", they were unlikely to raise any potential issues with their therapy voluntarily, choosing to continue even if not helpful:

> *"... we are pleasers ... so we'll go along with CBT and we'll do everything that we're told to do and pretend that it's working, but actually it's not. And if you … directly asked us… then we would say no, because we generally quite honest when it comes to things like that."* (Rachel).

It was noted that, because of these social communication difficulties, perhaps the onus should be on the therapist to ask the client if there were any issues, rather than relying on autistic clients to volunteer this information: *"So I guess it's nice when the therapist asked, like, "is there anything we can change?" because then you can feel like you can actually say something rather than you having to outright ask…{laughs}."* (Jade).

Discussion

This qualitative study aimed to consider the research question: "How do autistic people experience CBT interventions?" via Interpretative Phenomenological Analysis of semi-structured interviews with five participants. Analysis yielded three superordinate themes, along with 12 subordinate themes.

The first superordinate theme describes participants' experiences of finding aspects of CBT to be useful. It is important to note that most participants first mentioned the more generalisable, non-CBT-specific aspects of their CBT sessions to be useful, including that they felt the therapeutic space was a consistent space to both talk to a neutral person about their difficulties, and to process their experiences. This suggests that the therapeutic relationship may be one of the more important factors in any therapeutic modality. Useful CBT-specific aspects of their sessions were also discussed, including the use of visual formulation models that helped them to gain a better recognition and understanding of the interaction between their cognitions, emotions and behaviours. These benefits, however, were explained to be "secondary" in that they did not address the participants' presenting problems (associated with autism) satisfactorily. The second superordinate theme highlights that participants felt CBT, overall, was not a good fit for autistic people, and was not adapted for their needs. They reported feeling CBT was being used to "fix" something that (i) cannot be fixed, and (ii) it is seemingly not designed to treat. It was also noted that many of the

theories and strategies discussed in sessions were often misinterpreted, and then misapplied outside of the therapeutic context. This was compounded by a mismatch in communication styles between the therapists and the clients, which led to a disruption in their therapeutic engagement. Participants felt that communication was not adapted to meet their needs, and they discussed that successful adaptation required appropriate therapist knowledge of, and experience working with autism; this appeared to be lacking in many of their experiences.

The third and final superordinate theme suggests participants felt services providing them with CBT were inaccessible for autistic people; they were not designed for, nor adapted in a way that was accessible in terms of the structure of sessions (length & number), the therapeutic setting, and the communication methods employed. It was also highlighted that it was difficult to raise concerns with services because of their social communication difficulties, a fear of being seen as uncooperative leading to a felt pressure to continue, and perceptions of a lack of power, meaning that difficulties were often not addressed.

Analysis & reflections

An interesting aspect of these results was that there was a feeling that CBT was not a good fit for autistic people, and that it provided only secondary benefits. While there were positives to CBT, it was felt that it did not help them in dealing with their presenting problems any better than before they engaged with therapy. This is not entirely consistent with the existing literature in the area. CBT has been found to be effective in helping children and young people deal with anxiety (Sharma, Hucker, Matthews, Grohmann & Laws, 2021) and emotional dysregulation (Scarpa & Reyes, 2011), while Spain, Sin, Chalder, Murphy and Happe's (2015) systematic review found that CBT was useful in symptom reduction for autistic adults with comorbid mental health conditions. It could also be argued that one of the main benefits of CBT is that it focuses on the "secondary" elements mentioned by the participants in this study (developing emotional literacy, and understanding the interaction

between thoughts, feelings and behaviours through the use of visual formulation models);

psychoeducation and formulation are key elements of CBT that not only help in developing

an intervention plan, but also to improve client's understanding of themselves and of their

difficulties (Dudley & Kuyken, 2013), and so may be therapeutic in their own right.

Furthermore, developing literature concerning the use of CBT with autistic people suggests

that working with the secondary aspects associated with autism is perhaps the most effective

implementation of CBT with autistic people. It has been recognised that many autistic people

commonly struggle with understanding and communicating their cognitions and emotions

(Creed, 2015), therefore, it could be argued that CBT is helpful in this context. The negative

experiences of CBT reported in this study (i.e. poor fit) may be a result of autistic people

seeking support for autism-specific difficulties and being referred to mental health services

that are not appropriate to meet such needs. These inappropriate referrals may result from

healthcare professionals misinterpreting these difficulties, due to a lack of understanding of

and experience working with autism. This, however, was not explicitly addressed by the

present study, and so expectations of autistic clients in relation to CBT and services needs to

be further investigated.

Another poignant result from this study was that participants found the process of

extracting meaning from the content of the CBT sessions to be challenging. Autistic people

are known to struggle with both social communication difficulties as well as slower

processing speed (Ahlers et al., 2017; Doherty et al., 2022); the findings of this study suggest

that perhaps the information presented to them was either not communicated effectively with

them, or was presented in too great a volume, or too great a speed for them to process and

take meaning from. Another explanation for this could be the Central Coherence Theory

(Frith, 1989); central coherence refers so ones' ability to obtain meaning from a mass of

details, and Central Coherence Theory stipulates that autistic people have a "weaker" sense of

central coherence than neurotypical people. The process of CBT involves pulling together, and finding meaning from multiple forms of information (e.g. session content, homework, behavioural experiments etc.). It may have been that the participants struggled to find meaning in the mass of content presented in their CBT sessions because they have "weaker" central coherence. This may mean that the content presented in the sessions may need to be simplified and slowed down in order to be palatable for autistic people to process.

This leads to another interesting aspect of the results from this study - the perceived lack of adaptation for autism. Lorna Wing (1981) developed the Triad of Impairments theory for autism, highlighting that autistic people experienced differences in terms of their social interaction, communication and imagination, which disrupted their ability to explore the world and interact with people in the way that neurotypical people may be able to; the difficulties identified in this Triad are noted as potential barriers for therapeutic engagement (Ahlers et al., 2017; Doherty et al., 2022). It is clear, that the participants felt that the difficulties highlighted by the Triad of Impairments were not accounted for, both in terms of a session-to-session context (communication not being adapted in order to allow for better understanding and application of content), and from a service-wide perspective (with session number and length, therapeutic setting and inflexible communication being an issue). With regard to this study, the difficulty in the difficulty in appropriately adapting communication was a sticking point for many of the participants, and their reflections highlight the idea that autistic people and neurotypical people may struggle to communicate together effectively in the therapeutic setting – this has been labelled in the literature as the Double Empathy Problem (reference) and commonly refers to the mismatch in communication between autistic and neurotypical people in social situations; it is interesting to note that these difficulties in communication are also present in the more structured therapeutic setting, and is something which needs to be accounted for in CBT delivery. Difficulty in accounting for

the Triad of Impairments in therapeutic adaptation made engagement a challenge for the participants, and raised questions about CBT's fit with autistic people.

It is well-documented that therapeutic adaptations in line with the Triad of Impairments (e.g. adapting communication) are both recommended and proven to be useful when working with autistic clients of different ages, across various therapeutic modalities (Conner et al., 2018; Cullen & Barlow, 2002; Gaus, 2007; Pattni et al., 2022; Rogerson et al., 2019; Schweizer et al., 2014; Walters et al., 2016). Furthermore, reasonable adjustments are stipulated as part of the Equality Act 2010 in England and Wales, and as part of the NICE Guidance in relation to providing therapeutic services for autistic people (NICE, 2021). These recommendations are based, in part on addressing difficulties related to the Triad of Impairment. As such, there is ample evidence and policy pertaining to the idea that services should be adapted to allow for better accessibility for autistic people. Despite this, the results suggest that, due to a lack of service and therapist knowledge of autism, these adaptations were not successfully implemented meaning that engagement was difficult. Interestingly, the views of practitioners echo these sentiments; despite the above-mentioned recommendations from previous research that adaptations are key for engagement and outcomes, it has been found that services and health care professionals have routinely struggled to understand the needs of autistic clients, in terms of social communication and sensory needs - they have thus have found it challenging to adapt their services to meet these needs and allow for better engagement (Cooper, Loades & Russell, 2018). It has also been found that professionals report difficulties with therapeutic relationship a being a major barrier to treatment with autistic people (Horwood, Cooper, Harvey, Davies & Russell, 2021). It seems that both clients and services are somewhat uncomfortable and unsatisfied by the mental health provision for autistic people, and highlights the need for further work to be done in the area. Indeed, it is widely recognised that further research is needed in the area to inform

appropriate training and education for services and healthcare workers moving forwards

Horwood et al., 2021; Cooper et al., 2018), and the present study supports this idea. Future

research could consider in more detail the nature of the barriers in place that may make it

challenging for services and professionals to implement autism-specific adaptations; this may

help to facilitate changes that allow services and professions to feel more able to make these

adaptations, leading to better engagement, and improved outcomes for autistic people.

Strengths & clinical implications

The strength of this study is that it provided an opportunity for autistic people to talk in-depth

about their experiences of CBT, an area which is seldom addressed in the existing literature

despite the growing push for increased patient participation. This is important as the results

support and build upon the existing literature, while providing interesting points for

consideration in future research. Furthermore, the results have helped to identify multiple

clinical implications and areas for service improvement, discussed below.

Firstly, the finding that participants felt CBT and services were not a good fit, and not

adapted for their autism, suggests that services need to work on making reasonable

adjustments in order to be more accessible to the autistic population. As suggested by

participants in this study, this may be achieved through services adapting their policies on

session length and number (e.g. increasing the number of sessions, or shortening/lengthening

the time allowed for the sessions) to allow for more processing time for autistic people, as

well as allowing more time for autistic people to establish trust with their therapist.

Furthermore, adapting the presentation of CBT content, as well as communication during

sessions, should also be considered – for example using concrete, direct language, or perhaps

using more visual information, may allow their clients to better understand the content of the

sessions and apply appropriately outside of the therapeutic context. Next, practitioners could

utilise less open questions, providing scaffolding or choices when questions are asked, in order to help their clients better communicate their needs. Finally, therapists could also spend more time with their clients thinking about their expectations and goals in relation to therapy in the context of autism to improve accessibility. Such amendments to CBT practice may not fit with the typical delivery of CBT, but are very much in line with the NICE guidance on the matter which focuses particularly on adapting communication (NICE, 2021). It is also in line with more current thinking on the adaptation of therapy for autistic people, with research highlighting that increasing collaboration, simplifying communication, and allowing for more processing time are all important to improve therapeutic engagement for autistic people (Riches, Hammond, Bianco, Fialho & Acland, 2023).

Secondly, the now well-documented finding that services and therapists struggle to adapt their practice due to a lack of understanding of, and experience working with autistic people, suggests that further training and education may be needed not only within services, but in therapy training courses. However, further research is needed in order to consider the content of such training. It should be also noted that many UK, NHS-based services face significant funding and commissioning challenges and pressures, and so implementing these new ideas will take time, and may be easier said than done.

Finally, these findings may also suggest that there is a gap in service provision for autistic people in the UK, particularly if existing services are struggling to adapt appropriately. The nature of the diagnosis-only services within the NHS means that people receive autism diagnoses but are not offered autism-specific post-diagnostic services, as they tend not to exist. Therefore, future research and commissioning groups should consider the development of autism-specific support services in order to meet the growing clinical need, particularly in the context of the year-on-year rising prevalence of autism (McConkey, 2020).

Limitations & future research

Along with the clinical implications discussed above, there are some limitations to keep in mind regarding this study, as well as considerations for future research to address such issues. The first limitation involves participants' recall of the CBT sessions, as well as ensuring that they spoke about CBT specifically during our interviews. It was noted by many of the participants that they had multiple rounds of therapy, and not all of this was CBT-informed; so while attempts were made to ensure that they spoke exclusively about CBT during the interview (i.e. using direct questions), we cannot be certain that the ideas and stories they recalled were indeed from their CBT sessions. Furthermore, there was up to a two-year gap between participants having their CBT sessions, and our interviews being conducted. Psychological literature suggests that autistic people show difficulties with episodic memory recall (Griffin, Bauer & Gavett, 2022), and so reporting of events across this study's timescale may be inaccurate, thus influencing the validity of the information provided. It should also be noted that the length of time between the CBT sessions and the interviews may have differed by participant, and this was not measured nor accounted for in the analysis. Future research could focus on recruiting participants via NHS sites (as originally planned by this study) in order to obtain definitive confirmation that CBT was received. This recruitment strategy may also help to ensure that interviews are strictly CBT-related, and conducted within a shorter timeframe once sessions are concluded.

Another limitation is that that of potential bias in the results, in the context of a relatively homogenous and small sample. Given the negative experiences reported by the participants, it may be concluded that people who have had less favourable experiences are more inclined to volunteer for such research to get their voices heard. Equally, it may just be reflective of the general experiences of autistic people in CBT services. Future research could employ a recruitment approach that targets a balance of positive and negative

experiences in order to test these hypotheses. In line with this, it is important to consider the gender imbalance in this study, with three of the five participants identifying as female, one as male, and one as non-binary. While homogeneity in an IPA-based study itself is not necessarily a problem, and is often sought after for researchers conducting IPA (Alase, 2017), the imbalance in this study does not reflect the typical gender ratio when considering autistic people; males consistently outnumber females and other gender identities across various countries, including the UK (Zeidan et al., 2022). Autism presenting in females is perhaps less-well-understood (Gould, 2017), and this may have fed into the negative experiences reported by the female-dominated sample; a more representative sample therefore may have yielded different experiences and results. This then calls into question the sample size (N = 5). Recommendations as to a minimum sample size for IPA-based studies are unclear, however, a sample size of between four and 10 participants is recommended for a doctoral study (Clarke, 2010); therefore we would argue that the sample size of N=5 is sufficient in providing rich data for this IPA-based study. However, it should be considered that the sample itself may have been too small to be representative of autistic people in the UK, and therefore may have led to some form of bias in the results. Future research should focus on recruiting a larger, more representative sample, encouraging people who identify as different genders to take part. This would allow for a larger pool of richer data, and perhaps lead to a more rounded analysis of the experiences of autistic people in the UK.

There were also limitations related to the design of the interviews, and the scope within which the interviewer could, or at least felt comfortable straying from the topic guide. As such, certain topics, such as autistic people's expectations of the CBT, were not adequately followed-up. On reflection, it was noted that the interviewer felt uncomfortable challenging or following up on certain conversations in fear of: (1) the interview becoming too "therapy-like"; and (2) the danger of asking leading questions, which may further bias the

results. This suggests that PPI could have been better utilised in the design of the interviews, both in terms of the questions to ask, as well as consideration around effectively and appropriately following up on any topics. In order to address this, future researchers could, with the aid of PPI, design and use a more comprehensive topic guide that could be tested through pilot interviews. Furthermore, the introduction of a consultation period with the research team (and further PPI) following the interview as well as secondary interviews with participants, may be useful to follow-up on any ideas during analysis.

Conclusions

The autistic people who participated in this study explained that there were certain aspects of CBT that were useful for them, however, not all of these aspects were specific to CBT. There was also a feeling that CBT, and the services that provided them with CBT were not adapted, and therefore not accessible, and thus did not meet the therapeutic needs of autistic people. These results help to pave the way for future research to further consider the adaptation of CBT and relevant services in order to better meet the needs of autistic people. Furthermore, important clinical implications can be borne from these results, that can be implemented now, in order to improve the support on offer for autistic people, and lead to better therapeutic outcomes.

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Appendices

Appendix A   Search Terms

Medline Search Terms

(AB (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR TI (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR (MH "Autism Spectrum Disorder+")) AND (AB (India* OR "Indian culture*" OR "Indian Famil*") OR TI (India* OR "Indian culture*" OR "Indian Famil*") OR (MH "India+")) AND (AB (Experience* OR Perception* OR View* OR attitude*) OR TI (Experience* OR Perception* OR View* OR attitude*) OR (MH "Attitude to Health+")) AND (AB (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR TI (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR (MH "Caregivers") OR (MH "Parents+"))

PsycINFO Search Terms

((AB (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR TI (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR (DE "Autism Spectrum Disorders" OR DE "Autistic Traits")) AND (AB (India* OR "Indian culture*" OR "Indian Famil*") OR TI (India* OR "Indian culture*" OR "Indian Famil*")) AND (AB (Experience* OR Perception* OR View* OR attitude*) OR TI (Experience* OR Perception* OR View* OR attitude*) OR (DE "Mental Health (Attitudes Toward)" OR DE "Mental Health Stigma")) AND (AB (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR TI (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR (DE "Caregivers") OR (DE "Parents" OR DE "Adoptive Parents" OR DE "Expectant Parents" OR DE "Fathers" OR DE "Foster Parents" OR DE "Homosexual Parents" OR DE "Mothers" OR DE "Parental Characteristics" OR DE "Single Parents" OR DE "Stepparents" OR DE "Surrogate Parents (Humans)"))

CINAHL Plus Search Terms

(AB (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR TI (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR (MH "Autistic Disorder")) AND (AB (India* OR "Indian culture*" OR "Indian Famil*") OR TI (India* OR "Indian culture*" OR "Indian Famil*") OR (MH "India")) AND (AB (Experience* OR Perception* OR View* OR attitude*) OR TI (Experience* OR Perception* OR View* OR attitude*) OR (MH "Attitude to Health+")) AND (AB (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR TI (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR (MH "Caregivers") OR (MH "Parents+"))

AMED Search Terms

(AB (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome") OR TI (Autis* OR "Autism Spectrum Disorder*" OR ASD OR "Autism Spectrum Condition*" OR ASC OR Asperger's OR "Asperger's Syndrome")) AND (AB (India* OR "Indian culture*" OR "Indian Famil*") OR TI (India* OR "Indian culture*" OR "Indian Famil*")) AND (AB (Experience* OR Perception* OR View* OR attitude*) OR TI (Experience* OR Perception* OR View* OR attitude*)) AND (AB (Caregiver* OR Parent* OR Mother* OR Father* OR famil*) OR TI (Caregiver* OR Parent* OR Mother* OR Father* OR famil*))

Appendix B   Critical Appraisal Skills Programme (CASP)

Table

CASP answers from First Author (FA) and Research Assistant (RA)

Section	Question	Paper 1		Paper 2		Paper 3		Paper 4		Paper 5		Paper 6	
		FA	*RA*	*FA*	*RA*	*FA*	*RA*	*FA*	*RA*	*FA*	*RA*	*FA*	*RA*
Section A: Are the results valid?	1. Was there a clear statement of the aims of the research?	Can't tell	No	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell
	2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	3. Was the research design appropriate to address the aims of the research?	Yes	Can't tell	Yes	No	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
	4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
	6. Has the relationship between researcher and participants been adequately considered?	No	No	No	No	No	No	No	No	No	No	No	No
Section B: What are the results?	7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	8. Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
	9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix C   ERGO Application & Approval

ERGO II Ethics application form – Psychology Committee

1. Applicant Details

1.1 Applicant name	Sanu Pattni
1.2 Supervisor	Dr Melanie Hodgkinson
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	Dr Matt Symes

2. Study Details

2.1 Title of study	Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis.
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	Doctoral Thesis Project
2.3 Briefly describe the rationale for carrying out this project and its specific aims and objectives.	
Rationale: - Cognitive Behaviour Therapy (CBT) is a short-term, present-focused psychotherapy designed to challenge and change maladaptive beliefs, behaviours and maintenance cycles common among many mental health difficulties. - Outcomes research for CBT tends to be positive but there is a scarcity of research concerning clients' experiences of CBT. - A few studies have found that elements key to patient experience of CBT include the therapeutic relationship, the nature of therapy itself, having a therapy ending plan, and the opportunity to develop both an understanding of their condition as well as problem-solving skill and strategies. - Studies have found there to be certain facilitators (flexible, knowledgeable therapists) and inhibitors (perceived lack of support, and adapting to changes	

in routine) to engagement, which are found to be present across different forms of CBT delivery.
- The consensus among researchers is that further research is needed, and that therapists and practitioners should focus on treatment engagement and adherence throughout the course of the intervention in order to make the therapeutic experience as engaging and useful as possible (Dyrberg et al., 2021).
- Autism Spectrum Disorder (ASD) is a spectrum of neurodevelopmental disorders characterised by difficulties in social communication and interaction, and restricted, repetitive patterns of behaviour, interests and activities, not accounted for by any other intellectual disability or physical condition.
- Co-occurring mental health conditions are more prevalent in the autism population than in the general population (Lai et al., 2019); CBT is the evidence-based intervention for working with MH difficulties in people with Autism.
- Research suggests that that the difficulties experienced by people with autism may prove to be a barrier to therapeutic engagement; it follows that CBT-based research should also focus on CBT-specific adaptations for autistic people to ensure best practice and positive therapeutic outcomes.
- In order to contemplate which adaptations would be useful, the voice of people with ASD should be considered, however there seems to be a paucity of research in the area, with much of the research not considering CBT specifically, or only focuses on experiences of therapists and parents of people with ASD; the voice of the person with ASD is often lost.
- As such, there is a gap in the research to consider how CBT in particular can be adapted for people with ASD by collating and analysing the experiences of people with ASD.

Aims:
1. To consider the experiences of Adults with ASD who have had CBT interventions.
2. Use this information to inform ASD-specific CBT adaptations, and guide training for therapists working with people with ASD.

2.4 Provide a brief outline of the basic study design. Outline what approach is being used and why.

- Qualitative study aiming at considering the experiences of people with ASD who have had CBT.
- Participants will take part in explorative semi-structured interviews (interview schedule/topic guide to be co-designed with my research supervisors whom both have experience of working clinically with people with ASD, as well as an expert by experience via public and patient involvement (people who have had CBT, or ASD - experts by experience will be compensated for their time).
- Qualitative data analysis will be done through the use of Interpretative Phenomenological Analysis (IPA).

2.5 What are the key research question(s)? Specify hypotheses if applicable.
How do adults with Autism experience individual CBT interventions?

3. Sample and setting

3.1 Who are the proposed participants and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

- Six-to-eight participants will be recruited to take part in the interviews; this number is seen as acceptable for a doctoral thesis project (Turpin et al., 1997).
- Inclusion and exclusion criteria are outlined below.
  - Inclusion:
    - Adult (18 years+)
    - Diagnosis of ASD (confirmed by report sent by participant)
    - Experience of Receiving CBT in the last two years
    - Language proficient enough to engage in semi-structured interview in English
    - Capacity to consent to interview/involvement
  - Exclusion:
    - Children and Young people (<18 years)
    - Currently receiving therapy, or have had so in the last month
    - Presenting with severe mental health difficulties or risk to self/others, and for those whom taking part in the study would cause harm; cut-off to be used from CORE-10
      - Overall cut-off of 20+ (moderate-severe)
      - Risk question to be considered separately; cut-off of 3+ (Often)
      - "Participant Not Eligible" Letter to be sent to Participant via email with relevant signposting; if there is immediate concern, emergency services will be contacted..
    - Language not proficient enough to engage in semi-structured interview in English,
    - Diagnosis of Learning Disability
    - No capacity to consent to interview/involvement
- Participants will be recruited through local connections and Social Media (Twitter/X, LinkedIn, Instagram, Facebook etc.).

3.2. How will the participants be identified and approached? Provide an indication of your sample size. If participants are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

- Sample size:
  - 6-8 participants needed - this number is seen as acceptable for a doctoral thesis project (Turpin et al., 1997).

- Recruitment
    - Researchers will post the study advert on social media (Twitter/X, LinkedIn, Facebook etc.), and will also contact local Experts By Experience (EBEs) for them to pass on the study advert to potential participants.
    - Upon confirmation of interest from the potential participant, information sheet and consent form will be sent via email or posted if they so wish.
    - Potential participant will be required to provide a copy of a report confirming their autism diagnosis.
        - Self-report not sufficient because of the increase of self-diagnosis; for integrity of research, we require that each of the participants have received a clinical diagnosis in line with the DSM-V or ICD-11.
        - There is a section in the consent form outlining this; if they do not agree with and consent to sharing this information, then they will have to be excluded from the study.
        - Any reports will be redacted (PID/service details removed) and stored safely on password protected laptop until the researchers have checked the information, after which the report will be destroyed.
    - Inclusion/Exclusion criteria will be assessed.

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

No direct relationship between researcher and sample.

3.4 How will you obtain the consent of participants? (*please upload a copy of the consent form if obtaining written consent***) NB A separate consent form is not needed for online surveys where consent can be indicated by ticking/checking a consent box (normally at the end of the PIS). Other online study designs may still require a consent form or alternative procedure (for example, recorded verbal consent for online interviews).**

- Consent form along with information sheet to be given to potential participants (both to be attached)
- Participant will be sent one of two consent forms (Full or Accessible/Easy Read, where appropriate; this will be determined by an initial conversation with the researcher beforehand regarding the client's cognitive ability) and will be asked to read through this and sign the consent form – written consent will be required to proceed with the interview. If they require support, the researcher will be able to read through it with them, and answer any questions they may have regarding the information sheet/consent forms.
- Forms will be either given in person, or via email, depending on their preference, or the format of the interview itself (either in person, or virtual – phone or video call).

3.5 Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

- A participant would need to be able to demonstrate that they have capacity to consent to involvement in order to take part in the project.
- The researcher is a trainee clinical psychologist who is trained in assessing capacity and both supervising psychologists are working clinically with people with learning disabilities (LD) and/or autism and therefore are experienced in conducting capacity assessments. These will take place during the completion of the consent form together prior to the interview commencing. Research supervisors will know the time of the interview, and will be available to talk to if there is a question over capacity.
- Participants will be identified through local connections, Experts By Experience, and Social Media; if there are any questions around their capacity, no further action will be taken.
- On meeting participants, capacity will be assessed as follows:
    - Review participant information sheet together – check that participant has retained information about the project and is able to understand the process of involvement and make an informed decision about taking part. If there are doubts about the person's capacity, the interview will be terminated.
    - Review consent form and checking understanding of each point detailed in the form before signing.
- If there were any signs that an individual was not able to consent to involvement, they would not be involved in the project. If this became apparent on meeting with the researcher, the interview would be terminated and the participant would still receive reimbursement for their time in the form of a £25 gift voucher; this information (name, email address) will be stored on an Excel sheet on a password protected laptop, and will be deleted once the voucher has been received by the participant.

4. **Research procedures, interventions and measurements**

4.1 Give a brief account of the procedure as experienced by the participant. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on participants, including time and travel. *Upload copies of questionnaires and interview schedules to ERGO.*

1. *Advertising and recruitment*
    a. Researchers will post the study advert on social media (Twitter/X, LinkedIn, Facebook etc.), and will also contact local Experts By Experience (EBEs) for them to pass on the study advert to potential participants.

b. Upon confirmation of interest from the potential participant, information sheet and consent form will be sent via email or posted if they so wish.

c. Potential participant will be required to provide a copy of a report confirming their autism diagnosis.

    i. Self-report not sufficient because of the increase of self-diagnosis; for integrity of research, we require that each of the participants have received a clinical diagnosis in line with the DSM-V or ICD-11.

    ii. There is a section in the consent form outlining this; if they do not agree with and consent to sharing this information, then they will have to be excluded from the study.

    iii. Any reports will be redacted (PID/service details removed) and stored safely on password protected laptop until the researchers have checked the information, after which the report will be destroyed.

d. Inclusion/Exclusion criteria will be assessed.

2. ***Pre-interview***

a. An initial conversation will take place via email or by phone (whichever the participant prefers) to organise an interview – depending on logistics, geography and participant preference, the interview will either take place in person, via telephone or via video interview (Teams).

    i. This will be an opportunity to work through the consent form to ensure they agree and consent to taking part in the research; a capacity assessment will also be considered here; the consent form will be reviewed, and we will check understanding of each point detailed in the form before signing to consent. This will be signed by the participant and then sent virtually back to the researcher's email address.

    ii. We will also collect demographic information (age, gender, ethnicity etc) during this conversation; see attached Pre Interview Meeting Questions document.

    iii. A copy of their autism diagnostic report will then also be requested, redacted and then checked before being destroyed.

    iv. This conversation will also be an opportunity to find out if the potential participant has received CBT or not; researcher's knowledge of CBT will be used to direct the questions to collect this information. Questions are in the Pre-Interview Questions document (also shows what demographic information we are gathering).

b. One week prior to interview, the CORE-10 will be sent; anyone scoring above the cut-offs will be excluded from the research, sent the Participant Not Eligible letter, and signposted for relevant support.

3. ***The day of the Interview***

a. Upon meeting (either in person, online or by telephone), a capacity assessment will take place

      i. The participant and researcher will review participant information sheet together to check that participant has retained information about the project and is able to understand the process of involvement and make an informed decision about taking part.

      ii. If there are concerns about the person's capacity, the interview will be terminated and the participant will be reimbursed for their time (£25 voucher).

      iii. If capacity is demonstrated, we will then review the consent form again, and check understanding of each point detailed in the form before signing

  b. The interview will then take place as agreed with the participant.

      i. This will be a semi-structured interview, and will be led by the co-developed topic guide (attached), will last approximately 45-60 minutes, and will be audio recorded via an encrypted Dictaphone.

  c. Participant will then be fully debriefed (debrief sheet)

      i. Participant will be reminded again of the purpose of the research and of their right to withdraw consent (within a two-week period of the interview taking place (prior to interview being transcribed).

      ii. If there are any risk/safety concerns (to self or others), a safety plan will be co-developed and shared (template attached), they will also be signposted to relevant support services. Contact with supervisory team to support.

      iii. If there are no risk concerns, no further action needed.

  d. Participant will be reimbursed for their time (£25 voucher; either emailed to the participant (with read receipt), or given in person and signed for); information (name, email address) will be taken and stored on an Excel sheet on a password protected laptop, and will be deleted once the voucher has been received by the participant.

4. ***Post-Interview***

  a. The audio recording will be saved to password-protected and encrypted computer, and then, once two weeks have passed, the recordings will be sent to relevant person/company to transcribe (either Researcher, or PageSix transcription service), after which the recording will be destroyed.

  b. If participants wish to withdraw, notice would need to be given prior to interview being transcribed, with a cut-off being two weeks after interview takes place.

  c. Participants will be notified when report is complete; should they want a copy, this will be shared with them.

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

No deception involved.

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that participants may experience, including after the study, and what precautions will be taken to minimise these risks.

- The interview will focus on the participant's experience of CBT, which has the potential to bring up discussion of sensitive topics around the care their received, what went well and not so well. It is reasonably foreseeable that this may be distressing for some participants.
- Participants will be invited to only share information about their experiences of CBT that they are comfortable with.
- It will be made clear to participants that involvement in the research is entirely voluntary, and that saying no will have no impact on their current or future care in any way – this will be highlighted in the information sheet and consent form.
- Prior to the interview taking place, the researcher will confirm with the participant the relevant timings of the interview, and wellbeing measures (CORE-10) will be used to help assess that the participant's mental wellbeing is sufficient to engage with the interview; anyone scoring above the cut-off on the CORE-10 will be excluded from the research sent the Participant Not Eligible letter, and signposted for relevant support; researchers are Clinical Psychologists/Trainee Clinical Psychologists working in the local area, and so are aware of relevant local services.
- Alongside this, capacity to consent to the interview will be assessed - the researcher is a trainee clinical psychologist who has received training in assessing capacity, and both supervising psychologists are working clinically with people with learning disabilities (LD) and/or autism and therefore are experienced in conducting capacity assessments. If there are doubts about the person's capacity, the interview will be terminated.
- If the participant experiences any distress during the interview, the interview will either be paused or terminated as appropriate. A safety plan (attached template) will be co-developed and shared, they will also be signposted to relevant support services; researchers are Clinical Psychologists/Trainee Clinical Psychologists working in the local area, and so are aware of relevant local services.
- At the end of the interview, if there are any risk/safety concerns (to self or others), a safety plan (attached template) will be co-developed and shared, they will also be signposted to relevant support services researchers are Clinical Psychologists/Trainee Clinical Psychologists working in the local area, and so are aware of relevant local services.
- The primary researcher is a trainee clinical psychologist with clinical experience of supporting people in distress, working with people with autism and/or learning disabilities, and conducting capacity assessments. In addition, the supervising psychologists are highly experienced working clinically with people who are distressed and/or have autism or learning disabilities, and in providing capacity assessments – supervision in these areas will be provided throughout.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks. If the study involves lone working please state the risks and the procedures put in place to minimise these risks ([please refer to the lone working policy](#)).

- There is no psychological distress anticipated to the primary researcher, however there are a number of processes in place to take into account the researchers safety.
- Prior to the interview commencing, participants will provide consent for the team they worked with to be contacted to confirm the meeting and review any relevant information including risk information.
- If meeting face to face, the location will be confirmed via email/telephone contact, and the researcher will be made aware of relevant safety procedures (e.g. if the participant is in supported accommodation there may be systems for signing in/out and private room availability).
- It may be that interviews take place virtually however depending on the COVID-19 pandemic and/or participant preference the study may involve lone working and travelling off-site to meet with participants within normal working hours. In line with the lone working policy, the researcher will liaise with the university supervisor to update her of time/date/location of interviews and ensure contact on arrival/leaving.
- If meeting face to face, the researcher will also be mindful of positioning in the room e.g. sitting nearest the door, awareness of exits.
- Further, there will be opportunities to meet regularly with both supervising psychologists to discuss any concerns or issues should they arise.
- No further medical issues and the researcher is fit to work alone.

4.5 Explain how you will care for any participants in 'special groups' e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

- People with a diagnosis of autism are considered a vulnerable group. Capacity to consent will be carefully considered when completing the relevant forms with participants.
- Guidelines for supporting people with autism suggest the chunking of information and checking for understanding; this will be done throughout.
- The participant information and consent forms have been written in an accessible format with clear, concrete language, the recommended approach for delivering information to people with autism. The forms have been developed by the primary researcher under the guidance of both supervising psychologists, all of whom have clinical experience working with and supporting people with autism and developing accessible information.
- All resources (information sheet, consent form, interview schedule and debrief form) will be reviewed and co-developed with an adult with an autism diagnosis, in order to ensure they are as accessible as possible. The ethics committee will be updated if any revisions are made following this review. This

<table>
<tr><td>

- service user will not be a participant in the project and will be given a £25 voucher for reimbursement of their time.
  - If there is any indication that a person is unable to consent to participate (e.g. after discussion the person remains unsure of the purpose of the project, unable to say what will happen with the recording, seems to forget what we are doing or is unable to focus on the conversation) then the appointment will be terminated. The person will still be reimbursed for their time as agreed. Any support required will be arranged if needed e.g. signposting to relevant services.

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<table>
<tr><td>4.6 Please give details of any payments or incentives being used to recruit participants, if applicable:</td></tr>
<tr><td>

- Amazon vouchers (£25) to be given to each participant / experts by experience involved in the study to reimburse them for their time.
- Accounted for within the thesis budget.

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5. Access and storage of data

<table>
<tr><td>5.1 How will participant confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a participant's involvement in the study confidential, e.g. can people observe the participant taking part in the study? How will data be anonymised to ensure participants' confidentiality?</td></tr>
<tr><td>

- Confidentiality will be maintained from the outset; interviews will be recorded and saved with a non-identifiable number, on a password protected laptop.
- Use of participant names in recordings will be minimised and during the interview only first names will be used if absolutely necessary.
- Recordings (password protected audio files) will be passed onto transcription service (PageSix) who will transcribe with the use of the pseudonym, after which the recordings will be destroyed; all identifiable information will be destroyed.
  - o PageSix are on the University of Southampton's approved list of suppliers, and are aware of and have policies around confidentiality and data protection: https://www.pagesix.co.uk/academic-transcription .
- Transcripts will be saved on password protected laptop, and only accessible by people involved with the research (primary researcher, supervisors, and perhaps research assistants, if involved).
- The consent form indicates that confidentiality will be broken should there be any information shared within the interview that suggests risk to self or others. This includes any distress caused at interview so that relevant services can support where necessary.

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- Copies of reports will be requested from the participants to ensure that the participants meet the eligibility criteria (e.g. has an autism diagnosis); Self-report not sufficient because of the increase of self-diagnosis; for integrity of research, we require that each of the participants have received a clinical diagnosis in line with the DSM-V or ICD-11. There is a section in the consent form outlining this; if they do not agree with and consent to sharing this information, then they will have to be excluded from the study. These reports will be redacted, so that any superfluous identifiable information (address, NHS number etc.) is removed, and then the reports will be stored on a password protected laptop. Once confirmed that eligibility criteria are met (or not) and this information is recorded, the redacted report will be destroyed (permanently deleted from the laptop).

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?
- Study data will be recorded on a secure encrypted Dictaphone (and Teams – through university laptop); this recording will be stored on a secure, password protected computer which has been provided by the University. The files will be sent securely to a transcription service (PageSix) who will be DBS checked and bound by confidentiality. When the typed transcripts have been received, recordings will be deleted. Use of participant names in recordings will be minimised and during the interview only first names will be used if absolutely necessary.   - Any paper information e.g. consent forms, will be kept in a locked cabinet.   - Once transcribed, the anonymised transcripts will be stored securely and will be accessed only by the researcher and supervising psychologists. It may be that staff at the University of Southampton access the data for monitoring purposes and to ensure that the research complies with relevant regulations, if this is the case they will be bound by confidentiality.   - After the research is complete, the data will be deposited in "e-prints Soton" for storage in the longer-term (e.g. 10 years). The category of the research will be decided once ethical approval is granted which will determine the length of time data will be stored for.   - Data will not be made openly available for access due to the nature of the research topic being based around sensitive information.

5.3 How will it be made clear to participants that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.
- Participants will be told verbally, and it will be outlined on the consent form, that they can withdraw any time up to the point at which the data are anonymised (this will be once the data has been transcribed) – a time cut-off of 2 weeks after the interview takes place.   - If participant withdraws, they will still be reimbursed for their time.

6. Additional Ethical considerations

6.1 Are there any additional ethical considerations or other information you feel may be relevant to this study?
N/A

_____

COPY OF EMAIL FROM COMMITTEE CONFIRMING ETHICAL APPROVAL (06/12/2023)

ERGO II – Ethics and Research Governance Online
https://www.ergo2.soton.ac.uk

Submission ID: 80528.A1

Submission Title: Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis. (Amendment 1)

Submitter Name: Sanu Pattni

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

The following comments have been made:

•   Thank you for changing the Question H3 on the ERGO Questionnaire changed to reflect that you are not recruiting participant's through the NHS.

_____

Appendix D   Study Materials

Appendix D.1   Study Advert

Appendix D.2 Information Sheet

Participant Information Sheet

Study title: Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis.

Researcher name: Sanu Pattni

ERGO number: 80528

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
- I am a Trainee Clinical Psychologist and this project is part of my work in completing my Doctorate in Clinical Psychology at the University of Southampton.
- This project is concerned with the experiences of people with Autism who have had CBT; I would like to know what went well and not so well during therapy sessions, as well as what was helpful or not helpful during those sessions. This information can hopefully be used to help therapists understand what is helpful and going well when working with people with Autism, as well as letting them know if they can do things differently moving forwards.

Why have I been asked to participate?
- We will be looking to gather data from between 8 and 10 participants for this study.
- It is important we have the voice of people with Autism heard when considering how we should deliver therapy for people with Autism;

What will happen to me if I take part?
- I will ask for confirmation, by way of letter from you that you have a diagnosis of autism and have received CBT. Once checked for the relevant information, these letters will not be kept – they will be destroyed immediately.
- I will get in touch with you to send you the relevant information required for you to take part in the study (including this information sheet and consent form). We will also arrange a time to meet and conduct an interview with you; we may meet face-to-face, or meet via video conferencing/call – we can arrange this when we speak, depending on logistics and preferences.
- We will also require information regarding demographic information (age, ethnicity, gender identity etc.) as a way to understand a bit more about who has taken part in our research. Any identifiable information will be anonymised.
- One week prior to the interview, I will then send you a questionnaire (CORE-10); this is to ensure that you are currently feeling safe, and that you meet the criteria to take part in the study.

- o   If you meet the criteria, you will be asked to read through and sign the information sheet and consent forms respectively. the interview will go ahead as scheduled.
- o   if you do not the criteria, the interview will not go ahead, and we will discuss relevant support for you moving forwards, if needed.
- On the day of the interview, we will again check in on your safety, and your capacity to understand the purpose of the research; we will together consider the information sheet and consent forms, and should you understand and agree, you will be asked to sign the consent form before the interview takes place.
- The interview will last for about one (1) hour (with breaks if needed), and will be audio recorded; this will be the data that are collected for this study. The data will be transcribed by a trained company and then destroyed; this information will be stored confidentially, and shared with the research team.
- During the meeting, questions around your experiences of therapy will be asked; we will be interested in what therapy was like for you, what went well/not so well, what was easier/more difficult for you. You do not have to answer all the questions if you do not want to.
- At the end of your interview, we will talk about how you are feeling, and ensure that there is no risk to the safety of you or the people around you. If you report that you are not feeling safe, we will create a safety plan, and recommend that you get in touch with a relevant service for support, to ensure that you are feeling safe moving forwards.
- If taking part in this study does cause you discomfort or distress, you can also contact the following organisations for support:
  - o   Your GP
  - o   NHS "Talking Therapies" teams (https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/) – many of which you can self-refer to.
  - o   MIND – a charity which can help people with various mental health difficulties - https://www.mind.org.uk/
- You will be reimbursed for your time with a £25 gift voucher – this will be a thank you for your taking part in the study.

Are there any benefits in my taking part?

- There may be no current direct benefits to yourself for taking part, however, the information you provide may be helpful in increasing our understanding of delivering CBT to people with Autism. This may help future therapists and patients, and help us understand what is useful and not useful when working with people with Autism.
- You will be offered a £25 gift voucher to reimburse you for your time while taking part in this study.

Are there any risks involved?

- There are potential risks to taking part in this study, including the fact that we may discuss topics that may cause psychological discomfort or distress, as we will be discussing your experiences of therapy.
- You should know that, should you feel uncomfortable or distressed at any point, you are under no obligation to answer the questions, and the interview can be terminated if you so wish.
- If there are any concerns around your wellbeing during or following the interview, we will work together to develop a safety plan for you moving forwards. If taking part in this study does cause you discomfort or distress, you can also contact the following organisations for support:
  - o   Your GP
  - o   NHS "Talking Therapies" teams (https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/) – many of which you can self-refer to.

- o MIND – a charity which can help people with various mental health difficulties - https://www.mind.org.uk/

What data will be collected?

- The data you provide (the answers you give to the interview questions) will be analysed qualitatively; this means that the research team will look to identify themes that are common across the answers given by yourself, and the answers of other participants.
- These themes will be used to write up a report concerned with the experiences of people with Autism who have had CBT. The information you provide will not be included in any other projects.
- We will also collect and report information regarding your age range, gender identity and ethnicity, to give readers of the report a better understanding who took part in this research study. Information related to your name, where you live, and any other private information will not be include in the report.
- As per the University of Southampton data policy, the data will be kept for up to 10 years, but will not be used for any purpose other than for this study. This data will be stored securely in electronic format, under the University of Southampton data policy. Your data will not be made openly available for access due to the nature of the research topic being based around sensitive information.

Will my participation be confidential?

- Your participation and the information we collect about you during the course of the research will be kept strictly confidential.
- The interviews will be audio recorded, and the recordings will be kept on an encrypted, password protected laptop. These recordings will be sent to a transcription service; they will transcribe verbatim your responses, and then will send the transcriptions back to the research team. The transcription service and the research team will then destroy the recordings, and the research team will keep only the transcriptions on an encrypted, password protected laptop.
- The information you provide during the interview will be anonymised so that anybody reading the report will not be able to identify you.
- Only members of the research team (myself and my supervisors) and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.
- Should you want a copy of the report, your email address will be kept on file, on a password protected document, so that we can send you a copy of the report once it is complete – your email address will then be deleted.

Do I have to take part?

- No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

- You have the right to change your mind (without giving a reason and without your participant rights being affected), and withdraw up to two (2) weeks after your interview has taken place.
- After two weeks post-interview, the interview transcripts would be transcribed and anonymised, and so it would not be possible to withdraw the information you provided in your answers.

What will happen to the results of the research?

- The results will be written up into a report that may be published and shared with Journals and Staff/Teams.
- The study will involve direct quotations from participants, but these will be kept anonymous; names and details will be changed to protect your identity.
- Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you.
- Should you request this, a copy of the report can be sent to you upon completion.
- The data you provide will only be used for this project; it will not be used as part of any other research project.

Where can I get more information?

- Should you need any further information or have any questions regarding this project following reading this information sheet, please contact myself on the following email address: s.pattni@soton.ac.uk

What happens if there is a problem?

- If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The best email to contact is: REDACTED EMAIL
- If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

- The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).
- This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.
- Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf
- Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.
- Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.
- For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep

identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.
- To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.
- If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet and considering taking part in this research. We look forward to hearing from you.

Appendix D.3   Consent Form

CONSENT FORM

Study title: Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis.

Researcher name: Sanu Pattni

ERGO number: 80528

Participant Identification Number (if applicable*):*

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (*Participant Information Sheet v4*) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study, which will be shared with University of Southampton, Staff and Journals.	
I understand and agree to the research team having anonymised copies of letters confirming I have a diagnosis of Autism and have received CBT (once checked, these letters will be destroyed).	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I understand that demographic information, such as age, ethnicity, gender identity will be collected to help us understand who has taken part in our study.	
I understand that taking part in the study involves audio recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand and agree that if I take part, I do not have to answer all of the questions asked.	
I understand and agree that my participation is voluntary and I may withdraw (up to two weeks after the interview) for any reason without my participation rights being affected.	

I understand that after this point (two weeks post-interview), the data I provided will be anonymised (my personal information will no longer be linked to the data).	
I understand that if I choose to withdraw from the study at or beyond this point (two-weeks-post-interview), it may not be possible to remove the data (as it will be anonymised), and so the information I provided may still be used for the purposes of achieving the objectives of the study.	
I understand and agree that if I do not want to take part, it will not affect my care pathway, nor any care that I receive.	
I understand and agree that, should there be any worries around the safety of myself or the people around me, the researchers will need to inform relevant services in order to keep me and others safe.	
(OPTIONAL) I agree to receive a copy of the study results/write up once they are finalised.	

Name of participant (print name)...

Signature of participant...

Date.. ....

Name of researcher (print name)...

Signature of researcher ....

Date..

Appendix D.4 Debrief Form

Debriefing Form

Study Title: Exploring the experiences of adults with Autism who have had Cognitive Behavioural Therapy: An Interpretative Phenomenological Analysis.

Ethics/ERGO number: 80528

Researcher(s): Sanu Pattni

University email(s): s.pattni@soton.ac.uk

Version and date: Version 4, 15/11/2023

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore the experiences of people with Autism who have had CBT; I would like to know what went well and not so well during therapy sessions, as well as what was helpful or not helpful during those sessions.

It is important we have the voice of people with Autism heard when considering how we should deliver therapy for people with Autism..It is expected that the information you provided can hopefully be used to help therapists understand what is helpful and going well when working with people with Autism, as well as letting them know if they can do things differently moving forwards.

Confidentiality

Results of this study will not include your name or any other identifying characteristics.

Right to Withdraw

You have the right to withdraw any information you have provided to me up-to two (2) weeks after the interview has taken place; by this point the data will have been anonymised and transcribed, and so identifying your data to withdraw will not be possible.

Study results

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.

Further support

If taking part in this study has caused you discomfort or distress, you can contact the following organisations for support:
  - Your GP

- NHS "Talking Therapies" teams – many of which you can self-refer to (more information can be found here: https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/).
- MIND – a charity which can help people with various mental health difficulties - https://www.mind.org.uk/

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

Conner, C. M., DeVries, L., & Reaven, J. (2018). Cognitive behavioral approaches for treating adolescents with autism spectrum disorder. In N. W. Gelbar (Ed.), Adolescents with autism spectrum disorder: A clinical handbook. (pp. 117-148). Oxford University Press. https://doi.org/10.1093/med-psych/9780190624828.003.0005

Further information

If you have any concerns or questions about this study, please contact Sanu Pattni at s.pattni@soton.ac.uk who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

Appendix E   Pre-Interview Meeting Questionnaire

Pre-Interview Meeting questions:

Date:

Participant ID:

Demographic information
- Age:
- Ethnicity:
- Nationality:
- Gender Identity:
- Employment status:

CBT Checklist

List created using the core topics outlined in this book: Cully, J. A., & Teten, A. L. (2008). A therapist's guide to brief cognitive behavioral therapy. *Houston: Department of Veterans Affairs South Central MIRECC.*

Technique/Topic	Done
Psychoeducation about their MH difficulty	
SMART Goals	
Behavioural Activation (Values-based work)	
Graded Exposure	
Worry time	
Problem solving techniques	
Relaxation	
Mindfulness	
Identifying thoughts, beliefs, behaviours	
Challenging thoughts and beliefs	

Autism letter received?: Yes/No

Appendix F   Topic Guide

Topic Guide

An example of the questions we may ask during the interviews – this is not an interview schedule.

1. Tell us about your CBT experiences?
2. What went well?
3. What did not go so well?
4. What about CBT did you feel was helpful?
5. What about CBT did you feel was unhelpful?
6. Did the therapist do anything you felt helped you feel more comfortable?
   a. More comfortable
   b. Less comfortable
7. Do you feel the therapist was able to meet your needs?
   a. What did they do to meet your needs?
   b. What could they do to better meet your needs?

Appendix G   Risk Assessment & Management Plan

RISK ASSESSMENT
Remind of confidentiality! 5 Ws and FIDO, Likelihood/Severity – what Increases and Decreases risk? Function of the risk?

Suicide	- Ideation/Thoughts: - Intention: - Plans: - Actions: - Protective factors:
Self-harm:	- Current: - Historical:
Harm to others:	- Current: - Historical:
Harm from others:	- Current: - Historical:
Neglect	- Hygiene: - Appearance: - Diet: - Exercise: - Sleep: - Alcohol: - Drugs:

5 P's Risk Formulation

Presenting What have they done? Presently/Historically?	-
Predisposing Diagnoses, family history, demographics, own history, physical health, past life events/trauma?	-
Precipitating What happened before the risk event? Triggers?	Bio (Sleep, medication, diet, exercise, smoking, drugs, physical health?) - Psycho (MH, hopelessness, sense of control, thoughts, capacity?) - Social (relationships, family, school, work, bullying, gender?) -

Appendices

Perpetuating What maintains the risk?	-
Protective What protects them from the risk event?	-

<table><tr><td colspan="2" align="center" style="background:red;color:white">RISK MINIMISATION/ACTION PLAN</td></tr></table>

Questions:

What I can do to manage my own risks on a day to day basis:
-

What warning signs may mean I'm becoming unwell? What makes me vulnerable?
-

What triggers risk or crisis?
-

What support will my care team offer me to keep me safe or remain well?
-

What are my strengths? What are my reasons for living?
-

What have I done in the past that helps me cope and stay safe and well?
-

What I will do to help calm and soothe myself? What I will tell myself?
-

What could others do that would help?(Family, friends, support network)
-

Who do I want/not want contact with in a crisis?
-

Who can I call for help? (ensure contacts are clearly recorded and include friends, family and all support networks)
-

A safe place I can go to is:
-

If I still feel I'm in crisis or at risk to myself or others, how can I make my environment safer?
-

What would I say to a friend in the same position?
-

Who to call:

Appendix H　Details of Targeted Journal

Chosen Journal for both papers: ***Journal of Autism and Developmental Disorders;***

https://link.springer.com/journal/10803

_____

Journal submission guidelines can be found at:

https://link.springer.com/journal/10803/submission-guidelines

_____

The formatting of the main text, tables and figures is in line with JADD requirements (APA format), in terms of font size, style of headings etc. The formatting of the rest of the document has been left as per the UoS Thesis Template, or as per the original formatting (for documents such as information sheets etc.).

JADD asks for Appendices to appear before figures and tables. This has been adhered to and the Appendices, figures and tables for both papers have been combined into one section at the end for ease of formatting, as well as readability of the paper as a whole. They will be separated appropriately when submitted to JADD for review.
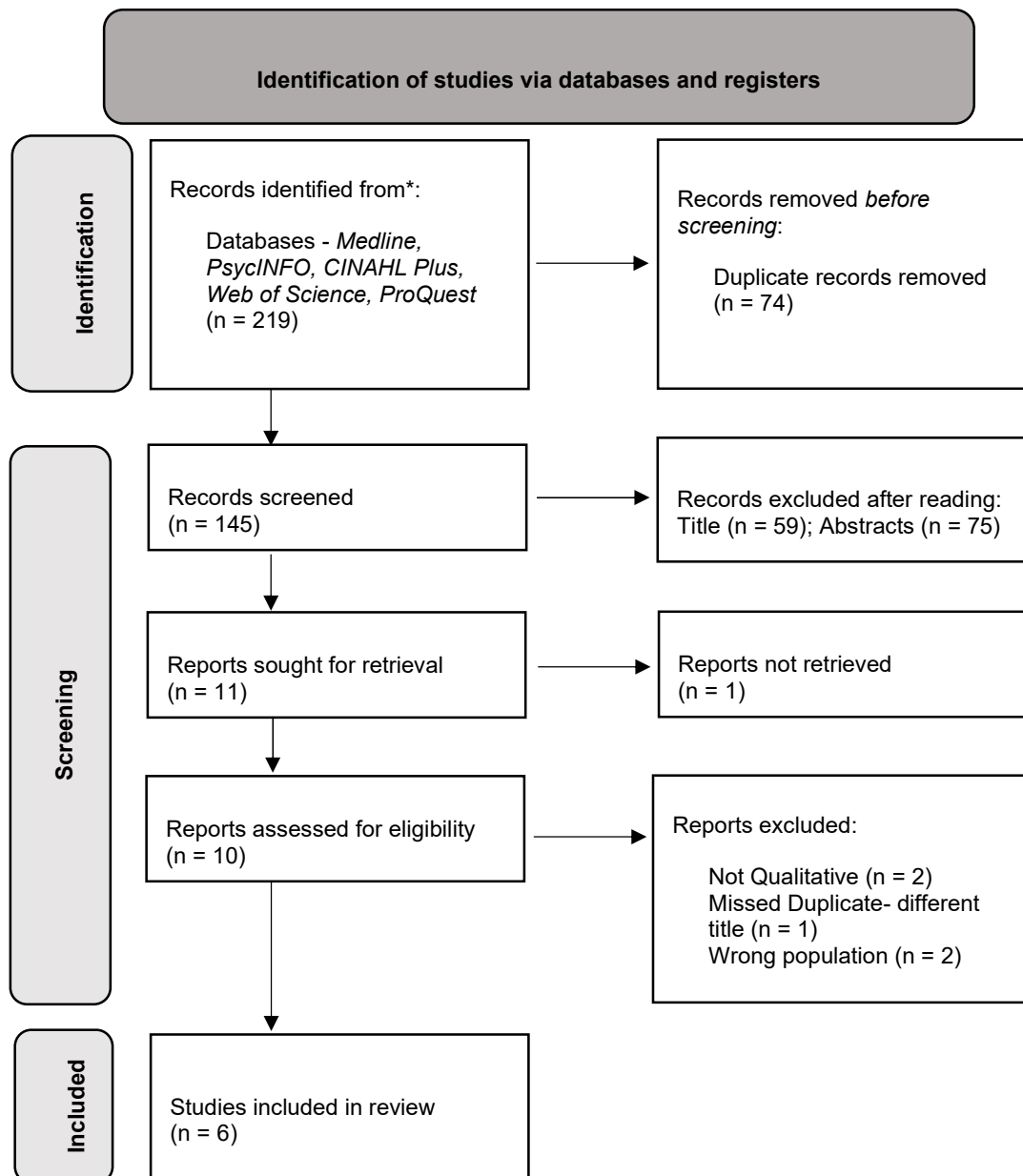
Both papers are within the 40-page upper limit for submissions to JADD (including their title page, abstract, main body, references, relevant appendices, figures and tables):

- Systematic review is 37 pages (including title page, abstract, main body, references, Appendices A & B, Figure 1, and Tables 1-3)
- Empirical paper is 36 pages (including title page, abstract, main body, references, Appendix C [just the email confirmation] and Tables 4-6 - no other appendices to be included as part of submission to journal, and are only included for the purposes of this Thesis).

Figures

Figure 1

PRISMA Diagram

Identification of studies via databases and registers

Identification

Records identified from*:

Databases - *Medline, PsycINFO, CINAHL Plus, Web of Science, ProQuest*
(n = 219)

→

Records removed *before screening*:

Duplicate records removed (n = 74)

Screening

Records screened
(n = 145)

→

Records excluded after reading:
Title (n = 59); Abstracts (n = 75)

Reports sought for retrieval
(n = 11)

→

Reports not retrieved
(n = 1)

Reports assessed for eligibility
(n = 10)

→

Reports excluded:

Not Qualitative (n = 2)
Missed Duplicate- different title (n = 1)
Wrong population (n = 2)

Included

Studies included in review
(n = 6)

Tables

Table 1

Inclusion and Exclusion Criteria

Include	Exclude
Parent, caregiver, mother, father	Teachers, educators, professionals, workers, patient experiences
Indian citizen, heritage, background	Native American, Asian (e.g. Chinese, Malaysian, Japanese, Taiwanese), West Indies, Indiana
Adult, over age of 18	Children, under age of 18
Autism, Autism Spectrum Disorder (ASD), Autism Spectrum Conditions (ASC), Autistic, Asperger's Syndrome	Other conditions, without autism mentioned.
Qualitative data	Quantitative data
Experiences, perceptions, views, attitudes	Correlation, ANOVA, MANOVA, t-test, regression, comparison
Interviews, surveys	Surveys/questionnaires with closed questions, Scales, scores

Table 2

Characteristics of the Included Studies

Study ID Number	Authors	Date	Country/ Setting	Sampling Approach	N	Data collection Method	Data analysis method
1	Desai, Divan, Wertz & Patel	2012	India/ Goa	Purposive – local services	12	Interview	Phenomenological Psychology
2	Divan, Vajaratkar, Desai, Strik-Lievers & Patel	2012	India/ Goa	Purposive – local services	10	Interview	Thematic Analysis
3	Heer, Rose, Larkin & Singhal	2015	India/ Delhi	Purposive – local groups	10	Focus Group	Interpretative Phenomenological Analysis
4	Lockwood Estrin, Bhavnani, Arora, Gulati & Divan	2023	India/ Delhi	Opportunity – from a larger study	5	Interview	Framework Analysis
5	Malhi, Shetty, Bharti & Saini	2022	India/ North	Purposive – local services	28	Interview	Thematic Analysis
6	Ranjan, Jain, Kumar, Sethi & Singh	2023	India/ Bihar	Purposive – local services	15	Interview	Interpretative Phenomenological Analysis

Table 3

Themes and Subthemes Extracted via TS

Theme	Subtheme
Theme 1: Misunderstanding Autism	1.1: General lack of awareness of autism
	1.2: Wide-held belief that difficulties were temporary
	1.3: Difficulty in the initial recognition of symptoms
	1.4: Varied explanations of autism/behaviours
Theme 2: Negative attitudes towards autism	2.1: Stigma experienced by children and families
	2.2: Acts of discrimination
Theme 3: Largely difficult experience working with services	3.1: High expectations of treatments and services
	3.2: Wide variety in services sought
	3.3: Negative experiences of services and outcomes
	3.4: Positive experiences of services and outcomes
Theme 4: Specific challenges parenting an autistic child in India	4.1: Disruption and deterioration of family and social life
	4.2: Significant life changes
	4.3: Parental blame
	4.4: Parental physical and mental health challenges

Figures & Tables

Table 4

Inclusion criteria

Inclusion	Exclusion
Adult (18 years+).	Children and young people (<18 years).
Diagnosis of autism (report showing confirmation required).	Currently receiving therapy.
Experience receiving CBT in last two years.	Presenting with significant mental health difficulties (CORE-10 score of 20 to be used as cut-off), or risk to self/others, and for those whom taking part in the study would cause harm.
Language proficient enough to engage in semi-structured interview (potential use of interpreter if required).	Language not proficient enough to engage in semi-structured interview, or no interpreter available.
Capacity to consent to interview/involvement.	Diagnosis of Learning Disability.
	No capacity to consent to interview/involvement.

Table 5

Participant demographic information

Participant	Gender	Age	Ethnicity	Employment status
Rachel	Female	39	White British	Self-employed
Ellie	Cis Female	39	White British	Part-time employed
Frank	Cis Male	42	White British	Full-time employed
Jade	Female	22	White British	Full-time employed
Emma	Non-Binary	18	White British	Part-time employed

Note: Gender identities reported in participants' own words.

Table 6

Superordinate and subordinate themes from IPA

Superordinate	Subordinate
1: Useful aspects of CBT	1.1: A neutral space to explore difficulties
	1.2: Improved understanding of symptoms
	1.3: Benefits were deemed secondary
2: CBT not a good fit for autism	2.1: Attempting to fix something that can't be fixed
	2.2: Content felt neither important nor meaningful
	2.3: Content not explained in autism-friendly way
	2.4: Social communication differences not accounted for
	2.5: Lack of knowledge of autism resulted in poor adaptation
3: Inaccessibility of services	3.1: Insufficient session length and number
	3.2: Uncomfortable, anxiety-provoking therapeutic settings
	3.3: Unhelpful communication methods from services
	3.4: Difficulty in raising service-based concerns