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Title

Recommended adaptations to therapy services for autistic adults from specialist clinicians

Abstract

Autistic adults are likely to receive co-occurring mental health diagnoses, however, the recommended therapies often fail to meet their diverse needs. Currently, recommended adaptations for therapies are confined to local clinical practices and are therefore widely variable. This qualitative study sought specialist opinion on achievable adaptations to psychological and occupational therapy with autistic clients, as well as adaptations for full service design. Seven semi-structured interviews were conducted with clinicians from a specialist autism assessment and therapy service in the UK. Clinicians described autism-related difficulties to be considered when designing services; they described the changes implemented within therapy and by the service as a whole. These included increasing understanding of what clients can expect when travelling, arriving and waiting for therapy, agreeing social etiquette within therapy appointments, reducing sensory demands such as from noise, smells and patterns in the environment and working systemically with families and care services. The solution-focused insights are intended to support practitioners working across specialist and non-specialist services by sharing the knowledge from specialist services that good practice guidance calls for. The findings are preliminary and need to be considered alongside descriptions of good practice from autistic people.

Keywords

Autism spectrum disorders, therapy, service design, qualitative research

Introduction

Research has consistently found that autistic people are more likely to be diagnosed with at least one co-occurring mental health disorder when compared with their non-autistic peers (Hossain et al., 2020). This co-occurrence is alongside lower quality of life, isolation and self-harm, and negatively impacts education and employment (Hedley et al., 2018; Camm-Crosbie et al., 2019). Autistic adults report lower quality of life across different domains, including mental wellbeing (Holmes et al., 2020). It is this context that signifies the need for clinical services to be adapted so that they are accessible and effective for autistic people.

The causes of the co-occurrence of autism and mental health disorders are multi-faceted (Hedley et al., 2018). They include confusion of the symptom descriptions of autism, depression and anxiety (Ainsworth et al., 2020; Cassidy et al., 2018). Considerations for appropriate therapy for autistic clients must also include the additional stress and fatigue caused by filtering sensory information, difficulties with reciprocal communication and intolerance of uncertainty (Crane, Goddard & Pring, 2009; Hwang et al., 2020). These impact the full journey of seeking support, attending and engaging with healthcare services (Camm-Crosbie et al., 2019; White et al., 2018).

When psychological therapy is recommended as the best-practice intervention (National Institute for Health and Care Excellence, NICE, 2012), recent evidence suggests that autistic adults will require a higher number of therapy sessions and that smaller therapeutic change will be demonstrated by outcome measurement (McFayden et al., 2021). In the US, autistic clients are more likely to be prescribed medication over the longer term and are less likely to receive psychological therapy (Maddox et al., 2018). This suggests that there are substantially different demands placed on clinicians when providing psychological therapy for autistic adults. The accumulating evidence from autistic individuals, their families and healthcare professionals (Camm-Crosbie et al., 2019; Maddox et al., 2020) shows that the quality of

therapy is reliant upon variable knowledge and confidence across services (Cooper, Loades & Russell, 2018; Ainsworth et al., 2020). Clinicians working within general community and mental health services have said that they do not understand autism or provide tailored therapy accordingly (Maddox et al., 2020; McFayden et al., 2021). This means that some clinicians hold local expertise, specifically of the diverse needs of autistic adults.

Therapy adaptations already described (Cooper et al., 2018; Spain & Happe, 2019) are mostly for Cognitive Behavioural Therapy, delivered by mainstream mental health services.

Therefore, we await further practice guidance using expertise from specialist services (NICE, 2012), which would disseminate local knowledge of important adaptations for therapy, with the aim of improving guidance available to clinicians on how best to adapt their practice (Maddox et al., 2020). This would mean that autistic clients are not restricted by their access to knowledgeable clinicians, or offered only a limited range of therapeutic approaches.

This study asks specialist clinicians (NICE, 2012) about their individual and service-level adaptations to practice for autistic adults. A specialist autism team is multidisciplinary by design and offers diagnostic, assessment and interventions for autistic adults (NICE, 2012), different from mental health or psychology clinics working with a broad range of mental health needs (Maddox et al., 2020; McFayden et al., 2021). The exploratory interview design expands our understanding beyond briefer, listed descriptions of therapy adaptations (Petty et al., 2021), and offers understanding into why adaptations are made and which adaptations are a priority. Therapy refers to post-diagnostic and therapeutic interventions delivered by psychologists and occupational therapists that address a range of mental health and social needs relating to autism.

Methods

Design

Qualitative design: individual, semi-structured interviews were conducted.

Participants

All clinicians delivering therapeutic interventions for autistic adults (without intellectual disability) within a specialist autism service in the North of England, UK, were invited to participate. The service delivered NHS and privately-funded contracts.

Seven allied health professionals (clinical psychologists, n=4; assistant psychologists, n=2; occupational therapist, n=1) formed a sufficient sample size (Guest, Bunce & Johnson, 2006). Participants were mostly female (n=6) and White British (n=5) with ages ranging 25-54 years; they had an average of seven years' work experience with autism, ranging 18 months-14 years, and most had a friend or family member with autism (n=6). Clinicians had a range of training experiences including doctoral training in psychology, a diploma in sensory integration and training in administering standardised autism assessments.

Materials

Twelve interview questions sought descriptions of practice across areas identified as important by prior research and clinical guidance (NICE, 2012; Cooper et al., 2018), including: challenges experienced by autistic adults before and during therapy, clinician and service adaptations to these known challenges, aspects of service delivery that work well and are prioritised, recommended improvements to practice and the physical environment.

Questions were open-ended. Interview prompts allowed follow-up questions and elaborations and typically asked about usual practice and recent examples. See supplementary materials for the interview guide.

Procedures

Interviews were conducted via online video-call, lasting on average 44 minutes, were audio-recorded and transcribed in full.

Data analysis

Thematic analysis of the interview data followed an inductive approach so that participants' wording and meanings were retained (Braun & Clarke, 2006). Main themes and patterns were identified following six phases: researchers familiarised themselves with the data, systematically coded all transcripts to identify answers to the research questions and created a coding framework. An independent researcher coded a random sample of transcripts to ensure reliability of coding and refine code descriptions. Group discussion refined the codes over a number of iterations to reduce researcher bias and ensure that participants' accounts were retained. Themes were a coherent explanation of all clinicians' perspectives collectively and were described with illustrative quotes. See Figure 1.

Compliance with Ethical Standards

The study was approved by the university and host service's ethics committees; the procedures used in this study adhere to the tenets of the Declaration of Helsinki. Informed consent was obtained from all individual participants included in the study.

Community involvement

All study materials were revised by an expert by experience with autism, including the outcome measures, the design of the study and the interpretation of the findings.

Results

There were four overarching themes: 1) considerations of autism; 2) clinician adaptations; 3) service adaptations; 4) recommendations for service improvements. The prioritised

recommendations for each theme are presented in Table 1. Illustrative quotes are shown in Table 2.

(Table 1)

1) Considerations of autism

Clinicians described the following challenges that autistic adults face when accessing therapy.

Intolerance of uncertainty All clinicians described unknowns and uncertainties, including processes to follow, the content of sessions and the service environment, perceived as unpredictable and causing anxiety. Meeting with a professional and not knowing what they might ask was described as overwhelming.

Sensory sensitives All clinicians said that sensory demands within the environment caused difficulties with attendance and engagement. Seemingly small things in the therapy or waiting areas were said to cause overload, including patterns, brightness or intruding sounds. The increased demands made it difficult for clients to participate in conversation, complete therapy tasks or access therapy at all. Clinicians described clients as being overwhelmed or under-stimulated when travelling to the service, often travelling large distances for a specialist service.

Emotional literacy Difficulties identifying, interpreting and discussing emotions were described, notably when clients are asked to think beyond their immediate experience, or to think forward to when they could make use of therapy resources.

Managing social expectations Most clinicians described clients actively managing social etiquette when attending therapy. For instance, maintaining eye contact, refraining from making repetitive movements or smiling frequently, though this made them feel uncomfortable. Clinicians referred to this as ‘masking’, when the client behaved differently to

comply with societal norms. One impact described was exhaustion due to the high concentration required.

Challenges were described as far-reaching and widely variable for each individual.

2) Clinician adaptations

Clinicians agreed that they responded to these difficulties spontaneously as a routine part of their practice. Prioritised responses are summarised.

Local etiquette Clinicians said that by giving explicit permission for clients to act in a manner in which they felt comfortable helped them to communicate and relax. Permissions included adapting the environment such as closing the blinds, using sensory or twiddle items, not requiring eye contact to be shared, changing the pacing of the session or allowing the client to take breaks away from social demands as needed.

Adapting communication Clinicians adapted communication at all stages of service interaction. For example, gathering initial information through email, letter or telephone as per the client's preference. Written communications were proof-read by autistic adults to reduce ambiguity. Clinicians said they used more closed or multiple-choice questions to explore emotions; one practitioner explained that not all clients wanted to answer verbally, but might prefer to provide written answers or express ideas using video clips. Four clinicians said they occasionally avoided figurative language, though for some clients it was important to assess abstract thinking without making assumptions based upon their autism diagnosis. Another practitioner described paying attention to their own tone of voice and arousal level.

Adapting psychological therapy Clinicians said that standard therapy techniques designed for the general population require adaptations to meet the needs of autistic adults. Most clinicians described using a flexible therapeutic approach with awareness of recommended content and delivery, alongside autism knowledge. Some clinicians said they focus on

practical changes to behaviours and less on identifying adverse thinking. Another practitioner said they made therapy tasks less imagination-dependant, such as by practicing walking away or looking back to an image or drawing of themselves. When drawing on therapy designed for children, such as sensory integration therapy, clinicians said they keep some exercises but reduce the amount of play. Collectively, clinicians said they allow more time to build therapeutic rapport before focusing on manualised therapy content. Clients' interests could be useful to build rapport or to support clients to complete therapy tasks. Some clinicians said that liaison with external services was a routine part of therapy work, such as helping other professionals to complete paperwork with an understanding of autism or contacting supporting services. Additions to traditional practice involved inviting family members into therapy.

There was consensus that a standard guide for adapting psychological therapies would be inappropriate. Instead, modifications should be based on an assessment and formulation of the client's presenting needs rather than on their autism diagnosis.

3) Service adaptations

Preparation Clinicians consistently described enhanced information given by the service to help reduce client uncertainty. This included information on what to expect when travelling to the service, entering the service environment and meeting clinicians. For some, this was achieved by sending information packs with maps and photographs of people. The service's website housed relevant information. Clear signposting, including written and visual information about staff members were part of the environment's design.

Multidisciplinary working All clinicians praised the value of different professional backgrounds in contributing to a responsive and holistic service. They described the importance of a learning culture with in-built reflective practice.

Low-sensory stimulation environment Most clinicians explained the benefits of a low-sensory stimulation environment. Clinicians refrained from wearing perfumes, jangling accessories and patterned clothing.

4) Recommendations for service improvement

Practitioners agreed that priorities for further improvement would be to increase the team's reach into community-based support, including offering employment support. They also stated that specialist autism training for all professions designing and delivering the service was essential.

(Table 2)

Discussion

This study presents clinicians' descriptions of their adaptations of therapy delivery, from a specialist autism service. Findings respond to the imperative on specialist services to upkeep effective practice and to lead on therapy standards across the UK (NICE, 2012). This full-service description is a novel addition for clinicians and policy makers.

Clinicians described ways to reduce the negative impacts of uncertainty, sensory demands, unshared emotional literacy and unarticulated social expectations that can contribute to increased anxiety and exhaustion for autistic clients. These specific challenges are well described as contributing factors to mental health symptoms and reduced therapy engagement (Camm-Crosbie et al., 2019; Crane et al., 2009; Hwang et al., 2020). Therefore, the recommended actions provide a valuable, solution-focused response to the questions posed in the research literature.

The findings describe modifications for therapy services as a whole. For example, clinicians recommended providing clients with a packet of service information to decrease uncertainty

when first accessing their organisation, offering a range of communication options and providing a low-sensory stimulation environment, applicable across the full service, with implications for investments in service design (NICE, 2012). Maddox et al. (2020) made complementary recommendations for waiting room and lighting considerations within community mental health services. These systemic changes should be in place at all clinics. Following intake, when understanding of each individual client improves, these additional adaptations could be considered within therapy: placing less emphasis on standard therapy techniques (such as identifying and challenging thoughts), finding alternatives to thinking abstractly and thinking hypothetically, agreeing the sensory environment within therapy, agreeing social expectations and session duration, allowing for a slower process of rapport-building with less emphasis on change initially, working as a multi-disciplinary team, working with family and liaising with external services. This list of options replicates recommendations made by autistic individuals, their families and community healthcare professionals in the US (Maddox et al., 2020) and CBT-specific recommendations from the UK (Spain & Happe, 2019), while also providing additional options.

These specialist clinicians prioritised psychological formulation as a means of selecting ways to modify practice for each individual (Hwang et al., 2020; Spain & Happe, 2019). There will need to be training in this particular clinical skill, to build consistency and clinician confidence in selecting tools across various situations in practice (Cooper et al., 2018). In a similar vein, improving communication between mental health services, offering formal training or a consultation role for specialist services would be beneficial (Ainsworth et al., 2020; White et al., 2018). As a starting point, sharing these options for therapy adaptations with autistic clients is recommended.

Finally, clinicians discussed outstanding challenges requiring solutions, including long wait times and the distance travelled to specialist services, discussed elsewhere by service users

and providers (White et al., 2018; Maddox et al., 2020). Additionally, communication between services was wanted, focusing on ambition to offer employment support and bridge the gap between therapy and daily life, with extra outreach into the community.

The findings are an attempt to find achievable and priority adaptations, whilst also identifying areas of need. The study supplements existing professional guidance (NICE, 2012; Cooper et al., 2018; Ainsworth et al., 2020) with specific examples for specialist and non-specialist services supporting autistic adults to consider. We call for more research whereby knowledgeable stakeholders share good-practice ways of working.

Strengths and limitations

The findings build a consistent description of good practice alongside previous research but require replication beyond one service. Importantly, this study did not include the voices of autistic adults or carers, who should lead with their expectations of therapy services (Maddox et al., 2020). Research is required to extend these findings with evaluation of the adaptations. The specialist setting is a strength and novel addition to the literature (Camm-Crosbie et al., 2018). Clinicians shared their experiences of working therapeutically with autistic adults as a whole service in order to make recommendations for other clinicians to consider.

Conflicts of interest

The authors have no conflicts to declare.

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Tables and Figure

Table 1

Recommendations for adapting therapy services for autistic adults

Theme	Recommendations
Considerations of autism	<p>Intolerance of uncertainty</p> <p>Sensory sensitivities</p> <p>Emotional literacy</p> <p>Social expectations</p>
Clinician adaptations	<p>Agreeing local etiquette</p> <p>Adapting communication by using closed and multiple choice questions, avoiding ambiguous language and using visual resources to support therapy</p> <p>Adapting psychological therapy by allowing extra time to build rapport, using specific interests within therapy, involving family members, increasing the behavioural focus, working as a multi-disciplinary team and liaising with external services</p>
Service adaptations	<p>Preparing the client with what to expect with information leaflets and website information about travel, the environment, the clinicians and processes of therapy</p> <p>Using multi-disciplinary knowledge of autism</p> <p>Providing a low sensory stimulation environment with neutral décor, avoiding visually distracting or noisy clothing/accessories and perfumes and signposting to options to adjust lighting and noise</p>
Recommendations for service improvement	<p>Increasing community support including housing and employment services</p> <p>Providing specialist autism training for all staff within a therapy service</p>

Table 2*Illustrative quotes from clinician interviews about therapy adaptations for autistic clients*

Theme	Illustrative interview quotes
Considerations of autism	
Intolerance of uncertainty	<i>'...ringing the bell at the building and wondering who will answer? Will they have to do any small talk? And then walking into the building and the noise, the unexpected waiting room, are there other people around?'</i> (Participant 5)
Managing social expectations	<i>'It's almost like someone's kind of on stage trying to be a certain person but also having to kind of do a job at the same time...'</i> (Participant 4) <i>'Am I performing enough? Do I need to try to put on a mask? Do I need to try to do typical social cues? Or is it ok not to?'</i> (Participant 5)
Clinician adaptations	
Agreeing local etiquette	<i>'encouraging clients to wear their sunglasses or to wear ear plugs...a lot of clients come a little bit differently the second or third session...they'll come in with their sunglasses and won't apologise'</i> (Participant 5) <i>'...it's fine to say do you want the lights turned off? or do you want the curtains closed? do you want the appointment to be half an hour not an hour?'</i> (Participant 3)
Adapting psychological therapy	<i>'getting the client to imagine stepping outside of their perspective...with a client with autism recently, I got them to draw a picture of themselves and put that on the chair so that it is something more concrete to look at as they were then stepping away so that they weren't having to hold an image of themselves their mind as well'</i> (Participant 1) <i>'flexibility in all aspects in terms of not sticking to a psychological model if it's not working'</i> (Participant 5)

Service adaptations

Preparation

'we'll talk through where the building is, who they'll be meeting, what will happen in the appointment, we'll send out a map, so they can see where the building is...it helps them to picture the journey, the route in their mind and picture where it is they are going and who exactly they're going to be seeing to take away some of that element of uncertainty and anxiety as well' (Participant 2).

Recommendations for service improvement

'There's so much support that could be offered to people with autism, especially around things like employment, or helping people to get out of the house...' (Participant 4)

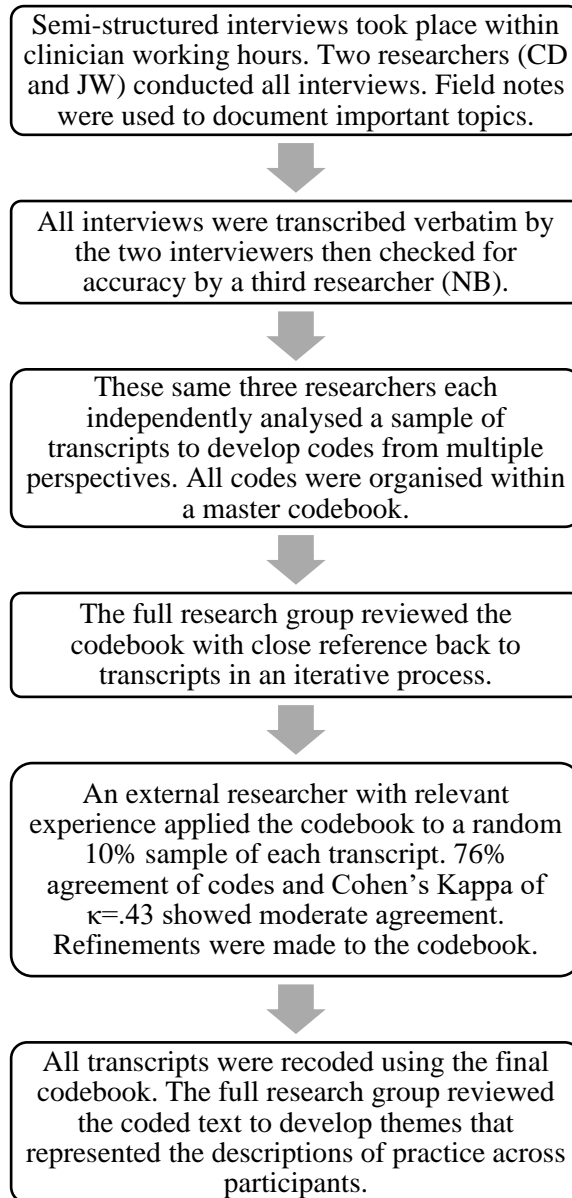


Figure 1 Data analysis processes.