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Anxiety in adults with autism: Perspectives from practitioners

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ABSTRACT

Background: Autism is a neurodevelopmental condition, characterized by differences in social communication and social interaction as well as restricted interests and repetitive behaviours (American Psychiatric Association, 2013). Research has suggested that 50% of adults with autism meet criteria for an anxiety disorder diagnosis (Russell et al., 2013). Despite a call for multi-disciplinary insights (White et al., 2018), few studies have included perspectives of practitioners in this field.

Method: We conducted interviews with eight practitioners (6 Clinical Psychologists, 1 Consultant Clinical Psychologist and 1 Nurse Practitioner) who work with adults with autism and anxiety on a regular basis.

Results: Via thematic analysis, four key themes were identified: 1. Modifications to psychological therapy 2. Thinking outside the box 3. Continued support 4. Issues with anxiety measures.

Conclusion: Modification of standard anxiety interventions are common in practice but the course and nature of these modifications are inconsistent and may depend on practitioner experience. Practitioners may consistently have to think inventively in order to best serve adults with autism and anxiety. Current anxiety measures could be improved in order to accurately gauge anxiety, specific to adults with autism. These findings are discussed in relation to practice and future research.

1. Introduction

Autism[1] is a neurodevelopmental condition that is characterized by differences in social communication and social interaction, as well as restricted interests and repetitive behaviours (American Psychiatric Association, 2013), and is estimated to be prevalent in 1.1% of adults in the UK (Brugha et al., 2012). Recent research indicates that there is a high prevalence of mental health difficulties in autistic individuals, with evidence of 79% meeting criteria for at least one psychiatric disorder at some point in their life (Lever &

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[1] We predominantly use identity-first language (e.g. autistic person) rather than person-first language (e.g. individual with autism) in this article, in order to respect the terminology preferences of the majority of the autistic community (see Kenny et al., 2016).

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Geurts, 2016). Anxiety, in particular, has been highlighted as one of the most common co-occurring mental health conditions in this population (Kerns & Kendall, 2012). Research has suggested that 50% of adults with autism meet criteria for an anxiety disorder diagnosis (Bakken et al., 2010; Hofvander et al., 2009; Russell et al., 2013). Moreover, it has been asserted that anxiety may be compounded by autism symptoms because of a bidirectional link between skills in social cognition and anxiety (White, Oswald, Ollendick, & Scahill, 2009). Hence, the precise manifestation of anxiety in adults with autism is not yet clear.

Kerns and Kendall aimed to classify the manifestation of anxiety in their 2012 review, reporting that although anxiety is not a fundamental part of the autism phenotype, the anxiety symptoms present in individuals with autism were not identical to those observed in anxiety in its independent form. They concluded that there is an unusual presentation and unusually high prevalence of anxiety in autistic individuals. In addition, Maisel et al. (2016) modelled the cognitive mechanisms linking autism symptoms and anxiety in adults. They proposed that three cognitive mechanisms were directly linked to anxiety in individuals with autism: adverse reaction to emotional experiences, difficulties in identifying and understanding emotions (which they define as 'alexithymia'), and intolerance to uncertainty (IU). These findings were supported by South and Rodgers (2017) and build upon the model that

presents IU as being central to the specific manifestation of anxiety in autistic individuals (Boulter, Freeston, South, & Rodgers, 2014).

A recent qualitative study conducted by Robertson et al. (2018) explored the experience of anxiety from the perspectives of autistic adults and their supporters (i.e. parents or partners) in semi-structured interviews. They found that three themes consistently arose: contributing and mitigating factors to anxiety (for example, uncertainty, change, and miscommunication contributed to anxiety while feeling accepted mitigated it), consequences of anxiety (negative judgement from self and others, feelings of missing out or being 'in limbo') and managing anxiety (trying to implement both preventative and 'in the moment' strategies- while recognising that awareness of anxiety in the moment can be difficult). In addition, a series of focus groups conducted with autistic adults with anxiety by Trembath, Germano, Johanson and Dissanayake (2012) reported similar themes. There is, therefore, a growing body of research dedicated to improving our understanding of how anxiety presents, from the perspective of autistic adults themselves.

There is a somewhat limited evidence base for the effectiveness of psychological therapies in reducing anxiety in autistic adults. White et al. (2018) reviewed the literature on treatments of anxiety and depression in adolescents and adults with autism and found that, for anxiety, Cognitive Behavioural Therapy (CBT) was the most commonly researched treatment and suggested that overall, CBT was found to have moderate to large treatment effects. However, treatment was frequently modified, with the changes across studies being varied. Examples of modifications included: an increased reliance on parents to support therapy, a slower pace of treatment, use of visual aids, and ensuring content was highly structured. Similarly, Spain, Sin, Chalder, Murphy and Happe (2015) conducted a review on the use of CBT for autism and co-occuring psychiatric disorders, and reported that there appears to be some improvement of anxiety symptoms in autistic adults with the use of CBT. However, it should be noted that the 'typical' structure of CBT was modified to best suit autistic service users in each study included in the review. Although there has been an effort to systematically identify modifications to CBT for young autistic people (Walters, Loades, & Russell, 2016), a similar evidence base for autistic adults does not yet exist.

There is, however, evidence that some studies have begun to explore this in more detail. For example, in a pilot study, Ekman and Hiltunen (2015) applied a modified version of CBT to autistic adults (namely, adapting basic CBT to focus of visual communication: 'visualizing and systematizing "the invisible" in the conversation'). They found a significant improvement in anxiety levels as measured by the behavioural excess and avoidance components of the Global Function Rating Scale, however, there was no treatment as usual or waitlist control group included as a comparison.

South and Rodgers (2017) proposed that adapting psychological therapies to incorporate improving alexithymia and tolerance of uncertainty, while increasing emotional acceptance, may be particularly useful in reducing anxiety in autistic adults. Supporting this, there is an emerging evidence base which suggests that mindfulness-based therapies may be useful in the management of anxiety in autism (Kiep, Spek, & Hoeben, 2015; Spek, van Ham, & Nyklicek, 2013). Sizoo and Kuiper (2017) compared a modified version of CBT to a modified version of Mindfulness Based Stress Reduction (MBSR). They reported that CBT and MBSR therapies were equally useful for managing anxiety. Overall, despite growing evidence that different kinds of modified psychological therapy may play a role in helping address anxiety issues, more empirical evidence is needed regarding its effectiveness in autistic adults.

There is a clear 'research-to-practice gap' in the application of interventions in autism (Dingfelder & Mandell, 2011). Clearer communication between research evidence and practice is needed for the implementation of effective interventions (Lane, Reynolds, & Dumenci, 2012) and so data from practitioners is an important addition to the scientific conversation surrounding anxiety in autism. Therefore, an exploration of practitioner experiences is imperative in creating more effective anxiety interventions for autistic adults. Moreover, an increased awareness of the practitioner – service user experience may help cultivate a more supportive environment for autistic adults, which in turn could improve adherence and reduce attrition. Despite a call for multidisciplinary insights (White et al., 2018), to our knowledge, only one study has explored practitioner perspectives of anxiety in individuals on the autistic spectrum. Spain et al. (2017) conducted focus groups with a multi-disciplinary teams of practitioners. Two major themes were identified in the data: conceptualizing social anxiety in autism, and service provision. Although Spain et al. (2017) indicated that CBT can be an effective treatment of anxiety, they highlighted that a considered approach is important, namely an adapted clinical delivery and a greater number of sessions. Focus groups are an effective means of generating discussion around a topic, however, there is evidence that one-to-one interviews can elicit a broader range of discussion points (Guest, Namey, & McKenna, 2017), hence, this study builds on Spain et al. (2017) by exploring practitioners' experience of anxiety in autistic adults through semi-structured interviews.

Table 1
Practitioner Characteristics.

ID	Gender	Job Title	Orientation of job
P3001	F	Clinical Psychologist	Community Mental Health Team
P3002	M	Consultant Clinical Psychologist	General Adult Mental Health
P3003	F	Clinical Psychologist	Community Mental Health Team
P3004	F	Clinical Psychologist	Child and Adolescent Mental Health Service
P3005	F	Clinical Psychologist	Not specified
P3006	F	Clinical Psychologist	Learning Disability Services: Half Inpatient, Half Community
P3007	F	Nurse Psychotherapist	Supportive Psychotherapy
P3008	F	Clinical Psychologist	Learning Disability and Autism

2. Methods

2.1. Participants and recruitment

Participants were recruited using purposive sampling: practitioners who had worked, or were currently working, with autistic individuals with anxiety were targeted for inclusion in this study. Practitioners were identified through NHS Greater Glasgow & Clyde (NHS GG&C) and NHS Lothian Adult Mental Health services. Recruitment was conducted as part of a wider online questionnaire study, where, at the end of the questionnaire, participants were asked if they would be interested in being interviewed. Hence, the survey was widely distributed and participants opted-in if they were interested in taking part in the interview component. Thirteen participants opted-in, and from there, we were able to schedule 8 practitioners for interview (the remaining 5 were unavailable or did not respond). The sample consisted of seven females and one male; six participants were clinical psychologists, one was a consultant clinical psychologist, and one was a nurse psychotherapist (for job characteristics see Table 1). All participants had experience working with autistic adults with anxiety and had varying caseloads (e.g. some with small caseloads, and some with ~40% individuals with autism and anxiety). This study was approved by NHS Research Ethics Committee (NHS REC) and informed consent was obtained from all participants before the interviews were scheduled. The interviews were conducted by HW. At the time of the interviews, she was actively working at the Mental Welfare Commission for Scotland. As a trainee psychiatrist, she had an interest in mental health improvement, but this was not perceived to influence the interviews in a negative way, or cause any conflict of interest. A preferred location for each interview was discussed with each participant in advance; all interviews took place in a location that was convenient to the participant, which was most often in their work environment. Each interview lasted between 45 and 60 min.

2.2. Interview structure

The interviews were semi-structured in nature (e.g. Drever, 1995). The interviewer asked a series of open-ended questions which had been set prior to the interview, as well as a number of follow up questions. This enabled the interviewer to follow up on pertinent information that arose during the interview, and allowed participants to elaborate on key points. The interview followed a broad schedule of questions surrounding therapeutic input to autistic adults with anxiety; the semi-structured nature allowed the interviewer the opportunity to follow up on points that were made by participants. The interview covered a) experiences of working with autistic service users who had anxiety, b) types of, and modifications to, therapy used to treat anxiety c) barriers to effectively reduce anxiety. The full interview schedule can be found in Appendix 1. All interviews were audio recorded using a digital dictation device that was situated between the interviewer and the participant. Recordings were later transcribed by a member of administrative staff.

2.3. Data analysis

Interview transcripts were coded following guidelines for thematic analysis (Braun & Clarke, 2006), and the analysis was conducted using NVivo-10 (NVivo Qualitative Data Analysis Software Version 10, 2012). Participant information was anonymised by applying codes to each participant, recordable only by one master document under password protection. All potentially identifying information mentioned during the interviews (e.g. names, specific locations, etc) was redacted. The coder (KA) familiarized herself with the data by reading though each transcript while simultaneously listening to the recorded interview. Any errors in the transcripts (e.g. terminology or wording that was not identical to the audio format) were identified and corrected. Apart from the removal of identifying information, all transcripts were written verbatim. At this stage, any initial ideas were noted down. The transcripts were then re-read, and initial codes generated by highlighting features in the data. Thereafter, initial codes were checked against the original interviews and formed into themes. These were then grouped together in order to build themes and sub-themes around the data. Lastly, themes and sub-themes were reviewed to check that they reflected the dataset as a whole, and quotes that best illustrated the themes were chosen.

In order to increase rigour, inter-rater reliability was determined (Gwet, 2014). This involved a second coder (HW) coding 20% of the transcripts; all eight interviews were included in this process. There was 85.71% agreement between codes attributed by KA and HW. Cohen's kappa revealed that the level of agreement was significantly higher than chance ($\kappa = 0.815$, $p < .001$). Intra-rater reliability (where KA coded 20% of the transcripts one month apart) was also high (87.30%), and significantly higher than would be

expected by chance ($\kappa = 0.794$, $p < .001$).

3. Results

Four overarching themes were determined to best fit the data using thematic analysis: modifications of psychological therapy, continued support, thinking outside the box and issues with anxiety measures.

3.1. Theme 1: Modifications to psychological therapy

The first, and most prominent, theme that was applied to the data was that practitioners consistently described modifying psychological therapy to better suit autistic clients. Practitioners described frequently adapting their therapeutic approach to each individual. Often these modifications were specific to the characteristics of autism, for example using fewer metaphors and less vague language, and focussing more on the behavioural aspects of therapy as opposed to the cognitive components. Two subthemes were present: the importance of addressing emotional awareness/understanding and the focus on behavioural aspects of psychological therapy. These are discussed in more detail below.

3.1.1. Emotional understanding

A key aspect to modifying psychological therapies to suit autistic service-users was undertaking preliminary work on emotional understanding. Almost all of the practitioners (seven out of eight) indicated that psychological therapy was often very difficult for their clients on the autistic spectrum, due to challenges in identifying and understanding emotions. One practitioner described an adaption to her psychological therapy as:

"doing more work around identifying emotions and what do they feel like and how do they know when they are feeling angry and sad and anxious. So you might need to do a bit more preparatory work" (P3004).

Another practitioner described that her experience working with autistic adults often revolved around emotional literacy, and that she used this as a starting point to improve the effectiveness of the psychological therapy:

"*The main thing is just to enable them to talk about what is going on inside of them and trying to notice what feelings are going on and what kind of emotions are there*" (P3007).

This idea was reflected in comments from several other practitioners, for example another practitioner indicated that, for psychological therapy to be most effective, preparatory work on emotional understanding may be key:

"*I think … just describing feelings and emotions [is difficult] or just getting them thinking about what might trigger things, what makes them stress, they just really struggle*" (P3005)

These experiences indicate that, where needed, it is important that preparatory work on emotional understanding is incorporated into initial sessions. Such work may provide a platform upon which clients more readily build their skills in managing their anxiety.

3.1.2. Behaviour focussed

Another modification that was consistently mentioned (six out of eight practitioners) was the increased use of behavioural components of psychological therapy teamed with the decreased use of cognitive components. One practitioner described using "*mainly a CBT sort of format, but sometimes it does become a bit more behavioural… maybe top heavy behavioural… sort of work than the cognitive part*" (P3004), while another practitioner discussed using an approach that was "*much more behaviourally focussed than looking at the cognitions as such, but drawing a lot on my behavioural sort of training and experience*" (P3002). Overall, there seemed to be a consensus that the behavioural aspects of psychological therapy were more accessible or useful to autistic individuals than the cognitive aspects, although it is uncertain what this conclusion was based on. For example, one participant reported that they increased focus on behavioural components, despite being unaware of evidence for this with autistic individuals:

"*sometimes, if somebody is really debilitated [with anxiety] I think we will …try maybe some sort of psychological therapy… it might be more behavioural based rather than cognitive based. The psychologists may do it from that angle just to help because I am not aware of any evidence based psychological therapies*" (P3005).

Taken together, the experiences described by the practitioners indicated that using the behavioural components of psychological therapy can be useful to support the management of anxiety in autistic adults. However, this appeared to be approached from an ad-hoc basis in which practitioners were trying to find what worked well.

3.2. Theme 2: continued support

The second theme was continued support for autistic adults. Practitioners reported that, in their experience, continued support after psychological therapy is important for on-going anxiety management. Participants highlighted that this may be particularly important for autistic clients, and that family members and friends are often relied upon for support outside of the clinical practice.

From the interviews, practitioners described that help from family members provided an invaluable support mechanism for autistic adults, in terms of obtaining long-term anxiety reduction. For example, one practitioner reported that "*the sort of stuff that we*

would run, we put a lot of onus onto the parents to help manage it" (P3005). This idea was reflected in discussion with other practitioners, for example "*adaptations might be involving family or a close other a little bit more if it's appropriate*" (P3002). It was also asserted that, in one practitioner's experience of working with adults with autism, extra support was particularly important:

"*what kind of makes delivering what's needed difficult is, say where somebody actually would, more than another [neurotypical] individual … need additional support to practice the strategy or the behaviour experiment at home*" (P3001).

In addition, another practitioner mentioned the importance of allowing family members to be involved in trying to reduce the anxiety of the service user, and the key role of training and support in this area.

"*I think if we could allow [family] opportunities to come and have [support] skills topped up… and more family members trained in that kind of information. I think that is what would make the biggest difference to our service users*" (3008).

Although support from family members was deemed particularly important for autistic service-users, the role of caregivers was complex. For example, one participant described that caregivers may be particularly invested in the therapeutic process:

"*sometimes it is difficult with engagement because sometimes the family want the person to come more than the person*" (P3001).

This practitioner also described the case of an individual that she had worked with in the past, suggesting that sometimes continued support is difficult when the service user does not feel engaged in the therapy:

"*actually that person may be seeking or have no desire to have people in their life [speaking as an autistic service-user] "they just make me anxious, I don't want to have friends and I am quite happy being home, being on the PC"*" (P3001).

Therefore, the data suggest that the continued support for autistic individuals is important, but complex. It was evident from the interviews that practitioners often experienced support or input from caregivers, which was important for giving an autistic client the best chance at effectively improving their anxiety symptoms. Additionally, practitioners sometimes found a disparity between what clients wanted and what caregivers wanted, which made it more complicated for practitioners to effectively deliver therapeutic input for anxiety.

3.3. Theme 3: thinking outside the box

The concept of 'thinking outside the box' was discussed among all of the practitioners that were interviewed. It was apparent that some practitioners (five out of eight) adapted their psychological therapy on an ad-hoc basis for autistic adults. However, it appeared to be the case that having the ability to confidently adapt therapeutic input was linked to the level of experience and confidence of the practitioner. This, in turn, led to a disparity in the quality of psychological therapy offered to autistic adults. These data suggested that there is a distinct lack of resources that can be utilised in order to support the improvement of skills, despite an appetite for support like this. Two sub themes were identified: 1) working on an ad-hoc basis and 2) training and evidence base.

3.3.1. Working on an ad-hoc basis

The data indicated that most practitioners adapted their psychological therapy on an ad-hoc basis for autistic adults. Thinking outside the box was mentioned as being important when adapting psychological therapy, with one practitioner describing her experience as follows:

"*I would say I have been more inclined to be quite inventive with people. I can think of three or four occasions, with people with autism where we have met in their home and we have used things that they have and like*" (P3008).

The ability to engage in this type of ad-hoc practice did, however, appear to be linked to how much initiative was taken by the practitioner. For example, one practitioner indicated her ability to adapt on a rolling basis "*I think you learn as you are going along*" (P3001), which was reflected in a comment from another practitioner "*so we have really had to kind of learn on our feet*" (P3002). One practitioner described her experience as follows:

"*…if you have got nothing else and somebody is struggling you just need to try what you have got even though it won't necessarily work. I think you are always trying to rattle your brain*" (P3005)

Overall, the comments from practitioners indicated that inventiveness and 'thinking on their feet' was important for therapy with autistic clients, in particular. The data suggested that practitioners are often left to their own resourcefulness when it comes to adapting their therapy and approach to meet the needs of their autistic service users and that, subsequently, it often depends on the confidence and experience of each individual practitioner. This evidence suggests that there could be real disparity in services provided by practitioners, which is dependent upon the experience and confidence of the practitioner. Therefore, it could be the case that specific training or support may be particularly useful for practitioners working with autistic adults with anxiety.

3.3.2. Training and evidence base

This web of 'thinking outside the box' appeared to be complicated by a shortage of training, for example one practitioner described training in delivering anxiety therapy for autistic adults as being sparse: "*certainly in the department we all recognised that we really don't have an awful lot of training, and not a lot of training in adaptation for CBT working with this group*" (P3002). Similarly, a lack of research/empirical knowledge could have a cascading effect in terms of how practitioners work effectively with autistic

individuals. For example, one practitioner described a lack of research resources to draw upon, despite feeling these would be very helpful for her:

"*I remember … thinking oh my gosh I don't know enough about this and I need to learn and read more about this and wanting to do it from a more psychodynamic perspective and found very little written about it"* (P3007).

Therefore, the idea of 'thinking outside the box' in every day practice evolved throughout the interviews from being key in aiding anxiety management in autistic individuals through to the recognition that these skills are linked to levels of training and available resources. It may be the case that increased peer support or knowledge exchange could alleviate some of the difficulties associated with having to rely on resourcefulness in this particular area of practice, as examined further in the Discussion.

3.4. Theme 4: Issues with anxiety measures

A recurring theme that was applied to the interviews was the issues associated with measuring anxiety levels in autistic service-users. This consisted of two sub-themes: 1) the inconsistency of measures used, and 2) the lack of appropriate measures. Data revealed that available outcome measures might not suit autistic clients, thereby compounding the issue of inconsistent measurement between practitioners. One practitioner indicated that the statements used in anxiety measures might be less well suited to autistic adults:

"*you sometimes have to look at what the statements they are saying and actually, if someone scored high it might not necessarily be indicative of this, it could actually be more linked to the spectrum"* (P3001).

Another practitioner indicated similar views, expressing that the standard measures used to assess anxiety may overlook the compensatory strategies employed by autistic adults.

"*So they have maybe still got quite a high level of anxiety but they are actually able to do a lot more even despite that anxiety. So on the sort of Beck's measures and things it doesn't pick up much"* (P3004).

One practitioner highlighted that, there was no specific anxiety measure used with adults with autism:

"Interviewer: Are there any outcome measures that you have used semi-regularly, particularly looking for anxiety in ASD?

Psychologist: Not in my head, there is not one I think that would be really good for ASD, but there might be and I don't know about it." (P3006)

In addition to this, when asked whether the same anxiety outcome measures were used on clients with autism as with those without autism, one practitioner responded: "I have done, only because I don't have any others." (P3002). Similarly, one practitioner described that "there is no standardised kind of anxiety specific measure." (P3003). One practitioner described using atypical types of anxiety measures, which were tailored to the individual with autism:

"I prefer to an extent to use things that are maybe a little more ad hoc. I do have anxiety thermometers [and] very visual things that I can use with people, you know, [you] wouldn't find it on a formal outcome scale" (P3008).

Overall, practitioners described either using the measures (but finding them unsuitable for autistic adults) or not using them at all. This is significant, as it highlights issues surrounding the importance of being able to measure the efficacy of psychological therapy for autistic adults.

3.5. Discussion and implications

Anxiety is highly prevalent in adults with autism (Russell et al., 2013) but understanding how anxiety truly manifests in individuals with autism is complicated due to difficulties with emotional understanding and diagnostic overshadowing (Kerns & Kendall, 2012). In order to reduce the usually high prevalence of anxiety in autistic individuals it is imperative that we not only explore the way in which anxiety presents, but also the way in which it is treated - and more specifically what barriers practitioners may be facing in order to best serve these individuals. This study is the first to assess practitioner perspectives of anxiety in autism in one-to-one interviews. Eight semi-structured interviews were conducted, with several commonalities being observed across participants. Thematic analysis was used to identify four themes: modifications of psychological therapy, continued support, thinking outside the box and issues with anxiety measures. Our results revealed similarities between previous studies that have reported on the experience of anxiety in individuals autism. For example, our data support previous findings that difficulties in identifying and understanding emotions may be linked to elevated anxiety levels in autistic individuals (South & Rodgers, 2017). Our data also support previous findings that an increased reliance on parents to support anxiety therapy was particularly important, and that modifications to CBT (especially a slower pace of treatment, use of visual aids and ensuring content was highly structured) were utilised for adapting anxiety therapy for autistic service-users (White et al., 2018). Our study provides a novel contribution to previous findings by exploring how anxiety is being treated in adults with autism, directly from the perspective of practitioners. Specifically, we were able to acknowledge that practitioners were working on a 'ad-hoc' basis with their clients with autism and anxiety, utilizing techniques that they thought worked best, but with limited evidence base or clinical guidelines. Our data also suggested that practitioners may face barriers in supporting their autistic service-users with anxiety because there was limited training and the measures used to quantify anxiety levels were not always reliable for autistic adults. Hence, our data provide not only information around the manifestation of anxiety in autism but also on the issues surrounding the clinical treatment of anxiety. This study, therefore, contributes to the narrative around anxiety in autism from a different but highly important perspective. It is hoped that this can serve as a stepping stone for future research.

Practitioners indicated that modifications were routinely made to psychological therapy for autistic adults, and also that these modifications were largely focussed on emotions and behavioural aspects of CBT. These results are in line with research that has suggested that for autistic *children*, CBT is usually heavily modified – often beyond the recommended National Institute for Health and Care Excellence (NICE) guidelines (Walters et al., 2016). Our results also support evidence from White et al. (2018) that although modifications are generally made on an individual basis, there are more commonalities in the modifications than differences. White et al. (2018) indicated that specific focus on concrete, behavioural elements of psychological therapy, such as structuring time and identifying and working toward goals, may be particularly useful for autistic adults. This may be especially important for those transitioning from child services into adult services i.e. adolescents/young adults developing skills for independent living. Adapting psychological therapy to be more behaviorally focussed and paying more attention to emotional literacy is also consistent with Spain et al. (2017), who reported that practitioners regularly observed difficulties with emotional recognition and regulation in their adult autistic clients. They discuss the idea of 'pre-therapy' interventions (e.g. Gaus, 2011; Spain et al., 2015) which may be a practical way of providing targeted additional support to therapy for anxiety without having to rebuild the entire structure of the content. Overall, modifications to psychological therapy was a major discussion point for practitioners and, in line with previous research, targeted focus on emotional and behavioural aspects of therapy might be key for this population in particular.

Our findings that specific modifications are commonly used to treat anxiety in autistic adults is promising. However, caution must be exercised when considering these results in terms of a guideline for practitioners. Currently, NICE provides guidelines for treating anxiety in autistic children (NICE, 2013) which includes a greater emphasis on the use of visual aids and emotion recognition training (both of which were highlighted by practitioners in the current study). However, Walters et al. (2016) found, in a systematic review of CBT for treating anxiety in children on the autistic spectrum, that only two of the twelve studies identified used all seven of the NICE guidelines. Moreover, all twelve studies developed their own tailored treatment manuals, rather than modifying the existing one. Hence, simply modifying the content of current treatment manuals (for example, CBT) may not be the most effective practice 'on the ground' because of a lack of consistency between practitioners. At the moment, there are no specific guidelines for adapting CBT or any other psychological therapy for autistic adults, and so the development of such tools should consider the complexity of this issue.

Practitioners suggested that a certain level of 'thinking outside the box' was required with their autistic clients. The need for 'thinking outside the box' is somewhat unsurprising, given the need for modification to psychological therapy paired with limited research into what works for autistic adults. From the interviews, it was apparent that practitioner confidence impacted the content of the therapy delivered by the practitioner. Therefore, it is likely that there are disparities in the level of therapeutic input for anxiety for autistic adults that is dependent on the skills and experience of each practitioner. Although there is little research in this domain, a recent study (Cooper, Loades, & Russell, 2018) surveyed 50 practitioners on their skills, experience and confidence in working with autistic people with anxiety. They found that practitioner confidence was not associated with years of practice or number of adaptations made but was, instead, positively associated with level of therapy training received. These findings reflect the comments from our practitioners, highlighting the need for training and ongoing supervision to increase practitioner confidence and ability to make suitable adaptations to CBT protocols for autistic people. Overall, it seems clear that there is a gap in the practitioner toolkit for modifying anxiety therapy for autistic adults (as discussed above) which is further compounded by the reliance on practitioner confidence and 'thinking outside the box' in order to provide effective treatment for this population.

Practitioners also discussed the role of continued support. They suggested that for autistic adults, support from family members is helpful to attain reduction of anxiety in the long-term. Continued support may be particularly important for this population as a result of key factors in the presentation of anxiety in autism, such as intolerance of uncertainty (Boulter et al., 2014). It may also be the case that family members are often generally more involved in the lives of autistic adults than for neurotypical adults (Volkmar & Wolf, 2013). The interviews highlighted that there may sometimes be a disparity between the motivations of clients themselves and their family members, i.e. that, in some cases, the family member might be the driving force behind the autistic client receiving services. Spain et al. (2017) also touched upon this in their focus groups with practitioners, indicating that autistic adults sometimes felt like their anxiety was not something that needed to be addressed, while caregivers and practitioners felt differently. Overall, it is clear that, although support from family can be a key factor in effective anxiety reduction in adults with autism, this is somewhat complex insofar as family motivation and extent of involvement.

Practitioners discussed the issues with using current measures for anxiety with autistic adults, describing the measures as being misrepresentative. In order to effectively research anxiety in autism, adequate measures are important. Currently, autism anxiety research utilizes measures of anxiety that have been validated in a typical population only. Hence, if standard measures are used to compare anxiety levels in autistic and typical individuals, it is possible that skewed or misleading results may be reported. There has been no published evidence about the suitability of anxiety measures for autistic *adults*. However, evidence exploring standardised anxiety measures in autistic children has suggested that the majority of these are neither effective nor appropriate. For example, in a robust systematic review, Lecavalier et al. (2014) found only four measures to be appropriate for assessing anxiety in autistic children and even so these were only deemed 'appropriate *with conditions*'. For example, these measures were only relevant for participants within a certain age range or for those with a specific diagnosis. In a pilot study, Findon et al. (2016) highlight that, despite the high prevalence of co-occurring mental health conditions in autism, there is no validated screening tool for this purpose. Although this study applies specifically to a more general measure of emotional distress (the SDQ) rather than anxiety itself, it highlights that there is a need for this kind of measure. The SDQ was completed by 98 autistic individuals and 126 parents. Findon et al. reported that the SDQ (both self- and parent-report) was significantly associated with measures of anxiety, depression and hyperactivity. Hence, the SDQ may show promise as an efficient and easy way to screen for co-occurring emotional difficulties in autistic adults. Future research would benefit from this kind of study specifically in anxiety measures. Kerns, Renno, Kendall, Wood and Storch (2017)

presented an addendum to the Anxiety Disorders Interview Schedule–Child/Parent, Parent Version (ADIS/ASA) specifically for autism. This was reportedly valid and reliable at measuring anxiety symptoms in children with autism, but there is no such addendum for autistic adults. There is evidence to suggest that other clinical measures, such as those for depression, may not be as appropriate for adults on the spectrum; many of the suggested reasons for this are applicable to anxiety measures (Cassidy, Bradley, Bowen, Wigham, & Rodgers, 2018). It is possible that differences observed in autistic people (e.g. literal interpretation, concrete thinking, and difficulties with tapping into emotions) make self-report measures developed for the general population less useful. Therefore, the practitioners in our study described experiencing issues with anxiety measures, which supports the emerging findings about the use of anxiety measures in *children* with autism, as well as other mental health tools in autistic adults. Lastly, in a recent study, Scahill et al., 2019 propose a new, parent-rated measure of anxiety for children with autism: the 25-item Parent-Rated Anxiety Scale for ASD (PRAS-ASD). Although this is not yet suitable for use with autistic adults, it provides a promising starting point, upon which future research can build.

This study highlights some specific areas of clinical practice that could be adapted in order to best serve autistic adults with anxiety. Modifications to cognitive behavioural therapy include longer sessions (or a slower pace of treatment), the use of visual aids and highly structured therapeutic content. There is currently a limited evidence base for modifications to therapy for adults (despite a somewhat growing literature for children), therefore, clinical modifications for this population would benefit from greater research attention. Practitioners also suggested that current measures of anxiety were somewhat ineffective for autistic adults. Currently, there are no adapted anxiety measures for use with autistic adults (although, new recommendations are increasing for autistic children). Clinical practice would benefit from greater standardised tools for this population.

This study has some limitations that should be considered for future research. Practitioners targeted for this study were recruited via opportunity sampling, and therefore the interviews were limited in terms of practitioner roles (we had mostly clinical psychologists) and geographical scope (practitioners worked in largely urban environments). These participants were motivated to take part and so may have had predisposed views on anxiety in their autistic clients. The sample was also predominantly female. These limitations might affect the interpretability of the present findings and so future research would benefit from an exploration of this topic across different settings.

This study is the first to directly investigate practitioner experiences with anxiety in autistic adults via one-to-one interviews. These practitioner interviews provide a unique insight into the many contributing factors to treating anxiety in adults with autism, an area of research that has called for collaborative approaches to identify and catalyze mechanisms of change (White et al., 2018). At the core of this is effective delivery of psychological therapy which involves complex modifications. As there is currently little evidence or guidance on how best to modify therapeutic input, outcomes are also influenced by the practitioner's resourcefulness and ability to 'think outside the box'. It is unknown whether measures of anxiety are currently valid or effective for use with adults with autism, which further compounds this issue. In addition to this, the need for extra support from family and the community surrounding the autistic individual is an important, and somewhat overlooked, component to effective treatment for anxiety in adults with autism. It is hoped that the insights from practitioners given here can provide a platform for future research.

Declaration of Competing Interest

The authors of this paper disclose no conflict of interest including any conflict of interest arising from any financial or personal means.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.rasd.2019.101457.

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