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An Evaluation of the Effectiveness of Psychological Therapy in reducing general psychological distress for Adults with Autism Spectrum Conditions and Comorbid Mental Health Problems

Abstract

Objective: To investigate the effectiveness of psychological therapy in reducing general psychological distress for adults with Autism Spectrum Conditions (ASC) and comorbid mental health conditions in routine clinical practice and to explore the effect of individual characteristics and service factors on change in general distress. .

Method: In a specialist psychological therapies service for adults with ASC, the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM) self-report questionnaire which measures psychological distress is completed by clients at start and end of therapy. Start and end scores of 81 of a total of 122 clients (66.4%) were compared, to assess change over time. Change category and reliability was assessed to identify reliable and clinical change. Data was extracted from online databases and all available diagnostic, referral, assessment and discharge reports, in order to assess the factors which may influence change over time in CORE-OM scores.

Results: There were no differences in demographics between those included and excluded. Overall there was a significant reduction in CORE-OM score over the course of therapy with a small effect size. The majority of clients showed an improvement in psychological distress over therapy (75.4% improved, with 36.9% of these showing a reliable change). Individual characteristics of the clients and service factors did not influence the extent of change in psychological distress over the course of therapy; significant and comparable reductions from pre- to post-therapy were seen across the sample. CORE-OM scores mediate the association between age of ASD diagnosis and

hours of therapeutic input required, with people diagnosed with ASD in adulthood expressing higher psychological distress and therefore being more likely to require a longer course of psychological therapy.

Conclusions: Our preliminary findings suggests that psychological therapy may be effective in reducing general distress for clients with ASC and comorbid mental health conditions and should be routinely offered, with appropriate adaptations made to make it accessible to this client group. Individuals who are diagnosed with ASD in adulthood are likely to require a longer course of therapy when their general distress scores are high.

Keywords: Autism Spectrum Conditions, Psychological Therapy, CORE-OM

Key Practitioner Message:

- Comorbid mental health conditions are common in adults on the autism spectrum but there is little evidence for what might be helpful in reducing rates of mental health conditions in this population.
- This study demonstrates that adapted psychological therapy offered in a specialist adult ASC service was somewhat effective in reducing distress for adults with autism.
- Individual characteristics and service factors did not influence the extent of change in general distress over the course of therapy; significant and comparable reductions in general distress from pre- to post-therapy were seen across the sample.
- Individuals who are diagnosed with ASD in adulthood are likely to require a longer course of therapy when their pre-therapy general distress scores are high.

- Adaptations that may need to be made to services and to therapy delivery are discussed.

Introduction

Autism Spectrum Conditions (ASC) are neurodevelopmental disorders marked by difficulties in social communication and rigid and repetitive thinking, which are estimated to affect up to 1% of the population (Brugha et al., 2016). Subsequent to the 2009 Autism Act (Parliament UK, 2009), there is an increasing awareness of the needs of people with ASCs, in particular their mental health needs.

High levels of psychiatric comorbidity have been well documented in people with an ASC, most commonly depression and anxiety disorders (Joshi et al., 2013; Hofvander et al., 2009). These are common mental health conditions in the general adult population, for which NICE recommends psychological therapy (usually Cognitive Behavioural Therapy; CBT) as a first line treatment in mild to moderate presentations (National Collaborating Centre for Mental Health, 2009; NICE, 2011).

Similarly, NICE guidance for adults with ASC suggests psychological interventions should be offered for comorbid mental health conditions, but not to treat core ASC features. Adaptations are suggested by NICE to meet the client's cognitive and social communication needs, when treating mental health conditions. These reflect adaptations to standardised CBT protocols, including for example an increased focus on behavioural rather than cognitive change, or use of visual supports within therapy (NICE, 2012).

A number of theoretical models which may underpin psychological intervention in people with ASC have been suggested, all of which tend to emphasise different ASC related difficulties in conceptualising the underlying problems. For example ASC has been conceptualised primarily as a disorder of information processing, leading to behavioural, social and daily living consequences, and so mental health problems

(Gaus, 2011). This implies that interventions should focus on developing skills to compensate for information processing difficulties, alongside traditional CBT based approaches to comorbid problems. An alternative perspective has been to view ASC as a disorder of emotion regulation, providing a trans-diagnostic approach to problems associated with ASC that may not conform clearly to diagnostic categories or where there are multiple comorbidities, as is common in this population (Weiss, 2014). This is based on observed emotion regulation deficits in young people with ASC (Mazefsky et al., 2013; Mazefsky & White, 2014) and suggests that interventions should focus on developing adaptive emotion regulation skills in order to reduce ASC related difficulties and comorbidities. Another trans-diagnostic approach posits intolerance of uncertainty as the primary driver of anxiety in ASC (Boulter, Freeston, South, & Rodgers, 2014; Rodgers et al., 2016), and therefore suggests that intervention should focus around developing the ability to cope with uncertainty. Both trans-diagnostic models emphasise the importance of including parents and other important social contacts, perhaps reflecting that they have been developed with children and young people (Rodgers et al., 2016; Weiss, 2014). In focusing more on adults, Gaus (2011) emphasises the role of others in therapy less, however all of these models have in common that they focus far more on skills development than may be seen in traditional CBT approaches. They are also somewhat different from the adapted versions of disorder specific treatment approaches suggested by NICE (2012), although thus far there is little evidence for any of these specific intervention models.

There is evidence of the efficacy of CBT for children and adolescents with ASC and comorbid anxiety problems in comparison to a waitlist control or treatment as usual, using both individual and group based approaches (Storch, Arnold, Lewin, & Nadeau, 2013; Wood et al., 2015; Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn,

2012). It is notable that these trials have mostly been conducted with children and adolescents who are relatively high functioning, and who have verbal skills sufficient to engage in CBT (Johnco & Storch, 2015). Adaptations are typically made to CBT protocols in trials with children and adolescents with ASC and comorbid anxiety or depression. Generally not all adaptations suggested by NICE are used in each trial, making it unclear what adaptations are most effective for what difficulties, although the most used modifications to standard CBT protocols are the use of visual aids and emotion recognition components to interventions (Walters, Loades, & Russell, 2016).

While the evidence for CBT for children and adolescents with ASC is relatively clear, in adults with ASC, research evidence for efficacy or effectiveness of CBT is more limited. Two recent reviews have highlighted the relative lack of evidence for psychological interventions for adults with ASC and comorbid mental health conditions (Binnie & Blainey, 2015; Spain, Sin, Chalder, Murphy, & Happé, 2015). Studies so far in specialist autism services have shown that CBT and anxiety management can be effective for anxiety disorders, including Obsessive Compulsive Disorder (Russell et al., 2013), and that mindfulness based approaches may show some promise (Kiep, Spek, & Hoeven, 2015).

The evidence that is available tentatively suggests that psychological therapy can be effective in treating adults with ASC and mental health conditions, (Binnie & Blainey, 2015; Spain et al., 2015). However, there is a lack of evidence of effectiveness in routine clinical practice, which can make it difficult for clinicians to judge the appropriateness of offering CBT or other psychological therapies to clients with ASC, and may explain why adults with ASC can report difficulties in accessing appropriate support for mental health needs (Griffith, Totsika, Nash, & Hastings, 2012).

This study sought to:

1. assess the effectiveness of routinely offered psychological therapy (most commonly CBT) in reducing psychological distress and;
2. explore the influence of individual characteristics and service factors for adults with ASC and a range of common mental health problems within a specialist tertiary service, using a self-report questionnaire outcome measure.

Method

Setting

The Adult Autism Psychological Therapies Service is a specialist tertiary service offering psychological assessment and intervention to adults with a diagnosis of ASC (confirmed by an appropriately qualified clinician using a gold standard assessment measure) and associated mental health problems, such as anxiety, depression or paranoia. Exclusion criteria are intellectual disability (i.e. an IQ below 70), substance misuse (unless this is being managed by appropriate services), moderate to high levels of risk of harm to self or others, and active psychosis.

Referrals come from a variety of sources, often from the linked adult ASC assessment service. Referrals are also received as clients age out of child and adolescent services, where they have previously been diagnosed with ASC.

The team is composed of Clinical Psychologists and CBT Therapists, who usually offer between 20 and 40 hours of CBT-based psychological therapy, adapted for the client's ASC related needs. Adaptations can be ASC specific, for example social skills work integrated into or in addition to the CBT intervention; or reflect the complex nature of some of the clients' difficulties. For example, it is common for people to present with

multiple mental health and social needs, and require liaison work with families, carers, and staff teams alongside individual therapy.

The primary intervention offered in the service is CBT adapted for ASC specific needs, based on a complex case formulation, following models including Gaus (2011). Adaptations used include increased treatment length (the standard package of treatment consists of 20 or more hours, in comparison to primary care interventions which consist of 6 to 12 hours of treatment); involvement of family members or other carers where appropriate (this occurs in less than 50% of clients seen); inclusion of written information and handouts to bridge sessions; and repetition to aid generalisation of skills learned. Social skills training is also offered in some cases (approximately 50%); this is part of broader skills training (including emotion recognition and regulation, and problem solving approaches) that is incorporated into adapted CBT. For those who present with neurodevelopmental comorbidities, in particular ADHD, specific approaches targeted at managing these conditions are incorporated (Young & Bramham, 2012).

The CORE-OM was routinely collected for adults who undertook psychological therapy in this Adult Autism Psychological Therapies Service based in a large mental health trust. Measures were completed as a minimum at the initial and final appointment, however where possible these were collected every ten sessions, allowing data to be included if clients dropped out prior to the end of the planned sessions. The CORE-OM is a generic measure of psychological distress and is used to capture the general difficulties that clients present with. It provides a measure that can be compared across the whole sample of adults presented here. There are no specific measures for adults with ASC that are appropriate to use in a routine clinical setting (e.g. due to client burden, the need for informants) and while disorder specific measures are used, the numbers of these available are too small for meaningful comparisons.

Data

The service evaluation was approved by the appropriate committee within this mental health Trust. The data was extracted for all recorded cases between January 2012 and June 2016, where patients had attended at least three psychological therapy sessions.

This study looked at the first session CORE score, the last session CORE score, the change in CORE score (from first to last COREs) and change category (reliable improvement, non-reliable improvement, non-reliable deterioration, and reliable deterioration). Referral letters, assessment and discharge reports and electronic clinical records were reviewed in order to extract written information regarding individual characteristics and service factors of interest.

Measures

Outcome measure: CORE-OM

The CORE-OM (Evans, John Mellor-Clark, Frank Mar, 2000) is a 34 item generic self-report measure of global distress (GD). The measure contains four domains: subjective well-being, commonly experienced problems or symptoms, social/life functioning, and risk to self and others. The measure is scored on a five-point scale ranging from 0 ('not at all') to 4 ('all the time') and can be pro-rated with up to 3 missing items.

The recommended clinical cut-off for the CORE GD is a clinical score of 10 (mean score of 1.0 times 10), with scores above this threshold considered to represent 'clinical caseness', identified from the distributions of a general population sample and a clinical sample (comprising primary and secondary care, as well as both outpatient and community settings). In order for a patient to exhibit reliable change over time there should be a CORE GD score change of at least 5, whilst clinical change is indicated by

a client moving from a mean CORE-OM GD score of one or greater, to a mean GD score of less than one (Connell et al., 2006; Evans et al., 2002).

Despite CORE not being validated specifically within the ASC population, it is designed as a pan-theoretical measure (Barkham et al., 2001) with good reliability and convergent validity with other measures used in psychiatric and psychological settings (Barkham, Gilbert, Connell, Marshall, & Twigg, 2005; Evans et al., 2002).

Individual characteristics

Individual difference variables that were extracted from all electronic records included attendance of therapy sessions (did the client attend all sessions offered or not), gender, whether ASD diagnosis was received in adulthood (aged 18 or over) or childhood (under the age of 18), the presence of co-morbid ADHD, depression or anxiety disorder and the nature of other presenting problems including aspects of personality disorder, anger, psychotic features.

Service Factors

The source of referral was extracted from referral letters and was categorised into GP referrals, referrals recommended by the national specialist ASD diagnostic service (Behavioural Genetics Clinic) and other referrals (clinical psychologists, psychiatrists, community teams). The funding structure of the APTS requires application for additional funding past 20 hours of therapy, as such data was extracted to indicate whether a client had received additional funding and attended more than 20 hours of therapy within the service.

Analysis

Statistical analyses were carried out using the Statistical Package for the Social Sciences (version 20). Box plots showed only moderate outliers and Q-plots were normal aside from the CORE-OM Risk subscale where this was expected. As such, as well as presenting descriptive statistics, the results from parametric mixed ANOVAs are outlined. A general linear model approach was chosen over an ANCOVA approach, as the aim of this study was to explore change and gains over therapy, rather than looking at the difference in means at post-therapy. It was only possible to analyse the influence of individual difference and service factors on significant change in mean CORE-OM scores, due to small sample sizes within sub-groups based on individual differences and service factors, meaning that data could not be analysed at the level of reliable or clinical change. Post hoc mediation analysis was completed to further explore key associations.

Sample

Of the 122 patients recorded as having started and ended psychological therapy between January 2012 and June 2016, 81 (66.4%) patients had complete records and form the study sample. Completeness of records has risen from 38.5% in 2012 to 83.3% in 2016. When comparing the study sample (81 clients) with those who did not have complete records (41 clients) no significant difference was found in terms of gender distribution ($\chi^2(1) = .067, p = .796$), ethnicity ($\chi^2(1) = 1.721, p = .190$), age ($t(120) = .108, p = .914$), or pre-therapy GD score ($t(97) = -1.045, p = -.298$), and full details can be seen in Table 1. Comparisons of diagnostic group between the study sample and those without complete records were not possible as more than 25% of cells contained a value less than 5. Nevertheless, it is important to be aware that this sample may not be entirely representative of all patients receiving psychological therapy.

Sample Characteristics

Within the study sample, the mean age at the start of psychological therapy was 30 years (SD: 10.64). There were 21 females (25.9%) and 60 males (74.1%), in line with the typical gender balance seen in this population (Fombonne, 2009). 59.3% were White/White British or Irish (48 patients), with the remaining 40.7% (33 patients) recorded as belonging to other ethnic groups.

The most common diagnosis of ASD was Asperger's syndrome (N=56; 69%), as illustrated in figure 1, and 77% (N=60) of individuals were diagnosed with ASD in adulthood (i.e. 18 years of age or older). 10% (N=8) of individuals had a diagnosis of co-occurring Attention Deficit Hyperactivity Disorder (ADHD). 80% (N=62) of individuals completed all sessions of therapy that were offered.

Extra funding was granted for over 20 hours of therapy for 37% (N=30) of the sample. 44% (N=35) of the sample were referred from their GP, 31% (N=25) were recommended referrals from the national specialist Behavioural Genetics Diagnostic service, and 25% (N=20) were referrals from other sources, including clinical psychologists, psychiatrists and community mental health teams.

The main presenting problems included mood and anxiety disorders, with anxiety disorders being most prevalent (50.6%, N=41) in line with research illustrating the high incidence of anxiety disorders in ASD (van Steensel, Bogels & Perrin, 2011); 13.6% (N=11) were diagnosed with depression, 22% (N=18) were diagnosed with co-morbid anxiety and mood disorders and 13.6% (N=11) of the sample had no diagnosed anxiety or mood disorder.

Other presenting problems included difficulties relating to psychotic experiences (7%, N=6), features of personality disorder (5%, N=4) and problems with anger and/or aggression (20%, N=16).

Results

Change in CORE-OM over time

Significant Change

Mean GD scores were significantly lower post-therapy (mean = 1.48, SD = .79) than pre-therapy (mean = 1.79, SD = .79) ($t(80) = 4.60$, $p < 0.001$, CI: 0.17-0.44), illustrating an average change of -0.31 in mean CORE-OM scores. This equates to an effect size of 0.39 (small) (Cohen, 1992).

Reliable Change

Of the patients who fell into the ‘clinical’ category at the start of therapy (i.e. met criteria for caseness on first session with a mean CORE-OM score ≥ 1 ; $N=65$), 75.4% improved from first to last session. Over a third of patients reliably improved (24 patients or 36.9%), with a reliable change defined as an increase or decrease in clinical score of 5.00 or more. Of the patients who improved, 38.5% (25 patients) did not experience a large enough change to be classified as reliable. A smaller proportion (26 patients or 24.6%) of patients experienced deterioration from first to last session, although only 4.6% reliably deteriorated. These results are summarised in Table 2 below.

Clinical Change

Of the individuals who met criteria for caseness on the ORE-OM at first session 18.5% ($N=12$) experienced clinical change, whilst 81.5% ($N=53$) did not show clinical change in general distress post-therapy.

Subscale analysis

There was a significant score decrease in all subscales (Wellbeing; $t(80) = 4.419$, $p < 0.001$, CI: 0.22-0.59, Problems/Symptoms; $t(80) = 4.318$, $p < 0.001$, CI: 0.21-0.56, and Functioning; $t(80) = 4.066$, $p < 0.001$, CI: 0.16-0.47) apart from the Risk subscale ($p = .091$). When excluding those where risk was not apparent at pre-therapy ($n = 50$) then the decrease in score became as statistically significant as the other subscales ($t(49) = 2.708$, $p < 0.001$, CI: 0.05-0.36). These results are summarised in Table 3.

Influence of Individual characteristics on Significant Change

The individual difference factors were found to have no effect on change in general distress (CORE-OM scores) over the course of therapy, illustrating psychological therapy is consistently effective for all clients with ASD, irrespective of their demographics, presenting problems and attendance¹.

The age that the individual was diagnosed with ASD did however influence overall levels of general distress, with those diagnosed in adulthood (aged 18 years or older) illustrating heightened levels of general distress compared to those diagnosed in childhood or adolescence (under the age of 18).

These results are summarised in Table 4 and depicted in Figure 2.

Influence of Service Factors on Significant Change

The service factors were found to have no effect on change in general distress (CORE-OM scores) over the course of therapy, illustrating psychological therapy is consistently effective for all clients with ASD, irrespective of the source of their referral into the service and for clients that require additional therapy sessions (>20

¹ Note that all clients included in the sample attended ≥ 3 sessions

hours). Requiring additional therapy sessions, over the standard 20 hours which is initially offered to clients, was however associated with heightened overall general distress compared to clients that did not require more than the standard 20 hours of therapeutic input. These results are summarised in Table 4 and depicted in Figure 2.

Age of diagnosis and number of therapy sessions required: Post-hoc analysis

As heightened general distress was present for clients who received their ASD diagnosis in adulthood, and for clients who required additional funding for more than 20 hours of psychological therapy, post-hoc logistic regression analysis was used to investigate the hypothesis that pre-therapy CORE-OM scores (general distress) mediates the effect of ASD diagnosis (childhood/adulthood) on duration of psychological therapy required ($\leq$ or $>$ 20 hours). The PROCESS macros was used to run the analysis (Hayes, 2012) and as recommended for small samples (Preacher & Hayes, 2004; Preacher, Rucker, & Hayes, 2007), bias-corrected bootstrapping analysis was used to test the indirect effect in the mediation analysis. Results based on bootstrap estimation with 10000 samples indicated that pre-therapy general distress scores (as measured on the CORE-OM) mediate the relationship between age of ASD diagnosis and duration of psychological therapy required ($\beta=.39$, $\text{BootSE}=.20$, $\text{BootLL}=.095$, $\text{BootUL}=.93$). As the bootstrapped 95% confidence interval for the indirect effect does not pass through 0, the indirect effects of each model are significantly different from zero at $p < .05$ (two tailed) (Preacher & Hayes, 2004; Preacher et al., 2007). The direct effect of age of ASD diagnosis on the number of therapy hours required, after controlling for pre-therapy general distress scores, was not statistically significant ($\beta=.22$, $\text{SE}=.60$, $z=.37$, $p=.71$, $\text{LL}=-.95$, $\text{UL}=1.40$). Pre-therapy scores are a significant mediator of the relationship between age of ASD diagnosis and number of hours of

psychological therapy required, with individuals diagnosed with ASD in adulthood likely to require >20 hours of therapy when their general distress scores are higher (Figure 3).

Discussion

This paper presents data on the effectiveness of psychological therapy in an Adult Autism Psychological Therapies service as measured by changes in the CORE-OM score and the individual difference and service factors which may influence changes in CORE-OM scores. The results provide preliminary evidence indicating that CBT based psychological therapy provided within a specialist service may be effective at reducing general psychological distress in adults with ASD and co-morbid mental health difficulties, in line with the findings of previous research in children (Weston, Hodgekins & Langdon, 2016) and adults (Spain, Sin, Chalder, Murphy & Happe, 2015).

Across the entire sample, there was a significant decrease in CORE-OM Global Distress score and in all subscales of the measure (where risk was apparent at pre-therapy). Over three-quarters of clients improved from first to last session, over a third improved reliably and only a small proportion (4.6%) reliably deteriorated. However, only 18.5% of clients showed clinically reliable reductions in general psychological distress and it is possible that this residual distress reflects the fact that ASD symptoms and associated difficulties can in themselves be related to stress and distress, due to their inherent impacts on everyday life (Hirvikoski & Blomqvist, 2015). Improvements in general psychological distress were independent of individual characteristics and service factors, showing that the outcomes of psychological therapy for adults with ASD are not affected by gender, whether ASD diagnosis was received in adulthood (aged 18 or over) or childhood (under the age of 18), the presence of co-morbid depression or anxiety disorders, anger problems, whether the client attended all sessions offered or not, the source of referral or requiring additional funding for more than 20 hours of psychological therapy.

Exploratory post-hoc analysis illustrated that pre-therapy general distress mediates the relationship between age of diagnosis (childhood/adulthood) and requiring additional funding for more than 20 hours of psychological therapy, with individuals who are diagnosed with ASD in adulthood more likely to require more hours of therapy when their general distress scores are higher. It is possible that being diagnosed with ASD later in life increases an individual's level of general distress as they do not have a framework by which to conceptualise and understand the challenges and difficulties they experience with social interactions, communication and idiosyncrasies of their behaviour. A lack of diagnosis earlier in life would also mean no or limited access to ASD support services at school and in their community and therefore opportunities to learn helpful coping strategies. As a result a greater number of psychological therapy sessions are required to ameliorate this distress. These results imply that additional health service funding should be provided for over 20 hours of psychological therapy input for individuals who were diagnosed with ASC in adulthood and have a high level of general distress.

These results provide a useful addition to the evidence base so far, which has tentatively shown support for psychological therapies for comorbid mental health problems in people with ASC (Binnie & Blainey, 2015; Spain et al., 2015). Generally this published evidence has focused on interventions targeted at specific comorbid mental health problems (e.g. OCD; (Russell et al., 2013)), or has taken a specific approach (e.g. CBT (Spain et al., 2015); mindfulness (Spek, van Ham, & Nyklíček, 2013)). While the data presented here do not demonstrate changes in specific problems, it does suggest that in general CBT based approaches are helpful in ameliorating distress for adults with ASC, perhaps providing some support for non disorder specific or trans-diagnostic approaches (Gaus, 2011; Rodgers et al., 2016; Weiss, 2014).

This is the first paper to consider the effectiveness of psychological interventions in the general population of people with ASC and mental health needs and as such adds to the evidence base by demonstrating effectiveness in routine practice as well as in trials, albeit in a specialist service where all interventions are routinely adapted to the needs of adults with ASC. Adults with ASC experience higher rates of mental health difficulties than the general population (Hofvander et al., 2009; Joshi et al., 2013), and yet often find it very difficult to access mainstream or specialist mental health services (National Development Team for Inclusion, 2012). This may be due to diagnostic overshadowing, whereby mental health needs are attributed to the person's ASC diagnosis and thus considered untreatable. Alternatively, a lack of understanding of and training in working with people with ASC (Dillenburger, McKerr, Jordan, & Keenan, 2016) and an associated lack of confidence in working with this population may contribute to psychological therapy not being routinely offered. Therefore these results suggest that specialist services for adults with ASC are able to provide psychological therapy that reduces self-reported general distress, and so imply that psychological therapy should be offered to this population, although whether therapy should be provided in specialist or mainstream services is not yet clear.

Outcome measurement in ASC

There are however specific difficulties with using outcome measures with this population. Alexithymia, or difficulty understanding internal states such as thoughts or feelings, is well documented among people with ASC (Bird & Cook, 2013; Budd & Hughes, 2009). Problems in recognising or understanding internal states may lead to difficulties in reporting these, therefore potentially leading to under-reporting of symptoms. This may result in an apparent increase in CORE-OM scores over time as clients engage in therapeutic work to help them begin to understand their emotions,

leading to more accurate reporting at a later point. Based on the data above, this may account for at least some of the approximately 25% of clients who showed deterioration.

Social and communication problems are the core features of ASC, and again these can impact on questionnaire answers (Berthoz & Hill, 2005; Mazefsky, Kao, & Oswald, 2011). While the CORE-OM is a relatively brief measure, and so should be quick to complete, it relies upon the client being able to understand the at times vague language used. For example someone with ASC may struggle to understand what it means to ‘be able to put my problems to one side’, potentially viewing this in a concrete or literal way. Rigidity of thinking is another core aspect of ASC, and this can lead to further problems in completing questionnaires, with clients finding it difficult to know exactly how frequent ‘sometimes’ is, and how this compares to ‘often’. At times this leads to non-completion of measures; it may also significantly affect the utility of the clinical information provided, as a client scores highly on measures (due to misunderstanding the questions) incongruent with self-report or observational data. This has been a difficulty in previous studies of the utility of psychological therapy with adults with ASC, which has been resolved in a number of ways including using multiple measures and a range of clinician/observer measures alongside self-report (Russell et al., 2013). In the present study, it was not possible to correlate observational data with CORE scores.

Unfortunately, as yet there are no generic self-report measures that have either been normed for adults with ASC, or developed specifically for this population, although there are measures in development. It is hard to ascertain what alternatives would be useful, given the twin difficulties of alexithymia and difficulties with the language often used in mental health services. Observational or clinician rated measures are likely to encounter similar problems given that people with ASC and mental health problems do

not generally present in the same way as their neurotypical peers, for example affect may be flat at all times and so it is hard to clarify if this represents depression or simply a lack of expressiveness.

Limitations

The data presented above provides practice based evidence (Barkham et al., 2001) to support the effectiveness of psychological therapy for people with ASC in routine practice in a specialist service. As with all practice-based evidence, there are some limitations in that there is no validation that a protocol has been clearly followed; however unlike with many common mental health conditions (e.g. OCD (Whittal & McLean, 1999); social anxiety (Clark & Wells, 1995); depression (Beck, 1979)), there is currently no clear evidence base for any specific protocol in working with adults with ASC. The NICE guidance (NICE, 2012) that is available is largely based on extrapolation from work with children or adults with intellectual disability (ID). This extrapolation may not be justifiable given that adults with ASC are more cognitively able although may present with specific cognitive differences (Wilson et al., 2014) which may impact on how therapy should be adapted. Adults with ASC without ID are also much less likely to have a supportive network, (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013) meaning that adaptations such as including family members or carers in treatment are often irrelevant.

Another limitation of this work is a lack of comparison group, meaning it is not possible to demonstrate that changes seen in CORE-OM scores are due to the interventions offered and not simply due to changes over time or other contextual factors. While this seems unlikely, given the high rates of mental health problems seen in adults with ASC

(Hofvander et al, 2009), nevertheless any conclusions that can be drawn about effectiveness are necessarily limited by this possibility.

While generally interventions within the service are CBT based, adherence to any specific therapy was not strictly monitored for this study. The service is composed of Clinical Psychologists and CBT therapists, all of who have some CBT training, and utilise aspects of CBT in their therapeutic work. However both the lack of a specific protocol and the multiple needs clients present with, which may require, for example systemic or family work, mean that it is not possible to conclude that any specific intervention is effective for adults with ASC and comorbid mental health needs.

It was beyond the scope of this study to assess maintenance of any gains made through therapy. Generalising therapeutic work to everyday life is often a challenge for clients with ASC (Spain et al., 2015) and without follow up measures, it is impossible to know whether any improvements were lasting.

The specialist nature of the service in which this data was collected leads to particular difficulties with generalisability, as it is not clear that the effectiveness of therapy here would be applicable elsewhere. Comparing the effectiveness of therapy in specialist and non-specialist services is an area for further research, as the Autism Act (2009) states that mainstream services should offer adapted approaches for people with ASC.

The CORE measures cover general distress; it is not intended to be able to detect disorder-specific distress. Therefore, it is still possible for a client with a reasonably low CORE score for "general distress" to be experiencing distress in particular areas which cannot be pinpointed by the CORE.

The existence of possible floor or ceiling effects of the CORE-OM have previously been highlighted (Shepherd et al., 2005), for example patients with high scores on the scale can only improve and the reverse is the case for patients attaining the lowest scores.

It is also important to note that there are an unknown number of unmeasured contextual variables which may impact on the outcome of psychological therapy, and therefore valid reasons why change may or may not occur following therapy, outside the effectiveness of the clinician or therapy.

Clinical Implications

This paper suggests that psychological therapy is effective for adults with ASC and comorbid mental health conditions in routine clinical practice in a specialist ASC service. This suggests that clients who present to mental health services can and should be offered access to psychological therapy as appropriate to their condition and in accordance with NICE guidelines (NICE, 2012), although it is unclear whether specialist or mainstream services should offer this input. The results of post-hoc analysis suggest that individuals who have received their ASD diagnosis later in life (≥ 18 years of age) may require a greater number of psychological therapy sessions, specifically more than 20 hours in total, because they experience heightened levels of general distress. It may be helpful for clinicians to consider the possible sources of distress associated with receiving an ASD diagnosis in adulthood, be that related to post-diagnosis adjustment or a carry-over from not having a framework within which to understand the difficulties they experienced during childhood and adolescence (pre-diagnostic distress). Exploring such avenues could inform formulation of the clients presenting problems and possible targets for psychological therapy.

There are some implications for services offering psychological therapy to clients with ASC. The service in which this work was completed provides specialist interventions, and a major difference between this intervention and standard practice for mild to moderate mental health conditions is the length of time taken to work with clients (usually between 20 and 40 hours). This implies that people with a comorbid ASC diagnosis should be offered longer interventions to enable them to make use of this work and services should be mindful of the influence of age of ASD diagnosis on distress when considering how many sessions to offer clients. Similarly, clients in this service are often involved with secondary care mental health or social care services, and while liaison work was not recorded for this study, routine practice frequently includes engagement with the client's wider network, which may have influenced any changes made.

To enable these adaptations to be made for specific clients with ASC, service design needs to be carefully considered. While the Autism Act and Strategy in England state that mainstream services should make themselves accessible for people with neurodevelopmental differences (Parliament UK, 2009), in order to do so, services may need to work in ways that challenges resources (such as offering more sessions than usual), or are unusual for an adult psychological therapy service (for example in an primary care mental health service it would be rare to include family members in a treatment session). This can pose challenges for individual staff in relation to training needs, for managers attempting to provide a service within budgetary constraints and for commissioners attempting to commission service that appropriately meet the needs of the population, of which those with ASC constitute a significant minority. Training is also required to support clinicians in feeling able to offer appropriate interventions.

Research Implications

This research adds to the current small evidence base for psychological therapy for adults with ASC. There are a number of implications for further research.

Comparison between specialist and mainstream service outcomes with adults with ASC would be of use, in order to understand whether mainstream services are able to effectively adapt psychological therapy approaches to adults with ASC. This would also inform service design by enabling decisions to be made about whether or not to develop specialist services.

As NICE guidance is largely extrapolated from children with ASC and adults with ID, it would be helpful for future studies to explore the adaptations for adults with ASC that are most appropriate as there is limited evidence for these thus far (Walters et al., 2016). For example focusing primarily on behavioural change may not be effective for someone experiencing problematic worry or rumination, and for those with significant alexithymia, mindfulness approaches to increase self-awareness may be the most appropriate starting point (Spek et al., 2013).

The impact of alexithymia on outcomes should be further explored, along with the possibility of this being amenable to change through psychological intervention. Furthermore, based on the findings of the current study, research is needed to explore whether being diagnosed with ASD in adulthood has wider impacts on adjustment, psychiatric disorders and social and environmental outcomes, and the mechanisms of action in any such associations. It would also be useful for services to routinely collect additional measures of client specific presenting problems so as to ascertain whether reductions in psychological distress are associated with improvements in the client-specific symptom burden and to explore the effectiveness of CBT in treating different

co-morbidities for people with ASD; however larger sample sizes will be required for such analysis.

While generally CBT is the intervention with the greatest evidence base, alternative forms of psychotherapy could be explored for people with ASC, enabling parity of choice with those who have mental health problems but do not have a neurodevelopmental disorder. Finally, an appropriate way to measure therapeutic change for people with ASC is also required, given the problems with self-report measures described above.

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Additional data

Table 1. Comparison demographics for clients with and without paired outcome measure

	Paired Outcomes		Non-paired Outcomes	
	(81)		(41)	
	n	%	N	%
Gender				
Female	21	25.9%	9	22.0%
Male	60	74.1%	32	78.0%
Ethnicity				
White British/Irish	48	59.3%	30	73.2%
Other ethnic background	33	40.7%	11	26.8%
ASD Diagnosis				
F84.0 – Childhood Autism	6	7.4%	4	9.8%
F84.1 – Atypical Autism	7	8.6%	3	7.3%
F84.5 – Asperger Syndrome	56	69.1%	23	56.1%
F84.9 – Pervasive Developmental Disorder	3	3.7%	4	9.8%
Autism Spectrum Disorder	2	2.5%	3	7.3%
High Functioning Autism	4	4.9%	2	4.9%
Diagnosis not specified	3	3.8%	2	4.9%
Pre-therapy Score	Mean: 1.79, SD: .792		Mean: 1.56, SD: .939	
Age	Mean: 30.07 years, SD:10.64		Mean: 30.29 years, SD: 10.38	

Table 2. Clinical and reliable change results

Clinical Change	
Clinical to non-clinical	18.5%
Remain clinical	81.5%
Reliable Change	
Reliable improvement	36.9%
Non-reliable improvement	38.5%
Non-reliable deterioration	20.0%
Reliable deterioration	4.6%

Table 3. Means and Standard Deviations for total score change and each subscale for both pre- and post-therapy.

	n	Pre-therapy Score Mean (SD)	Post-therapy Score Mean (SD)
Total Score	81	1.79 (0.79)	1.48 (0.79)
Wellbeing Subscale	81	2.14 (1.04)	1.73 (1.03)
Problems/Symptoms Subscale	81	2.15 (0.95)	1.76 (0.79)
Functioning Subscale	81	1.99 (0.85)	1.68 (0.83)
Risk Subscale	50*	0.79 (0.56)	0.58 (0.63)
*this analysis excludes those clients where risk was not apparent at pre-therapy (31 clients)			

Table 4.

Influence of individual characteristics and service factors on change in CORE-OM over therapy.

Measure		Mean CORE-OM	Standard Deviation	Effectiveness (Time)	Group differences	Group differences in effectiveness
Child/Adult Dx	<i><18 years</i>	Pre= 1.41, Post=1.11	Pre= .58, Post=.69	F (1,76) = 15.25 * $\eta^2 = .17$	F (1,76) = 5.72 * $\eta^2 = .07$	F (1,76)=.082 $\eta^2 = .001$
	<i>≥18 years</i>	Pre=1.88 , Post=1.54	Pre=.82, Post=.79			
Gender	<i>Female</i>	Pre=1.70, Post=1.36	Pre=.83, Post=.79	F (1,78) = 17.13 * $\eta^2 = .18$	F (1,78) = .47 $\eta^2 = .006$	F (1,78) = .81 $\eta^2 = .001$
	<i>Male</i>	Pre=1.81, Post=1.51	Pre=.79, Post=.79			
Anxiety/Depression	<i>Anxiety</i>	Pre= 1.75, Post=1.47	Pre= .84, Post=.82	F (1,77) = 19.46 * $\eta^2 = .20$	F (3,77) = .06 $\eta^2 = .002$	F (3,77) = .75 $\eta^2 = .03$
	<i>Depression</i>	Pre= 1.92, Post=1.37	Pre= .74, Post=.82			
	<i>Mixed</i>	Pre= 1.75, Post=1.54	Pre= .78, Post=.77			
	<i>Neither</i>	Pre= 1.88, Post=1.55	Pre= .73, Post=.83			
Anger	<i>Anger</i>	Pre= 2.04, Post=1.81	Pre= .90, Post=.75	F (1,79) = 10.94 * $\eta^2 = .12$	F (1,79) = 3.18 † $\eta^2 = .04$	F (1,79) = .32 $\eta^2 = .004$
	<i>No Anger</i>	Pre= 1.73, Post=1.4	Pre= .76, Post=.79			
Attendance	<i>Full</i>	Pre= 1.72, Post=1.42	Pre= .79, Post=.79	F (1,76) = 18.84 * $\eta^2 = .20$	F (1,76) = 3.31 † $\eta^2 = .04$	F (1,76) = .39 $\eta^2 = .01$
	<i>Incomplete</i>	Pre= 2.16, Post=1.72	Pre= .73, Post=.84			
> or < 20 Sessions	<i>< 20</i>	Pre= 1.65, Post=1.38	Pre= .79, Post=.82	F (1,77) = 22.48 * $\eta^2 = .23$	F (1,77) = 4.49 * $\eta^2 = .06$	F (1,77) = .93 $\eta^2 = .01$
	<i>>20</i>	Pre= 2.07, Post=1.67	Pre= .72, Post=.71			
Referral source	<i>GP</i>	Pre= 1.74, Post=1.42	Pre= .85, Post=.86	F (1,77) = 20 * $\eta^2 = .21$	F (2,77) = .12 $\eta^2 = .003$	F (2,77) = .004 $\eta^2 < .001$
	<i>BGC</i>	Pre= 1.83, Post=1.51	Pre= .72, Post=.72			
	<i>Other</i>	Pre= 1.81, Post=1.50	Pre= .82, Post=.80			

*p<0.05; † p<0.01

Figure 1: Distribution of Autism Spectrum Disorders diagnosis across the study sample.

Child or Adult ASD Diagnosis*

Gender

Anxiety/Depression

Figure 2. Mean CORE-OM scores over time, by individual characteristics and service factors.

Note: * group differences $p < .05$.

Figure 3: Standardised regression coefficients for the relationship between age of ASD diagnosis (childhood/adulthood) and number of hours of psychological therapy required ($\leq$ or > 20 hours) as mediated by pre-therapy general distress scores. Note: Adult ASD diagnosis coded 1, > 20 hours of therapy coded 1. * $p < .05$.