The lived experiences of practitioner’s facilitation of and adults with high-functioning autism spectrum disorder (HFASD) undergoing psychological therapies.

By
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Statement of Anonymity

To ensure the confidentiality and anonymity of all clients, supervisors and research participants, all potentially identifying information has either been omitted or replaced with pseudonyms throughout this portfolio.
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Preface

A literature review was carried out to examine what is currently available in terms of theories, literature, and research regarding practitioners who have worked therapeutically with both children and adults with autism spectrum disorder (ASD) and regarding this client group undergoing psychological therapies. It was deemed necessary to include both children and adults as well as both clients with diagnoses of ASD and high-functioning autism spectrum disorder (HFASD) due to the scarcity of research obtainable. Questions raised and indication of research paucity helped form the research questions for the following two investigations. The second year research project investigated the lived experience of practitioners who have worked with adults with HFASD and the third year research project investigated the lived experience of adults with HFASD who had undergone or are undergoing psychological therapies. Both research projects utilised qualitative research methods.
Introduction to the Research Dossier

The research dossier includes my literature review, my second year research and my third year research. Throughout the three years on this course, I have been investigating what the experience is for adults with high-functioning autism spectrum disorder (HFASD) who have undergone psychological therapies. I chose this particular subject as I have family members who have been diagnosed with Asperger’s Syndrome and have undergone psychological therapies but I noticed that there was not a lot of research nor teaching around this subject. This made me curious, especially as I also had two clients in my first year placement with autism and I spoke to qualified practitioners who showed a reluctance to work with this client group or said that this client group were incapable of undergoing psychological therapies.

My first year literature review first looked at what research is currently available in the field and brought up interesting potential research questions. In my second year, I wished to pursue how practitioner’s made sense of working with this client group and then in my third year, to investigate how adults with HFASD made sense of their experience of undergoing therapy. I wanted to tie together both sides of the therapeutic experience – the practitioner and the client. The overall aim and objective of this research was to help understand what it is currently like facilitating and undergoing psychological therapies (with and for this client group) within this country to give an insight and information to current practitioners, trainees, and lecturers/trainers. To see if there are things that are particularly effective or particularly unsuccessful, so that we may all learn from the participant’s experiences and alter or adapt how practitioners are working or what choices are open for the client group.

As a reflective scientist practitioner, I appreciate the opportunity to utilise all four pillars of counselling psychology (academic, clinical, research and, personal and professional development). It is very important to not only undertake research as a counselling psychologist in order to understand how it is carried out and to be critical of it, but to also be up-to-date with current research so that we are always evolving and learning as practitioners. This is to ensure we stay ethical and knowledgeable in our interventions and dealings with others in this profession. It may also be that in our future professions we are asked to or wish to undertake research to help understand certain client groups or evaluate current services. It stands well in
our stead to be armed with the ability to carry out and evaluate research to help promote change within our own organisations.
Working therapeutically with adults with high-functioning autism and Asperger’s syndrome: A literature review

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Abstract
This article reviews studies investigating working therapeutically with adults with high-functioning autism and Asperger’s Syndrome. Due to core autistic symptoms, psychiatric co-morbidity and problems of an everyday nature, individuals from this population may require professional support. They may seek or are offered a talking therapy to help with these problems and difficulties. Particular emphasis is placed on research into using psychodynamic, cognitive-behavioural and other counselling therapies with this population. A critical analysis of empirical data is presented. Findings indicate that: case studies and control trials (including RCTs) are mainly used to measure efficacy of therapy with this population; psychodynamic, cognitive-behavioural, mindfulness-based and multimodal therapy are currently represented in the literature; and limitation’s to methodology and considerations/implications for practice are discussed. Personal reflections of a counselling psychologist in training are included in brackets.

Keywords
Autism; Asperger’s syndrome; high-functioning; psychotherapy; cognitive-behavioural therapy; counselling; adults; review.

Introduction

Research into both counselling and therapy has grown and developed over the last five decades and has been gaining strength in recent years due to an emphasis on more rigorous analysis of methodology and theory. This has been shown by the vast amount of research that is done using evidence based approaches such as randomised-control trials
(RCTs) but there are also many other forms of research that has contributed to our knowledge such as case studies and qualitative studies (Kazdin, 2008).

However, it appears that research into adults with high-functioning autism (HFA) or Asperger’s syndrome (AS) using forms of counselling or psychotherapy is highly lacking. Some research has been carried out using children and adolescents but research looking at adults from this population is even scarcer. Considering there is limited research available currently, it is important to look at why it is an interesting and important subject to investigate and if further research is required and thus, it is part of this review to include information from research with children and adolescents as we must use whatever we have available to us. Children, adolescents and adults with HFA and AS report having difficulties and problems due to their developmental disorder such as impairment in social interaction, communication and presence of stereotyped behaviour and restricted interests (American Psychiatric Association, 2000) as well as a co-morbidity of depression and anxiety with a higher prevalence than other populations (Gaus, 2004). They also face the same problems as the rest of the population such as bereavement, divorce, loss of job, as well as other problems and difficulties. Keeping these factors in mind, it would seem only natural that they may require help and support from practitioners. They are vulnerable due to the nature of their disorder as well as having a prevalence of co-morbid mental health problems. If this were to be ignored by the professional community, then that would be showing inequality towards these individuals.

This review will be investigating and discussing what it is like to work therapeutically with these individuals and how this may be achieved whilst taking into account the difficulties that can be present due to their disorder such as communication problems and high levels of anxiety. Research that is currently available will be discussed in terms of their limitations and critically evaluated to see if there is any information that can be drawn down from it so that we may be able to form a cohesive standpoint that may inform the practice of counsellors and therapists who wish to or are already working with adults from this population. The information drawn from research which is presented below encompasses studies using children, adolescents and adults with HFA and AS due to the limited amount of information available. It may prove to be useful and we may be able to utilise what has been learnt from this research, however, clear distinction between these will be made. I have chosen to look at research into individuals with HFA and AS as the majority of the research uses this population and also because it appears that they are more likely to be able to utilise talking therapies due to their higher ability of communication.
The purpose of the present article is to review the empirical evidence and address the following questions:

1) What types of studies have been done into working therapeutically with people with HFA/AS?
2) What are the limitations of the research into working therapeutically with people with HFA/AS?
3) What implications for clinical practice or considerations are apparent when working therapeutically with people with HFA/AS?
4) What is the gap in the research into working therapeutically with people with HFA/AS and what can be suggested for the future?

[I have had a long standing interest and association with both children and adults with autism spectrum disorder (ASD) as I have family members with Asperger’s syndrome and have worked extensively in educational settings with children, adolescents and adults with ASD. One could say that I have a special place in my heart for individuals from this population as I have witnessed and help support them with their own personal problems, difficulties and issues. It came to my attention that the adults in my family who have Asperger’s syndrome have both had psychotherapy and found it incredibly beneficial to them. This got me thinking about the reasons why they seek help and how their therapist was able to work effectively with them. Both of my family members reported feeling like they were not “normal” compared to the rest of society, feeling anxious in certain social situations, and finding things harder than they felt they should be for an adult in their circumstances. This precipitated help-seeking behaviour such as speaking to a GP and seeking psychotherapeutic help. They felt that the empathy and non-judgment they received was a big step towards accepting their difficulties and realising that they have these problems due to their disorder and that they could learn to cope with situations in a positive manner as they understood them better than before. It also helped them in their marital and social relationships as well. I found this very interesting as I have also had clients in my current placement with different forms of ASD and have found several challenges and considerations come up that I have not experienced with other individuals without ASD. I felt it would be interesting and important to find out more about working with these individuals, the kinds of problems they present in therapy, how to work with them, the challenges and considerations they put forth and also what it is like for them to work with counsellors and therapists.]
High-functioning autism, Asperger’s syndrome and mental health

Individuals with HFA have average or above-average IQ (Baron-Cohen, 2002) and individuals with Asperger’s syndrome have normal language development but share the characteristics of autism in terms of impairment in social interaction and having repetitive and stereotypic patterns of behaviours (Ghaziuddin and Mountain-Kimchi, 2004). However, no clear distinction between HFA and AS can currently be made (Meyer & Minshew, 2002).

The prevalence of autism spectrum disorder (ASD) in children is currently estimated at 1 in 100 but no prevalence studies have been carried out on adults, but it is estimated that more than 650,000 people in the UK live with ASD (The National Autistic Society, 2013). However, the NHS released a report in 2012 stating that the prevalence rate of ASD in adults in England is 1.1% (NHS, 2012). This appear to be fairly high numbers of children and adults living with this disorder in the UK and it would be logical to assume that some people in this population seek help and support from professionals. The information in terms of how many people who have been diagnosed is limited and there is also the possibility that many children and adults may have a form of autism but it has not be diagnosed yet or ever will be as they may not fit into the criteria currently being used by the DSM-IV-TR and the ICD-10 especially as there appears to be a large amount of controversy over the precise way to define ASD (Gaus, 2004). If there is no agreement over diagnostic criteria, it will be difficult to produce clear prevalence studies and it will be more difficult to diagnose people who do not quite fit the criteria. According to the BACP (2013), it is very difficult to have a definitive figure for people attending psychotherapy and counselling in general and there are no figures indicating how many people with any form of autism seeking and utilising these services. There is also evidence that individuals with ASD are likely to be underrepresented in psychotherapy services (Royal College of Psychiatrists, 2004). It is a limitation that the professional community do not have enough information about individuals from different populations possibly seeking their services and how great the need is for their services. This would be something that it would be beneficial to investigate to see what the figures are truly like.

Levitan and Reiss (1983) have spoken about ‘diagnostic overshadowing’ in which a primary diagnosis can over shadow or mask the presence of secondary problems of a psychiatric nature such as depression and anxiety. This can make it difficult for people to realise that they may have other problems on top of their diagnosis but it can make it more difficult for professionals to be vigilant. It is well reported that individuals with HFA and AS
suffer from co-morbid psychiatric problems even though estimates vary greatly from 4-81% (Levy & Perry, 2011). Problems such as depression (Ghaziuddin, Ghaziuddin & Greden, 2002; Stewart, Barnard, Pearson, Hasan, & O’Brien, 2006; Sterling, Dawson, Estes, & Greenson, 2007), anxiety (Bellini, 2004; Gillot & Standen, 2007), ADHD and OCD (Klin & Volkmar, 1997) are very common. There is also evidence to show that these individuals have difficulties such as social skills deficits (Bellini, 2004), with romantic relationships (Aston, 2012) and emotional problems such as a feeling of alienation, sense of frustration, depression as a central emotion, and a pervasive sense of fear and apprehension (Jones, Zahl & Huws, 2001). They have also reported that their quality of life is highly related to support characteristics such as effective professional support and supportive social networks (Renty & Roeyers, 2006).

It appears to suggest that individuals with HFA and AS do have mental health problems, difficulties that the rest of the population may have, as well as problems that come as part of their disorder and all these may need to be addressed and support given by the professional community. Nonetheless, there is not a vast amount of research into these difficulties, the samples tend to be fairly small and there are many varied studies using children, adolescents, adults and with different forms of ASD. This can make it difficult to generalise across the population especially as each person’s developmental disorder manifests in unique and highly varied ways. However, it would be negligent to ignore such results as it does appear to show that there are very real problems that need to be looked at and appropriate support made available.

Looking at forms of therapy and support in a historical context, there seems to be a large emphasis on treatment of ‘behaviour problems’ such as tantrums and disruptive behaviour that rely heavily on pharmacology to control these behaviours or to utilise non-pharmacological approaches for ‘behaviour modification’ such as Applied Behavioural Analysis (Alford & Locke, 1984) during the last century. “Talking therapies” were not offered to people with developmental disorders during the 1950’s to 1980’s as they were deemed inappropriate (Gaus, 2004). It appears that there is a complete lack at looking at the individual as a whole human being with thoughts, feelings and desires who deserve to gain help and support with their difficulties.

[The problems described above such as depression and anxiety have presented themselves in the consulting room across all the clients that I have seen this past year and I am sure that these symptoms and problems will be present in future clients I will be seeing. I believe it to
be very important to pay attention to the above research to help inform us about why a client with ASD may seek out our help and to be aware of the current research as well as vigilant of other symptoms and problems that we may become aware of in practice so that we can inform our fellow practitioners and inform future research and practice.

**Psychodynamic therapy and high-functioning autism and Asperger’s syndrome**

Psychodynamic therapy includes psychoanalysis, as well as object relations frameworks and a more relational approach to working with clients (Rizq, 2010). It involves looking at the client’s individual relational environment, the therapist’s use of countertransference as indicative of the client’s internal world, and the importance and centrality of the therapeutic relationship.

Bettelheim (Gerland & Sainsbury, 1999) believed that autism was caused by rejecting mothers and Mahler (2009; Shapiro, 2000) believed that autistic children were unable to utilise the “mothering principle”; that is using the mother and gaining feelings of separateness to help understand stimuli and the environment. Both these assumptions are suggesting that it is an outside factor causing their disorder but this idea has been rejected and a more biological view has been accepted (Gerland & Sainsbury, 1999). Both Bettelheim and Mahler are of a psychoanalytic persuasion and Mahler was the first person to carry out psychotherapy with autistic children and included their mothers in a dyadic or triadic treatment (Shapiro, 2009). Nonetheless, classic analytic interpretations of dynamics/genetics are said to leave Asperger’s patient’s feeling like the therapist is trying to force upon an alien system of understanding on them and that they have completely misunderstood them (Rhode, 2004). It has been reported by many researchers that classic psychoanalytic therapy is ineffective and/or deleterious for children with Asperger’s (Fitzgerald & Bellgrove, 2006; Ghaziuddin, 2005; Ruderman, 2002). This is shown through Gerland (2003) and Gerland and Sainsbury (1999) who both have had psychodynamic therapy and have described a first-hand experience that left them feeling misunderstood and that the therapy was not only useless but can in some cases even be harmful. It felt like the exchange was a monologue only based on the analyst and barely brushed the phenomenology of the client. They also criticised Anne Alvarez’s (1992) work *Live Company* which described working psychoanalytically with an autistic boy called Robbie who received 24 years of treatment. They believed that her claim that he showed positive progress due to his treatment and the efficacy of psychoanalysis was therefore guaranteed, was both flawed and presumptuous. Many factors throughout the 24
years may have contributed to his progress and he is only one case study, one cannot claim effectiveness from this one instance. Only one study has been found that discusses psychoanalytic treatment and explanations of dysfunction in children with autism; Haag et al. (2005) describes how a child will after the initial stage of “severe autism”, go through stages of ‘recovery of skin’, the established “symbiotic phase”, subdivided into ‘vertical then horizontal splitting of the body ego’; and finally the stage of ‘individuation’. These explanations are wordy, confusing and appear to be meaningful only to classic psychoanalysts. It would be difficult to draw any concrete knowledge of working with this population for professionals working in different settings and of different modalities especially as it appears that the authors are “fitting” symptoms into their established theories and not basing their knowledge on tangible evidence. It is reported that psychoanalytic and psychodynamic therapies are not well studied and there is limited data on efficacy (Chalfant, Rappee, & Carroll, 2007; Kestenbaum, 2008).

Case studies are the most utilised forms of research when working psychodynamically with these individuals. These are both shown in articles as well as in manuals of how to do psychotherapy with people with AS (Jacobsen, 2003).

<table>
<thead>
<tr>
<th>Authors</th>
<th>Case study</th>
<th>Sex</th>
<th>Age</th>
<th>Autism</th>
<th>Type of therapy</th>
<th>Presenting difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mero (2002)</td>
<td>Leo</td>
<td>M</td>
<td>7</td>
<td>Asperger's Syndrome</td>
<td>Psychodynamic play therapy</td>
<td>Emotional disorder and anxiety</td>
</tr>
<tr>
<td>Levy (2011)</td>
<td>Brendan</td>
<td>M</td>
<td>11</td>
<td>Asperger's Syndrome</td>
<td>Psychodynamic play therapy</td>
<td>Anger, anxiety and social</td>
</tr>
<tr>
<td>Topel &amp; Lachman (2011)</td>
<td>Carl</td>
<td>M</td>
<td>8</td>
<td>Asperger's Syndrome</td>
<td>Psychodynamic play therapy</td>
<td>Emotional, social &amp; anxiety</td>
</tr>
<tr>
<td>Topel &amp; Lachman (2011)</td>
<td>Sam</td>
<td>M</td>
<td>42</td>
<td>Asperger's Syndrome</td>
<td>Psychodynamic therapy</td>
<td>Felt something was &quot;missing&quot;, social</td>
</tr>
<tr>
<td>Sugarman (2011)</td>
<td>Spock</td>
<td>M</td>
<td>25</td>
<td>Asperger's Syndrome</td>
<td>Psychodynamic therapy</td>
<td>Sadness due to rejection from friend</td>
</tr>
</tbody>
</table>

Figure 1. Showing case studies using psychodynamic therapy with children and adults with Asperger’s syndrome.
When looking at case studies involving children (shown in Figure 1.) the psychotherapists utilise play therapy. There are commonalities across these studies in the importance put on the relationship between the client and therapist, how the children engage in play – usually in an aggressive manner where they wish to “destroy” the therapist in the games; they enact scenarios of violence and aggression, and in how the therapist uses self-object experiences to facilitate the therapy. All interpretations, if any, are given in the context of play. These are very typical examples of this type of research in that it is based on one therapist working with one child and they all report that the children’s symptomology in separation-anxiety, social skills deficits, physical reactions and depression had decreased. Levy (2011) even states that he “intuitively” knew that the therapy was working. The limitation of such research is that this type of therapy is not used with adults and most likely will never be and therefore may bring about different outcomes. It is difficult to state the efficacy of this type of therapy as only the interpretations of the therapist is being used as a means to calculate success or effectiveness.

Case studies involving adults with HFA or AS using psychodynamic therapy (shown in Figure 1.) stress emphasis on self-object experiences with the client, shifting the paradigm to mutative action by teaching the client to be more insightful, looking at the consequences of recurring mutual affective mismatches in their relationships and stressed the importance of the relationship between client and therapist. The relationship appears paramount as the client will then become interested in both the therapist’s mind and the therapist’s understanding of the client’s mind. Across both child and adult case studies, we can see three commonalities that can be drawn out and learnt from. They all (1) utilise the client-therapist relationship in a self-object experience to facilitate experiences of security and regulation within the therapeutic relationship which paradoxically permits destabilisation of the rigid organisation of the self-states, (2) they stress the importance of a relationship based on common humanity and emotional meaning, and (3) the use of experimentation as means to develop the capacity to hold ambivalence, regulate anxiety and self-states to promote a version of mentalisation or insightfulness of themselves. This is something that seems to be effective across all ages in this population.

However, when reviewing this type of research it is important to look at the limitations that they bring with them. Due to the fact that all individuals used in the case studies have different manifestations of their autism; the fact that they are not homogenous creates difficulties in generalising the results across the population. One can only draw out possible effects but not state categorically that this therapy is successful in decreasing
symptomology. This can also be said about the small sample sizes and the fact that one therapist shows efficacy using their own interpretation of the outcome. It has not been verified or been replicated with a larger sample. No evidence-based research has been conducted using this type of therapy and it would be interesting to see what results they would show. The therapists in the research shown in Figure 1., have not considered how other factors may have had an effect on their clients. The clients may have been seeing language therapists, psychiatrists, using medication, or their teachers/work colleagues/family members/friends may have had some effect on them. These factors seem to have been slightly, if not completely, overlooked. It is also important to look at case studies written in manuals such as by Jacobsen (2003), though no new information was specified that the articles had not already mentioned. A therapist is able to draw information from this type of manual but as this is not peer-reviewed as the articles are and only show one person’s perspective, it also comes with its own limitations.

It is also often described how psychodynamic therapy is needed to be modified in order to work with this population. Shapiro (2000; 2009), Sugarman (2011) and Jacobsen (2003) have all described how a therapist must gauge if the individual with HFA or AS has a theory of mind (Baron-Cohen, Leslie, & Frith, 1985), can communicate fairly effectively, and have the capacity to be imaginative but if not, then this limits the individual to utilise this type of therapy or makes it impossible. Jacobsen (2003) also describes how there are challenges when looking at the individual’s ability to have a theory of mind, use of executive functioning and use of central coherence. She also describes that the therapist may encounter challenges such as perceiving the individual to be arrogant, feeling hurt, the attribution of their intention, the choices made out of the clients own awareness, and that their spontaneity or impulsivity may be odd or seem disinhibited. These are very important points as it has not been reported in the articles above but may enable therapists to rethink their own practice and what they need to take into account when working with this population.

There appears to be hardly any information or research when looking at the amount of training a therapist receives and also what the perspectives of therapists are who work with this population. Lunsky, Weiss, & Morin (2010) found that developmental disorder training for psychology graduates in Canada was insufficient and most pronounced amongst students with an adult-focus, however, no such study has been conducted in the UK or the USA. One study (Brookman-Frazee, Drahota, Stadnick, & Palinkas, 2012) was found that looks into the perspective of therapists working in an American Community Health Service; 76% work psychotherapeutically with children with ASD and they reported that they found it
challenging and frustrating due to slow progress, the ineffectiveness of typical psychotherapeutic strategies, had system issues, and that they have limited training but are highly motivated for additional training. These results seem to suggest that a large amount of therapists encounter individuals with ASD and that they feel that their training is not sufficient enough. Research such as this is highly important as it informs us what is currently working and what needs to be changed or introduced so that the professional community may provide effective treatment. Similar research should be carried out in the UK to see if opinions match and if there needs to be a shift in training and treatment.

[The research presented above has given me a lot of food-for-thought in terms of my own training and use of therapeutic interventions when working with these individuals. It appears that the current forms of training seem insufficient and maybe ASD specific interventions/treatment is something that needs to be explicitly addressed during initial training and subsequent professional development.

I was particularly moved by the case study by Topel and Lachman (2011) as Topel used animal-assisted therapy using an antquarium. I was very surprised by this intervention as it was something I had not come across before and I thought it was incredibly creative of the therapist to utilise this to highlight to Carl the importance of society and each person’s place in it. The emotion, importance of support, and relational work that came across in this form of therapy showed me the uniqueness of an individual with ASD and the importance of a therapist in giving them an interactive way through their confusion and anxiety.]

**Cognitive-behavioural therapy (CBT) and high-functioning autism and Asperger’s syndrome**

Children who had developmental disorders such as autism and exhibited “behavioural problems” would, historically, be given educational treatments based on behavioural learning theory and operant conditioning theory (Skinner, 1953) such as Applied Behavioural Analysis (ABA: Wolery, Bailey, & Sugai, 1988), TEACCH (Mesibov, 1996) and the Lovaas Method (Lovaas, 1981). Such treatments utilised positive reinforcement, shaping, modelling behaviours, specific skills, behavioural techniques and cognitive-social learning strategies to aid in the autistic child’s development. These treatments are still being used but mainly with children and they do not address any psychiatric problems that the child may have such as depression or anxiety. It can be argued though that if a child is given the skills to adapt their
behaviour it can help them use them as adults when in anxiety-provoking situations and may therefore feel less anxious and depressed due to this.

Moving on from educational treatments, cognitive-behavioural therapy (CBT) is derived from the same principles as behavioural learning theory and was devised by Beck (1970). If put in simplistic terms, CBT can teach people to observe their own thoughts and perceptions with the hope that they will become more aware of their interpretive errors (Gaus, 2007). It has shown its efficacy in many disorders (Butler, Chapman, Forman, & Beck, 2006) and is widely used by the health system in the UK (NHS, 2013). It is often recommended to people with ASD (Attwood, 1998; Gaus, 2000, 2007; Paxton & Estay, 2007) but not a lot of research has been undertaken to look into its efficacy. There are few studies that show case studies and evidence-based control trials that look into using CBT with children, adolescents and adults with HFA or AS.

Seven case studies were found, five looking at children and adolescents and two looking at adults. Looking at the case studies in Figure 2., all stated their efficacy as the individuals symptomology decreased and the client and/or their families reported a positive change in their problems.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Case study</th>
<th>Sex</th>
<th>Age</th>
<th>Autism</th>
<th>Type of therapy</th>
<th>Presenting difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sze &amp; Wood (2007)</td>
<td>Sophie</td>
<td>F</td>
<td>11</td>
<td>HFA</td>
<td>Modified Building Confidence CBT</td>
<td>Anxiety, OCD &amp; social</td>
</tr>
<tr>
<td>El-Ghoroury &amp; Krackow (2011)</td>
<td>Allan</td>
<td>M</td>
<td>Pre-School</td>
<td>ASD</td>
<td>Multimodal Anxiety &amp; Social Skills Intervention</td>
<td>Disruptive behaviour</td>
</tr>
<tr>
<td>El-Ghoroury &amp; Krackow (2011)</td>
<td>Jenny</td>
<td>F</td>
<td>School Age</td>
<td>PDD-NOS</td>
<td>Multimodal Anxiety &amp; Social Skills Intervention</td>
<td>Rigid sleep routine problems</td>
</tr>
<tr>
<td>El-Ghoroury &amp; Krackow (2011)</td>
<td>Michael</td>
<td>M</td>
<td>Adolescent</td>
<td>AS</td>
<td>Multimodal Anxiety &amp; Social Skills Intervention</td>
<td>OCD</td>
</tr>
<tr>
<td>El-Ghoroury &amp; Krackow (2011)</td>
<td>Joseph</td>
<td>M</td>
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<td>ASD</td>
<td>Multimodal Anxiety &amp; Social Skills Intervention</td>
<td>Anger</td>
</tr>
<tr>
<td>Cardaciotto &amp; Herbert (2005)</td>
<td>No name</td>
<td>M</td>
<td>23</td>
<td>AS</td>
<td>Modified CBT based treatment protocol</td>
<td>Social anxiety disorder</td>
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<td>Beebe &amp; Risi (2003)</td>
<td>Randy</td>
<td>M</td>
<td>19</td>
<td>HFA</td>
<td>Modified CBT - not specified</td>
<td>Depression &amp; anger</td>
</tr>
</tbody>
</table>
Figure 2. Table showing seven case studies looking at children, adolescents and adults with high-functioning autism (HFA), autism spectrum disorder (ASD), Asperger’s syndrome (AS), or pervasive developmental disorder – not otherwise specified (PDD-NOS).

All seven case studies utilised modified CBT treatment schedules that involved techniques such as role-playing, cognitive structuring, initiating coping and problem-solving strategies, goal training, using emotional thermometers, homework assignments and visual support. Some cases were short term and only lasted a few weeks and some were still ongoing after 9 months of treatment. The main limitations that are very apparent are that even though they all use CBT treatments, they all appear to use different and modified versions. It may not be able to state that CBT is effective if different treatments are being used for many different symptoms and problems. It may be easier to determine efficacy if the same treatment protocol is used for the same problems and then they are able to examine the results side by side. Also, using small samples are difficult in terms of results as it only examines one individual’s experience of this treatment. The researchers did not use any follow-up’s to see if the treatment had lasting effects or are being used by the client for other problems that come up in their lives. This may have also highlighted if there are any other factors that may have influenced their results such as outside influences like school or home life or if any medication was being used.

It appears that only two studies, as shown in Figure 3., have been carried out using either control trials (CT) or randomised control trials (RCT) with modified CBT treatments for children with HFA. Both studies showed significant decrease in anxiety in the CBT groups after treatment and this was backed up by either 3 and 6 month follow-ups or report measures carried out by the participants, their parents and their teachers. This kind of evidence-based research goes a long way in showing larger samples with HFA, significant positive results and also using measures that validate the results by using people other than the researchers to give their opinions. Using follow-ups, report measures using different people involved with the participant, independent clinical evaluators, randomising the selection, and being blind to the condition are positive ways forward to gain a better understanding of how effective different types of therapy are for this population. These factors are more likely to give impartial, grounded, and holistic results. Especially when using measures that include people such as parents or teachers that may be able to evaluate outcomes and have the insight that individuals with HFA or AS may not be able to.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Participants</th>
<th>Type</th>
<th>Autism</th>
<th>Type of therapy</th>
<th>Presenting difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reavan, Blakely-Smith, Culhane-Shelburne &amp; Hepburn (2012)</td>
<td>50 (RCT)</td>
<td>Children</td>
<td>HFA</td>
<td>Modified Face Your Fears CBT treatment and Treatment-As-Usual (TAU) for 12 wks, 3&amp;6 months follow-up, structured interviews pre and post treatment</td>
<td>Anxiety</td>
</tr>
</tbody>
</table>

Figure 3. Table showing CBT and TAU control trials using children with HFA.

Across all studies, researchers used different modified CBT treatment schedules so as discussed above, this would make it difficult to compare the results as they did not use the same type of CBT interventions across the board. The two control trials stated that they have small samples and if you included the case studies, it is also difficult to generalise across this population with such low numbers. The researchers from the trials said they need larger samples to account for potential moderating factors such as age, intellectual functioning, severity of core autism symptoms, complexity of co-occurring psychiatric conditions and the presence of parent psychopathology. It is, however, good to see that researchers are using control trials as well as case studies and seeing if there are differences or similarities is interesting especially as this is not being done with psychodynamic therapy. They all claim that they show the efficacy of CBT but this can only really be shown with more research, more structured and uniform research methods, larger samples with different ages, gender (as most participants seem to be male), cultural diversity (as most participants seem to be Caucasian), intellectual functioning and co-morbid psychiatric conditions.

All research showed versions of CBT that contended with cognitive restructuring, developing and utilising coping and problem-solving techniques, the relationship between therapist and client was still very important especially as it gave the structure and safety to experiment with new situations, efficacy of the treatment could extend to many environments such as school/work/home, all treatment was symptomatic and not curative (this could mean that long-term CBT may be more helpful to assist with on-going problems but the same can be said of psychodynamic therapy), and all treatments were modified to the unique symptoms and individuals.
Leather and Leardi (2012) has published an article about what clinicians need to know about mental health and AS. This is the only paper of its kind that was found as it shows clinicians who have had experience with this population and wish to share their knowledge in a common-sense and efficient manner. They also talk about the efficacy of CBT, how important the therapeutic alliance is, to take into account the medication clients with AS may be on due to co-morbid psychiatric conditions and how this may affect treatment, and also the psychosocial support your client may already be receiving or may benefit from receiving. It is astounding that only one paper of this kind exists and that this information has only come out in the last year. Practical manuals on how to do CBT interventions with people with ASD and AS by clinicians such as Gaus (2007) and Paxton & Estay (2007) have only been available in the last 5 years. Again, the information they give are case studies which are not peer-reviewed but can be informative as you can draw knowledge from their experience. It appears to be helpful in that concise intervention protocols are mentioned that can be followed and used with clients.

It seems that we may be coming into a time where more research is becoming necessary so that professionals are getting the level of training and information they need in order to aid their clients with ASD and to feel confident in doing so. I have noticed that the research we have looked at has come about mainly in the last ten years and the most helpful research such as evidence-based trials and practical information for clinicians has only come about in the last 3 years.

[Considering the fact that cognitive-behavioural educational treatments have been used with individuals with autism for some time now with success, it would only make sense to use this knowledge and use this for talking therapies as well. I would personally feel more comfortable as a counselling psychologist in training to have “tools” such as these techniques in order to help my clients decrease their anxiety and depression. From reading the above articles and the practical manuals mentioned, it has given me a broader view of what is available out there and what I can use in my own practice.]

Other counselling therapies and high-functioning autism and Asperger’s syndrome

Looking at the information and research available, there are rare cases of therapy done outside of psychodynamic and CBT approaches. In the last three years there have been 2 studies looking at Mindfulness- based therapy (MBT) with adolescents and adults with HFA.
and AS. Mindfulness (Kabat-Zinn, 1990) looks at enabling individuals to learn self-management skills to help regulate their own behaviours and to achieve self-selected goals. It helps you to pay attention to experiences in the present moment in a non-judgemental and accepting way and this includes your thoughts and feelings.

Singh et. al. (2011) taught 3 mothers to teach their adolescent sons the procedure “Meditation on the Sole of the Feet” to manage their physical aggression. This procedure required the adolescents to rapidly shift the focus of their attention from the aggression-triggering event to a neutral place on their body, the soles of their feet. Incidents of aggression per boy per week were 14-20 at the beginning of treatment and went down to 0 rates during last 4 weeks of intervention. During a 3 year follow up, they reported 1 incident per year. This seems to show that this population may be able to learn these techniques to be able to self-manage their episodes of immense emotion and this could be applicable to other scenarios and conditions. Nonetheless, we must note that this study is done with three Caucasian boys, it is a small sample, only one age group and looking at no other cultural diversity. As their mothers did the “therapy”, not a professional it would be difficult to see what the effects are from this without having other studies to compare this with. These case studies also look at aggression and not psychiatric problems such as depression or anxiety; it would be interesting if we were able to see research using MBT addressing difficulties and problems such as these. A positive side effect found by the researchers, showed that it also decreased the anxiety experienced by the participants mothers as they utilised the procedures as well; this may suggest that incorporating the family into the intervention may help the whole family.

Spek, Van Ham & Nyklicek (2013) carried out a modified MBT randomised control trial on 42 adults with HFA for 9 weeks, either doing MBT or being in a Waiting List control group. Results showed significant reduction in depression, anxiety and rumination in the intervention group. It is the first study of its kind which appears to show that you can do RCTs with modified MBT with this population but we need more studies like this to make the results clearer. Also, the MBT given was done by professionals, not a family member and this may have different consequences or results. It would be interesting to see if this was looked into more closely to see if they are just as effective as each other or if there are any differences that present when taught by different people. Both these studies cannot be generalised to the ASD population with below average verbal abilities due to the high level of communication used in this type of therapy.
Both MBT studies show using different variations of MBT, usually with modifications. This is the same limitation as the CBT research as no cohesive agreement is given as to which type of therapy is the “correct one” to use as so many variations are being utilised. Though it is encouraging to see that both case studies and RCTs are being used with modified MBT and if more research is conducted using these methods, we may be able to see a strengthening of their argument that this is an effective therapy for individuals with HFA and AS.

Only one multi-modal study (Stoddart, 1999) appears to have been conducted which showed that a practitioner can use individual and family therapy using more than one approach with adolescents with AS. He used a systems-based and structural approach using parts of theories from communication, role, psychoanalytic, behavioural, cognitive, psycho-educational and developmental theories. He used this in three long-term case studies – Brian (15-19 years), Andrew (13-17 years) and Grant (15-17 years), who were all diagnosed with Asperger’s syndrome. He found that presenting problems decreased over time due to training and interventions used. All three boys finished therapy with a wider social circle, being more integrated at school, fewer problems at home and some of their core autistic symptomology decreased. It seemed effective to have both individual and family therapy for all parties involved as quite often the parents and siblings have been living in an environment that has been stressful, tense and centred around the person with autism. It also makes sense to take the parts from different theories and approaches that best fit with this population and see if it works for that individual; it behoves a creativity to therapy that may open the way to a disorder-specific treatment.

What appears to be the most positive from looking at the above three research articles, is that there are clinicians who are open to different approaches and therapies to see what fits best with the population and individuals. People are prepared to experiment, research different approaches, with different groups and the information garnered will enrich what we know and what we will do in the future. This can happen if we find a cohesive way of reporting and conducting research that can actually inform practice with individuals with HFA and AS, otherwise research that informs and extends practice will be limited.

Discussion

The intent of this review is to examine and discuss the research and information available to clinicians who are already working with or will be working with adults with HFA or AS. Four main questions were posed at the beginning to help direct and pinpoint what may
be the most interesting and important to note. It is also important to discuss the theory behind the talking therapies that have been used by clinicians and to see if any of these therapies may have been more effective than any others.

It appears that the psychodynamic therapies utilise self-object experiences, use mutative action to teach insightfulness, use experimentation and put the therapeutic relationship central to the therapy. Cognitive-behavioural therapy also utilises experimentation in role-playing and puts the therapeutic relationship central. It differs in that it also initiates coping and problem-solving strategies, teaches goal training, uses emotional thermometers, gives out homework assignments and visual support. Psychodynamic therapy, CBT and MBT all used modified versions of the “original” type of therapy and even use variations within that type of therapy. This can make it difficult when trying to compare the research as there is no cohesive agreement and utilisation of the same version of therapy.

Each individual or group is given therapy that is specific to their presenting problem or their manifestation of autism. This, however, can be helpful for the client as it is so specific for each person or group. When looking at Mindfulness-based therapy, it is difficult to be able to express much of an opinion or have a lot of evidence to back up any assertions as there have only been two studies (Singh et. al., 2011; Spek, Van Ham & Nyklicek, 2013) that have looked into the effectiveness of working with individuals with HFA and AS. It appears to empower individuals to manage their own anxieties and emotions using visualisation techniques and promotes an in-the-moment experience. It also advocates non-judgment as all talking therapies do. However, more research needs to be conducted in order to strengthen any claims of efficacy.

It cannot be categorically claimed that any therapy is more effective than the other as there would need to be more research conducted across the board in order for clinicians and psychologists to be able to compare effectively the limitations and positive effects.

In terms of the types of methods used to research which type of therapy may be effective when working with this population, it appears that case studies and control trials are the two main methods. Throughout this review, the pro’s and con’s of these methods have been discussed. Considering that case studies seem to be a popular way of researching these topics; producing qualitative version of events and showing a more in-depth perspective on an individual basis, there appear to be quite a few negatives. Even though they are able to describe interventions made by the clinicians that the professional community can learn from, they are written in such a way that it is difficult to draw down information in a cohesive and structured manner. It is also difficult to compare results or to say that a therapy is effective if
the people stating the efficacy are the people who have written the article. Surely it is in the interest of the therapist to say that their work with their client has been effective and when they say they knew “intuitively” (Levy, 2011) that the therapy worked then it is difficult not to have a sceptic opinion about this article and its claims of efficacy. There are often no follow-up’s in case studies which would make it hard to ascertain if the therapy had any lasting outcome and also cannot show if any outside factors may have had an impact on the client that may have resulted in a positive outcome; such as the influence of school, work, friends, family or any medication they may have been taking. One cannot generalise the findings of case studies with this population due to the nature of there being such a small sample and also as each client’s therapy has been modified according to their presenting problems and/or their type of autism. Though it could be argued if there is a need or choice to generalise across the population; it may be argued that, as with working therapeutically with the neurotypical population, each therapist always modifies the treatment they can provide depending on the personality of the client and their presenting problems.

When looking at the research that utilises control trials, throughout all the research discussed above, some have been randomised and some have not. It would be easier to compare the research and its results if they were the same but unfortunately, this is not a reality. In the best case scenario, the research method used would be randomised, have blind controls, use independent clinical evaluators, have larger samples, use self-report measures using the participant and people they socialise with such as family, friends and colleagues. However, as this has not always been the case, some of the research is not quite as based in evidence as one would like. Even though samples have been used that appear large due to the singular case studies we are used to, the researchers do state that even larger samples would be beneficial as this would explore any moderating factors such as age, intellectual functioning, severity of core autism symptoms, complexity of co-occurring psychiatric conditions and the presence of parent psychopathology.

It would appear that due to the scarcity of research across different types of therapies and utilising different research methods, more research needs to be conducted in order to fill the gaps that we are now seeing. We are also very limited when it comes to cultural diversity as it appears that mainly Caucasian participant’s take part in these studies. There may be clinicians in other parts of the world who are also working with children and adults with ASD and may benefit from any information or support that they can find. It seems that in the last few years, researchers are starting to look into the effectiveness of other types of therapy available to people with HFA and AS such as MBT and multi-modal therapy. This may be an
area where more research will be conducted and may even open the path to enabling clinicians to think and be creative when it comes to working therapeutically with this population. It also appears that researchers are starting to look into what clinicians think and feel about working therapeutically with these individuals and this is very important as the results of such research can help inform practice. Not only are we starting to become aware that people working in the psychology field feel that they have inadequate training for developmental disorders (Lunsky, Weiss, & Morin, 2010) but that the clinicians working with this population find it challenging and frustrating due to slow progress, that they are not equipped with the right psychotherapeutic strategies, that their system fails them and that they feel they need more training (Brookman-Frazee, Drahota, Stadnick, & Palinkas, 2012). Without information such as this, we as a community would not know about the discontent that may be out there amongst them and what they feel they need in order to grow as clinicians and also to ensure that they are able to provide a service that works. More research needs to be conducted especially in the UK to see if results compare to that from the USA and Canada and to see if there are any issues or considerations specific to this country. It is also important to facilitate more research such as the study by Leather and Leardi (2012) where clinicians are told in a concise and coherent manner what we may expect and what we need to know to work with individuals with HFA and AS who have co-morbid psychiatric conditions. This is most beneficial and helps inform how we treat our clients.

No research seems to have been conducted in asking or exploring the opinions of adults with HFA and AS who seek and attend therapy. We know nothing about their interactions with clinicians, if they are happy with the service they are given, if they feel that it was worthwhile having therapy and if their symptoms/problems decreased or were resolved. Only one article (Jones, Zahl, & Huws, 2001) explored the emotional experiences HFA adults have in a qualitative study using thematic analysis, nothing similar has been conducted elsewhere to garner a more phenomenological perspective of this population. It would be both interesting and important to look into their experiences of going to therapy as any information would help inform the community as to the effectiveness of the therapy, if they feel they need specific interventions, if there is anything lacking or if anything is particularly helpful for them. It would be a common-sense approach to evaluate the service and to learn from it. It would also give a voice to this population as they are service users and members of society as much as anyone else is.

One of the main questions posed by this review is if there are any considerations or implications for practice that have been highlighted in the research. This is an important
concern as without this, clinicians may be blind to future problems and may result in unsuccessful or even harmful experiences for the client. Jacobsen (2003) spoke about looking at the individual’s ability to have a theory of mind, use of executive functioning and use of central coherence. This is something that needs to be determined before the client is taken on. A clinician may encounter challenges such as perceiving the individual to be arrogant, feeling hurt, the attribution of the clients intention, the choices made out of the clients own awareness, and that their spontaneity or impulsivity may be odd or seem disinhibited. This is very much connected to the individual’s core autistic symptomology and may manifest in different ways. Clinicians should be aware before treating an individual with ASD how their disorder may manifest and what kind of symptoms they exhibit as this may confuse the clinician or cause them to make wrong formulations about their client. Due to the heterogeneous nature of ASD it is difficult to cater to each individual as the clinician will, most likely, have to modify their interventions according to the client (Shapiro, 2000; 2009). Co-morbid psychiatric conditions may also play a factor in modifying the therapy according to the client as each individual may have any type of condition or combination of them. Also as specified above, it appears that clinicians find it challenging to work with this population and that they feel they are not trained sufficiently to support them to the standard they require. It is important for the clinician to feel confident in their interventions and therefore, they may need to gain further training or specific training for this population is made mandatory in the training undertaken by clinicians before they qualify and practice.

Conclusion

It appears that the lack of research in the area of working therapeutically with adults with HFA and AS make it difficult to make assertions about the outcome of therapy or the methods used to measure its effectiveness. More research is required in order to be able to compare different types of therapy and what the most effect way of measuring its outcome is. There are many considerations for a clinician to gauge if a client is able to utilise a form of therapy and due to their possible lack of training or feelings of frustration of working with them, they may have some issues in their own practice. Gaps in the research may suggest further exploration of the opinions and experiences of clinicians working with this population and also exploring the phenomenology of adults with HFA and AS utilising therapy. Both theory and methodology has been explored and addressed though no clear and coherent form of research has been identified as being the strongest contender for efficacy.
[Due to having worked humanistically with individuals with HFA and AS, I have some knowledge in this area and have experienced the same feelings of frustration due to slow progress or that certain interventions do not work. I have found it at times very challenging as I have not always known what to do and I would have appreciated more training specifically to do with CBT interventions as they seem to me to be effective tools that can empower a client to manage certain anxieties and emotions. I am also very interested in the recent research done into MBT with this client group as it shows that they are able to have insight and also utilise self-management skills in order to work with their problems in the here-and-now moment.

I can see why there may be a lack of research asking opinions and insight from individuals from this population as it can bring up issues of ethical considerations (is the researcher taking advantage of someone who may be seen as vulnerable?) or the researchers may be worried about not being able to find such individuals or be worried about working with them.

I have found it incredibly interesting to research this field, especially as there were some clinicians who have been working in this field for many, many years and wanted to impart their hard-gained knowledge. It has been lovely to hear that in each form of therapy, the clinicians spoke about the importance of the therapeutic relationship and placing it so central to the whole experience. They often emphasised the human aspect to each exchange and this is something I would not want to feel like it would be missing and I would like to ensure happens in my own practice.]
Over the last two years, further literature has been carried out and is presented in Figure 1. below:

<table>
<thead>
<tr>
<th>Authors</th>
<th>Participants (age and type of ASD)</th>
<th>Type</th>
<th>Type of therapy</th>
<th>Presenting problems</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ehrenreich-May, Storch, &amp; Queen</td>
<td>20 x 11-14 yr old with mixed ASD plus anxiety</td>
<td>Open trial</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety</td>
<td>Significant reduction in anxiety severity</td>
</tr>
<tr>
<td>Selles et. al. (2014)</td>
<td>32 x 8-16 yr old with mixed ASD plus anxiety</td>
<td>10-26 months follow up of past CBT</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety</td>
<td>Small effect for return in symptoms and significantly fewer individuals were rated as responders at follow-up</td>
</tr>
<tr>
<td>Reaven et. al. (2015)</td>
<td>13 clinicians - Clinical Psychologists. 16 x 8-14 yr old with mixed ASD and anxiety.</td>
<td>Transportability of CBT for anxiety. Clinicians trained in CBT and therapy efficacy.</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety</td>
<td>53% of kids had meaningful reduction in anxiety. Clinicians felt positive to CBT protocols and showed initial effectiveness and transportability of therapy.</td>
</tr>
<tr>
<td>Storch et. al. (2015)</td>
<td>7 x 12-15 yr old with HFASD with anxiety</td>
<td>RCT for CBT augmenting SRI treatment.</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety</td>
<td>4/7 kids had Much or Very Much Improved. Showed preliminary support for CBT augmenting SRI treatment.</td>
</tr>
<tr>
<td>Authors</td>
<td>Age Range</td>
<td>Description</td>
<td>Treatment</td>
<td>Outcome</td>
<td></td>
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<tr>
<td>Van Steensel &amp; Bögels (2015)</td>
<td>79 x 7-18 yr old with mixed ASD plus anxiety</td>
<td>CBT for anxiety versus waiting list</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>CBT more effective than waiting list. 2 years follow-up showed 61% free of anxiety.</td>
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</tr>
<tr>
<td>White, Schry, Miyazaki, Ollendick, &amp; Scahill (2014)</td>
<td>22 x 12-17 yr old with ASD plus anxiety</td>
<td>RCT for CBT for anxiety</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety reduction in anxiety was partially maintained by 1 year follow-up.</td>
<td></td>
</tr>
<tr>
<td>Wood et al. (2015)</td>
<td>33 x 11-15 yr old with ASD plus anxiety</td>
<td>RCT for CBT for anxiety</td>
<td>Modified CBT for anxiety</td>
<td>Anxiety CBT outperformed waiting list in anxiety severity.</td>
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<tr>
<td>Nadeau, Arnold, Storch, &amp; Lewin (2014)</td>
<td>1 x 9 yr old Boy with ASD with OCD</td>
<td>Case study of Family-based CBT</td>
<td>Modified CBT for anxiety</td>
<td>OCD and ASD difficulties Boy's parents reported improvements in emotion regulation, school participation and relationships.</td>
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<tr>
<td>Hesselmark, Plenty, &amp; Bejerot (2014)</td>
<td>68 x 19-53 yr old with ASD plus co-morbid psychiatric problems</td>
<td>RCT for Group CBT versus Recreational Group</td>
<td>Modified CBT for psychiatric ASD patients.</td>
<td>Co-morbid psychiatric problems and ASD difficulties. CBT group rated themselves as more generally improved than recreational group.</td>
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<td></td>
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<tr>
<td>McGillivray &amp; Evert (2014)</td>
<td>32 x 15-25 yr old with HFASD plus depression, anxiety, and stress</td>
<td>Group CBT versus waitlist</td>
<td>Modified CBT for depression, anxiety and stress.</td>
<td>Co-morbid depression, anxiety and stress. After intervention, 3 and 9 month follow up reported significantly lower depression and stress scores than WL.</td>
<td></td>
</tr>
</tbody>
</table>
The research presented in Figure 1. show 11 studies that have been carried out using modified CBT interventions with both children and adolescents, and various co-morbidity of psychiatric problems but mainly anxiety. No new information has emerged from these efficacy studies but show moderate effectiveness rates for modified CBT interventions. They have given further evidence for effectiveness but do not help to answer questions that have been raised in the literature review.

The research presented in Figure 2. show systematic literature reviews that have been carried out in the last two years:

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Age</th>
<th>Autism</th>
<th>Type of therapy</th>
<th>Outcome</th>
</tr>
</thead>
</table>
Kasari, Shire, Factor, & McCracken (2014)  Systematic literature review - 56 studies  Any age  Mixed ASD  Modified CBT  Increase in social outcomes intervention studies, lack of new knowledge, noticeable absence in research on adults.

Spain, Sin, Chaldern Murohy, & Happé (2015)  Systematic literature review - 6 studies  18 - 65 years.  Mixed ASD  Modified CBT  Narrative analysis suggested CBT including MBT, were moderately effective.

Figure 2. Table to show research (systematic literature reviews) carried out from 2014-2015 not in original literature review.

The information in Figure 2. seem to show that systematic literature reviews have been carried out for the first time and the first of its kind was published in 2014. Their findings appear to echo what has been suggested in the literature review by Coxon & Williams (unpublished) that as the studies show mixed ASD presentations, different ages, different co-morbidity, different interventions used and an apparent large lack in research with adults; it would be very difficult to show how effective certain interventions are. The more specific the inclusion and exclusion criteria are, the more likely that they can say with confidence what the strength of effectiveness of an intervention is. 

The research presented in Figure 3. show three articles that have looked at specific HFASD presentations for both children and adults and gives information for mental health practitioner’s on ASD presentations, problem with co-morbidity, as well as suggestions on how to work therapeutically with this client group.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Article</th>
<th>Age</th>
<th>Autism</th>
<th>Discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tebartz van Elst, Pick, Biscaldi, Fangmeier, &amp; Riedel (2013)</td>
<td>HFASD as a basic disorder in adult psychiatry and psychotherapy.</td>
<td>Adults</td>
<td>HFASD</td>
<td>Speaks about how HFASD has a high co-morbidity for psychiatric problems, therefore ASD should be regarded as a basic disorder with causal relevance for secondary psychiatric syndromes. FASTER and FASTER-S treatments are discussed.</td>
</tr>
<tr>
<td>Woods, Mahdavi, &amp; Ryan (2013)</td>
<td>Treating clients with Asperger's Syndrome and autism.</td>
<td>All ages</td>
<td>HFASD</td>
<td>Speaks about specific HFASD presentations and difficulties and brings forth counselling interventions with emphasis on social interactions and understanding the client group.</td>
</tr>
<tr>
<td>Koelkebeck, Riedel, Ohrmann, Biscaldi, &amp; Tebartz van Elst (2014)</td>
<td>HFASD in Adults</td>
<td>Adults</td>
<td>HFASD</td>
<td>Speaks about specific HFASD presentations and pharmacology as well as psychotherapeutic interventions for this client group.</td>
</tr>
</tbody>
</table>

Figure 3. Table showing articles about individuals with HFASD and how to potentially work with them

The information presented in Figure 3. is particularly helpful as we are presented with information about the specific difficulties individuals with HFASD deal with and how they can be managed both pharmacologically and therapeutically. They are far more concise than practice manuals and are therefore more digestible by the mental health practitioner. This was one of the limitations found in Coxon & Williams’ (unpublished) literature review and appears to be something that is being addressed in the literature.
An encouraging piece of research has been undertaken recently – a thematic analysis of the lived experience of four adults with HFASD growing older. Elichaooff (2015) discovered six themes that included: depression, effects of diagnosis, experiences with mental health professionals and therapists, the inverted relationship between educational level and career, the participant as autism expert, and communication/social interaction. This was the first venture into investigating the phenomenology of adults with HFASD from a qualitative stance. Elichaooff (2015) identified that some participants talked about experiencing depression before and after diagnosis and seeking psychology therapies for help and finding that some therapies were more helpful than others and that a lack of ASD knowledge had a big effect on their therapy. As auspicious as this research is, its focus is the experience of growing older with HFASD and talks about psychological therapies as important but not being fundamental to the research, thus, potentially giving us only an idea of what information may be obtainable.
References


British Association of Counselling and Psychotherapy (2013, 5th March). Personal correspondence with Charlie Jackson – Research Intern at BACP.


Appendix A. – Notes to contributors

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Year 2 – Research Report

What is the experience of practitioners working with adults with a high-functioning autism spectrum disorder: an interpretative-phenomenological analysis.

Abstract

Adults with a high-functioning autism spectrum disorder (HFASD) can show impairments with social skills, finding it difficult to maintain interpersonal relationships, having a theory of mind, language, and exhibiting restricted, repetitive patterns of behaviour. They also suffer from co-morbid psychiatric problems even though estimates vary greatly from 4-81%. This would suggest that adults with HFASD would seek help from support systems such as psychotherapists and counselling psychologists. However, after conducting a systematic literature review it appears that there is a paucity of research into the experience of practitioners of working with this client group. This type of information would greatly enhance understanding and training for current and future psychotherapists and counselling psychologists. Carrying out an interpretative phenomenological analysis on the interviews of 6 practitioners from various therapeutic orientations has brought forth three main themes that may give some indication of the experience of practitioners working with this client group. The three themes are: 1) the importance of the therapeutic relationship, 2) feelings of limitations, and 3) the effects of an autism label. Within this study the reviewed literature, method, results, discussion and areas for future research will be reviewed and discussed.
Introduction

Within the U.K., we have an estimated 1 in 100 children who are diagnosed with autism spectrum disorder (ASD) but no prevalence studies have been carried out for adults suffering from this and it is therefore difficult to ascertain how many people have high-functioning autism (HFA) or Asperger’s Syndrome (AS) (The National Autistic Society, 2013). According to the latest DSM-V (American Psychiatric Association, 2013), in order to be diagnosed as having an ASD, an individual must show persistent impairment in reciprocal social communication and social interaction and restricted, repetitive patterns of behaviour, interests, or activities. These symptoms are present as a young child and limit or impair everyday functioning. They may also have intellectual impairments and/or language impairments, as well as, motor deficits. It is diagnosed four times more often in males than in women. It is also interesting to note, that the DSM-V does state that this is not a degenerate disorder but it is typical for learning and compensation to continue throughout life.

Considering that the DSM-V is a manual that categorises human experiences and is fully entrenched within the medical model, it does appear to take into account that the ASD phenomenology is one that is not hopeless and people can manage very well with the resources they do have within them or from support systems.

Individuals with HFA have average or above-average IQ (Baron-Cohen, 2000) and individuals with Asperger’s syndrome have normal language development but share the characteristics of autism in terms of impairment in social interaction and having repetitive and stereotypic patterns of behaviours (Ghaziuddin and Mountain-Kimchi, 2004). However, no clear distinction between HFA and AS can currently be made (Meyer & Minshew, 2002) and I will therefore place both groups of individuals with HFA and AS in the category of having a high-functioning autism spectrum disorder (HFASD) and are placed at one end of the spectrum.

It is well reported that individuals with a HFASD suffer from co-morbid psychiatric problems even though estimates vary greatly from 4-81% (Levy & Perry, 2011). Problems such as depression (Ghaziuddin, Ghaziuddin & Greden, 2002; Stewart, Barnard, Pearson, Hasan, & O’Brien, 2006; Sterling, Dawson, Estes, & Greenson, 2007), anxiety (Bellini, 2004; Gillot & Standen, 2007), ADHD and OCD (Klin & Volkmar, 1997) are very common. There is also evidence to show that these individuals have difficulties such as social skills deficits (Bellini, 2004), with romantic relationships (Aston, 2012) and emotional problems (Jones,
Zahl & Huws, 2001). They have also reported that their quality of life is highly related to support characteristics such as effective professional support and supportive social networks (Renty & Roeyers, 2006). This seems to suggest that these individuals not only have the everyday problems of loss and relationships but also have a high prevalence of co-morbid psychiatric problems that would need to be addressed by professionals in order for them to improve. Thus, going to therapy and working with professionals, could give them the support and help they require.

A systematic, critical literature review by Coxon & Williams (unpublished), appeared to show several imbalances and gaps within the literature. It was found that the vast majority of the research into therapeutically working with this client group are based on the medical model as they look at how effective certain therapies are, such as cognitive behavioural therapy and Mindfulness-based therapy in control trials and randomised control trials (El-Ghoroury & Krackow, 2011; Sze & Wood, 2007; Cardaciotto & Herbert, 2005; Beebe & Risi, 2003; Singh et. al., 2011, Spek, Van Ham, & Nylicek, 2013), which showed an absence in the research of other types of models such as the social disability approach. The only other types of research that have been carried out are single case studies looking into the effectiveness of psychodynamic therapy (Mero, 2002, Levy, 2002, Topel & Lachman, 2011, Sugarman, 2011, Koenig & Levine, 2011) which are difficult to get an understanding of how the therapy works with this client group as it is only the experience of one client and one practitioner. It seems to suggest that other models are underrepresented in the research and that there are at least two current ways of investigation being utilised – control trials and single case studies. They do not give a deeper and richer understanding of a person’s experience nor show an adherence to more rigorous research methods to give the research the understanding, relevance and scientific merit needed to be more comprehensive.

There appears to be hardly any research looking at the experience of practitioners¹ working with this client group and also the experiences of the client group undertaking therapy. Due to the nature of their problems, people with a HFASD are more likely to be able to have “talking therapy” as there is a higher level of cognition, empathy and awareness of feelings required. Only one study appears to have looked into the emotional world of adults with HFA or AS but not how dealing with these emotions using professional help and support

¹ Practitioners – this includes practitioners working in psychotherapy and counselling psychology.
has impacted them as individuals (Jones, Zahl & Huws, 2001). Three studies were found that looked into what it is like for a therapist or clinician working with this group of individuals - Leather & Leardi (2012) found that clinicians sharing knowledge in a common-sense and efficient manner was very helpful when working with this group, Weiss, Lunsky & Morin (2010) showed that inadequate training for developmental disorders caused problems and worries for psychology graduates and has implications for a clinicians professional development, and Brookman-Frazee, Drahota, Stadnick & Palinkas (2012) found that clinicians working with this group found it challenging and frustrating due to the slow progress, they felt they weren’t equipped with the right psychotherapeutic strategies to be effective, that their organisational system failed them, and that they needed more training. The three studies carried out by Leather & Leardi (2012), Weiss, Lunsky & Morin (2010) and Brookman-Frazee, Drahota, Stadnick & Palinkas (2012) again came from a medical model perspective, they used various types of enquiry (questionnaires and focus-groups) and wished to inform their practice. These studies were carried out to look into the efficiency of their staff and their current levels of happiness as well as their training needs. They were also all carried out either in the U.S.A or in Canada, not in the U.K.

Following on from my literature review the following points have been found: research into working therapeutically with this client group seems to be more firmly based in the medical model and no other models are represented, there is a gap of research between working with control trials and single case studies, there is scarcely any research looking into the personal experiences of working with this client group and of this client group undertaking therapy, there appears to be a lack of research carried out in this country, research has shown that practitioners do have a voice that would like to be heard regarding their needs in their training and informing their practice, and no qualitative studies have been carried out except one which only looks at the emotional world of someone with ASD and not into working therapeutically with them.

In order to update the literature review carried out by Coxon & Williams (unpublished) it is pertinent to seek further research either that was not available at the time or have since been published. Seven studies have since come to my attention. Two studies deal with psychodynamic single case studies (Olesker, 1999; Goodman & Athey-Lloyd, 2011) which whilst they are interesting to read show only the experience of working with one client and neither are able to give helpful advice to other practitioners when working with this client group. Olesker (1999) was particularly difficult to read due to its highly psychoanalytic content and would only make sense to a psychodynamic practitioner. Three articles
(Jacobsen, 2004; Munro, 2010; Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman, 2005) describe working with this client group after many (collective) years of experience. Between them they describe the importance of having a knowledge of autism and how it may affect individuals, to use the client’s frame of reference, and to use a pragmatic and structured therapeutic style. This type of research will help enhance understanding around the experience of working with this client group and as well as delve into specifics that may help other practitioners in their work. One study by Gawronski et. al. (2011) carried out a two part analysis (qualitative and quantitative) on 97 individuals with ASD to find out what their expectations are concerning psychotherapy. They found that ASD individuals did express problems that were disorder specific core symptoms and that the focus on psychotherapy should be on training (psycho-education) and development of social-communication. This study is starting to show awareness of the issues that arise for these individuals but also what they would like in psychotherapy and what might be useful to them. One final study carried out by Tebartz van Elst et. al. (2013) showed a psychiatry and psychotherapy stance on working with this client group. They suggested both out- and in-patient group and individual psychotherapy should be utilised to teach skills and use the therapeutic space for experimentation. However, their argument was firmly ensconced in the medical model and described the autistic experience as a disease; this does not suggest a very empathic and non-pathologising stance which would be necessary for a therapeutic encounter. Overall, it appears as if there are tentative steps being taken to gain some understanding in both the experience of the ASD individual and the therapist in therapeutic encounters but it also seems that the information comes from countries such as the U.S.A., Canada and Germany, not in the U.K.

It is beyond the scope of this research to look into all the points that have been flagged up in the literature review by Coxon & Williams (unpublished), therefore, this research will be more specific and investigate the personal experience of practitioners working with adults with a HFASD. Certain aspects may come up and be mentioned within this research that may well address some of the above points, such as their training needs. This is being investigated because one can see from the imbalances and gaps in the literature that need to be addressed that a good starting point would be to look into what the personal experience is of a practitioner working with this client group using a qualitative research method. This may bring up what kind of struggles, challenges, and successes they may have in working with this group and how they may feel things may or may not be lacking in their training, practice or knowledge. This is relevant to the world of psychotherapeutic and
counselling psychology as it may help to inform others who wish to work with this client group and inform the organisations who employ the practitioners about what may be effective (or not) and help inform their systems.

In order to be able to fulfil the aims and objectives from the research, it asks the question: What is the experience of practitioners working with adults with a high-functioning autism spectrum disorder?

The question that is being asked is hoping to explore a broader scope of experience due to the paucity of the current research, especially in this country. Due to the quantitative data out there and absence of qualitative research, the researcher has decided to use the qualitative research method of interpretative phenomenological analysis (IPA). This is also due to the research question as an exploration of individuals’ broader experience is required. A qualitative research method gives a depth of understanding as the data found is richer, can be more descriptive and also allows for a sensitivity to context that may not be present in a quantitative method (Lyons & Coyle, 2007). The researcher is using IPA as they wish to capture what the experience is like for this group of individuals and to see what meaning they give to those experiences. IPA would be appropriate to utilise in this case as it focuses on the individual’s inter-subjective experience and its idiographic approach allows the researcher to look more specifically at their unique experiences (Lyons & Coyle, 2007; Howitt, 2010). The researcher wished to focus on the individual’s sense-making and the similarities and differences between individuals and IPA allows for this due to its commitment to exploring the individual’s inter-subjective sense-making. IPA embraces a critical realist position (that there is no such thing as a subjective reality and is a co-construction between people) as the epistemological framework as the researcher is aware that knowledge is not objective, as their presence can be a factor in their participants’ answers and that a researcher comes with their own perspectives and perceptions (Lyons & Coyle, 2007). The method for data collection required one-to-one, semi-structured interviews as it is the grounding aspect of qualitative research and also gives the opportunity to gather in-depth data on the topic to help create meaningful information (Howitt, 2013). This approach is able to provide a set of flexible guidelines that can be adapted by each researcher in light of their research objectives (Smith & Dunworth, 2003) but still sit firm in the ontological and epistemological positions that have been stated and have been consistent in the methods utilised within this study.
Within this research, the researcher chose IPA (Smith, Jarman, & Osborn, 1999) and this choice of method was informed by the epistemology of the researcher and always starts with the research question. With this in mind and taking into account the critical realist position of the research question and the researchers own stance, the natural choice was IPA as formulated by Smith, Jarman, & Osborn (1999). It would not be appropriate to use Grounded Theory (Charmaz, 2006) as there is some information already out there and the researcher was not looking to develop an inductive theory, nor to use Discourse Analysis as the aim was to explore a reflection of an individual’s experience which is not the aim of this method, and nor was it appropriate to use Narrative Analysis as this method is too individualistic in nature and does not look for commonalities which did not fit with the aim of this research (Lyons & Coyle, 2007).

IPA comes with its own limitations such as the fact that it only contends itself with the ‘how’ and not the ‘why’ which only shows the relational unit of self and the world and this makes it difficult to advance our knowledge of why such experiences happen, there is also an assumption that each participant is fully able to vocalise their experiences in a way that is suitable enough for this method and to gain viable results, and even though we analyse the participant’s language within IPA in terms of meaning the researcher does not look at the role of language – many researchers argue that language constructs rather than describes reality and this not taken into consideration within this method (Willig, 2008). To the researcher, it would seem that the limitations listed are also the strengths listed in why other methods would not have been appropriate to be utilised with this research question and this appears to highlight how qualitative research can be a very personal experience and each method is chosen for specific reasons. Some qualitative methods may appear better than others and each have their strengths and limitations, however, each research project is unique, specific and personal.

Method

Participants

Participants were chosen using purposive sampling as the researcher is researching a specific demographic of individuals and will have an inclusion criteria (Smith & Osborn, 2008). IPA uses a fairly homogenous sample (Smith & Osborn, 2008) and they therefore
chosen to use participants who have been or are working therapeutically with adults with a HFASD in the field of psychotherapy or counselling psychology and have been working at least two years post-qualification. The professionals were all registered (or had during their psychotherapy work) with a governing body such as the British Association of Counselling and Psychotherapy, the British Psychological Society, or the Health and Care Professions Council to validate their credentials as a working professional. The practitioners came from different theoretical backgrounds and the researcher recognises that this may bring up similarities or differences (if any) but as this is an explorative study it will be part of the information garnered and can be looked at in further research. Participants were recruited by contacting the National Autistic Society and using the therapist contacts they pass on to their members and also contacting therapists directly who advertise as having a speciality in working with adults with a HFASD. The sample size is 6 participants due to the limitations of time for this study and also to ensure that there will be an in-depth, detailed analysis of the information given (Smith & Osborn, 2008).

All six participants have been anonymised for confidentiality reasons and have therefore been given pseudonyms that fit with the humanistically informed model of a person within IPA (Graham, 1986). Please see below for demographic information.

Table 1.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Registered</th>
<th>Therapeutic Orientation or Interventions Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daniel</td>
<td>52</td>
<td>M</td>
<td>White British</td>
<td>National Association for Counsellors, Hypnotherapists and Psychotherapists (NACHP)</td>
<td>Integrative – analytics psychotherapy and transactional hypno-analysis.</td>
</tr>
<tr>
<td>Sally</td>
<td>61</td>
<td>F</td>
<td>White British</td>
<td>British Association for Counselling and Psychotherapy (BACP)</td>
<td>Integrative – counsellor and psychotherapist (CBT, TA, Gestalt, NLP, Mindfulness, and Animal Assisted Therapy).</td>
</tr>
<tr>
<td>Melanie</td>
<td>35</td>
<td>F</td>
<td>White British</td>
<td>British Psychological Society (BPS) and Health and Care Professions Council (HCPC)</td>
<td>Counselling Psychologist – CBT, Existential-Humanistic, Psychodynamic, Solution Focused, and Systemic Therapy.</td>
</tr>
</tbody>
</table>
All participants were White British, ranging in ages from 35 to 61, and consisted of two males and four females. A range of therapeutic orientations are represented in this sample and all participants are registered with a governing body.

**Ethical Considerations**

The main aim of this study is to produce an ethical research design that upholds moral data gathering and analysis (Mason, 2002) and to prioritise the safety of the participants (in terms of possible power potentials, informed consent, and causing no harm). It is the researcher’s intention to be empathic, curious, open and flexible with the participants. It is always the intention to avoid causing harm, conduct the research with sensitivity and care, review and reflect on the work throughout, and to work with the supervisor to anticipate any potential safety issues. This is assured by adhering to the code of ethics as outlined by the British Psychological Society (2011) and the Health and Care Professionals Council (2008). Safety issues may include the breach of confidentiality of the participant’s clients or the integrity of a participants profession be compromised if their information is made public. Participants of this study are not classified as vulnerable adults and therefore it was not deemed necessary to submit an ethics form to the Faculty Ethics Committee of the University of Surrey. It was considered ethically acceptable according to the ‘ethical guidelines for teaching and research’ and was carried out under the guidance of the ‘code on good research practice’. This is to ensure it is monitored and audited by the committee for adherence to
legal/ethical requirements and good practice. Due to the private nature of the therapeutic experience and the information given out, all participants were ensured of their anonymity and that information will stay confidential. The raw and unedited data transcripts were only seen by the researcher and any information is anonymised and pseudonyms are used. All work will be stored on a password protected computer and any paperwork or recordings will be locked away in a storage cabinet to ensure the protection of the information. The interviews are audio recorded but destroyed after transcription. The transcripts will be kept in accordance to the Data Protection Act (1998) for up to ten years on a password protected computer but will be completely anonymous.

Participants were contacted and given information about the interviews and what will be involved by way of an Information Sheet (Appendix A.) from the start. It provided information about the nature of the research, confidentiality, on how to access any support needed if they feel that any problems or distress has arisen due to this study and the contact details of my supervisor and myself. Participants gave informed consent (Consent forms in Appendix B.) and they have the right to withdraw at any point until one month after the interview. Participants are also given a Debrief Information Sheet (Appendix C.) after they finish to be able to put their participation into context, answer any questions they may have had, or get in contact with us if they experience distress or have more questions.

Procedure

Participants were recruited via emailing (recruitment email in Appendix D.) psychotherapists or counselling psychologists that were advertising their specialist services through the National Autistic Society. Once participants were recruited, an Information Sheet (Appendix A.) and Consent Form (Appendix B.) were sent to them via email. Consent forms were either sent back via email or by post and all participants gave their consent. An interview schedule consisting of six questions (Howitt, 2010) was devised which is semi-structured to allow participants to freely recall their experiences. The questions are open-ended and non-directive but will ask participants to speak about their experiences when working with this group of individuals. Each interview was recorded and then transcribed fully. There was one extra question at the beginning that asked the participant what their age, gender, ethnicity, qualifications and registration with a governing body were.

All interviews were conducted over the phone except with Melanie, who the researcher met at her work office and interviewed there. Each interview was conducted in a relaxed atmosphere in order to provide the participant with space to recall their experiences.
Each interview lasted between 45 minutes to 1 hour and 15 minutes and was recorded from start to finish. The researcher did have a specific research aim with their questions but there was ample opportunity for the participant to lead the interview in their direction and to address anything that was particularly pertinent to them. This allowed for a richness of exploration and meaning within the original frame set by myself. After the interview, each participant was sent a Debrief Information Sheet (Appendix C.) and given the opportunity to raise any questions or problems.

Analysis

In order to show transparency (Yardley, 2000) within this research, it is important to show the analysis process. Once an interview has been transcribed, it is read through first on its own to feel the coherency of the discussion, it is then split into a table with blank columns on each side of the text. A second read through provided the initial coding (Smith, Jarman, & Osborn, 1999) in which, the researcher, wrote down any initial ideas, thoughts, concepts that were present within the text but also that came to mind whilst reading it. The third read through provided the sub-themes that later on would help create the master themes (Smith, Jarman, & Osborn, 1999). This process required looking back at the text as well as the initial coding but then using the skills of a qualitative researcher and psychologist to bring them together and use context within this. This meant that larger themes or connections were starting to become more visible. Now that the themes have started to emerge, the next step required creating a list of the emerging themes and grouping them together due to connections and shared meanings. Some themes became subordinate and some became superordinate (Smith, Jarman, & Osborn, 1999). This process brought together five master themes which appeared to be connected and important but after reflection, careful selection and discussion with my supervisor, they were brought cohesively together to make three master themes. A sample of a transcript with “Hope” is given in Appendix F for information.

Credibility of the study

In order to assure and check for credibility, the researcher used Yardley’s (2010) principles of credibility when using qualitative research methods. The researcher will ensure their sensitivity to context, commitment and rigour in the analysis, be transparent and coherent and show impact and importance of the data in the wider community. They will also
use Fossey, Harvey, McDermott & Davidson’s (2002) principles to ensure rigour, reflexivity and validity.

Results

Participants came from various therapeutic orientations, training, and philosophies of therapy but some commonalities started to emerge from the data. This data helped create, by the use of the selection perceptions and skills of the researcher, certain sub-themes that were eventually cohesively put together into three master themes. Using the analysis guidelines from Smith, Jarman, & Osborn (1999) as described above, the process of analysis appear to have brought forth three master themes. These themes are 1) the importance of the therapeutic relationship, 2) feelings of limitations, and 3) the effects of an autism label. The following will show a detailed overview of the three master themes and will be discussed fully in the discussion. It is also important to note that all participants were very verbose and found it easy to connect to the questions. They spoke about their experience without much hesitance and were eager to share their experiences especially in the interest of research and spreading the word of their clinical work.

Overview of three master themes

Theme one – The importance of the therapeutic relationship.

The therapeutic relationship as defined by Clarkson (2003) includes five facets – the working alliance, the transferential/countertransferential relationship, the reparative/developmental relationship, the person-to-person relationship, and the transpersonal relationship. All six participants spoke at length about the therapeutic relationship in various facets in their interviews and how this is the most important aspect of the therapy. Even though all six participants came from different therapeutic orientations, they all stated that without the therapeutic relationship there would be no therapy. This highlighted by the following quotes of the participants:

Hope: “it is no different to working with anyone in a therapeutic way, especially working from a person centred perspective, because counselling of any sort with any individual is about forming a relationship with that person, and that is the most important thing”
Sally: “but we have to try to find a way, a clinical bridge, you know, a way in to communicating with these clients, because, you know, they need our help and the onus is on us really to find a way of helping”

Stacey: “to have a proper therapeutic relationship, the key to that is good communication and interaction. So if you can overcome those, the barriers that they have to good communication and interaction, then they can engage as well as everyone else”

Roger: “I think every counsellor has to be person-centred, even though if you’re not trained in that, it has to be a, part of what you do. Even if you’re doing CBT you have to have elements of person-centred to build the relationship. And, so, my focus is always on developing that relationship immediately, and, so, I use whatever I can to establish that”

Melanie: “you have to step into this client’s world view and into their world, that is so important, and I know on the counselling courses we train this, we talk about intersubjectivity, we talk about the strength of the relationship, but if you don’t do that you won’t understand them, you won’t be with them. It’s important to be able to be with and I understand at times this group can be extremely intense and that can be hard to sit with, but, you know, if you can’t do that then why are you a therapist?

Daniel: “as with most people, whether they’re on the spectrum or not, we understand that not everybody might like us, and so, yeah, in terms of therapeutic relationship it’s usually quite a good idea to establish some sort of rapport with the client, and if we feel that we can’t help then we’ll have a look at recommending somebody else”

As shown in the quotes above, all participants explicitly state the importance of the therapeutic relationship, but as Clarkson (2003) has shown that there are many facets to the relationship, so does the participant’s definitions of or inclusion of other aspects as well. Every participant spoke about meeting the client’s needs, as shown by Stacey:

Stacey: “that’s what we’re committed to doing, is to, you know - we’re a specialist service, so we’re committed to meeting those particular needs for this client group that might not be able to be met in a more mainstream service”
Every participant also spoke about flexibility of the therapist, as shown by Hope:

Hope: “It can be anything and we try and be as flexible as we possibly can to give individuals that come through the door the opportunity to engage with what we’re offering, so there are no strict and rigid rules and regulations. We’re as flexible as we can be”

Every participant spoke about using creativity as a therapist, as shown by Roger:

Roger: “well, I think creativity is really important with someone with, on the spectrum, but creativity is important for anything, because… each person doesn’t fit and, er, they’ve got A, B and C so I’m going to do this here. Er,… it’s only until we kind of explore, we find out or, er, maybe more this, er, or, the, the, they’re suited this”

It seems that meeting client’s needs, being a flexible therapist, and being a creative therapist helps to facilitate the therapeutic relationship and shows engagement from the therapist and want to help the client. It also shows the therapist as someone who cares and is proactive in their part of the relationship.

Another aspect that appears to be something that is necessary for the therapeutic relationship to be effective for this client group is structure and goals – a more pragmatic approach to sessions. This is shown by a quote from Melanie:

Melanie: “I think there needs to be a practical element, psycho-educational. If you’re trying to work with a client who has never reflected on a relationship before whatsoever, never heard of the word ‘reflectivity’, ‘reflect’, what would you do? You’re stripping back the fundamentals and you’re almost building that up, developing that, whether you’re going to call it teaching, development, whatever, whatever, you are, you’re developing that with them”

It is also very important to highlight that all six participants were adamant that adults with HFASD can maintain a therapeutic relationship and that they are able to utilise it within the context to help facilitate growth and change. This is shown by a quote by Hope:
Hope: “can you have that therapeutic relationship, and absolutely 100% yes you can, and 90% of the people that walk through the door, yes we do have a therapeutic relationship. There are one or two that really do struggle with engaging in a therapeutic process, but I think that’s true of everybody. There are some people out there that struggle with that”

Unfortunately, due to constraints that make this beyond the scope of the study, it is not possible to speak in further depth about this theme. It is still pertinent to mention other sub-themes that presented themselves within the data but due to not all participants sharing them they were not as strong – these included: being adaptable/accommodating as a therapist, being integrative as a therapist, the use of visual communication, being open-minded, being non-judgmental, and the feeling of being rewarded or enjoying the work as a practitioner.

**Theme two – “Feelings of limitations”**

Within the data, it emerged that all participants felt feelings of frustrations about various things; they felt it limited their experience as a practitioner working with this client group. This meant that it impacted not only them but also the client’s quality of their experience. All participants showed feelings of limitations, as shown by quotes below:

**Limitations on the lack of support services for people with ASD** – Daniel: “quite frustrated in the lack of specialist therapeutic support around some of these kinds of issues, for example, with depression and anxiety and things on the spectrum. The answer was often medication of some sort and for some that was appropriate and suited them, but I think for many the medication was given just because we didn’t have anything else to do”

**Limitations of funding for services** – Melanie: “Have more funding from the government, more funding from these tight arse commissioners, between us, drives me bonkers, would be good. I think the problem is in the past, because there’s been this kind of view of Asperger’s can’t be cured, why give it therapy, because therapy’s always been viewed as a treatment as such, how can you treat Asperger’s? So this has been the ongoing debate, it’s been stuck in pragmatics as far as I’m concerned”

**Limitations of top-down changes** – Roger: “there’s only so far you can go with bottom-up changes. So I think there needs to be more top-down changes coming from, er, strategic thinking, policies, er, autism bills”
**Limitations of current training and ASD knowledge of professionals** – Stacey: “I don’t think people have been trained up to understand the needs of those people with hidden disabilities like autism, so the assessors might be very good at being able to tell if you’ve got you know, actual physical problems or mobility problems, but actually a lot of them, in my experience, haven’t had really any idea about the impact of autism on somebody’s ability to work and things like that”

The limitations and frustrations expressed above seem to be cohesive in their connection to organisations and services. There is a feeling of no agency and understanding in conjunction with the clinical work that they as practitioners are doing. The participants appear to feel like they do the work but others make the decisions on the funding, support services, government social changes, and training. Overall, there is a feeling of dissatisfaction and a want for change in order to enhance the well-being of their clients as well as help the practitioner do their work.

**Theme three – “The effect of the autism label”**

The effect of the autism label is a theme that has emerged from all six participants. Within this theme co-exists three sub-areas – label, fear, and stereotype. Each participant spoke about how the label of having autism has an effect on each individual, whether it be positive or negative. This is shown by a quote by Stacey:

*Stacey: “the majority of people who seek a diagnosis and then get a diagnosis, actually it’s a really positive thing for them to get answers to why they’ve maybe always felt a bit different to other people, you know, why certain things in their lives have happened. And also what I have counselled people for quite a long time who have then struggled to come to terms with that diagnosis. So even though they’ve wanted it, then being given it, can still be a shock and some people need more help than others in sort of re-evaluating their lives really in the light of that diagnosis”*

Participants also spoke about how access to services is very diagnosis specific. This can be very difficult for individuals with ASD as there is an element of gate-keeping involved in their care and they would have to fulfil certain criteria in order to access services. A quote highlights this:
Melanie: “And it is a label that come into all these things, but within the systems of which we work now people, individuals, they can’t have therapy, specialist therapy, because they haven’t got an official diagnosis, you know, in the NHS that’s quite important, not so much in private practice but NHS it is”

Participants also highlighted that individuals are often misdiagnosed with other problems until a professional appraises them correctly or has the right knowledge in order to specify that they do indeed have an ASD. Daniel is able to show this very eloquently in the below quote:

Daniel: “I was talking to a lady today who was thinking of coming to see me, she was diagnosed at the age of 23 and had previously been diagnosed with a number of things, including borderline personality disorder, bipolar disorder, obsessive compulsive disorder and obsessive personality disorder, all of which have now been discounted and superseded by her diagnosis of Asperger Syndrome, and when she was telling me her story, to me it was patently obvious that that’s what she had. She said, yeah, one psychiatrist two years ago told her that she couldn’t have autism because she looked at him! I mean, that was going out of fashion when I first started 30 years ago”

All participants spoke about the fear of other practitioners, that their ignorance around autism caused them to believe myths which in turn created a fear which stopped them from taking on individuals with ASD. Quotes below highlight this fear:

Hope: “it upsets me that people believe that, and like I said before, it is fear and ignorance of what’s going on. There are some really quite damaging misconceptions about autism still. Even though there is a lot more awareness now than there ever used to be, I do think there still quite a lot of damaging ideas out there about what autism actually is”

Sally’s quote below is particularly interesting as she is showing that she only gets referrals to her service via people who have knowledge of autism, know there are services available to this client group, and are willing to suggest this to the clients. She feels some professionals are ‘enlightened’ and by this the researcher is assuming she means enlightened to ascertain the symptoms and signposting them to the correct and helpful service.
Sally: “I get the odd referral through a psychiatrist or a GP, from professionals who I consider to be enlightened, but it’s not widespread, the vast majority of my referrals will come through something like the National Autistic Society or residential facilities, or parents with autistic children”

What appears to be particularly damaging to individuals with ASD are the stereotypes or misconceptions people have of them and they are not able to ‘pigeon-hole’ them as they would like.

Daniel: “I’ve had a number of conversations with therapists who themselves have referred people on to us because they feel a bit out of their depth. Now in some cases that might be the case, …….., it’s just the idea that people have, that because a person with autism or Asperger’s can’t necessarily engage socially in the same way as everybody else the myth seems to be that therefore they can’t engage in the counselling process, because there is inevitably some sort of social contract that exists between the client and the therapist”

As Daniel shows in his quote above, practitioners are reticent to work with individuals with ASD because they have certain opinions about what makes a person autistic and consequently prohibits their ability to work with them. It may be that they do require additional support but the question appears to be whether or not a practitioner will be willing to try to help these individuals. A diagnosis or label may set up an individual to come with certain stereotypes or misconceptions attached to them; this in turn can cause them to be turned away from services or receive support that might be damaging towards them.

Discussion of analysis

Within this investigation, the researcher utilised an IPA style advocated by Smith, Jarman, & Osborn (1999) which describes how this method is able to be used in a step-by-step guide. The exact procedure is discussed in the Analysis section above, so the researcher will not repeat this. The three master themes that were created from the data were – the importance of the therapeutic relationship, feelings of limitations, and the effects of an autism label.

Once a transcript has been read through for the first time, the researcher started to read through a second time and note initial thoughts on the left side of the text and on the third read through, the researcher would note conceptual ideas that utilised the researcher’s
psychology training and knowledge (Smith, Jarman, & Osborn, 1999). Taking the following quote, the process looked like this: *Hope: “it is no different to working with anyone in a therapeutic way, especially working from a person centred perspective, because counselling of any sort with any individual is about forming a relationship with that person, and that is the most important thing”*. Initial ideas quoted to the left hand side were: “difficult for practitioner to answer as no different to non-ASD, it’s about the therapeutic relationship, no expectations/preconceived ideas, open to their experience, person centred perspective”. With the third read through, all the initial ideas were taken into account but the researcher looked for something that would sum the experience up and this quote in particular spoke to the researcher about the importance of the therapeutic relationship, which is what was quoted on the right hand side of the text. Throughout the text, once initial ideas had been reanalysed, the researcher kept looking for how often certain ideas/concepts were repeated. This was taken to the researcher’s supervisor and both text and concepts were discussed to see how accurate they felt. Once this was done, the researcher wrote each concept down on a Post It note and started grouping the concepts/Post It notes together into larger groupings that spoke of the similar experience. For example, under the theme of the ‘importance of the therapeutic relationship’ the researcher also grouped therapist traits, therapist understanding the client, therapist flexibility and creativity, therapist interventions, meeting client’s needs, being accommodating, enjoyment of work, therapist curiosity, transpersonal aspects of the work, empathy, individualisation, containment, exploration, imagination, and clarity. All these concepts/ideas were either instrumental to the therapeutic relationship or the therapeutic relationship impacted their efficacy in the therapy, thus the researcher felt it came full circle and encompassed multiple concepts within the one master theme.

To show further examples, using the following quote from the master theme ‘feelings of limitations: *Limitations on the lack of support services for people with ASD – Daniel: “quite frustrated in the lack of specialist therapeutic support around some of these kinds of issues, for example, with depression and anxiety and things on the spectrum. The answer was often medication of some sort and for some that was appropriate and suited them, but I think for many the medication was given just because we didn’t have anything else to do”. With this quote, initial ideas quoted on the left side of the text included: “became frustrated, lack of specialist therapeutic care for LD, answer is medication, lack of knowledge, balance, system anxiety, fix the problem”. These are initial thoughts, concepts, and ideas that popped into the researchers head during the second read through. The right hand side of the text had this summed up as ‘frustration with the system and lack of support’ as the researcher felt this
encapsulated the concept in the best way possible and took into account the experience as a whole. The same analytic system as described above was utilised for this theme too – discussion with supervisor for concept accuracy, using Post It notes for the concepts mentioned and then grouped into larger master themes. Within these Post It notes, concepts such as: lack of support services, lack of funding for services, lack of top down changes, lack of current training and ASD knowledge, clients help seeking behaviour, lack of communication, lack of openness and honesty, lonely world for ASD practitioners, politics/economy, problems with peers, gate keeping, frustration and unhappiness were included. These were all felt by the researcher to be connected to the practitioner’s feelings of limitations and insufficiency and how this impacts the practitioner experience of working therapeutically with this client group.

The master themes were created as they included concepts and ideas that appeared most frequently within the data and then the researcher attempted to find some order within this and fit them together. This was to try to show how practitioners described their experience, how the researcher made sense of what they described and bring this together in a coherent manner for the reader to be able to digest this and possibly take this further in terms of their own education or in their own practice.

Discussion

Looking at the prior knowledge gained from systematic literature review carried out by Coxon & Williams (unpublished), it appeared that there was a paucity of research in the experience of practitioners working with adults with HFASD, especially in the U.K. The majority of research came from a medical model and looked at the effectiveness of certain therapeutic interventions (El-Ghoroury & Krackow, 2011; Sze & Wood, 2007; Cardaciotto & Herbert, 2005; Beebe & Risi, 2003; Singh et. al., 2011, Spek, Van Ham, & Nylicek, 2013), and there was an attempt at balance by looking at single-case studies that also claimed effectiveness of their therapeutic interventions ((Mero, 2002, Levy, 2002, Topel & Lachman, 2011, Sugarman, 2011, Koenig & Levine, 2011). Few studies looked into what it was like for practitioners working with this client group and what they feel might be lacking or helpful (Leather & Leardi, 2012; Weiss, Lunsky & Morin, 2010; Brookman-Frazee, Drahota, Stadnick & Palinkas, 2012, Jacobsen, 2004; Munro, 2010; Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman, 2005, Gawronski et. al. 2011).
With this in mind, the objective was to carry out qualitative, in-depth research looking into the experience of practitioners working with adults with HFASD within the U.K. It was deemed that IPA was the best research method to utilise as it ensures a rich, in-depth, meaning-making analysis (Smith, Jarman, & Osborn, 1999) that takes into account a critical realist perspective. The researcher is part of the dynamic process of interviewing and analysis and bring with them opinions, meanings, and perceptions of their own that will colour what the participant has said. The research question that emerged was one that was very broad due to the vast experience out there but also due to the paucity of research. It was not possible to be specific at this point in time and therefore an exploratory stance was needed. Six participants were recruited, acquired informed consent, interviewed and their interviews were fully transcribed. Their data was analysed following the guidelines of Smith, Jarman, & Osborn (1999) and three master themes emerged. These themes are: 1) the importance of the therapeutic relationship, 2) feelings of limitations, and 3) the effect of the autism label.

The importance of the therapeutic relationship was expressed by all six participants and it came across as the most vital part of the therapeutic exchange, especially if the individuals wanted to work together. It is highly important to show and stress that individuals with HFASD are able to engage in therapy and are able to maintain a therapeutic relationship. A way to try and demystify autism is to carry out research such as this study so that practitioners become aware that it is a possibility to work with this client group. This is strongly highlighted by the quotes presented and in the overall data that was gathered.

It was interesting to see that all six participants spoke about how when working with this client group, a therapist needs to have the ability to be flexible, and therefore be able to accommodate the client’s needs, as well as, the ability to be creative in the therapeutic space. If a client has particular needs or certain struggles (including neurotypical clients), a therapist should be able to try different ways of communication and engaging the client. This may be through visual props and communication, through the use of play and toys, or through taking the therapy outside the office or working with an animal. It also appeared that even though all practitioners were from different therapeutic orientations, it did not really seem to matter as all of them were integrative and adapted themselves to the needs of the client as long as the therapist and client had a working therapeutic relationship. There seemed to be a stylistic detail that all practitioners commented on and this was to do with making sure that the sessions were structured and were of a more pragmatic therapist style. This was explained as something that is specific to the client groups needs as the transparency of the sessions made the encounter less anxiety-provoking. The importance of the pragmatic style and attending to
the client’s needs are backed up by findings by Leather & Leardi (2012); Jacobsen (2004); Munro (2010); Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman (2005).

Feelings of limitations that arose were of an organisational and services nature – not enough support services, not enough funding for services, not enough top-down government social changes, and not enough adequate training for current and future practitioners. The feelings were ones of frustration and also lack of control. Amongst the participants, there was a sense that they carried out their clinical work as best they could within the limits of their contexts. All these limitations have huge effects on the work of practitioners because without funding and the support of the government and the organisations they work in, it would be futile to even try to provide therapeutic services. It would make a lot of sense that if there are these limitations to contend with, then a feeling of having no agency would be prevalent and would highly affect a practitioner in the work they were doing. It also has a knock-on effect on the practitioners who are in training now, if they are not equipped with the right knowledge in order to carry out the work and may even harm the clients. These results are echoed in the findings of Weiss, Lunsky & Morin (2010) and Brookman-Frazee, Drahota, Stadnick & Palinkas (2012).

The effect of the autism label is an incredibly powerful concept. The way a client makes sense of their diagnosis may be part of the therapeutic work but also may be how others want to categorise human experiences. As shown in the quotes, some clients may find it a positive or negative experience having a label but if they are grossly misdiagnosed, then this can impact the therapeutic relationship. How a client interacts with services will be hugely dependent on how they are treated and how they assume they will be treated in the future. It is also important to note that gatekeeping is within this concept, as people will only gain access to services if they have a diagnosis. This can feel incredibly limiting to the individual especially if they have an illness that needs to be “treated” or “cured”. The fear and ignorance a client may come across from practitioners can also be incredibly damaging to their self-esteem and future use of services. The practitioner who is unwilling to be flexible or creative (as mentioned above) and blindsided by misconceptions, appears to be a practitioner in need of more training and supervision nor does it mesh well with the ethos of counselling psychology. This theme appears to be a newly emerged concept as it has not been apparent in existing research. It is an interesting concept to possibly delve into deeper as it has huge consequences for both the practitioner and the client.

Whilst conducting a literature review (Coxon & Williams, unpublished) as well as the looking for existing theory and research stated in the Introduction of this research, some
information garnered was influential in the creation of the master themes during analysis and also gives credence to what has been found in the data within the participant’s interviews. Numerous case studies looking at psychodynamic therapy (Mero, 2002; Levy, 2011; Topel & Lachman, 2011; Sugarman, 2011; Koenig & Levine, 2011) and numerous modified CBT studies (El-Ghoroury & Krackow, 2011; Sze & Wood, 2007; Cardaciotto & Herbert, 2005; Beebe & Risi, 2003; Chalfant, Rapee & Carroll, 2007; Reavan, Blakely-Smith, Culhane-Shelburne &; Hepburn, 2012; Ehrenreich-May, Storch, & Queen, 2014; Selles et. al., 2014; Reaven et. al., 2015; Storch et. al., 2015; Van Steensel & Bögels, 2015; White, Schry, Miyazaki, Ollendick, & Scähill, 2014; Wood et. al., 2015; Nadeau, Arnold, Storch, & Lewin, 2014; Hesselmark, Plenty, & Bejerot, 2014; McGillivray & Evert, 2014; Kiep, Spek, & Hoeben, 2015) with both children and adults with ASD stated that the therapeutic relationship is paramount in the therapy, as was also found within the analysis. This may suggest, especially as other researchers and practitioners have found this to be the case that the relationship is a fundamental aspect within therapy, just as it is with neurotypical clients.

Leather & Leardi (2012) provided guidance for clinicians working with this client group (garnered from their own experience) and stated that the therapeutic relationship is vital but also that a clinician needed more knowledge of the HFASD presentation, the medication they are on and how this impacts the therapy, and also how the social support a client may or may not be receiving is important. This information as stated is echoed in the findings of this research. As shown in the second master theme ‘feelings of limitations’, practitioners find specific ASD knowledge is highly beneficial for them to have and it can negatively impact a client if the practitioner is untrained or ignorant of their specific core symptomology. This includes knowing about the uniqueness of ASD presentations, what medication they may be on and how this may affect the therapy, as well as the practitioner’s knowledge of the social and system support available to the client and how this may impact the care that the client is receiving. Participants in this research lamented about the lack of training of their peers and how deficient the systems and support available out there is. This is supported by Lunsky, Weiss, and Morin (2010) who found that mental health practitioners were hugely lacking in training for developmental disorders especially in care for adults and also by Brookman-Frazee, Drahota, Stadnick, & Palinkas (2012) who found that practitioners would often find it challenging to work with this client group due to their usual interventions not working, they were insufficiently trained, and there were system problems hindering their work.
As stated in the Introduction, there seems to be a lack in literature and research on how practitioners work with and experience therapy with clients with HFASD. However, Jacobsen (2004), Gaus (2007), and Paxton and Estay (2007) have published practice manuals for information and several articles (Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman, 2005, Munro, 2010, Tebartz van Elst, Pick, Biscaldi, Fangmeier, & Riedel, 2013; Woods, Mahdavi, & Ryan 2013; Koelkebeck, Riedel, Ohrmann, Biscaldi, & Tebartz van Elst, 2014) have been written in recent years about how a practitioner may be able to work with this client group. Within these publications, the authors have not looked at the personal perspectives of practitioners in a qualitative manner as with this research but they bring forth valuable educational information for current and future practitioners. Within these publications, the researcher appears to find echoes of what has been found in this research and specific codes found within the text are: the importance of the practitioner having knowledge of ASD presentations, how this may uniquely affect the individual, using the client’s frame of reference (also can be seen as part of the therapeutic relationship as it facilitates growth and change), that the practitioner should have a structured and pragmatic attitude to their sessions and interventions, willingness to understand the client, and to take on board their co-morbidity and the psychiatric needs of the client. It is difficult to state how influenced the analysis is by the theory and research read by the researcher before they created the master themes but it is safe to state that they had an impact and may have shown the researcher the importance of some codes over others and helped create the themes.

The first two master themes, “importance of the therapeutic relationship” and “feelings of limitations” appear to be discussed in some current research as shown above, however, the third master theme “effects of the autism label” is not as prevalent. There is some discussion of clients being misdiagnosed before an ASD diagnosis and that there is an aspect of gatekeeping involved in services but what seems to be lacking is the voice that practitioners can give to their clients. As found within this research, stereotypes and misconceptions around this client group abound freely and this can “put off” other practitioners. It is obvious that not every practitioner will want to or need to work with this client group but as Brookman-Frazee, Drahota, Stadnick, & Palinkas (2012) showed that 76% of practitioners had work therapeutically with ASD children within a Community Mental Health service, practitioners are highly likely to work with this client group at some point in their career. It seems important that fear of working with and misconceptions about this client group are laid aside and ideas refuted.
Due to the paucity of the research available and the researchers own understanding of the field, it would appear that this study has the potential to give new insight into this area and add to the understanding that has been established. It is also important to note that this study does have some limitations. It is an explorative study which is only beginning to scratch the surface of what could be an incredibly rich field of research. The scarcity of practitioners to interview seems to suggest that this is a small, undervalued area that works hard to do the best with what they are given but are still nonetheless doing important work with a client group that needs support. Unfortunately, it was not able to find practitioners of diverse ethnic backgrounds which may limit some of the information that was gathered but both genders have been represented and no apparent gender differences seemed to emerge. The aim of qualitative research is not to be able to generalise results (Willig, 2013) such as in quantitative research but to be able to give an insight to personal experiences and what it means to them. It is possible to infer from the data gathered and make possible assumptions about how this may be helpful to other practitioners.

The use of IPA as a methodology brings with it various limitations that are important to be noted and discussed. Willig (2008) states that this methodology contends itself with the ‘How’ of the participant’s experience and does not look at the ‘Why’ they are experiencing this. This can sometimes leave the analysis feeling less well rounded and some researcher’s feel that this is leaving out a large chunk of information that could be vital to the overall picture. Willig (2008) also speaks how IPA does not look at the role of language in the data as many researchers believe that language constructs reality and not just describe it and IPA does not take into account the fact that some participant’s may not be able to fully vocalise their experience in a manner that would help to produce rich data. This can make the analysis harder to interpret for the researcher or even render some of the data as inadequate.

The researcher found that the methodology did present certain limitations when interpreting the data in the analysis. As Willig (2008) stated above, the methodology looks at the ‘How’ and not the ‘Why’ of the participant’s experiences, which the researcher found difficult to stick to as it was in their nature to question the status quo and made them feel like they were not presenting the full picture available. It may be reasonable to take the results as found in this research project and conduct further research into the ‘Why’ this has happened and help to bring the research further. Within this research, the researcher was able to find very vocal, well educated, and well informed participants which made the process of analysis easier than if the participants found it difficult to vocalise their experiences.
The researchers own experience of using IPA has been a mostly positive one as it was interesting to speak to each participant about their experience, it is a rare experience to take someone’s dialogue and look at it in fine detail and really think and analyse what has been said, and the results help bring information, education and may change in how things may be operating currently. In the ways that have been described, it was quite an empowering experience. However, it did come with some limitations. Due to time being limited it did not feel like the analysis was as in-depth as it could have been and this method needs plenty of time in order for the analysis to be as thorough as possible, this is difficult to do unless the researcher and the project has that opportunity. On a personal level it also felt like quite an isolated way of working as it is you and the text working together and when hours are spent on this it can be quite isolating.

Interpretations of the data presented by participants may be influenced by the existing research and theory read by the researcher such as Leather & Leardi (2012), Lunsky, Weiss, & Morin (2010), and Brookman-Frazee, Drahota, Stadnick, & Palinkas (2012). They have been influential in that they all echo similar findings and may have helped the researcher mould their master themes due to having come across this type of information before. However, it could be argued that the results in this research are giving evidence for information that has already been discussed in existing literature. IPA does recognise the role of the researcher within this process and that this will influence how the themes are created (Smith, Jarman, & Osborn, 1999) but it does not show this explicitly and does not show how much of the data was used and how much of the researcher’s perceptions were brought into the analysis.

Within this research, participants were interviewed both face-to-face as described by many researchers as the ‘gold standard’ of interviewing (Novick, 2008; Deakin & Wakefield, 2013) but also interviewed using the telephone. It has been argued by some researchers that the use of the telephone can result in the loss of contextual and non-verbal data due to the lack of visual cues that we use to have interactions, that it can compromise rapport, the use of probing in the interview and how the responses are interpreted (Novick, 2008), and that subtleties can be missed when not face-to-face (Holt, 2010). However, it has also been argued on the other hand that due to this ‘lack’ of visual cues, the researcher is able to stay closer to the text rather than be distracted by context, non-verbal data, and visual information we gather which we may impose on the results we find (Holt, 2010). It has also been pointed out that using telephone interviews hold many practical benefits such as allowing greater scheduling flexibility, last minute changes being less problematic, less feelings of obligation
towards the researcher due to their travelling to the participant and it being more time and cost efficient (Holt, 2010). Novick (2008) also speaks about participants feeling more relaxed and therefore able to disclose sensitive information and how there appears to be a lack of evidence showing that telephone interviews produce lower quality data. Sturges & Hanrahan (2004) carried out a study which compared face-to-face interviews to telephone interviews and found no significant differences in the interviews and the data that they garnered. Recent researchers advocate the use of telephone interviews as a viable and productive alternative or choice in qualitative research (Sturges & Hanrahan, 2004; Novick, 2008; Holt, 2010; Hanna, 2012).

The experience of this researcher has been a most positive one when using telephones in interviews and no real difficulties seemed to appear whilst interviewing nor when analysing the data. Rapport felt natural and many clients would apologise about ‘going on too much’ as they would become so entrenched in their dialogue. From the researcher’s perspective this was a wonderful reaction to the questions being asked and communication tool being used, as it enabled the participant to forget about the researcher’s presence enough to really delve into their personal experiences. It appeared the participants were relaxed, comfortable and very willing to speak using the telephone.

**Conclusion**

The importance of the therapeutic relationship, feeling of limitations, and the effect of the autism label are three pertinent concepts within the experience of practitioners. It shows that whatever the therapeutic orientation of the practitioner, it is still important to attend to the therapeutic relationship and that it is possible to maintain one with an individual with HFASD. Practitioners also have to contend with certain limitations within their clinical work and this will affect how they work with clients and for their therapist identity. How the autism label affects clients can have a direct impact on the therapeutic relationship and how they will access the services the practitioners provide. It also impacts how current and future practitioners will work therapeutically with this client group.

There is a hope that this study has in part given some insight into what the experience is like for a practitioner to work with an adult with HFASD. The study hopes to open up the field of research and hopefully create more questions that need to be answered. A beginning has been made into investigating the experience of practitioners but there is still scarcely any
research into how this client group experiences therapy. Not only can the themes that have been found in this study be expanded upon but other avenues can also be looked at for future research.
References


Appendix A – Information Sheet

Participant Information Sheet – June 2014

Investigation into the experience of a practitioner working with adults with a high-functioning Autism Spectrum Disorder (HFASD)

Introduction
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?
I am investigating what the experiences are of practitioners who are working with or have worked with adults who have a diagnosis of a high-functioning autism spectrum disorder (HFASD). The investigation will look at the therapeutic experiences involved in this relationship between practitioner and client.
The study will involve one-to-one interviews in a confidential setting and audio-recorded and the interview will last approximately 30 minutes. The interviews can be done face-to-face or via telephone or Skype.

Why have I been invited to take part in this study?
I am interested in participants who work as Psychotherapists or Counselling Psychologists who are registered with any of the following bodies: BACP, HCPC, BPS, or UKCP, and have worked with adults (18 years plus) with a diagnosed high-functioning autism spectrum disorder. The participants need to be at least two years post qualification.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will then be asked to sign a form agreeing to take part. If you decide to take part you can still change your mind and withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way.

Will my taking part in this study be kept confidential?
Yes. All information that is collected about you during the course of the research will be anonymised so that those reading reports from the research will not know who has contributed to it. I will need to analyse and store all the results. It will not be possible to identify you from any of the stored material. Data will be stored securely in accordance with the Data Protection Act (1998) and the audio-recording will be destroyed after the research has been concluded.

What are the possible disadvantages and risks of taking part?
There are no known risks expected to result from taking part in this study however considering that sensitive material may surface due to the nature of the topic (psychotherapy) you could potentially experience some emotional discomfort or distress.
Who should I contact for further information?
Sabrina Coxon – s.coxon@surrey.ac.uk
You can also contact my supervisor – Dora Brown – dora.brown@surrey.ac.uk

This copy is for you to keep. If you decide to participate, you will also be given a copy of the signed consent form to keep.

Thank you for considering participation in this study!
Appendix B – Consent Form

Consent Form – June 2014

Investigation into the experience of practitioners working with adults with a high-functioning Autism Spectrum Disorder (HFASD)

I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS) .............................................................

Signed  ..........................................................

Date  ..........................................................

Name of researcher taking consent (BLOCK CAPITALS) .............................

Signed  ..........................................................

Date  ..........................................................
Appendix C – Debrief Information Sheet

Information Sheet:

Dear Participant,

Thank you for participating as a research participant in the present study concerning your experience of working as a practitioner with adults with a diagnosed high-functioning autism spectrum disorder (HFASD). The present study sought to explore in depth, your personal and lived experience of working as a practitioner with this client group and how your training, current practice (challenges and successes) and ideas of future practice have informed your experience. It is ultimately the hope of this study to investigate the “felt” quality of working with this client group and how your experiences may help other practitioners currently or in the future.

If you know of any friends or acquaintances that are eligible to participate in this study, please ensure that you do not discuss it with them until after they have had the opportunity to participate. Prior knowledge of questions asked during the study can invalidate the results. Your cooperation is greatly appreciated.

If you have any questions regarding this study, please feel free to ask the researcher at this time or otherwise contact them via email: s.coxon@surrey.ac.uk. You can also contact the researcher’s supervisor via email if you so wish: dora.brown@surrey.ac.uk.

Thanks again for your participation.
Appendix D – Recruitment Email

Dear

My name is Sabrina Coxon and I am a second year PsychD in Psychotherapeutic and Counselling Psychology student at the University of Surrey. I am currently looking for a maximum of six participants for my thesis work on Psychotherapist’s and Counselling Psychologist’s who work with adults with a diagnosis of high-functioning autism spectrum disorder (HFASD).

I was given your details from the lovely people at the National Autistic Society and was hoping that you may consider taking part in my research. I am asking participants for 30 minutes of their time to be interviewed by myself regarding their practice and work with adults with HFASD. This interview can either be done face-to-face (I would travel to you) or if the distance is too far it would be possible to do an interview via telephone or Skype.

My participants would need to have worked with adults with HFASD in a therapeutic way (integrative, CBT, psychodynamic, or humanistically) and be at least two years post qualifying. They would also have to be registered with any of the following: BACP, HCPC, BPS, or UKCP. The interviews would then be analysed using interpretative phenomenological analysis.

If you would like to ask for more information or you would like to participate, please contact me on xxxxxxxxxx or email me at s.coxon@surrey.ac.uk. I would be happy to email across an information sheet and consent form if you would like to participate.

I look forward to hearing from you.

Best wishes,

Sabrina Coxon

PsychD Psychotherapeutic and Counselling Psychology - Year 2
University of Surrey
s.coxon@surrey.ac.uk

Sabrina Coxon - Request for research participation - practitioners working with adults with a high-functioning ASD.
Appendix E – Interview Schedule

**Interview schedule**

1. Could you please tell me a little about yourself and your practice?

2. What would you say is your experience of working therapeutically with people who have been diagnosed with High-Functioning Autism or Asperger’s Syndrome?

3. What do you think it is like to attend therapy for people with HFASD?

4. What would you recommend other psychotherapists when working with people with HFASD?

5. What was your training like, if any, in conjunction with working with this group?

6. What would you like to see in the future for working with this group therapeutically?
Appendix F – Sample Transcript – “Hope”

Interviewer: Sabrina Coxon
Respondent: “Hope”

Interviewer: You got my email with the information sheet and the consent form I presume?
Respondent: I did yeah, and I haven’t sent it back have I?
Interviewer: So that’s all fine and you’re happy with the information I’ve given and everything?
Respondent: Yeah it’s fine, yes. I need to sign that and send you it back.
Interviewer: Yes please. That would be lovely if you could.
Respondent: I will do when I find it. I can’t find it at the moment. It may well have been deleted. You’ll have to resend it. But yeah that’s no problem. I did read it through.
Interviewer: Are there any questions before we start?
Respondent: No.
Interviewer: If you could just give me some demographic information about yourself, so your age, gender, ethnicity; that kind of stuff please.
Respondent: I am 47, white British, female obviously.
Interviewer: And could you tell me what your qualifications are and if you’re accredited with any bodies?
Respondent: I am registered by not accredited with the BACP, currently working towards accreditation. I have a level four diploma in the theory and practice of counselling, and a BSc in therapeutic counselling.
Interviewer: And could you just tell me a little bit about yourself and your practice, so just generally?
Respondent: I work with the “S” Adult autism service. Do you want the practicalities of me in my practice or what? What do you want to know? History or…?
Interviewer: Anything that’s pertinent to you, so if you feel like something about your history and also the current situation that you’re in as well; that would be fine.
Appendix G. – Notes to contributors

Author Guidelines

INSTRUCTIONS TO AUTHORS

AUTISM RESEARCH welcomes the submission of your manuscript. Please follow these instructions carefully. Failure to do so will delay the processing of your manuscript. Submitted papers that do not conform to the descriptions below of types of manuscripts will be returned to the communicating author.

SCOPE AND OBJECTIVE

AUTISM RESEARCH will cover research related to Autism Spectrum Disorder (ASD) and closely related neurodevelopmental disorders. The Journal focuses on basic genetic, neurobiological and psychological mechanisms and how these influence developmental processes in ASD. The Journal encourages the submission of research articles that take a developmental approach to the biology and psychology of autism, with a particular emphasis on identifying underlying mechanisms and integrating across different levels of analysis. Individuals included in research studies can span the full spectrum of ASD, including the broader phenotype, and there are no restrictions on study participants in terms of age or intellectual ability. The Journal also encourages papers reporting work on animals or cell or other model systems that are directly relevant to a greater understanding of ASD. The journal will also publish reports of carefully conducted clinical trials of treatments for the core symptoms or one of the common co-morbid symptoms of ASD. Papers reporting clinical trials will be judged, in part, on whether there is an empirical justification for using the treatment that is reported.

TYPES OF MANUSCRIPTS CONSIDERED FOR PUBLICATION

**Please Note: Word Limits Do Not Include Abstracts and References, Only the Main Body of the Text**

Research Article. Submissions of original research articles of broad interest and potential for high impact are encouraged. The text of these articles should include an Abstract, Introduction, Methods, Results and a Discussion. Research articles should be a maximum of 5,000 words in length. If there are extenuating circumstances that would require an author to extend the length of an article, please contact the editorial office with specific details and rationale for the Editor-in-Chief’s consideration.

Short Reports. These are research articles that report a well-conducted preliminary study or a novel finding of high potential impact. Typically these articles should not exceed 2,000 words. The text of these manuscripts should be organized appropriately.

Review. Review articles are generally invited. However, authors are encouraged to contact the Editor-in-Chief if they are interested in preparing a review on a timely topic that has not recently been covered by the journal. Reviews are of two types: Comprehensive reviews of up to 8,000 words and "101" type reviews that are generally on the order of 2500 words. The "101" type reviews provide a succinct summary of a topic or technique to educate the readership of Autism Research and INSAR. Authors interested in developing a Review Article of either type should contact the Editor-In-Chief for more information concerning manuscript preparation.

Commentary: These are short articles (1500 - 3,000 words in length) that are intended to 1) draw attention to developments or needs in a specific area of research, 2) bring together observations that point the field in a new direction, 3) give the authors’ personal views on a controversial topic, or 4) direct well-reasoned and substantive criticism of some widely held
theoretical view or widely used technique or practice. Commentaries may also provide an historical perspective on an area of autism research. Authors should make their Commentary understandable to a broad readership. Potential authors are invited to submit a letter of interest to the Editor-in-Chief indicating the topic of a potential Commentary. The letter should also contain an outline of the contents and a brief statement on why it is a good time to review the topic in question. Commentaries will not be accepted for editorial processing unless pre-approved for submission.

EDITORIAL POLICIES
Authors should carefully review and implement these instructions. Manuscripts will be returned that do not substantially conform to specifications. If questions remain, authors may contact the Editorial Receiving Office for guidance (rdipshan@wiley.com). When necessary, the editorial staff can refer unanswered questions to the Editor-in-Chief or Associate Editors. Electronic mail is preferred for editorial correspondence. Authors who submit to the Journal may also be asked to make themselves available for an interview should the editorial team wish to highlight the author’s work in a podcast.

Submission policy: Manuscripts should be submitted solely to AUTISM RESEARCH and may not have been published, or be under consideration for publication, in any substantial form in another periodical—professional or lay. If there is a related paper under consideration at another journal, a copy of that paper should be submitted with the primary manuscript as supporting information.

Ethical compliance: If applicable, the editorial office should receive assurance that work performed on human and animal subjects complies with standards established by an appropriate ethics review committee (IRB or IACUC in the United States) and the granting agency. If the manuscript includes data or description of humans, the authors must provide either of these two assurances: (1) a statement in the manuscript that the research was prospectively reviewed and approved by a duly constituted ethics committee or (2) a statement in the cover letter to the editor that the manuscript is a retrospective case report that does not require ethics committee approval at that institution. Any other situations not covered by these two scenarios should be discussed with the Editor-in-Chief. Similar assurances should be provided in the manuscript that institutional approval has been obtained for any animal research that is reported.

Conflict of Interest Disclosure: AUTISM RESEARCH requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise, that might be perceived as influencing an author’s objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or indirectly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to, patent or stock ownership, membership on a company board of directors, membership on an advisory board or committee for a company, and consultancy for, or receipt of speaker’s fees from, a company. The existence of a conflict of interest does not preclude publication in this journal. If the authors have no conflict of interest to declare, they must also state this within the submitted manuscript.

It is the responsibility of the corresponding author to review this policy with all authors and to collectively list in the cover letter to the Editor-in-Chief, in the manuscript (under the Acknowledgment section), and in the online submission system ALL pertinent commercial and other relationships.
SUBMISSION OF MANUSCRIPTS

Cover letter: Authors must submit a cover letter, in a separate file, stating that all contributors have read and approved the submission to AUTISM RESEARCH. All submissions are required to be made online at the AUTISM RESEARCH Manuscript Central site (http://mc.manuscriptcentral.com/autismresearch). If you are submitting for the first time, and you do not have an existing account, create a new account. You will be asked to assign keywords to your profile. Returning users should check for an existing account.

Once you are logged onto the site, submission should be made via the Author Center page. Submit your manuscript and all figures as separate files. You do not need to mail any paper copies of your manuscript. You will be required to submit suggested reviewers, however, the editorial office reserves the right to not use these suggested reviewers. At the end of a successful submission, a confirmation screen with manuscript number will appear and you will receive an e-mail confirming that the manuscript has been received by the journal. If you do not receive this mail, please check your submission and/or contact tech support at E-mail: support@scholarone.com.

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Appendix H. Self-Reflection

Self-reflection

Since I was 12 years old, I have always worked or volunteered with people with learning disabilities. It was an eye-opening experience to see children and adults struggle with many different issues. In this particular path of my life, I have always worked with people with ASD and have always been interested in the things that make them unique. The way some individuals are able to speak about a subject of their interest for large lengths of time, to have an openness and honesty that is very unique to them, and to also struggle with sensitivities and changes that a neurotypical person may take for granted. It also so happens that my sister was diagnosed with Asperger’s Syndrome in her mid-30’s a few years ago and this (now looking back) makes a lot of sense. She would be extremely loud and not be aware of this, she would find certain sounds painful to hear, she would find it difficult to interact with people and find that she does not understand them. She decided to seek personal therapy as she felt that something was “wrong” with her and wanted to know why. My sister went to a personal therapist for a few years and feels she gained huge insight into her difficulties. My husband’s cousin also sought personal therapy a few years ago, for the same reason as my sister; he felt he was not “normal” and did not understand why.

As people around me, not only in my working/volunteering life but also in my personal life were connected to autism and were seeking personal therapy, it got me thinking about what it is to be autistic and what therapy is like for them. People with ASD were obviously seeking out therapy and were finding it helpful, however, being in the field of psychology and psychotherapy/counselling, there seemed to be a misconception that due to the lack of empathy, lack of theory of mind, and lack of social skills exhibited by people with ASD, this meant that they would not be able to engage in a therapeutic relationship nor be able to participate in successful psychotherapy. There seemed to be a contradiction going here. People with ASD were seeking and participating in therapy and therapists were offering their services to people with ASD. So the question formed in my mind – what is going on here? Is it because people with ASD cannot take part in therapy, are therapists intimidated by the disorder, are therapists not trained enough to work with this client group, are people with ASD inherently unable to connect with others? The questions kept coming and therefore, carrying out a systematic literature review would be logical next step. As it is shown above,
the literature is scarce, barely in its infancy, but researchers are showing an interest and asking important questions. There are limitations such as most research is carried out outside of the U.K. and the majority comes from a medical model vantage point.

To be able to carry out a qualitative study is a new, interesting but also intimidating experience for me. It is incredibly satisfying to be able to carry out research that is in-depth, looks at meaning-making and rich in content. However, it is also a daunting and challenging process of interviewing, transcribing, and analysing that is new territory for me. I look at this as another contribution to my skill set and bag of tools that will round me out as a counselling psychologist. To be able to have the opportunity to take part in and create original research is a dream that few are able to realize, especially when, as a counselling psychologist you have the part of you that has clinical work and experience but also the part that is rich in research abilities.

The process of recruiting participants was a very difficult part of this journey as there is a great scarcity of practitioners who advertise themselves as having worked with or are willing to work with this client group. It is also a balancing act in finding participants, organizing time when both interviewer and interviewee are free and sorting out all the organizational aspects of the research (such as consent forms, etc.). However, once you are talking to the participant it reminded me why I was doing this research – because I am genuinely interested in the work of other practitioners and on their opinions on this client group. Are the misconceptions true or are they actually myths? What is actually going on out in the clinical field? This reminded me of the excitement of working with this client group and showing how they are important people who are often forgotten about because their disability is not as visible as a wheelchair.
How do adults with a High-Functioning Autism Spectrum Disorder (HFASD) make sense of and give meaning to their experience of undergoing psychological therapies – a grounded theory analysis

Abstract

According to the American Psychiatric Association, 1% of the U.S and non U.S. population have a diagnosis of Autism Spectrum Disorder. Within this population, a large proportion of adults with high-functioning autism spectrum disorder (HFASD) also experience co-morbid psychiatric problems as well as life stressors which cause the individuals to seek help in the form of psychological therapies. This research utilised a grounded theory approach to analyse data from 7 interviews questioning their personal experience of undergoing psychological therapies. Analysis of data provided information for the construction of three categories: living with high-functioning Autism Spectrum Disorder (HFASD), lack in psychological therapies, and harm caused by professionals. Data suggests that the majority of participants felt that they were stereotyped by others in their social context and by professionals they were seeing, that they experienced implicit and explicit harmful interventions by professionals and that they wished their practitioners had had training in autism specific knowledge to feel more understood. Discussion links are made to counselling psychology, limitations, strengths of the study, and directions for future research following on from the findings of this study.
Introduction

Autism Spectrum Disorder

In the UK, there is an estimate of 1 in 100 children who have a diagnosis of autism spectrum disorder (ASD henceforth) (The National Autistic Society, 2013). Statistics referring to how many adults live with this particular disorder are not so clear (The National Autistic society, 2013). The American Psychiatric Association (APA, 2013) believe the prevalence to be 1% of the population for both children and adults across U.S and non U.S countries. Before the DSM-V (APA, 2013), autism used to be classified within three categories – autistic disorder, Asperger's Syndrome (AS) or pervasive developmental disorder (PDD). However, it has now been classified together under the umbrella term of autism spectrum disorder (ASD). The DSM-V states that 5 diagnostic criteria should be used to gauge and assess an individual for the condition – these include persistent deficits in social communication and social interaction, restricted and repetitive patterns of activities, interests and behaviour, present in early development, cause clinically significant impairment in current functioning, and disturbances not better explained by intellectual developmental disorder or global development delay (APA, 2013). The DSM-V also looks at severity of the symptoms and has three levels of severity to help with classification and are all clustered around the level of support needed by the individual. It is also interesting to note that males are four times more likely to be diagnosed than females (APA, 2013). This may be due to female’s subtler presentation of symptoms or successful ability to use social mimicry to aid their navigation through society (Attwood, 2012).

The ICD-10 (World Health Organisation, 2015) categorise autism under pervasive developmental disorders and have a separate classification of Asperger’s Syndrome (AS) which is on the high-functioning end of the autism spectrum of difficulties. People diagnosed with AS are believed to have a ‘normal’ intellectual development but show qualitative abnormalities in reciprocal social interaction, exhibit intense, repetitive and restricted behaviour and activities, and not be attributed to other PDD’s. The difficulty with using the ICD-10 is the use of language, which is highly pathologising and unhelpful. The use of words such as ‘mental retardation’, ‘disintegrative disorder’, ‘disease’, and ‘atypicality’, can give the impression of someone being ‘less than others’ and firmly grouping people into a phenomenology that is disordered and pathological. Baron-Cohen (2000) states that
individuals with HFA have average or above average IQ and individuals with AS have normal language development but struggle with social impairments and having repetitive and stereotypic patterns of behaviours (Ghaziuddin and Mountain-Kimchi, 2004). As there is no clear distinction between AS and high-functioning ASD, the researcher grouped these individuals together in the category of high-functioning autism spectrum disorder (HFASD henceforth). This is merely to help distinguish between the two ends of the spectrum and their level of social and intellectual functioning. Due to the nature of their problems, people with a HFASD are more likely to be able to have “talking therapy” as there is a higher level of cognition, empathy and awareness of feelings required.

Co-morbid psychiatric problems and life stressors

There is a large amount of research available that gives evidence of levels of co-morbidity of psychiatric problems for individuals with HFASD but they vary between 4-81% (Levy & Perry, 2011). These include problems such as anxiety (Bellini, 2004; Gillot & Standen, 2007), ADHD and OCD (Klin & Volkmar, 1997), and depression (Ghaziuddin, Ghaziuddin & Greden, 2002; Stewart, Barnard, Pearson, Hasan, & O’Brien, 2006; Sterling, Dawson, Estes, & Greenson, 2007). Within the literature it also shows that these individuals show difficulties with social skills (Bellini, 2004), emotional problems (Jones, Zahl, & Huws, 2001), and with romantic relationships (Aston, 2012). Renty and Roeyers (2006) have reported that their quality of life is highly related to support characteristics such as effective professional support and supportive social networks. The empirical evidence seems to suggest that these individuals deal with everyday problems with relationships and emotional upheaval but they also have a high prevalence of co-morbid psychiatric problems. It has been reported by Richa, Fahed, Khoury, & Mishara (2014) that clinical samples suggest that suicide occurs more frequently in HFASD rather than people with lower-functioning ASD possibly due to their ASD specific difficulties (difficulty in expressing emotion and thoughts, making friends and having intimate relationships, and with adapting to change) and/or co-morbid psychiatric problems but the difficulty is knowing if they are separate or connected issues. They suggest that it is difficult for practitioners to be able to diagnose their suicidal ideation and that there is a need for them to adapt their psychotherapeutic interventions. The information above gives credence to and makes logical sense for them to seek psychological therapy in order to help with their distress and problems, maybe caused by their experience of having ASD or due to co-morbid psychiatric problems.
Review of the current literature

A systematic, critical literature review carried out by Coxon & Williams (unpublished) into research around the topic of adults with HFASD having undergone psychological therapies, put in evidence how the majority of research in this area follows the foundations of the medical model to look at therapy effectiveness and outcomes. Control trials and randomised control trials were used to look at two types of therapy, either cognitive-behavioural therapy (CBT) or mindfulness-based therapy (MBT) (El-Ghoroury & Krackow, 2011; Sze & Wood, 2007; Cardaciotto & Herbert, 2005; Beebe & Risi, 2003; Singh et. al., 2011, Spek, Van Ham, & Nylicek, 2013; Reaven, Blakely-Smith, Culhane-Shelburne, & Hepburn, 2012). This would suggest that other models are not being as represented in the literature. Some research was carried out in the form of single case studies, mainly looking at the use of psychodynamic therapy with HFASD individuals, and found that children with either ASD or HFASD were able to utilise this type of therapy when the practitioner is willing to be creative and flexible (Mero, 2002, Levy, 2002, Topel & Lachman, 2011, Sugarman, 2011, Koenig & Levine, 2011). Single case studies only provide the perspective of one practitioner working with one client which does not allow for further analysis or general understanding of the ASD population.

Further, reviews of the literature (Coxon & Williams, unpublished), suggest that the information available to practitioners and researchers was mainly concerned with children with ASD and there was a marked paucity of research including adults. Sometimes studies used individuals with HFASD, with ASD and sometimes a mixture. This makes it difficult to see if any patterns in the literature emerge and if there are any concepts that need further research or research questions have already been answered. It makes evaluating the information harder as there is no coherent structure or therapeutic models being followed. The field appears to be wide and vague. This also includes looking at individuals from different ethnic backgrounds and gender, there is a tendency for research to include male, Caucasian participants. This again makes it difficult to see how different ages, genders, cultures, and races are being represented and what their experiences are. The only qualitative study that was found looked into ASD individuals with emotional problems - Jones, Zahl and Huws (2001) reported that adults with HFA and AS experience emotional problems such as a feeling of alienation, sense of frustration, depression as a central emotion, and a pervasive sense of fear and apprehension. Even though this was important to highlight as it shows that
these individuals are capable of intense emotions, this does not look at how these individuals dealt with these emotions and feelings.

The literature review brought up many questions that could be looked at in terms of research and it seemed to suggest that there was paucity in the field of practitioners working therapeutically with adults with HFASD. To date, only three studies have looked into practitioners working with this client group – Leather & Leardi (2012), Weiss, Lunsky & Morin (2010) and Brookman-Frazee, Drahota, Stadnick & Palinkas (2012) and none of which looked at the phenomenology of the practitioners in a qualitative and in-depth manner. An IPA analysis (Coxon & Brown, unpublished) was carried out with 6 practitioners who had worked with adults with HFASD. The findings showed the importance of the therapeutic relationship, the feelings of limitations expressed by the practitioners, and the effect of the autism label on individuals with HFASD. All practitioners were adamant that adults with HFASD could participate in and maintain the therapeutic relationship, they also felt certain limitations of lack of training for ASD knowledge in professionals as well as in funding and top-down changes, and also that adults with HFASD live with labels, stereotypes and are categorised in some way. This approach seemed to demystify the idea that you cannot work with this client group and that certain aspects can be frustrating and also limiting. Having researched this topic on the one hand, it would be prudent to investigate how clients with HFASD undergoing therapy make sense of their experience on the other hand.

Further, several studies including children and adolescents with ASD have been conducted in the last couple of years. Studies looking at the moderate effectiveness of modified CBT protocols (Ehrenreich-May, Storch, & Queen, 2014; Reaven et. al., 2015; Selles et. al., 2014; Storch et. al., 2015; Van Steensel & Bögels, 2015) including randomised control trials (White, Schry, Miyazaki, Ollendick, & Scabill, 2014; Wood et. al., 2015). Interestingly, only one study was conducted looking at the effectiveness of family therapy with children with ASD (Nadeau, Arnold, Storch, & Lewin, 2014) but only looking at CBT interventions. It would appear that there is enough research out in the field investigating effectiveness of CBT with children with ASD as two systematic reviews were undertaken by Ung, Selles, Small, & Storch (2015) and Ho, Stephenson, & Carter (2015). They both found moderate levels of evidence of efficacy but both suggest that more research is needed in the area to show a good enough effect size. Looking at adults, it would appear that only two studies have been conducted looking at modified CBT efficacy, both utilising group therapy (Hesselmark, Plenty, & Bejerot, 2014; McGillivray & Evert, 2014) and only one looking at efficacy of Mindfulness based therapy (Kiep, Spek, & Hoeben, 2015). Two reviews have
been conducted looking at adults with ASD undergoing modified CBT (Kasari, Shire, Factor, & McCracken, 2014; Spain, Sin, Chalder, Murphy, & Happé, 2015) and showing that it can be effective but again states that more research needs to be undertaken and have larger and varied samples. Since 2013, three articles have been published that provide more general information about individuals with HFASD, looking at their presentation, co-morbid psychiatric problems and psychosocial interventions that might be helpful to them (Tebartz van Elst, Pick, Biscaldi, Fangmeier, & Riedel, 2013; Woods, Mahdavi, & Ryan, 2013; Koelkebeck, Riedel, Ohrmann, Biscaldi, & Tebartz van Elst, 2014). This is a promising beginning as this suggests that interest in this subject has gone up and that this client group is not only important but that there are specific adaptations that may need to be utilised when working with them. A promising piece of research has recently been undertaken – a thematic analysis of the lived experience of four adults with HFASD growing older. Elichaoff (2015) discovered six themes that included: depression, effects of diagnosis, experiences with mental health professionals and therapists, the inverted relationship between educational level and career, the participant as autism expert, and communication/social interaction. This was the first foray into investigating the phenomenology of adults with HFASD from a qualitative standpoint. Elichaoff’s results showed very similar issues arose from her participants interviews that were echoed in the study by Coxon & Brown (unpublished), showing the importance of diagnosis and the autism label and experiences with mental health professionals. Elichaoff (2015) stated that some participants talked about experiencing depression before and after diagnosis and seeking psychology therapies for help and finding that some therapies were more helpful than others and that a lack of ASD knowledge had a big effect on their therapy. As promising as this research is, it looks mainly at the experience of growing older with HFASD and talks about psychological therapies as important but not being central to the research, thus, potentially giving us only a taster of what information may be available.

Current study

Within the literature review (Coxon & Wiliams, unpublished), certain issues where highlighted. Unfortunately, it is beyond the scope of this research to address all these issues and it has been deemed prudent to look at the lived experience of first, the practitioner and secondly, the client group. It would appear to be a natural progression to look at the lived
experience of a client undergoing therapy now that we have preliminary insight into the first group (Coxon & Brown, unpublished).

This research therefore is specific to and emphasises the lived experience of adults with HFASD having undergone psychological therapies To capture this experience a qualitative perspective is adopted here as qualitative research provides a rich, in-depth, and descriptive account of an individual’s phenomenon under investigation (Smith, 2008). To gather data a semi-structured interview format was employed as it enables the researcher to keep their research question mind whilst being guided by the participants dialogue (Lyons & Coyle, 2007). To analyse this data a grounded theory (GT henceforth) research method was deemed suitable.

The social constructionist grounded theory research method by Charmaz (2006) was adopted here as this method is ideal for aiding expansion of the wider knowledge base given its facility to capture the intricacies of subjective phenomena (Charmaz, 2006). The method is based around the principle that both the participant and the researcher are part of the world and come with their own values, perspectives and background which informs the data given and the analyses undertaken and that grounded theories are constructed through our past and present interactions with people, environments, and research perspectives. Any theoretical rendering gives an interpretive picture of what is being studied and not an exact picture of it. This is demonstrated by the use of ‘discovery’ and ‘construction’ of categories rather than they ‘emerge’ from the data as we take into account the social construction of the information and analysis (Pidgeon & Henwood, 1997). The researcher is looking for ‘knowledges’ and not just one ‘knowledge’. The researcher produces an explication, organisation and presentation of the data rather than discovering order with the data, this also includes the discovery of the researcher’s ideas about the data after interacting with it (Charmaz, 2006). The researcher captures the lived experience and tries to explain its quality in terms of wider social processes and their consequences (Pidgeon & Henwood, 1997). Grounded theory was chosen due to its ability to help broaden the knowledge base as it is able to capture the complexities of subjective experience, it also allows data to be focused due to the flexibility within the data collection, and is able to construct new and fresh theories firmly grounded in the data rather than just be descriptive (Charmaz, 2006). Grounded theory’s ability to provide an exploratory method that looks at the lived experiences of the participant is particularly pertinent to what is being investigated.

The Grounded Theory (GT) method as described by Charmaz (2006) will be used as the researcher identifies with a social constructionist stance and this method was chosen as it
fit with both the researchers’ stance and also with the research question that was being posed. It was not appropriate to use Interpretative Phenomenological Analysis (IPA; Smith, Jarman, & Osborn, 1999) as it was the researcher’s goal to look at the wider context and being critical of it rather than looking at the meaning making of the individual. This fits with the researcher’s initial goal of looking at what might be happening in these instances, to comment on them, and then to see if this could be developed into a theory of commentary that may help to educate people and possibly create some change for this client group. It would also be inappropriate to use Discourse Analysis as the researcher was not looking at language in constructing categories and it would not help the researcher’s goal in wanting to reflect a person’s reality, nor to use Narrative Analysis as this method attempts to look more at experience rather than trying to give an explanation of what might be occurring within the participant’s experiences plus it does not look for commonalities amongst the participant’s which was part of the researcher’s goals within this research - in order to find and comment on commonalities meant that something may be possible in changing the client groups current experience for the better (Willig, 2008; Lyons & Coyle, 2007).

According to Hawker & Kerr (in Lyons & Coyle, 2007), GT has its own strengths and weaknesses. They state that it allows researchers the freedom to cultivate their theory through detailed and methodical consideration of the information garnered from participants as it is data driven, it works very well where there is scant knowledge available as it helps to understand complex behaviours and their meanings through the investigation of the social processes which produce them, and has its own source of rigour as the researcher is continuously looking for more data that may disprove what has been found so far. Hawker & Kerr (in Lyons & Coyle, 2007) state that it is not a very straightforward method due to the data becoming fragmented during coding and categorising and this can make it difficult for the researcher to keep the data in their mind in its totality, this method also requires the researcher to use their imagination and use of insight which may not be as easy to do as it seems, and due to its iterative nature it takes up a lot of time to analyse the data and in an environment as academia this can be very difficult due to deadlines and funding.

This research method was utilised to help answer the following research question:
How do adults with a High-Functioning Autism Spectrum Disorder (HFASD) make sense of their experience of undergoing psychological therapies?
The study aims to widen the knowledge that practitioners have of HFASD with the objective of incorporating this knowledge into practice. The aim is linked to the overall goal for this research which links this research to the field of psychotherapy and counselling psychology – to address some of the imbalances and gaps within the literature that have been stated above, to gain information for other practitioners/trainees/lecturers, and to see if any changes can be affected in the field of psychotherapy and counselling psychology in how this client group is viewed and treated.

Method

Participants

Theoretical sampling (Charmaz, 2006) was utilised in order to find participants to take part in semi-structured interviews. Initially, five participants were interviewed to gain some insight into the research question. These participants did need to fulfil an inclusion criteria (Smith & Osborn, 2008): over 18 years of age, have a diagnosis of high-functioning autism disorder, and have undertaken psychological therapies (e.g. humanistic, psychodynamic, and/or cognitive-behavioural therapy) for at least 6 sessions. Five participants were interviewed and their data analysed using initial coding which brought up some preliminary codes and categories. In order to develop my emerging theory(s) and refine my preliminary categories, one potential category was picked out (“level of specific ASD training”) and added as a question to the interview schedule (see Appendix F.) to enquire further in this area. After the sixth interview, another preliminary category was picked out (“possible harm caused by professionals”) and added to the interview schedule (see Appendix G.) as a question investigating in this area. The first five participants were recruited via an ASD assessor with Surrey and Borders NHS Trust and an ASD group facilitator for The National Autistic Society who advertised on my behalf. To recruit the sixth and seventh participant, the researcher took part in an ASD group meeting with The National Autistic Society, observed group members and picked two individuals who appeared outspoken, able to be critical of their experience, and wanted to speak about their experiences. These individuals felt like they would be able to speak about and bring some insight into the two new questions in the interview schedules and help refine the preliminary categories.
Seven participants participated and are shown in Table 1. for a comprehensive overview. Participants were aged 21-38 years, were diagnosed between ages of 2-33 years, there are 4 males and 3 females, 6/7 participants were Caucasian British and one participant was Caucasian/Asian, and all seven participants had experience of one – four different types of psychological therapies. All participants have been anonymised for confidentiality reasons and have therefore been given pseudonyms.

Table 1.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Age when diagnosed</th>
<th>Type of therapy undertaken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>32</td>
<td>Female</td>
<td>Caucasian British</td>
<td>31</td>
<td>CBT, EMDR, &amp; Gestalt.</td>
</tr>
<tr>
<td>Mark</td>
<td>21</td>
<td>Male</td>
<td>Caucasian British</td>
<td>2/3</td>
<td>CBT/Counselling.</td>
</tr>
<tr>
<td>Saul</td>
<td>22</td>
<td>Male</td>
<td>Caucasian British</td>
<td>16</td>
<td>Counselling, CBT, &amp; Psychodynamic.</td>
</tr>
<tr>
<td>Yvonne</td>
<td>38</td>
<td>Female</td>
<td>Caucasian/Asian</td>
<td>33</td>
<td>CBT, Psychodynamic, Couples Counselling, &amp; Psychiatrist.</td>
</tr>
<tr>
<td>John</td>
<td>24</td>
<td>Male</td>
<td>Caucasian British</td>
<td>5</td>
<td>Counselling.</td>
</tr>
<tr>
<td>Rachel</td>
<td>24</td>
<td>Female</td>
<td>Caucasian British</td>
<td>23</td>
<td>Psychodynamic Group therapy &amp; CBT including psychoeducation.</td>
</tr>
<tr>
<td>Oscar</td>
<td>23</td>
<td>Male</td>
<td>Caucasian British</td>
<td>13/14</td>
<td>Counselling.</td>
</tr>
</tbody>
</table>

‘EMDR’ stands for Eye Movement Desensitisation and Reprocessing and ‘CBT’ stands for Cognitive-Behavioural Therapy.

Ethical considerations

The first and foremost priority of this research is to avoid causing any harm, thus, this research has been conducted with sensitivity, care and respect. A researcher’s duty is to be empathic, flexible, curious, and open with participants and to prioritise the safety of participants. Close attention was used to ensure that the code of ethics for conducting research outlined by the British Psychological Society (BPS, 2011) and the Health and Care Professionals Council (HCPC, 2008) had been adhered to. This study was given a favourable ethical opinion by the University of Surrey Faculty of Arts and Human Sciences Ethics Committee. Adhering to the above stated ethical codes of research practice, issues of confidentiality were strictly followed. According to the 1998 Data Protection Act, the anonymised transcribed interviews can be kept for up to ten years in a password protected
computer but all digitally recorded interviews will be destroyed after the completion of this research.

All participants were given an information sheet (see Appendix A.) about the research. They were given the opportunity to withdraw their consent and data up until one month after their interview. They were also given a consent form (see Appendix B.) for evidence of consent and after their participation they were given or sent a debrief sheet (see Appendix C.) detailing any other information about the research and reiterating that they may contact the researcher if they have any questions or felt distress after their interview.

Throughout this research, it has been endeavoured to uphold the high standards of personal conduct and ethical research as outline by the BPS (2011) and HCPC (2008). The researcher has always attempted to act in the best interests of the participants, respected their confidentiality, ensured informed consent, respected their autonomy, privacy, and dignity, kept accurate records and data, as well as ensure that the researcher behave with honesty, integrity, transparency and show evidence of their accountability. For transparency, a sample transcript is added in the appendix section of this report (see Appendix I.).

Procedure

Participants were recruited following they met the inclusion criteria and allowed them to choose a medium of communication that was comfortable for them – either meeting face-to-face, over the telephone or via Skype. A recruitment email was sent to the participants which included the information sheet (see Appendix A.) and consent form (see Appendix B.). All participants gave consent. Participants were interviewed using an interview schedule (see Appendix E.) that was semi-structured with 4 main questions devised keeping in mind the overall research question and the aims of the research. The four main questions worked as an initial structure to the interview but there was ample opportunity to speak as if in conversation with the participant to help garner quality rich data but to also facilitate a feeling of comfort for the participant. Each interview lasted between 25 – 70 minutes. The interview schedule was amended twice in the course of interviewing participants as this method includes data driven collection and theoretical sampling (Charmaz, 2006). The second interview schedule (see Appendix F.) included a new question that was added due to information that had been discovered in initial coding of the first 5 interviews and the third interview schedule (see Appendix G.) included another extra question that had been discovered in the first 6 interviews. The purpose of this was to help illuminate and define the
boundaries and relevance of categories that were being discovered. Once the participant had consented to participate and had asked any questions they needed to ask, demographic information was recorded. The participant’s interview was then digitally recorded and was individually transcribed to be analysed later on. At the end of the interview, all participants were asked if they had any concerns or questions and were told they would be given or sent a debrief sheet (see Appendix C.) that thanked them for their participation, explained aspects of the research and gave them another opportunity to withdraw or to contact the researcher if anything came up for them. All digitally recorded interviews will be destroyed upon the completion of this project, all transcripts have been anonymised with pseudonyms given to the participants, any data kept on a computer is password protected and any physical data is kept in a lockable cabinet. All transcripts were analysed using the GT method outlined by Charmaz (2006) and results have been written up.

Credibility of the study

In order for this research to adhere to BPS (2011) research ethics guidelines for scientific integrity, as a researcher I must show evidence of its credibility. This is achieved by adhering to certain principles outlined by Yardley (2000) and ensure my sensitivity to context, commitment and rigour in the analysis, being transparent and coherent, and showing impact and importance of the data in the wider community. This will be enhanced by my use of Fossey, Harvey, McDermott & Davidson’s (2002) principles to ensure rigour, reflexivity and validity.

Analysis

Transparency is an important aspect of qualitative research (Yardley, 2000) and enables the researcher to adhere to the research ethics outlined (BPS, 2011; HCPC, 2008) by making the analysis process open and visible. Data that is gathered throughout is looked at under a constant comparative method (Glaser & Strauss, 1967). The researcher placed each transcribed interview into a table which had two empty rows beside it, then read through the data multiple times, and note down any impressions, thoughts, and feelings. Data was analysed using initial coding (Charmaz, 2006) via an incident-by-incident method to establish analytic distinctions. Then initial codes were analysed using focused coding to make codes more selective and conceptual with the intention of forming categories so that they help
synthesise and explain larger sections of data. The researcher was constantly revising their codes and looking back through the data. In the final stage of analysis, the researcher used theoretical coding to attempt to look for relationships between focused codes in order to formulate a theory or story within them. The researcher looked for clarity within the data to make the theory more comprehensible and either a ‘core category’ or a handful of categories is constructed that helps to clarify an individual’s experience (Charmaz, 2006). This was done when the researcher felt the data had reached theoretical saturation (Charmaz, 2006) as new theoretical insights are no longer being stimulated when collecting fresh data.

It is important to note the role of the researcher within this, as they created a ‘sense’ out of the information that had been given to them and informed how they created them. They had to be very self-aware and reflexive in the process as they were part of the co-creation of the theory. Being self-aware and reflexive in this process required them to write memo’s throughout the analysis and a section on self-reflection within the process (see Appendix I).

Findings

The three main categories are – 1) living with HFASD, 2) lack in the psychological therapy, and 3) harm caused by professionals. Looking at these categories they can appear quite negative and, indeed, they do show a darker side to the participant’s experiences but that is not to say that participants did not gain support, help and insight into their problems whilst working with their practitioners. A detailed overview of the categories will be presented in the sections below and will be fully discussed in the discussion section further in the report. It is important to note that all 7 participants were eager to discuss their experiences of undergoing psychological therapies especially as they wished to do so in the interest of helping other adults with HFASD thinking of undertaking therapy; some also stated that they felt that this was a cathartic exercise for them to talk about their experiences.
Overview of the three main categories

Living with High-Functioning Autism Spectrum Disorder (HFASD)

Within the category of ‘living with HFASD’, sub-categories include the HFASD diagnosis, disclosure of the diagnosis, the participant’s social context, being stereotyped, the specific ASD presentations each individual has, as well as reasons for seeking therapy and engaging in help-seeking behaviour in order to get support through psychological therapies.

The following six quotes have been chosen specifically to attempt to explain and highlight aspects of living with HFASD. The researcher placed them all together to highlight a particular dialogue throughout:

John: “I got diagnosed very young, roughly, I believe when I was 5 years old, which was quite handy, really, because I have had a lot longer to understand myself, find out where my strengths are ….. I got a lot of help with school that I needed, which I think has had a massive influence on my life, because I think, if I hadn’t had that support, I would be a very, very different person to the one I am now.”

Saul: “Basically, seemingly everything, apparently. I seem to hear, see, observe, smell, taste, touch, even in terms of senses of things like proprioception and in between senses like hunger and stuff like that I seem to experience, based on outside measurement - both people being presented a stimulus and myself finding it unbearable and then someone else not finding it unbearable.”

Amy: “Not necessarily. I think that is equally another problem. I think I meet one stereotype – I am probably like the nerdy Sheldon Cooper type, that’s fine, but that is just damaging, because there are two pictures of people: you are either a person screaming in the asylum or you are the super genius.”

Yvonne: “I don’t have many friends. In fact, where we live right now – we have just recently moved to a new place – I don’t have any friends. I find it very difficult to make friends. People tend to think I am weird. Even now I have a daughter, I go to these mummy things and I don’t click with anybody, because I am trying to do the small talk, I am really trying to, but I can’t do it sometimes.”
Oscar: “So I ended up having an emotional breakdown. That is what ended it for me. I just couldn’t deal with work anymore. That is why I was in therapy, because they [his family] were worried I was suicidal. I wasn’t.”

Mark: “Well, it actually started when I was in St Dominic’s, because, when I was that young, because it started when I was about 13, 14, maybe a little bit younger, and I had always found change very difficult …. I found that quite difficult to begin with, for the first two years, until I started meeting and getting to know some of my classmates a bit more, started to make new friends. Eventually, they brought in a counsellor.”

The researcher felt that the above quotes weave together and produce a cohesive story in an attempt to try to highlight particular aspects of what it is like for the participants to live with HFASD. Each participant spoke about their journeys in terms of pre- and post-diagnosis, as if their lives were fundamentally changed by this event. Diagnosis is an extremely important part of their identities and sense of self. As John describes, the timing and impact of his diagnosis was vital to who he believes he is now and how it shaped his life. In this sample, some participants were diagnosed in childhood and some in their adulthood. When diagnosed in childhood, participants showed gratitude as it enabled them to access services and support specifically for their ASD difficulties but when diagnosed as an adult, participants spoke about regret and wishing their life had been different. This may be due to feeling like they needed an explanation or some understanding about what is going on for them. Only Oscar spoke about how his diagnosis negatively impacted him as he felt people treated him differently and that he was ‘lumped’ in with people who were more disabled than him. This suggests that not all individuals with HFASD welcome a diagnosis and that how their social context deals with their diagnosis can be vital in how it impacts the participants.

Each participant spoke about how HFASD affects them all individually and the researcher chose Saul’s description of his difficulties in order to show an aspect about these individual’s that often gets overlooked – how sensory difficulties can affect them and how much this has an impact on their lives. He also makes a point about how other people make him feel ‘weird’ as their measurement of his difficulties is different and do not understand what he is going through. If practitioners know about ASD, it is usually more in terms of their social difficulties and less about their sensory issues. Saul appears to highlight what he deals with every day and how this should be taken into account when working with an individual with HFASD.
This feeds well into the next point, which talks about how participants have felt stereotyped by other people in their social context. As Amy demonstrates very well, is how she feels she can be put into one of two boxes – either ‘genius’ or ‘screaming lunatic’.

Participants spoke throughout each interview how they felt like other people, or neurotypicals (as participants called non-autistic people), felt they should fit a particular idea they had of who they should be according to their understanding of autism or that they were made to feel marginalised or ‘other’. Yvonne’s quote really highlights how she finds it difficult to make friends as others think she is ‘weird’ and how lonely this existence can be. This has huge implications for their feelings, self-esteem, and sense of self.

Oscar and Mark’s quotes are very good examples of why participants seek help and seek psychological therapies. It appears to show that not only do they have specific HFASD-related issues such as problems with change and difficulties in making friends but that certain life stressors that we all have, can impact their mental well-being.

The participants paint a picture that appears to show a human experience that is quite specific to their HFASD such as social and sensory problems but that this can also cause them to feel marginalised and alone in their world. They appear to be placed into ‘boxes’ of what people do or do not understand about autism, which has implications on their feelings, self-esteem and sense of self. Their social context has a large impact on how they orient themselves in who they are and what this means about them. It also seems to suggest that they face issues and problems that asks for them to seek help but this can be dependent on the services they find or are offered.

**Lack in the psychological therapy**

Within this category, all 7 participants spoke about aspects of their therapy that they felt was lacking. Within this category, sub-categories were identified. This included:

**ASD specific knowledge** is a sub-category that includes how participants felt that had they had a practitioner with ASD specific knowledge/training their therapy might have been different as they may have felt understood, accepted and validated.

*John: “I don’t know. She wasn’t very understanding of people on the autistic spectrum as well, because, largely, most people are neurotypical and I think most people she would have seen were neurotypicals …. because I am a different person and you have to do something a}
bit different to connect with people with it, I think. So I think it was just the way I communicated with her, because I do communicate in different ways than someone like a neurotypical. I don’t think she quite understood how I was feeling as well, because, obviously, I have different emotions; I see things differently. I have got a different way of processing information. Things I might see as more important, she might not see as important and we didn’t see eye-to-eye in that way.”

Practical/Logical interventions is a sub-category that includes how many participants wished to have interventions that helped them in a practical manner, such as trying different ways of communicating, using sensory objects to help them concentrate, problem solve situations together, and so on.

Yvonne: “give me homework, give me options, solutions ... he never said anything like that. He was just empathetic, whereas she said, ‘Yvonne, maybe you should turn it around.’ And I was like, ‘Oh my God, yes!’ ... so she gave me two options.”

Communication is a sub-category that includes how some participants felt they were not communicating well due to the practitioner’s inability to try to understand their lived experience and about different ways of communicating.

Amy: “I would honestly rather talk to someone like you remotely than go and see someone face-to-face, if it was somebody I knew, knew how to deal with somebody on the spectrum ... I think somebody who would be open to, say, talking via Skype, like typing. Something like this, but I think maybe if it was something really emotional, I would find it easier to write it out rather than to speak it.”

Flexibility/Adaptation is a sub-category that includes how participants wished that some of their practitioners had been more flexible or able to adapt what they had been doing. This included interventions, types of communication, and a willingness to be creative and try different things.

Rachel: “So I actually said, ‘Look, I’m not coming back.’ She wasn’t happy with that decision, and I have since spoken to her on the phone for over an hour on how she can make
her group more accessible to autistic people. So I think she is improving what she is doing, but I wouldn’t say it is necessarily the best group to get support for that.”

The participants spoke at length about things they felt were lacking in the care they had been provided and many spoke about their particular needs that, even when told to the practitioner, seemed to be ignored. All participants except Mark, saw non-ASD specifically trained practitioners and felt that in some way their care could have been made more helpful and effective if the practitioner had had more knowledge about ASD. As they didn’t have these ASD trained practitioners, the participants felt misunderstood, like something was wrong with them, or that they were just not as important as neurotypical people. As John stated, he felt he had different ways of communicating, and processing information as well as different emotions and feelings that were not being understood by his practitioner. This would be very invalidating of their lived experience and what they face every day.

An interesting point was made by several participants that they felt that empathy was helpful and a basic aspect of therapy but they also felt they had specific practical needs that were not being met by their practitioners. As Yvonne stated, she liked having empathy but needed options or homework to be able to feel effective and to help deal with her specific HFASD issues. Again, this seems to suggest that the participants did not feel listened to, nor, that their practitioners took their needs into account. This possibly may be due to the practitioners therapeutic modality, however, this would mean the client is being ‘forced’ into a way of working that may not be right for them. This is also to be said for the next sub-category of communication, as participants spoke often about how they felt they were being misunderstood by their practitioner as they ‘operated’ in a different way to neurotypicals or that they had to fit in with specific ways of communicating (sitting in a room, face-to-face) when something like Skype or email may have been more appropriate, as Amy speaks about in her quote.

What it appears to boil down to, seems to suggest that practitioners are unable or reluctant to be flexible or to adapt their style, modality, or way-of-being to suit the needs of their clients. They often are made to feel like there is something ‘wrong’ with them as they are not able to ‘do’ therapy, such as when they may be ‘forced’ into a particular way of ‘doing’ therapy that does not work for their particular needs, HFASD issues, or ways-of-being. As Rachel describes in her quote above, she saw how her group therapy was not suitable for her needs and attempted to explain this to the practitioner. However, the practitioner seemed to ‘force’ Rachel to work in a psychodynamic way rather than adapt or
take on board her particular needs. Rachel felt that the practitioner was learning but, ultimately, felt like she had been disappointed by this experience.

**Harm caused by professionals**

Within the category of ‘harm caused by professionals’, there are 11 sub-cATEGORIES that fit into it. These would include: therapy outcomes, therapist interventions, therapist understanding, therapist harm, therapist traits, client’s needs, therapeutic relationship, various psychological therapies utilised, therapist skills, expectations of therapy, and services and systems. This is highlighted by the following quotes:

*Oscar:* “I don’t think there is anything more harmful than an unqualified therapist, because you are, essentially, getting given advice over a coffee or something, in that respect. Anyone can give you an advice like an agony aunt, but therapists are supposed to know the ins and outs of the human psyche, and this woman just had absolutely no clue.”

*Saul:* “It was always framed as, or they would come up with things every now and then, when they would be like, ‘Well, that shows a lot of emotional understanding, which, to me, suggests that maybe you’re not quite as autistic as you think.’ I would be just like, ‘Huh? That implies that none of us have any emotional understanding and that’s complete nonsense.’ I often felt quite agitated by a suggestion that, because I could understand someone’s emotions every now and then, that I would not be autistic and that actually meant that I was fine or maybe my problems with different things, my difficulties, my way of thinking about things was only a temporary thing and I just grew out of it.”

*Rachel:* “If you’ve tried in the group and you haven’t got stuff out of it, she wasn’t that keen on me going elsewhere; she thought I hadn’t tried hard enough. I was like, actually, there is a point at which you know yourself better than they know you, so you just do what’s right for you.”

*Amy:* “They never told me ‘you were wrong’. There were comments like, ‘You just want to be special,’ or not really knowing how to relate to the sensory things I tried to explain ... It made me feel like I was either a freak or making things up or it was all in my head.”
John: “My mum said there is nothing for people on the autistic spectrum in terms of counselling. People might feel like they want to kill themselves and have to wait a year, which is terrible, really, because people have gone and done it by then ... It is terrible when you have to wait a year, because a lot of people have gone and done it. It is just sad when that happens, it really is, especially when you can do something about it; someone can help you and you can resolve the problem.”

The five quotes given above, appear to paint a bleak picture of what the participants have experienced whilst in psychological therapies. The overall feeling given by the participants seems to be a negative one, however, it is important to note that Yvonne and Mark felt they had been helped and supported by their practitioners and all seven participants would undergo therapy again if they found the right practitioner and type of therapy. Nonetheless, the majority of participants felt invalidated, offended, or worse off for going to therapy.

Oscar’s quote highlights how an unqualified or untrained practitioner is able to cause harm as it would suggest they might as well go and see a person for a chat over coffee. He felt that his mental health problems were not being taken seriously, he was misunderstood and gave the impression to him that he was not important enough to be ‘given’ a well-trained professional. Saul felt offended by his practitioner’s interventions as it seemed to suggest to him that as he didn’t fit the practitioners idea of what autism is, therefore, he did not have autism – this is a highly dangerous assumption for the practitioner to make as they are not qualified or informed enough to make this judgment. This has huge implications for Saul’s identity and his mental well-being. As in the category above, there appear to be instances where a participant was ‘given’ a therapy and ‘forced’ to take part in it, even though Rachel described her difficulties to them and how to be more autism-friendly, she appeared to be told ‘you are not making enough effort’ and ‘don’t go elsewhere’ to get your needs met. This seems very harmful as the practitioner seems to be fitting the client into their therapy rather than trying to gauge and meet the client’s needs. It might have been more ethical or responsible for the practitioner to say that this therapy may not suit this client and to suggest or refer her on to another type of therapy. Instead Rachel left her experience feeling judged and invalidated.

There appears to be explicit and implicit ways of practitioners being harmful towards their clients. Amy describes in her quote above feeling like she had been implicitly told that she is the reason why she is having all her problems, that she was deliberately trying to be
‘different’ to stand out. Amy seems to feel completely misunderstood by her practitioner as they did not see that her being different from others around her is the reason why she feels unwell and struggles so much and, ultimately, made her feel worse about herself than when she started therapy. This does not seem to suggest that the practitioner is making an effort to listen, be empathic, nor understand the client’s way-of-being in the world.

John makes an excellent point in his quote about individuals with ASD, feeling like they are not as important as neurotypicals or other people with mental health problems. He speaks about his and his family’s experience of either none or scarcity of services and resources available for this client group and that they are only available if the person is very severely unwell. This seems to give a message to this client group that their mental well-being is not as important as others, that the government may be ignoring or unaware of their needs, or that they are not as interesting or ‘fashionable’ to work with.

The above experiences seem to suggest that adults with HFASD are experiencing very difficult, if not, harmful treatments of psychological therapy and giving the message that they are imagining things, that they are not trying hard enough, and that they are not as important as other people. Not only do the participants have to contend with mental health problems, problems due to their HFASD and life stressors but the professionals they come and see may also have an adverse effect on them.

Discussion of analysis

The researcher utilised the Grounded Theory (GT) method as stated by Charmaz (2006) and described in the Analysis section of the Method. To show to a more detailed effect how the researcher went about creating their categories, examples will be described. With each text, the researcher re-read each transcript several times to get a ‘feel’ for the material and the text was then split with two empty rows to the right-hand side of it. The researcher used various types of coding methods- initial coding (incident-by-incident coding was used instead of line-by-line due to time limitations to this research), these codes where then analysed using focused coding, codes are constantly revised, then in the last stage theoretical coding was used to find relationships between focused codes to formulate a theory or story, and this is only possible once theoretical saturation has been achieved as the data is not providing any further insights (Charmaz, 2006). The three categories that were created are: living with HFASD, lack in psychological therapies, and harm caused by professionals.

How the researcher carried out analysis can be demonstrated with the following quote from the category ‘living with HFASD’: John: “I got diagnosed very young, roughly, I
believe when I was 5 years old, which was quite handy, really, because I have had a lot longer to understand myself, find out where my strengths are ..... I got a lot of help with school that I needed, which I think has had a massive influence on my life, because I think, if I hadn’t had that support, I would be a very, very different person to the one I am now”. The multiple reading through of the text provided a feel for John’s story and the researcher was getting the impression that he was an intelligent, well-balanced man who appears to have evaluated his experience as challenging, sometimes negative, and has understanding of his difficulties. Initial coding was the first step of writing ideas/impressions/feelings down. In the first row next to the text, ideas stated were: young diagnosis, felt it was helpful to have more understanding from early on, supportive family, supportive friends, support changed his life, would be different without comparison with ASD people diagnosed later as have difficulties he doesn’t, grew up knowing about ASD, and learnt acceptance of his ASD earlier. These initial codes were analysed further and grouped into three focused codes of: diagnosis, social context and acceptance. In this instance, the researcher did not feel they needed to amend these codes and they stayed as they were. Once the researcher decided, due to being so intimate with all the transcripts, that theoretical saturation had been reached, they could see that these focused codes could be used to help formulate a theory/story of John (and other participant’s experiences) and be formulated into theoretical coding. All focused codes were written on Post It notes and put together to be grouped to help formulate a theory about the participant’s experience. John’s quote fit with data garnered from the other participants and showed that this was a heavily weighted concept. This helped the researcher to see that these codes were important and thus easily put together to create a main category – in this case: ‘living with HFASD’. Within this category, many focused codes were included such as diagnosis, disclosure, social context, stereotyped, specific individual ASD presentations, reasons for therapy, help seeking behaviour, support, identity, self, timing, impact, gratitude, regret, explanation and understanding. The researcher felt that this particular category was an integral part of the participant’s experience as this is their reality and how they described it, thus the focused codes fit in with this category and helped to validate their experience. It may seem like a vague title for a category but its broadness allowed the category to fit more of the participant’s experience to be discussed and hopefully allowed their reality to be more accurately depicted.

The ‘living with HFASD’ category came out of the direct questioning from the first interview schedule. Categories ‘lack in psychological therapies’ and ‘harm caused by professionals’ were created in response to changing the interview schedule and adding more
questions as the researcher observed what trends/concepts appeared to be arising when speaking with participants and through numerous re-reads of transcripts and re-analysis of focused codes. Category ‘harm caused by professionals’ was something that was either an undercurrent in some texts or outright explicit but had not been explicitly asked about up until the interview schedule was changed. As per the method described by Charmaz (2006), the researcher knew to change the interview schedule in anticipation of a participant who would be able to speak about that topic and to recruit such a participant. Having been present in a few meetings of a National Autistic Society social ASD group and getting to know their members and the types of opinions they exhibited, the researcher was able to recruit “Oscar”. This is in keeping with this method of GT (Charmaz, 2006) as the method requires a participant that is outspoken, critical of their experiences and willing to speak about it. “Oscar” was used to help explore this trend/concept that appeared to be spoken about in the other transcripts and used to confirm the focused codes that the researcher had been able to create with the already present data.

Using “Oscar’s” quote, a description of analysis will be demonstrated: *Oscar: “I don’t think there is anything more harmful than an unqualified therapist, because you are, essentially, getting given advice over a coffee or something, in that respect. Anyone can give you an advice like an agony aunt, but therapists are supposed to know the ins and outs of the human psyche, and this woman just had absolutely no clue”*. Initial coding of this incident brought forth the following impressions: should be trained in specific skills, might as well speak to a friend, frustration, upset, anger, harm, and worry about the care given. This initial coding was then used to create focused codes which the researcher chose to call ‘therapist harm’. The researcher used this focused coding and wrote down other focused codes on to ‘Post It’ notes which were then grouped together to create main categories and helped facilitate theoretical coding. Within this category, the focused codes that made up the theoretical coding that enabled the story of the participants to be explained, are: therapy outcomes, interventions, not feeling understood, therapist harm, therapist traits, client’s needs, therapeutic relationship, various therapies utilised, therapist skills, expectations of therapy/services/systems, lack of ASD knowledge, negative experiences, condescension, and not feeling accepted.

With this in mind, the researcher was able to place the focused codes within a main category of ‘harm caused by professionals’. Not only was this a heavily weighted category but the researcher had to utilise their own imagination and psychology training to decide which data fit together the best, which help formulate a coherent theory about the participants
experience, and what was important to be reported upon in order to uphold the goals of the research question and the goals set out at the beginning of the research project. The researcher decided this was a very important category as it showed the participants described reality which had a negative impact on them and is something that if it is reported enough, practitioners can be educated about what they may or may not be doing in therapy with this client group.

Discussion

The research question for this study asked about the way adults with HFASD who have undergone psychological therapies made sense of their experience. Using the grounded theory method by Charmaz (2006), extensive and in-depth analysis has been conducted using a constant comparative method (Glaser & Strauss, 1967). The data has been co-constructed by the participants and how the researcher has interpreted it. With this in mind, the data analysis has constructed three categories that make sense of and give meaning to the participant’s experience. These three categories are: 1) living with HFASD, 2) lack in psychological therapies, and 3) harm caused by professionals. The seven participants that took part in this research were not uniform in all their answers as they were all individuals from different backgrounds, ages, gender, and beliefs. This is part of how the researcher made sense of the co-construction of the categories and they would not expect there to be 100% identical answers. The participants showed individual differences in their experiences and how they made sense of them. However, it was possible to find strands of relationships between the participants, which helped to interpret a cohesive theory.

Looking at the category ‘Living with HFASD’, it was important to include this category about the experience of these individuals as it would be unreasonable to not include the social context and their background when thinking about how they create meaning for their experience of undergoing therapy. This included getting a diagnosis as many people seemed to talk about their lives in terms of pre- and post-diagnosis and how this affected their lives. Many participants spoke about finding a reason as to why they felt ‘different’ from others as well as having the opportunity to have access to other services that may or may not help them. Only one participant felt like his diagnosis was a burden and described how people treated him differently after disclosing his diagnosis to them. Participants spoke about how the timing of their diagnosis could be quite vital, as the participants who were
diagnosed younger were able to access services and support that aided their development and the participants who were diagnosed later spoke about feeling regret that their problems had not been picked up earlier so that they could have received help earlier.

Participants spoke about how their HFASD symptoms caused certain problems for them in terms of sensory issues, social problems, and in times of change. They also described feeling stereotyped by not only people around them but also by professionals they were seeing. This seemed to cause them distress and some felt offended by this experience. This also included feeling ‘other’ compared to ‘normal’ or neurotypical people, people perceiving them as ‘weird’, or that something was wrong with them. When taking into account the amount of research discussed in the Introduction above around particular ASD problems, co-morbid psychiatric problems, the stress of feeling ‘different’ to others and also the data gathered in this research, it seems to be highly apparent that this group of individuals do need help and support via professional services such as psychological therapies.

The category of ‘Lack in psychological therapy’ appeared to highlight aspects in the participants experience that they felt was missing or that they wished they had had. This seems to suggest that the practitioner is not necessarily looking at the needs of their client’s but adhering to other tenets or agenda’s that are important to them. The most apparent lack in all of the participants interviews (except one) showed that a lack of ASD specific knowledge appeared to have a huge impact on how the participant felt they were treated in therapy and the types of interventions they were given. John spoke about how he had specific needs such as his emotions, ways of processing things, way of communicating, and specific ASD presentation would mean he would need a service that took this into consideration but that the practitioner he saw did not know how to contend with this and therefore they struggled to facilitate a therapeutic relationship, which most would argue is one of the most important aspects of therapy. It also seemed that some participants felt that they as a client group were not as important as other client groups such as the LGBTQ community. Many participants spoke about how they did find empathy important in their experience of therapy but that many practitioners lacked in providing concrete practical/logical interventions (which people with HFASD find very helpful due to their ASD presentation and particular issues), failed to take into account other ways of communicating with participants (via Skype, phone, email, etc), and also that many practitioners were not willing to be flexible or adapt what they were already doing to take into account their needs. As a client, it is possible to imagine that these experiences make a person feel invalidated and not as important as other people undertaking therapy. It would even be plausible to call this discrimination.
The category ‘Harm caused by professionals’ is a category that is shocking to have seen appear within the data. Participants have described that they felt their therapist may have been unqualified/untrained in not just ASD specific knowledge but also in core therapeutic skills. Some participants also spoke about feeling like some of the things said to them was offensive and condescending towards them but can also be more subtle and implicit with their harmful interventions. Rachel spoke about how she felt like the practitioner was imposing their own agenda and values onto her which felt harmful and also that her needs were not as important. It also seemed to show that people with HFASD seeking help via services and systems found that there was a scarcity of interventions and support available to them. This reiterates aspects for the second category that this client group seems almost forgotten about or that people may not be willing to adapt to their needs.

Looking at the results and discussion above it does seem to suggest that adults with HFASD have had quite a negative experience of undergoing psychological experiences. However, it is not the intention of the researcher to only show one aspect of the data. A few of the participants did specify that they found therapy extremely helpful and would definitely undergo therapy again. The reason that the above categories appear like there is a more negative slant is because the majority of data that was found and co-constructed showed negative experiences and ways they felt their care had been neglected. In many ways, it seems that this category is important to be reported as this may open a dialogue and provide an avenue where change within this sphere might be enacted.

The information presented in the Findings section and reiterated above, work well together to bring about a cohesive story for the participant’s experiences. The overall feeling given by the participants is a story that involves a journey from the moment they are born up until this point. It is taking into account how the participants grew up and developed in their childhood and how their development and integrating into society was hugely impacted by when they were diagnosed and how their social context took this on-board. These factors affected them in their sense of self, their identity and self-esteem. All participants sought help due to either their HFASD problems, co-morbid psychiatric problems, life stressors or a combination of these issues and entrusting their well-being with professionals they assumed would be helpful, and understanding. Both Mark and Yvonne displayed the possibility of this happening for these individuals, Mark saw an ASD trained practitioner but Yvonne did not, however, both practitioners were able to take their client’s needs on board and listened to what their clients said and needed. The data found suggests that the majority of participants only saw non-ASD trained practitioners and felt worse off for it so this might show that this
is an important factor in feeling understood as a client. Nonetheless, it seems that practitioners are able to facilitate a therapeutic relationship and effective interventions without the training, it just seems to be a rarity. What seems to be a real shame and even shocking, is how practitioners, who one assumes has been trained in the core tenets of psychological therapy (such as Rogers, 1957, six conditions for therapeutic change), are unable or reluctant to be flexible, creative, or adapt themselves or their interventions to the client sat in front of them. It is not the intention of the researcher, to state that all practitioners have to work with individuals with HFASD, but it seems that many practitioners have worked with these individuals and not been open and honest about their own difficulty in the therapeutic process. One might suggest that this may be a point of vanity or fear of failure on the practitioner’s part, but as Oscar states above, it is very dangerous when the practitioner is not taking the persons mental health problems seriously and only do an ‘ok’ job of it. Many practitioners will be coming across this client group and they may not be aware of the implicit or even sometimes explicit harm that they can cause.

The story also continues with how these individuals have felt let down by services and by professionals. Participants have shown how they have put themselves into the professional’s care assuming that they would take their best interests into consideration. However, participants such as Rachel are then ‘forced’ to fit into a particular modality or type of therapy rather than thought being put into the suitability of this therapy for Rachel and her specific needs. Maybe the practitioner is working from a place of wanting to help but in some cases, it may seem that this can potentially harm the client or at the very least, waste their time and the services resources.

When participants state they are made to feel like they are ‘different’, ‘weird’, or ‘odd’ by the people around them or categorised into a particular ‘box’, it seems their assumptions is that the practitioner will not do this either. Nonetheless, what the participants have apparently shown in the data is that not only does their social context discriminate against them and marginalise them but that they feel this has happened to them whilst under the care of a professional. It seems to be suggested by the data, that participants are being given an overall message of “You are not as important or valid” as other people in society. Not only does their social context around them marginalise and stereotype them, professionals and services do as well, especially when they are told: “You are not trying hard enough to fit in”, “Are you just trying to be different from everyone else?”, and “There are no services around or available for your specific needs”. This is incredibly disheartening and must feel devastating to the people it truly affects. By highlighting these points within this
data, there is a hope that something can be done about it. That practitioners’ eyes may be opened to their own vanity or fears of failure, of how they could be unintentionally harming a client, how they could develop themselves as a more effective and empathic practitioner, and to see individuals with HFASD as people who need help and are so often misunderstood.

With the creation of three categories from the analysis carried out by the researcher, certain exiting theory and research has heavily influenced how the researcher made sense of the data available. The three categories “living with HFASD”, “lack in psychological therapies”, and “harm caused by professionals” were created from the descriptions given by the participants but it is by the discretion of the researcher and how heavily weighted some codes were that truly focused the creation of the categories.

The category “living with HFASD” was a category that had many focused codes comprised within it. Research such as by Gerland (2003) and Gerland & Sainsbury (1999) gave credence to concept of individuals with HFASD undergoing psychological therapies have often felt misunderstood or that their practitioner caused them harm of some kind, as well as studies stating that classic analytic therapy can be ineffective or even deleterious for children with HFASD (Fitzgerald & Bellgrove, 2006; Ghazuddin, 2005; Ruderman, 2002). This echoes how participants in this research have had mainly negative experiences and was something that the researcher had in their back of their mind throughout carrying out the analysis.

One particular study at the back of the researcher’s mind, which also seemed to fit in well with this particular category, was carried out by Elichaoff (2015). It appeared to be the first qualitative study using thematic analysis looking at the lived experience of 4 adults with HFASD growing older. Elichaoff (2015) found 6 themes – depression, effect of diagnosis, experiences with mental health professionals, inverted relationship between educational level and career, the participant as autism expert, and communication/social interaction. These themes were very interesting as they helped the researcher see if their own concepts were relevant or had evidence in the literature. As shown above, many aspects were mirrored in the analysis and are part of the categories. It showed the importance of the client’s mental health, how their diagnosis or lack thereof affected them, how their interaction with mental health practitioners fared, needing ASD knowledge, and how vital communication is.

In terms of the category “lack in psychological therapies”, it was suggested that this client group expressed a wish for psychological therapies to be more pragmatic, structured or problem-solving in nature. This was also found in a study by Gawronski et. al. (2011), who found that 97 ASD adults expectations of therapy included the teaching of psycho-education
The sheer number of modified CBT protocol studies (El-Ghoroury & Krackow, 2011; Sze & Wood, 2007; Cardaciotto & Herbert, 2005; Beebe & Risi, 2003; Chalfant, Rapee & Carroll, 2007; Reavan, Blakely-Smith, Culhane-Sheblurne &; Hepburn, 2012; Ehrenreich-May, Storch, & Queen, 2014; Selles et. al., 2014; Reaveyn et. al., 2015; Storch et. al., 2015; Van Steensel & Bösels, 2015; White, Schry, Miyazaki, Ollendick, & Scahill, 2014; Wood et. al., 2015; Nadeau, Arnold, Storch, & Lewin, 2014; Hesselmark, Plenty, & Bejerot, 2014; McGillivray & Evert, 2014; Kiep, Spek, & Hoeben, 2015) who showed moderate to high levels of improvement in clients symptomology compared to the small number of psychodynamic case studies (Mero, 2002; Levy, 2011; Topel & Lachman, 2011; Sugarman, 2011; Koenig & Levine, 2011) seem to suggest that a more psycho-educational and structured psychological therapy is being advocated to this client group and may actually be helping them. Five out of seven participants within this research, took part in CBT but mainly spoke about the practitioner not being willing to modify the protocol to fit their HFASD presentation. It may be suggested that if this client group were able to benefit from HFASD specifically modified CBT protocols, then this may help the experience to be positive and helpful. This also fits in with the category “harm caused by professionals” as it may be that this client group would be able to ‘do’ modified CBT if the professional was willing or trained with specific ASD knowledge.

The three categories seem to suggest that this client group wish to feel contained, understood, and safe. However, this does not appear to be the case considering the experiences they spoke about. This echoes what is stated in articles by Ramsay, Brodkin, Cohen, Listerud, Rostain & Ekman (2005); Munro (2010), Tebartz van Elst, Pick, Biscaldi, Fangmeier, & Riedel (2013); Woods, Mahdavi, & Ryan (2013); Koelkebeck, Riedel, Ohmann, Biscaldi, & Tebartz van Elst (2014) who have written after many (combined) years of working with this client group about the importance of gaining specific ASD knowledge, using the client’s frame of reference so they feel understood, how their diagnosis may affect them, using a pragmatic/structured therapeutic style, and also keeping in mind the client’s co-morbidity and psychiatric needs. By the sounds of the participant’s descriptions, the majority of their practitioners did not utilise any of those skills, traits, or interventions even though there is information available to the practitioners. This information was used by the researcher in that, it made them realise how harmful a practitioner can be and that it is vital to highlight this. There is information available to practitioners but the fact that they appear to be ignorant, lazy, unwilling, or not open to experimentation is incredibly dangerous as this can affect their client to a point where their lives may be in danger. The fact that the
participant’s spoke about this problem throughout each description just highlighted how important it is.

Specified in the Introduction above, an aim and objective was stated for this particular research. This was to widen the knowledge that practitioners have of HFASD with the objective of incorporating this knowledge into practice. When looking at the analysed data and the three categories, the most simple way of possibly answering these was to say that adults with HFASD have an experience before, during and after therapy that includes their social context as well as what happened in their therapy. Some had positive experiences but the majority of participants appeared to have negative experiences which included feeling stereotyped, condescended upon, and not as important as other client groups. They appeared to make sense of their experience as mainly negative but that they would not completely rule out having psychological therapies again – if anything, they all appeared to have hope that there is someone out there that can help and support them but it may not be a practitioner of psychological therapies. Most participants spoke about how they would look to their occupational therapists, psychiatrists or their ASD assessor (post-diagnosis) for guidance or somewhere to go where they felt their experience was validated (this usually included the person having a good understanding of ASD).

It was also to try and address some of the gaps in the literature as discussed in the introduction. As scarce research appeared to have been conducted around the experience of adults with HFASD undergoing psychological therapies, it seems that this research has started to attempt to look at this field and bring some insights to the fore. The information that has been constructed via the three categories may help to give information and guidance to other practitioners and trainees who are either working with this client group or will do at some point in their career. As it would seem that 1% of the population (APA, 2013) have been diagnosed with ASD, it is highly likely that a practitioner or trainee may come across such a client. It would be unethical for the practitioner to work with this client from an unqualified or untrained stand-point; it would be highly advisable that practitioners gain some understanding or training about this disorder in order for them to work with respect and sensitivity. This also includes any trainers or lecturers who are giving the training to the practitioners as they should be versed in the most current research and knowledge available to them in order for them to provide the most effective training.

It is also important to discuss how it seems that this client group may be viewed by practitioners in the field. From the perspectives of the participants, many have come across professionals who have made them feel ‘weird’, ‘different’, and that something is ‘wrong’
with them. Possibly even that they do not want to work with them as they might be a difficult client group to work with. It is not the intention of this research to state that all practitioners have to work with this client group and that they have personal choice in the matter; this research speaks to the practitioners who have worked or will work with this client group and for them to be informed about the process and perspectives of the client group. This kind of attitude that some practitioners may have can give the impression that this client group is not a valuable piece of work or that they are hard to work with and this can only make the client group feel more marginalised than they already are in society. A person with neurodevelopmental problems, comorbid psychiatric problems, and/or life stressors may reach out for help and these helpers may stereotype, demean, or make them feel hopeless. This seems both unethical and dangerous. As shown by Richa, Fahed, Khoury, & Mishara (2014) people with HFASD are more likely to take their lives than people with lower functioning ASD.

From the scarcity of research into adults with HFASD it seems to appear that the voice of these individuals is quite a quiet one at present. They are a part of our society and they do require help and support just like the rest of us. In some ways, this research can also shed some light on how adults with HFASD can change their help-seeking behaviour. It may help them to be more specific in having their needs met and possibly find the kind of support they are looking for.

This study works well with the IPA investigation undertaken by Coxon & Brown (unpublished) as it found three themes within the data provided by practitioners who work with this client group that appear quite similar to the categories constructed above, which are: 1) the importance of the therapeutic relationship, 2) feelings of limitations, and 3) the effects of an autism label. They described the importance of making a connection with the client group and giving them understanding and validation of their experience, they spoke about how certain practitioners and services are lacking in certain aspects that make undergoing therapy for this client group very difficult, and they spoke about what living with HFASD is like on a day to day basis and how this can influence their help-seeking behaviour as well as their experience of therapy. The similarities are very closely linked and appear to show a unity of experience for both the practitioners who often work with this client group and also with individuals undertaking the psychological therapies.

This particular research has its own strengths and limitations. As this seems to be the beginning of investigating this field of research, it has opened the doors for further research. A level of saturation was reached within the data around the seventh participant mark but that is not to say that this research would be able to be undertaken with a more varied sample due
to the fact that it only looked at the perspective of relatively young adults (aged 21-38) and does not include older adults living with this condition. The sample mainly consists of Caucasian British people and it would be pertinent to gain a wider ethnic diverse sample. It was possible to have a fairly equal gender split in the sample and no particular gender specific codes or categories came out of the data. That is not to say that future research could not look into any gender differences or similarities when undergoing psychological therapies if it emerged in the data. This sample also looks at individuals living in the U.K. and it would be appropriate to see what data might emerge when looking at samples from different countries or cultures. These are all potential research questions that could be taken up by researchers.

Grounded theory is a methodology that has both strengths and limitations. The researcher was given freedom to cultivate a theory through careful consideration of the texts due to the core basis of the methodology being data driven and it also ensured its own source of rigour as the researcher is constantly looking for data to disprove ideas that have been formulated thus far (Hawker & Kerr, in Lyons & Coyle, 2007). It is particularly useful when there is a paucity in current literature, as was the case here, and helped provide a critical way to look at ‘Why’ participants were experiencing what they were experiencing (Hawker & Kerr, in Lyons & Coyle, 2007). However, this methodology has been criticised for being very time consuming due to its iterative nature, that it is not straightforward as the data can become fragmented during coding and categorisation and make it difficult to keep in mind the overall picture of the data, and requires the researcher to utilise their imagination and use of insight (Hawker & Kerr, in Lyons & Coyle, 2007).

The researcher found this methodology as very time-consuming and could have affected the interpretations of the data as the researcher felt rushed and under time pressure to adhere to the methodology and remain in the remit that academia affords. The researcher was a novice when it came to this methodology and it took time to hone the skills of insight, imagination and training as a psychologist. As mentioned above, time is a critical area when facing deadlines in academia but this is a balance the researcher has to find. In terms of the data becoming fragmented, it was not a problem that the researcher came across as they cross referenced the data in the text and using memo’s as part of the analysis helped to keep things in context. This may be a problem with larger sets of data and more participant’s to keep in mind.

It is difficult to be able to say which aspects of the analysis, interpretation and subsequent creation of categories were influenced by the participant’s description of their
experience and the researcher’s own perspective, background, and reading of existing literature. GT acknowledges the important role of the researcher and how they are the ones who discern what information is kept and reported upon (Charmaz, 2006). Without this acknowledgement it would be render the analysis moot as this is a co-creation between researcher and the participant. It is also important to note that a participant may be trying to provide the interviewer with what they feel they want or are looking for, known as social desirability (Jones, Torres, & Arminio, 2013), and that this may have affected how participants told their stories. Participants were all adults diagnosed with HFASD and this in itself may bring forth the question of their ability to communicate their experiences affectively. However, all participants were well educated, verbose, convivial, and open to discussing difficult and sensitive information. This may be a way forward in which adults with HFASD are not stereotyped as uncommunicative, shy, unintelligent, or unable to express themselves coherently.

The use of Skype, telephone and face-to-face interviews is also a valuable aspect to discuss. There appears to be an assumption in the current field of qualitative research, that the use of telephones or synchronous, online modes of communication such as Skype are second choice for interviews or only as an alternative out of necessity and that face-to-face interviewing is the ‘gold standard’ (Novick, 2008; Deakin & Wakefield, 2013). This may be due to worries around authenticity of the participant, ethical concerns, technical problems (Sullivan, 2013), loss of contextual or non-verbal data (Holt, 2010), and rapport (O’Connor et. al., 2008). There appears to be a lack in current research looking into the benefits, drawbacks and other general debate around the use of Skype or telephone interviewing versus face-to-face interviewing, but though some research is new it seems to be growing (Deakin & Wakefield, 2013).

In terms of the use of telephone interviews, Novick (2008) states that participants feel relaxed and are able to talk about sensitive subjects, possibly due to the lack of visual cues that may distract their dialogues, Sturges & Hanrahan (2004) compared telephone interviews with face-to-face interviews and found no significant differences in the interviews, and Holt (2010) states that even though some subtleties may be lost, it does however, help the researcher to stay closer to the text, she also stated that all participants reported positive feedback after their experiences, that researchers benefit from better scheduling flexibilities and that it removes the feeling of obligation a participant may have if the researcher had travelled to meet them. The research quoted above fits in well with the personal experience of this researcher. It felt at times that participants were able to feel more freedom in their
dialogue as they did not have to concentrate on what I was doing and were able to concentrate better on their stories. There were also no problems in terms of creating or feeling rapport with the researcher and participants as there was still humour in the conversations and as it was in real-time, any confusions or questions could be dealt with there and then.

When looking at Skype interviews, Hanna (2012) speaks of the control participants gain by being able to choose their mode of communication and this helps with the power dynamics that can spring up in interviews as well as the participant being able to be in a ‘safe location’ of their own choice which may help facilitate their dialogue and stories. Sullivan (2013) states that even though there is a worry participants are not showing an ‘authentic self” due to modern societies dependence on technology and the internet and the vast amount of time we spend on them, our presentations of ‘self’ are potentially more accurate than they were 20 years ago especially with younger generations whose ‘self’ can almost be said to be synonymous with the ‘online self’. Deakins & Wakefield (2013) also state that there are also many practical benefits such as it being cost and time efficient and samples are more geographically dispersed but they also stated that rapport was still possible and only lacked if the participant was more reserved or less responsive. In the experience of this researcher, it was very helpful to have the use of both Skype and telephone as some participants were geographically dispersed and it enabled me to speak to them. It also helped due to financial and time constraints, not only is funding always a problem but as participants have their own lives to contend with it is good to be able to work around their schedules and therefore ensure their contribution to the research. What felt particularly helpful, was that there was a ‘third’ (Winnicott, 1971) in the room (a psychoanalytic term which speaks of a space or even object that allows a client to explore, speak through, or use to help facilitate change and difficulties), this being the use of the telephone or Skype which opened a space where participants felt less anxious. Adults with HFASD that the researcher has spoken to have stated that it gives them a little distance where they have more space to breath and think and feel a lot less pressure about social cues. It seemed to really work for them and may be a very useful tool for psychotherapy and counselling with this client group as it can take the pressure off and reduce the anxiety provoking issues that may arise when being face-to-face with another person.
References


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Participant Information Sheet – 2015

Investigation into the personal therapy experience of adults with a high-functioning Autism Spectrum Disorder (HFASD)

Introduction
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?
I am investigating what the personal therapy experiences are of adults who have a diagnosis of a high-functioning autism spectrum disorder (HFASD). The investigation will look at the therapeutic experiences involved in the relationship between practitioner and client, including challenges and successes.
The study will involve one-to-one interviews in a confidential setting and audio-recorded and the interview will last approximately 30 minutes. The interviews can be done face-to-face or via telephone or Skype.

Why have I been invited to take part in this study?
I am interested in participants who have a diagnosis of a high-functioning autism spectrum disorder including Asperger Syndrome, who have undergone personal therapy for at least 6 sessions. The personal therapy undertaken can be versions of psychodynamic, cognitive-behavioural (CBT), or humanistic therapies.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will then be asked to sign a form agreeing to take part. If you decide to take part you can still change your mind and withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way.

Will my taking part in this study be kept confidential?
Yes. All information that is collected about you during the course of the research will be anonymised so that those reading reports from the research will not know who has contributed to it. I will need to analyse and store all the results. It will not be possible to identify you from any of the stored material. Data will be stored securely in accordance with the Data Protection Act (1998) and the audio-recording will be destroyed after the research has been concluded.

What are the possible disadvantages and risks of taking part?
There are no known risks expected to result from taking part in this study however considering that sensitive material may surface due to the nature of the topic (psychotherapy) you could potentially experience some emotional discomfort or distress.
Who should I contact for further information?
Sabrina Coxon – s.coxon@surrey.ac.uk
You can also contact my supervisor – Dora Brown – dora.brown@surrey.ac.uk

This copy is for you to keep. If you decide to participate, you will also be given a copy of the signed consent form to keep.

Thank you for considering participation in this study!
Appendix B. – Consent Form

Consent Form – 2015

Investigation into the therapeutic experience of adults with a high-functioning Autism Spectrum Disorder (HFASD)

I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS) ............................................................

Signed ........................................................

Date ..................................................

Name of researcher taking consent (BLOCK CAPITALS) ....................................................

Signed ........................................................

Date ........................................................
Information Sheet:

Dear Participant,

Thank you for participating as a research participant in the present study concerning your experience of personal therapy. The present study sought to explore in depth, your personal and lived experience of having taken part in personal therapy including its challenges and successes. It is ultimately the hope of this study to investigate the “felt” quality of being in personal therapy and that your experiences may help inform practitioners, current or in the future, when working with this client group.

If you know of any friends or acquaintances that are eligible to participate in this study, please ensure that you do not discuss it with them until after they have had the opportunity to participate. Prior knowledge of questions asked during the study can invalidate the results. Your cooperation is greatly appreciated.

If you have any questions regarding this study, please feel free to ask the researcher at this time or otherwise contact them via email: s.coxon@surrey.ac.uk. You can also contact the researcher’s supervisor via email if you so wish: dora.brown@surrey.ac.uk .

Thanks again for your participation.
Appendix D. – Recruitment Email

Dear [insert name],

Your email has been kindly forwarded to me by [ASD assessor] who said he has spoken to you about possibly participating in my doctorate research into the experience of adults with ASD engaging in psychological therapies.

There are a few criteria that I have to make sure you qualify in order to do the research - 1) be over 18 years old, 2) have a diagnosis of autism spectrum disorder, 3) to have participated in at least 6 sessions of psychological therapies (such as cognitive-behavioural therapy CBT, IAPT, humanistic, person-centred, or psychodynamic therapy). If you fit this criteria, then I would be very eager and happy to have a chat with you.

I would be able to do the interview face-to-face, speak over the phone or via Skype. The interview would be recorded so that I am able to use this data for my research.

Please find enclosed an information sheet and consent form to have a read over. If you have any questions or worries, do not hesitate to email me or give me a call on xxxxxxxxxxxxx. I would love to be able to set up at time, date and place to do the interview in the next week or so if you are available.

I look forward to hearing from you!

All the best,

Sabrina Coxon

PsychD in Psychotherapeutic and Counselling Psychology - Year 3
University of Surrey
1) Could you please tell me a little bit about your diagnosis of high-functioning autism spectrum disorder?

2) What would you say is your experience of personal therapy?

3) What advice, if any, would you give to other people with a diagnosis of HFASD who are thinking of undertaking personal therapy?

4) Would you undergo more psychotherapy in the future for your HFASD?
Appendix F. – Interview Schedule 2

Interview Schedule

1) Could you please tell me a little bit about your diagnosis of high-functioning autism spectrum disorder?

2) What would you say is your experience of personal therapy?

3) What advice, if any, would you give to other people with a diagnosis of HFASD who are thinking of undertaking personal therapy?

4) Other participants in this research have observed that the level of autism training of their therapist had influenced their therapy, would you say you have as well?

5) Would you undergo more psychotherapy in the future for your HFASD?
Appendix G. – Interview Schedule 3

Interview Schedule

1) Could you please tell me a little bit about your diagnosis of high-functioning autism spectrum disorder?

2) What would you say is your experience of personal therapy?

3) What advice, if any, would you give to other people with a diagnosis of HFASD who are thinking of undertaking personal therapy?

4) Other participants in this research have observed that the level of autism training of their therapist had influenced their therapy, would you say you have as well?

5) Other participants in this research have observed that the therapist may unintentionally say something harmful about them or about autism, would you say you have as well?

6) Would you undergo more psychotherapy in the future for your HFASD?
Appendix H. – Sample Transcript – “John”

Interviewer – Sabrina Coxon
Participant – “John”

Interviewer: To start off could I get demographic information about yourself, just to have it on the record – age, gender and ethnicity?
Participant: I am 24, I am male and I am white British, or Caucasian.
Interviewer: Could you just please tell me a little bit about your diagnosis of Autism Spectrum Disorder?
Participant: I got diagnosed very young, roughly, I believe when I was about five years old, which was quite handy, really, because I have had a lot longer to understand myself, find out where my strengths are. So, yes, when I was very little, about two/three years old, when I started talking, my parents noticed something different and my mum fought very hard for me, and I got my diagnosis when I was around five years old and I got a lot of help with school that I needed, which I think has had a massive influence on my life, because I think, if I hadn’t had that support, I would be a very, very different person to the person that I am now. So, I was diagnosed young and that has had a big impact because I know people who were diagnosed much later, so they find it much more difficult doing things in life and understanding it and getting to grips with it. When you are diagnosed younger, you have grown up knowing it and you learn to accept it.

Interviewer: OK, that’s good. What would you say are the difficulties that you have specifically that are on the spectrum?
Participant: I think I do find meeting new people sometimes quite challenging, especially groups of new people. I am getting much better socialising. At work, I do like talking to people, in my general job. I do like to try and socialise where I can, but I find it can be a bit awkward meeting new people, especially big groups of new people. Change sometimes is quite difficult still. I am much better at coping with change than I used to be, though, which, again, is just something that I have managed to learn to deal with, growing up, but some big changes I can find quite difficult. There is quite a lot I want to say but I just can’t get it in my mind at the moment.
Appendix I – Self-Reflection

I feel I have a personal connection to people with high-functioning autism spectrum disorder (HFASD) as my sister has been diagnosed with Asperger’s Syndrome (AS), various members of my husband’s family have been diagnosed or suspected having AS, and I have volunteered since I was 12 in educational organisations for children and adults with autism. I think this personal experience and connection to people with autism has made me feel like they are often misunderstood or do not have a voice that should be heard. Coupled with this personal connection, sense of injustice and opportunity to conduct research, I felt I finally had a platform to have their voices heard. The beauty in doing this course and being able to do two separate pieces of research meant that I was able to look at not only the perspectives of adults with HFASD but also the practitioners who are working with them. I feel this gives the research, as a whole, a complexity and understanding that has been lacking in the research so far. This is especially evident as I have not come across any research that shows the ‘felt’ experience and the phenomena of having HFASD and undergoing therapy for their co-morbid mental health problems. Certain questions would form in my mind – if all I have are outcomes, how did I even know what the participants felt throughout their experience? Did the participants actually feel that it was helpful for them? Did the participants feel they connected with their practitioner? What did the participants think was particularly good or unhelpful?

It seems that feelings of injustice and people’s voices not being heard, are subjects that hit a chord with me and makes me passionate to investigate them. I was also particularly struck by the implicit and sometimes even explicit examples I had come across in my three years of training where practitioners actively avoided working with people with learning disabilities and/or autism because they were afraid of their complexity, that they felt the clients would be unable to do “proper” therapy, or did not understand the client’s presentations. This made me a bit angry if I am perfectly honest because it felt like people could not be bothered to try to understand people who make up a fair percentage of our society nor could they utilise their flexibility or willingness to be open. This feels odd to me as it feels like those are primary tenets of being a practitioner of psychological therapies. Maybe I am being unfair and even judgmental, which could also be true but I have also met a handful of practitioners who have and do work with clients with special needs who enjoy their work and feel like this client group is able to engage in psychological therapies.
Something that I have taken away from talking to these practitioners, is the willingness to be creative and flexible in your approach.

Having undertaken this particular research, it has invigorated my passion for research as the experience of interviewing the participants was a highly enjoyable experience and it felt like this was the reason why people carry out research – so that people’s voices can be heard and change could be instigated. At times, I did feel guilty for making participants speak about painful and distressing things but they commented on feeling like they were doing something positive by using their bad experience and turning it into a positive experience (by helping others by taking part in the research) or spoke about the experience feeling cathartic. It also felt like they had an avenue in which to have their experience validated and what they said was important and may have an effect on other people’s therapeutic experiences.

A huge influence on my research has been the experience of meeting a man who works in the NHS assessing adults for ASD and also facilitates a group for youths with ASD for the National Autistic Society. He has been extremely helpful in helping me find participants and allowing me to come to the group to speak to them about my research. What I found very interesting about him is that he is not a therapist of any description but as part of his post-diagnostic work, he often ends up being a type of counsellor to the individuals he has just assessed. He also used flexibility, creativity, empathy, validation of experiences, and unconditional positive regard with these individuals – all tenets and primary aspects of what a practitioner should be utilising and providing to their clients. What I found extremely upsetting to me, was the level of harm reported to me that has been caused by practitioners who have not given any of the above qualities as part of their service. This is something important to report on and to hopefully help implement some kind of change in how practitioners work with this client group.

Analysing the data for this research has been interesting as I was writing memos throughout the process and it was really helpful to note certain patterns I noticed or things that felt pertinent at the time. It also gave me a platform to speak about how I felt the interview had gone, what it was like reading it back via the transcript and how interacting with the participants had felt like for me. It made me note if a certain participant’s answers annoyed me, made me feel empathy towards them, and so on. It made me realise how my ‘felt’ sense of being with them interacted with the data as well. For example, one participant was annoying me a bit as he had very cynical opinions about therapy and I felt defensive and I noticed that I had written his codes in a more abrupt manner but after noticing this I went back through the data and looked to see if I had missed anything and needed to amend my
codes. This is why it felt using grounded theory was so appropriate as it made me a more conscientious researcher.
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