Mothers' Experiences of Accessing Mental Health Care for their Child with an Autism Spectrum Disorder

Abstract

Objectives: Despite the recognition that a high proportion of individuals with an Autism Spectrum Disorder (ASD) will also reach the diagnostic threshold for at least one other mental health condition, many families struggle to access the appropriate mental health support. This study aimed to systematically explore the lived experiences of raising a child with an Autism Spectrum Disorder (ASD) and comorbid mental health condition and describes their attempts to access support via mental health services in the United Kingdom. **Methods:** Seven mothers of children aged between 11 to 15 years with ASD and who were referred for mental health issues, took part in semi-structured interviews. Interpretative Phenomenological Analysis (IPA) of the transcribed interviews revealed gaps and inconsistencies within the process of gaining access to mental health services, in addition to the impact it had on the mothers' own mental health. **Results**: The themes generated were psychological impact on caregiver; negative experience accessing mental health services, and breakdown in relationships with professionals. Managing the impact of their child's mental health condition, including suicidal ideation and self-harm, alongside their child's neurological condition, commonly led to feelings of isolation, self-blame, guilt and powerlessness; impacting on the mother's own mental health. **Conclusions:** The themes emphasised the importance of ensuring appropriate referrals are made, enhancing the therapeutic alliance with both the child and parent during the referral process, and in providing continuity of care.

Keywords: Autism; Comorbidity; Mental Health Services, Barriers to care; Child Welfare

Autism Spectrum Disorders (ASD) are complex neurodevelopmental disorders categorized by deficits in social interaction and social communication, alongside restricted or repetitive interests (APA, 2013). The prevalence of ASD has increased greatly over the last decade, with the Centers of Disease Control and Prevention (CDC) in the United States stating increases from 1 in 150 children in 2002 (CDC 2007) to 1 in 68 (or 1.47 %) in 2012 (Christensen et al., 2018). The rise in diagnoses have in part been due to higher specificity and validity of the new DSM-5 diagnostic criteria, which has entailed changes to age of onset, removal of language difficulties to the core criteria, and the allowance of comorbid diagnosis with other developmental disorders (APA, 2013). However, increases in the frequency of ASD have also coincided with an increase in the demand for services in early detection, evaluation and treatment, leading to more problems in the supply and demand of these services (Zablotsky et al., 2017).

In the UK estimates of psychiatric comorbidity in children with ASD are reported to be as high as 70%–75% in community clinic studies (Simonoff et al., 2008), and 83% for psychiatrically referred youth with ASD (Joshi et al., 2010). More recently, data from 29 publicly funded mental health programs found 92% of children with ASD meeting criteria for at least one comorbid psychiatric condition (Brookman-Frazee, Stadnick, Chlebowski, Baker-Ericzén, & Ganger, 2018). Amongst the most commonly identified comorbid disorders have been anxiety disorders, communication disturbance, attention deficit hyperactivity disorder and depression, obsessive compulsive and eating disorders, schizophrenia and psychosis (Brereton, Tonge & Einfeld, 2006; Gillberg & Billstedt, 2000). With the indication of high comorbidity between mental illness and autism, national statistics suggest this vulnerable population is at increased risk of suicide, with the NSPCA reporting suicide to be the second highest cause of death for adults with an ASD diagnosis (NSPCA, 2017). Research has also suggested that children with ASD are 28 times more likely to experience suicidal ideation or attempt suicide than a typical developing child (Halberg, Panksepp, Otsuka & Johnson, 2005). Reasons for these high statistics could be due to individuals with ASD not being able to access helplines, support lines and difficulties with accessing mental health support.

Importantly, individuals with ASD have also been identified as a group who are substantially at higher risk of non-suicidal self-injury (Cassidy et al., 2014). Despite this, there has been limited research to understand the occurrence and nature of non-suicidal self-injury in this group. This may partly be due to the difficultly in defining self -injury in this population, as the presence of high-frequency self-injurious behaviours, such as head-banging and biting, are often categorised as being repetitive behaviours. While no significant differences in the reasons provided for engaging in self-harm have been found between autism and those typically developing, a higher proportion of women with autism than men with autism have been shown to be at increased risk for engaging in these behaviours (Moseley, Gregory, Smith, Allison & Baron-Cohen, 2019).

The high frequency of individuals with an ASD meeting criteria for a mental health condition, has resulted in the National Institute for Health and Care Excellence (NICE) issuing guidance on best-practice for health and social care services for people with autism (NICE, 2012). According to the NICE Quality Standard on autism, people referred for a diagnostic ASD assessment should have an assessment within 3 months, with co-existing physical or mental health conditions also being assessed. Furthermore, the guidelines clearly stipulate that mental health professionals should have knowledge of ASD, to understand how symptoms impact on the treatment of coexisting mental health disorders. Further, where needed, they must seek advice from a specialist autism team regarding the delivery and adaptation of interventions (NICE, 2013).

Despite legislation many families struggle to access appropriate care and support for comorbid mental health in their children (Bromley, Hare, Davidson & Emerson, 2004). For example, research by the National Autistic Society identified a shortage of appropriate support for parents, with professionals lacking the right understanding of their child’s ASD and mental health condition (NAS, 2010). Many young adults with ASD report difficulty accessing services, due to the minimisation of symptoms, or only gaining access at crisis point (Crane, Adams, Harper, Welch, & Pellicano, 2018). Moreover, symptoms of ASD often overshadow mental health symptoms, making access to services more difficult (Gillberg & Billstedt, 2000).

The ability to accurately identify comorbid psychiatric disorders in children and adults with ASD is made more difficult due to the wide variation of IQ ranges and communication problems (Mazzone, Ruta & Reale, 2012). This can make personal interviews more problematic, requiring input from caregivers (Simonoff et al., 2008). The process is further hindered by diagnostic overshadowing, when comorbid psychiatric issues are missed due to more pronounced ASD symptomology (Meera, Kaipa, Thomas & Shivashankar, 2013); or as ASD behaviours, such as avoidance of social situations, also underlie mental health symptomology (Cath, Ran, Smit, Van Balkom, & Comijs, 2008).

Additionally, multiple professional services and pathways are involved in the assessment of children with ASD including mental health, developmental disability, and special education, creating difficulties in the referral process. Each service tends to only concentrate on a specific set of core symptoms, leading to many individuals with ASD being seen in mental health services which are not designed for individuals with ASD (Brookman-

Frazee, Baker-Ericzén, Stadnick & Taylor, 2012; Crane et al., 2018). This continues into adulthood, with at least one in three adults with ASD experiencing severe mental health difficulties due to lack of support (Rosenblatt, 2008). The implications of not accessing appropriate care are significant; with adults with autism and depression reporting a high incidence of suicidal thoughts, plans, and attempts (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2018).

Given the disproportionate rates of mental health in individuals with ASD (McGorry & Van Os, 2013), it is crucial to understand the lived experience of parenting a child with ASD and comorbid mental health issues. The is particularly important, given that having a child with ASD is a strong factor in parental anxiety and depression (Hastings, 2003). Previous research has shown parents of children with ASD to have poorer psychological outcomes, such as experiencing higher parenting stress and more symptoms of depression and anxiety compared to parents of typically developing children and children with other developmental disabilities, such as intellectual disability and Down Syndrome (Lai, Goh, Oei & Sung, 2015). Importantly, when the child with ASD has a comorbid mental health issue, 88% of parents also experience some form of mental health issue and 91% of families believe it impacts the whole family (NAS, 2010). Therefore, the aim of the current study was to gain an in-depth understanding of parents' experiences of gaining access to mental health services for their child with ASD and mental health comorbidity.

Method

Participants

Seven mothers aged from 34 to 47 years old (Mean = 42 years, S.D 1.8 years) with a child aged between 11 and 15 years old (Mean=13 years, S.D 1.3years), were recruited from local charity groups. The sample represented all the mothers who had expressed an interest to take part in the study. All the children had a formal ASD diagnosis for at least 12 months to ensure that parents were not newly navigating a diagnosis. The child had to be aged between 11 and 16 years. Five of these children had already accessed mental health provision, while two were currently waiting for a referral. Participant information is provided in Table I. In the following accounts, names of people were changed to preserve anonymity.

Insert Table I around here

Procedure

The current study was conducted in a south eastern county in England, which had been noted as having a high number of people aged under 18 with a diagnosable mental health problem. For example, local county research indicates a shortfall in access to services, and long waiting times between referral and treatment (*N*=9months).

Recruitment took place using a criterion sampling technique. It involves the identification and recruitment of participants that are knowledgeable or experienced in the phenomenon of interest. Therefore, participants were recruited via local Hertfordshire Charities supporting families with ASD. Parents interested in participating received an information sheet describing the purpose of the study, the topics of the interview and the plan for dissemination of the findings. All participants signed a consent form agreeing to take part in the study and were assured of their anonymity. Participants were also informed of their right to withdraw from the study at any time without given a reason for doing so. After the interview a debrief sheet was given which provided further information about the study, a reminder of how to withdraw their data, and they were also given contact details of local support groups.

As the researcher had professional involvement with the local NHS trust, an understanding of the procedures and services was already in place. A literature review and local service knowledge guided the semi-structured interview schedule. This schedule was reviewed and refined by two academics with professional and personal experience of children's mental health services and ASD. The first part of the schedule covered the socio-demographic background of the parents, and details surrounding their child's ASD diagnosis. The second part focused on their families' experiences of mental health services. The interview schedule is shown in table II.

Insert Table II around here

Open-ended questions allowed participants to express their personal views and experiences whilst keeping with the aims of the research; prompts were used to elicit further information. Interviews were conducted at a time of the participants' choosing in their home, and except for one short interview (20 minutes), lasted between 37-50 minutes (Mean = 43.5, SD 9.19). Interviews were audiotaped. Once completed, participants were asked if they had any questions, thanked for their time and given a debrief sheet. Interviews were then transcribed verbatim. All transcribed interviews were checked by the participants, before audio files were deleted.

Data Analysis

Interpretative Phenomenological Analysis (IPA) is a phenomenological and social constructionist approach informed by hermeneutics (e.g. Smith, Flowers & Larkin, 2009). This methodology was chosen for its ability to explore individuals' lived experience of parenting a child with ASD and comorbid mental health issues. The IPA approach encourages examination of the individual experience, but also how it is contextualised by history, society and dominant cultural forces (Lopez & Willis, 2004). Therefore, this method may be most appropriate to individuals with ASD whose impairments tend to be defined by social contexts (MacCleod, 2019).

Each interview was listened to more than once and each transcript read thoroughly. A line by line analysis of claims, concerns and perceptions was utilized for each participant (Larkin, Watts & Clifton, 2006). Alongside initial notes, exploratory, descriptive and linguistic comments were also added. Each transcript was then re-read and emerging themes deriving from the data were drawn out; the aim was to capture the essence of what was said and allow the researcher to make interpretations. Emergent themes were used to develop final master and subthemes through the use of abstraction (putting similar emergent themes together to develop subthemes), subsumption (deriving super-ordinate themes from emergent themes) and numeration (the frequency in which a theme is presented).

The researcher was a PhD student whose youngest child has complex needs and a diagnosis of ASD. Prior to this she worked as an NHS play therapist for children waiting for, or with, a diagnosis of ASD. Thus, she had both clinical experience in supporting children with autism and their families and lived experience of the struggles of raising a child with autism. Due to her close relationship with this disorder, provisions were applied to reduce bias. Reliability, rigour, validity and transparency in data collection, analysis and reporting, were achieved via: 1) extensive verbatim quotations and highlighting disparities within themes 2) Independent assessments of transcripts and themes were made by two different researchers who were not familiar with the project and had limited previous personal and/or work experience in ASD 3) Furthermore, 'member checking' of the final list of common themes was employed to add rigor to the analysis and its findings. No participants requested any changes upon seeing both the transcript of the interview and the resulting themes with relevant quotations from their interviews.

Results

Analysis of the seven semi-structured interviews resulted in eight subthemes grouped into three master themes and outlined in Table III: Psychological impact on the caregiver; negative experience accessing Mental Health Services; and Breakdown in relationships with professionals.

Table III around here

Psychological impact on the caregiver

All mothers discussed the negative and psychological impact of managing their child's comorbid mental health.

Aloneness

Five mothers (71%) talked about feelings of isolation and lack of support when managing their child's mental health condition evoking a sense of aloneness. One mother, reflecting on their child's suicidal ideation, felt unable to manage alone: "I am overwhelmed I can't do this by myself." (Pippa).

Taney, a single mother whose child often talked of suicide, spoke about not knowing where to turn for support and guidance, stating *'*I don't know where to turn now(..)I'm on my own'*:* the aloneness with managing his mental health was poignantly demonstrated in the short statement 'I'm on my own'.

This sense of aloneness was also documented in the accounts of mothers of ASD of children not showing self-harm or suicidal ideation, for example, Natalie emphasised the lack of understanding of others "I don't feel listened too or understood."

Nicky described feeling *lost* when left to research strategies and support on the internet. Taking responsibility and independently finding strategies to manage life also resonated with Amy: "it's up to me and me only (to) basically to find things to feed him for a little bit*"* a sentiment that was also reiterated by Wendy, "so I thought I can't manage this on my own anymore."

Feeling Guilty

Three mothers (50%) spoke in depth about feelings of guilt, worrying they allowed their child's distress to escalate before realising the seriousness of the situation. Pippa's son's anxiety and suicidal ideation had a profound impact on her, beyond the ASD. She stated she was *"*a terrible mum(…)I feel I really missed the boat there.*"* Self-critical comments such as 'terrible mum'*,* 'rubbish parent', and how her son had been 'damaged' seemed to underpin her sense of guilt and self-blame: "all the times I said to him what's wrong with you? Or other rubbish parent things you say, I didn't realise how his self-esteem had been damaged*."*

Nicky, whose daughter self-harmed also questioned her parenting after finding a suicide note: she *"*wasn't expecting that so young either, I was thinking what I did wrong?" Taney echoed this when speaking of her son's decline in mood: *"*I didn't know if I'd done something to make it worse.*"* Guilt seemed to emerge with a realisation that her 'trust*'* in others may have been misplaced:

"well I think I was naïve and just trusted I would be told about all these services that were on offer (…)I should have pushed not just accepted, does that make sense?" (Taney).

Vicarious Traumatisation

Given the self-blame, guilt and aloneness mothers had in caring for their child whilst worrying their child might self-harm or commit suicide, it was no wonder five mothers (71%) described traumatic-type emotions carrying this without access to professional mental health support for their child. The extremity of the emotive words used highlighted this: 'absolutely bloody terrifying'; 'horrendous'; 'never been so scared'; 'verge of a nervous breakdown'; 'atrocious'.

When waiting for a referral, Pippa's son told her he was going to walk in front of a train on the way to school; she became emotional and tearful saying: "I was like oh my god (…) he's not going out of my sight he's staying with me, it was absolutely bloody terrifying (…) I've never been so scared in my life."

Further, Wendy and Nicky stated that carrying their child's mental health concerns had vicariously created marriage strains and difficulties at home. For Wendy it had been "awful. It has been horrendous" and Nicky, was "really struggling*"* to come to terms with her daughter's self-harming behaviours and suicidal ideation. Some had to seek professional support for their own distress. Natalie spoke openly about the effect her daughter's anxiety disorder and restrictive eating had on her: "I have actually got to a point where I was on the verge of a nervous breakdown."

The pervasive impact of their child's mental health issues meant Amy and Pippa appeared to be traumatised when disclosing their child's suicidal ideation to their GP or school. For example, Amy admitted the experience was "atrocious(..) I couldn't even speak I was so upset" and Pippa stated: "having to say those words, to say my son had suicidal thoughts. I had to take someone to the school with me cos I couldn't say it". Given the psychological impact and isolation these mothers found themselves in, there was an almost inevitable negative view of systems purported to support their children.

Negative experiences accessing mental health services

The resounding narrative from all mothers' accounts were negative experiences accessing services, and once attained, with the professional support on offer.

The Waiting Game

All mothers (100%) believed they waited too long for their child to be seen by mental health services, without support or advice. Amy became "desperate" during her wait to manage her son's fluctuating moods and depression, which was echoed by some of the other mothers:

"Yeah desperate to get her seen hoping something would bring her mood up. Every minute is another minute she's still feeling miserable and not able to cope with normal life" (Sam).

"It has a huge impact(…)we don't know how to support her we were just looking at the letter on the notice board for months so it's hard to know how you're going to get through it" (Nicky).

"It was terrifying I didn't know what to do. And I just had to wait…and then wait some more" (Pippa).

With mental health so fragile in their children, and the traumatisation from bearing witness to this, the sense of urgency for support was clear; at 'crisis point', Natalie talked about her concerns of getting her daughter through the next few months whilst they waited:

"We were at crisis point and the referrals take quite long to come through so your(…)kind of really struggling at the time and you've still got this, I can't remember how long the wait was but it was quite a few months, and(...)I need the help now, it was just like what do I do now? How do I get through these next few months?"

Mothers of children who showed self-harming behaviours were noted at being particularly vulnerable being on a waiting list, meanwhile having to watch their child deteriorate.

"referral to xxx because xx was threatening to kill himself …in between this whilst we were waiting I decided to pay for private support because he needed, he needed something….and that…we couldn't afford to wait any longer" (Taney).

"I saw xxx in desperation last summer and you know he was atrocious I couldn't even speak I was so upset and she didn't know what to do…so she referred me to xxx, I don't think they'll take you...another long wait…and then of course we were told no" (Amy).

Mental Health services had even acknowledged to some of the parents that part of the delay in accessing their child's mental health referral was due to the co-existing ASD diagnosis.

"xxxx said they're not seeing her because she's autistic so we had 6 months of them arguing between themselves and then (an autism service) took them on and then we had a year's wait to be seen" (Wendy).

Rejected

Six mothers (85%) felt rejected on completing their child's therapy or when service criteria were not met. When told after 6 weeks that her son's play therapy was not suitable for him, Pippa felt the service prematurely "took it away from him." Mental health professionals seemed unaware of the additional time needed to adapt to a play therapy scenario with a relative stranger for children with ASD.

The perceived short-lived nature of mental health interventions for children with ASD, and inability to adapt to the child's needs, was echoed by Wendy when describing her feelings of frustration and disbelief when the services transitioned her daughter out of therapy for OCD:

"they then said, well we've reached the end of our sessions so we need to start(…)exit plan or whatever, she can't put any of the suggestions into practice,(…)in their mind they had given her the tools and strategies and because she wasn't doing it, they didn't think it was their problem or anything to do with them."

This feeling of rejection and disbelief continued when Nicky's daughter was discharged after an initial assessment despite active self-harming and suicidal intent. Nicky explained;

"we were discharged(…)she was still self-harming at that point in maths, so I think they thought it was more an issue with the teacher and school and said well what are they going to do about it?"

There was a sense of professional responsibility shifting, and when speaking of her concerns regarding the short intervention offered for her daughter who was suffering with Generalised Anxiety and Panic Disorders, Natalie could not believe a rejection had happened:

"She did form a bond and start to feel comfortable and then it was taken away, the 6 sessions were done and off she went" (Natalie).

Thus, discrepancy between service provision and threshold criteria led to feelings of rejection, confusion and frustration. Taney's son frequently explained ways to kill himself; when she managed to get her son seen she was told he did not meet criteria and was referred to an autism specialist service, who then also stated they could not see him. Taney reflected:

“they said the same thing, because he hadn’t hurt himself they referred back (…)so he threatened to jump out the window, he threatened to hurt himself with scissors, he threatened to get a knife and cut his throat(…)but because he hadn’t actually done anything they didn’t offer support.”

Clearly in this instance, the mere presence of repeated intense distress had not been enough to access service support.

Fighting to be heard

Feeling heard was one of the strongest sentiments presented by all mothers (100%) when accessing mental health support, yet only one mother felt listened to:

“I mean my background is in nursing so I can word things in a certain way and the Dr got what I was saying straight away and I know the right things to say to get the help that we need, we have a good relationship with the GP so I think it’s a different relationship it was almost like colleagues so I don’t think it’s typical(…)he did what I asked because I had the background and had researched it all(…)I knew what I wanted” (Sam).

By her own admission Sam suggested ease of acceptance was not ‘typical’. She was able to research ‘what I wanted’ before the appointment and had a shared professional language with the referrer. In contrast, the sense of fighting to be heard extended to Natalie’s child when she attempted to express her anxiety and need for support to their GP:

“I don’t feel like my daughter gets listened to when it takes her weeks of support from people around her to get her to the doctors, for the doctor to then turn around and say, what do you want me to do to help you. I don’t feel that’s listening or understanding mental health in anyway” (Natalie).

The frustration from this fight to be heard, spilled into anger when Pippa expressed rage towards the service when her concerns about her son’s suicidal ideation were ignored:

“when there was a crisis and xxxx said well he hasn’t done anything, I wasn’t listened to(…)I have no psychiatric qualification but even I know this people! You lot have years of study and you don’t care!”

In addition to feeling unheard, Amy and Wendy felt professionals minimised their concerns by stating their child's 'behaviours' were typical, to that point Amy had to "stand up for myself and was picking them (behaviours) out".

The 'fight' continued with Nicky pleading to be heard during assessments:

"Please just acknowledge there's an issue(…)I needed to fight more, I should have been more 'she needs this, she needs that" (Nicky).

The enduring quality of the fight persisted for Taney through her metaphors of 'banging my head again a wall' and 'going around in circles', summing up the emotional impact of seeking mental health support:

"I just feel like I've been banging my head against a wall actually I'm going around in circles I keep being sent back to where we started, and they say, no we can't help, so on to the next bit who then send us back. No one listens" (Taney).

Breakdown in relationships with professionals

All mothers (100%) indicated the importance of continuity to build trusting relationships for their children; when they finally accessed mental health services this had been their hope, yet this was not reflected in their actual experience.

Broken Trust

Mothers often referred to broken trust in services and, more specifically, the therapist involved with their child's care.

When talking about her son's relationship with his therapist, Pippa compared her experiencing of NHS services and private clinics. Pippa explained that her private service gave her peace of mind as she 'believed' her son 'trusted' his private therapist enough to be truthful. The importance of the therapeutic relationship was highlighted by Pippa:

"With his private therapist he has a good positive relationship and that...I feel...I believe…he will tell how he really is. And that for me was the key difference (between NHS and private)"

Trust in the therapist was further highlighted by Sam, whose teenage daughter experienced anxiety and restrictive eating. Her experience of services, and lack of knowledge therein, gave no faith they had the ability to help her daughter.

“The trainee psychologist just didn’t feel like she was in the right position to be able to give us the help we needed. I think she was very text book very wooden and it almost felt like she was going home and reading up on CBT strategies and we only had 3 sessions with her in the end”.

Natalie used the term ‘bond’ to highlight the importance of building an alliance, however, she did not see this occur:

“I feel you have to form a bond and I don’t think if you don’t have that bond, that connection, you’re not going to get what you need from the child”

Natalie again expressed frustration about lack of continuity, raising concerns about the tailored support her daughter was offered. This lack of trust impacted on her own trust in the utility of local NHS services:

“It’s getting there and when they do give it it’s not long enough, it’s not consistent, they give strategies of things not being nasty you can get off the internet” (Natalie).

Two other parents also raised concerns in their overall confidence in accessing ‘bonkers’ mental health provision to support their children:

“I have zero confidence in accessing support because(….)he’s 12, we’ve been there for 6 years and nothing yet and even if I get offered something it’ll be a 6-week block and his problems are not going to be solved in 6 weeks, to think it can be is just bonkers” (Amy).

“I would never send her(…)ever again. I don’t feel very confident” (Wendy).

Feeling Blamed

Three mothers (42%) felt feedback from professionals blamed them for their child’s distress. When discussing her son’s mood swings and challenging behaviours within the home, Amy reflected how school staff informed her the professional who visited them had asked school about her son’s home life and commented “mmm perhaps mum needs to think about her boundaries at home.”

Likewise, after Wendy’s daughter had completed a group therapy anxiety course, she recalled staff saying there was nothing to be concerned about regarding her daughter’s OCD and intrusive thoughts. When she queried this, she was told:

“...you’re enabling her behaviour, you need to look at what you’re doing with her (….) I was made to feel it was my fault. That was my last conversation with xxx; I actually put in a complaint”

Similarly, when recalling her first assessment with an autism service, Natalie stated: “it was almost like I, as the parent, was making up my child’s mental wellbeing, like it was my fault”. By Sam reflecting on the sense that ‘permission’ was needed from others ‘to parent’ her child’s unique needs, she linked the external blame with her own self-blame: “You almost need permission on how to parent how you know what’s right because you are frightened of your child’s fragile state and thinking it’s your fault”.

Discussion

Previous literature has highlighted that raising children with ASD can make parents feel isolated and alone (Johnson, 2012). This increases for families dealing with multiple behaviour concerns differentially displayed due to interactions with ASD symptomology (Mazzone et al., 2012). Therefore, this study aimed to explore the experiences of raising a child with ASD and comorbid mental health. With the added burden of managing their child’s mental health, qualitative analysis revealed that mothers reported a sense of aloneness, self-blame, guilt and vicarious traumatisation. This was exacerbated by difficulties gaining access to children’s mental health services; once there, they often felt blamed and rejected by services.

Research has consistently demonstrated the trauma of raising a child with ASD due to social stigma and challenging behaviour (Gray, 2002); however, this study has further highlighted a specific trauma exists for parents raising a child with ASD and comorbid mental health. The vicarious nature of mother’s traumatisation was understandable given their children repeatedly talked about suicide or witnessing their child self-harm or restrictive eating. Managing this alongside their child’s ASD diagnosis, commonly led to feelings of isolation, self-blame, guilt and powerlessness; impacting on the mother’s own mental health (Hastings, 2003).

The process of diagnosis of an ASD regardless of having a comorbid mental health problem can be severely problematic, due not only to the differences in which the early signs of autism are often expressed, but also the age at which they develop (Daniels & Mandell, 2013). For example, children with higher levels of intellectual disability and/or certain symptoms types (e.g. severe cognitive and language deficits, repetitive motor mannerisms), have been associated with earlier age of diagnosis (Landa, Holman, & Garrett, Mayer, 2007; Maenner et al., 2013). The late diagnosis of the children in the current study may reflect certain diagnostic characteristics of our sample, including being female and living in rural areas (Giarelli et al., 2010). However, the age at diagnosis of ASD may be particularly important to consider in relation to an increase in mental health problems, as some research suggests that later diagnosis to be more predictive of difficulties in both the child’s mental health as well as the parents (Mandell, Novak, & Zubritsky, 2005).). For example, while 32% of individuals with ASD are estimated to be diagnosed with depression, this statistic rises to 45 % when a diagnosis is given later in life (Barnard, Harvey, Potter & Prior, 2001).

Despite the recognition that many children with ASD have at least one other comorbid mental health disorder (Leyfer et al., 2006), many parents felt unable to access the appropriate services to support their child (Bromely et al, 2004). In the current study, nearly all mothers discussed concerns with multiple professionals (e.g. school, GP), which did not result in appropriate support; one mother stated her GP admitted a lack of knowledge managing a child with ASD and suicidal ideation. Consequently, many mothers took an advocacy role to fight for the right support (Ryan & Cole, 2009). The importance of mothers having knowledge from the outset was highlighted as a way of fostering more positive experiences of mental health services.

The prevalence of ASD with mental health conditions are thought to have increased over the last decade (Arvidsson, Gillberg, Lichtenstein, & Lundström, 2018), which may have led to more strain in accessing services, as was highlighted in these mothers' accounts. This current study highlighted that, whilst they were desperate to access support, once they did, it did not meet the mental health needs of their child resulting in negative experiences of blame, alongside rejection. Parents of children with ASD who self-harm appeared to be particularly vulnerable to negative experiences and may even be at risk themselves for their own mental health concerns.

There is a need for better communication between professionals and parents to improve knowledge. Discussion with the main caregivers at the time of the ASD diagnosis, particularly with a late diagnosis, should also feature comorbid mental health symptoms associated with ASD, alongside how to access help if required. As one parent stated, had she been made aware earlier of the high comorbidity between mental health and ASD, she would have better known what to do. It could also be suggested that parent's expectations need to be managed regarding the length of intervention and plans for the family's support. There is also a strong case for involving service users/carers in staff training, given the complexity and heterogeneity of the presentation of ASD (Markham, 2019).

A key theme for professionals to take away from the current study was the feeling of broken trust in the system. This study stressed the importance of continuity to build the alliance between the child and therapist. While previous research highlighted the importance of a strong alliance to outcome ratio within child psychotherapies (Shirk, Carver & Brown, 2011), there was no incorporation of alliance measures as a variable in treatment trials in Child and Adolescent Mental Health Services (Green, McGinnity, Meltzer, Ford, & Goodman, 2005).

Additionally, research indicated that a strong parent-therapist alliance predicted better therapeutic outcomes and implementation of strategies in the home (Kazdin & Blase, 2011). Three mothers reflected on the impact of a lack of bond between their child and the therapist. In the same vein mothers' experience of conversations with professionals felt persecutory, with some mothers seeking private therapy afterwards. Mothers' faith in mental health services could be re-established through better management of these relationships. For example, as one mother suggested the impact of waiting could be alleviated by a short phone call acknowledging the wait.

Some professionals advocate for acknowledgement of symptom complexity and variability in children with ASD. This would aid more individualised treatments and allow the recognition of psychiatric comorbidity (Brookman-Frazee et al., 2018). This could take many forms, but one suggestion is placing less emphasis on the process of diagnosis, and more on the recognition of symptoms through the process of formulation. This would then provide more focus on proposing relationships among the psychological mechanisms and other factors that are causing and maintaining disorders and problems, rather than concentrating on whether a person meets the threshold for certain diagnoses. Supporting calls for a more integrated pathway extending from 12-25 would enhance continuity preventing vulnerable children with ASD and mental health falling between service gaps (McGorry et al., 2013), particularly as they transition into adulthood. Alternatively, the roles of the different services need to be more explicit, to ensure assessment and intervention addresses a wide range of clinical issues in children with ASD. Finally, more importance should be placed around the need for professionals to recognise the symptoms of self-injury behaviours in ASD, to provide a fast track route to mental health services for these individuals. Not only does this account for a large proportion of individuals with ASD who are at risk of suicidal ideation (Cassidy et al., 2014; Halberg et al., 2005), but as shown by the current findings, it has an impact upon the family.

Although this study did not explore contextual factors for comorbid mental health issues, the propensity of blame evidenced in this study should be noted; not only did mothers blame themselves but they experienced professionals blaming them for their child's distress. To improve understanding and reduce stigma, further context is needed to understand why up to 92% of children with ASD have a diagnosable mental health condition (Brookman-Frazee et al. 2018). Perhaps it should also be noted that children with ASD often attend school, and whilst away from their family, are more likely to be the victim of bullying; one meta-analysis estimated 44% of children with ASD to be victims of bullying (Maïano, Normand, Salvas, Moullec, & Aimé, 2016). The mothers’ in this study were deeply committed to accessing support for their children and were vicariously traumatised by the distress of their child; clearly the issues are not always homebased.

Due to the qualitative nature of the study, the sample in this research was small, nevertheless, it did encompass parents attempting to access the mental health system. The children already had a formal diagnosis of ASD, with some children also receiving formal mental health diagnoses. However, there are several study limitations worth noting. For instance, the limited geographical area covered within the study and the nature of the self-sampling. As interviews often require extensive and intimate self-disclosure, it may lead to a sample of individuals who have greater interest than the general sample population (Robinson, 2014); such as, those who had detrimental experiences introducing a ‘participant bias’. Furthermore, parents were recruited from one region within the UK and represented a narrow demographic (e.g. white, middle class), a generalization of our findings in terms of typical views parents hold about UK services assessing children is, therefore, not possible; for that a survey based on a representative sample of parents who went through the process of receiving a mental health diagnosis for their child would be required.

In summary, accurate, reliable diagnosis of comorbid mental health conditions and factors underlying this in children with ASD is of major importance. Comorbid mental health disorders may cause significant clinical impairment and additional burden for these children and their families (Leyfer et al., 2006); by acknowledging behaviours as symptomatic of a comorbid mental health condition rather than due to autism, more specific and specialised treatment can be given. To facilitate engagement in children with a communication disorder, mental health provision should be provided by autism specialist professionals; otherwise services will become more burdened with highly complex entrenched presentations due to interactions between specific neurological issues within ASD and mental health. This, alongside signposting to specialist autism charities, could provide parents with relief and comfort whilst waiting for more specialist help.

Conflict of Interest:

The Authors declare no conflict of interest.

Ethical Approval:

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent:

Informed consent was obtained from all individual participants included in the study. Ethical approval was granted for the study by The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority. UH protocol number: LMS/PGT/UH/03293/

Author Contributions: LJ: collaborated in the design and executed the study, analysed the data, wrote the results and collaborated in the writing of the study: SK: collaborated with the design and in the writing of the paper and editing of the final manuscript. AL: collaborated with the design and writing of the paper and editing of the final manuscript.

References

Arvidsson, O., Gillberg, C., Lichtenstein, P., & Lundström, S. (2018). Secular changes in the symptom level of cliically diagnosed autism. Journal of Child Psychology and Psychiatry, 59 (7), 744-75. doi.10.1111/jcpp.12864

APA (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. American Psychiatric Association: Washington, DC

Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). *Ignored or ineligible. The reality for adults with autism spectrum disorders*. London: National Autistic Society.

Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders, 36*(7), 863-870.

Bromley, J, Hare, D J, Davidson, K and Emerson, E. (2004). Mothers supporting a child with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism, 8*, 409–423. doi.10.1177/1362361304047224

Brookman-Frazee, L., Baker-Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspectives on community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies, 21*(4), 533-544. doi.10.1007/s10826-011-9506-8

Brookman-Frazee, L., Stadnick, N., Chlebowski, C., Baker-Ericzén, M., & Ganger, W. (2018). Characterizing psychiatric comorbidity in children with autism spectrum disorder receiving publicly funded mental health services. *Autism, 22*(8), 938-952. doi.10.1177/1362361317712650

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). ‘People like me don’t get support’: Autistic adults’ experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431-1441. doi.10.1177/1362361318816053

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry, 1*(2), 142-147. doi.10.1016/S2215-0366(14)70248-2

Cath, D. C., Ran, N., Smit, J. H., Van Balkom, A. J., & Comijs, H. C. (2008). Symptom overlap between autism spectrum disorder, generalized social anxiety disorder and obsessive-compulsive disorder in adults: a preliminary case-controlled study. *Psychopathology, 41*(2), 101-110. doi.10.1159/000111555

Centers for Disease Control and Prevention (2007). Suicide and Autism. Retrieved July, 18, 2018, from [ONLINE] Available at: https://www.cdc.gov/media/pressrel/2007/r070208.htm.

Christensen, D.L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J.N., Daniels, J., Durkin, M.S., Fitzgerald, R.T., Kurzius-Spencer, M., Lee, L., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M.S., Zahorodny, W., Yeargin-Allsopp, M. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years– autism and developmental disabilities monitoring network, 11 sites, United States, 2012. Morbidity and mortality weekly report. *MMWR Surveillance Summaries 65*(13), 1-23. doi: 10.15585/mmwr.ss6513a1

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2018). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*, 1362361318757048. doi.10.1177/1362361318757048

Daniels, A. M., & Mandell, D. S. (2013). Children's compliance with American Academy of Pediatrics' well-childcare visit guidelines and the early detection of autism. *Journal of Autism and Developmental Disorders, 43*(12), 2844-2854. doi.10.1007/s10803-013-1831-

Gillberg and, C., & Billstedt, E. (2000). Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatrica Scandinavica, 102*(5), 321-330. doi.10.1034/j.1600-0447.2000.102005321.x

Giarelli, E., Wiggins, L. D., Rice, C. E., Levy, S. E., Kirby, R. S., Pinto-Martin, J., & Mandell, D. (2010). Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal, 3*(2), 107-116. doi.10.1016/j.dhjo.2009.07.001

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734-749. doi.10.1111/1467-9566.00316

Green, H., McGinnity, Á., Meltzer, H., Ford, T., & Goodman, R. (2005). *Mental health of children and young people in Great Britain*. Palgrave MacMillan.

Halberg, F., Cornelissen, G., Panksepp, J., Otsuka, K., & Johnson, D. (2005). Chronomics of autism and suicide. *Biomedicine & pharmacotherapy, 59*, S100-S108.

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47(*4-5), 231-237. doi.10.1046/j.1365-2788.2003.00485.x

Johnson, J. (2012). Treating couples raising children on the autism spectrum: A marriage-friendly approach. *Contemporary Family Therapy, 34*(4), 555-565. doi.10.1007/s10591-012-9213-7

Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., Kotarski, M., Walls, S & Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders, 40*(11), 1361-1370. doi.10.1007/s10803-010-0996-9

Kazdin, A. E., & Blase, S. L. (2011). Interventions and models of their delivery to reduce the burden of mental illness: Reply to commentaries. *Perspectives on Psychological Science, 6*(5), 507-510. doi.10.1177/1745691611418241

Lai, W., Goh, T.J., Oei, T.P.S., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders, 45*(8), 2582-2593. doi.10.1007/s10803-015-2430-9

Landa, R. J., Holman, K. C., & Garrett-Mayer, E. (2007). Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of general psychiatry, 64*(7), 853-864. doi: 10.1001/archpsyc.64.7.853

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3(*2), 102-120.

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J. Tager-Flusberg, H & Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *Journal of Autism and Developmental Disorders, 36*(7), 849-861.

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726-735. doi.10.1177/1049732304263638

MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders, 64,* 49-62. doi.10.1016/j.rasd.2019.04.005

Maïano, C., Normand, C. L., Salvas, M. C., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Research, 9*(6), 601-615. doi.10.1002/aur.1568

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.

Markham, S. (2019). Diagnosis and treatment of ASD in women in secure and forensic hospitals. Advances in *Autism, 5*(1), 64-76.

Mazzone, L., Ruta, L., & Reale, L. (2012). Psychiatric comorbidities in asperger syndrome and high functioning autism: diagnostic challenges. *Annals of general psychiatry, 11*(1), 16. doi.10.1186/1744-859X-11-16

McGorry, P., & Van Os, J. (2013). Redeeming diagnosis in psychiatry: timing versus specificity. *The Lancet, 381*(9863), 343-345. doi.10.1016/S0140-6736(12)61268-9

Meera, S. S., Kaipa, R., Thomas, J., & Shivashankar, N. (2013). Brief report: An unusual manifestation of diagnostic overshadowing of pervasive developmental disorder—not otherwise specified: A five-year longitudinal case study. *Journal of Autism and Developmental Disorders, 43*(6), 1491-1494. doi.10.1007/s10803-012-1691-9

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. (2019). A 'choice', an 'addiction', a way 'out of the lost': exploring self-injury in autistic people without intellectual disability. *Molecular Autism, 10*(1), 18.

National Autistic Society, (2010). You Need to Know'. Retrieved December 1, 2018, from https://www.autism.org.uk/get-involved/campaign/successes/you-need-to-know.aspx.

NSPCA (2017). Suicide and Autism. [ONLINE] Available at: http://www.nspa.org.uk/wp-content/uploads/2017/02/1b.-Suicide-in-autism.pdf. [Last Accessed 3rd December 2018].

The National Institute for Health and Care Excellence, (2012). Autism spectrum disorder in adults: diagnosis and management, CG142. Retrieved July, 31, 2018, from https://www.nice.org.uk/guidance/cg142/resources/autism-spectrum-disorder-in-adults-diagnosis-and-management-pdf-35109567475909

The National Institute for Health and Care Excellence (2013). Autism spectrum disorder in under 19s: support and management, CG170. Retrieved July, 31, 2018, from https://www.nice.org.uk/guidance/cg170/resources/autism-spectrum-disorder-in-under-19s-support-and-management-pdf-35109745515205.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology, 11*(1), 25-41.

Rosenblatt, M. (2008). I Exist: the message from adults with autism in England. The National Autistic Society. Retrieved July, 18, 2014 from www.scie-socialcareonline.org.uk/i-exist-the-message-from-adults-with-autism-in-england/r/a11G00000017z7hIAA,

Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43-53. doi.10.1111/j.1468-3148.2008.00438.x

Shirk, S. R., Karver, M. S., & Brown, R. (2011). The alliance in child and adolescent

psychotherapy. *Psychotherapy, 48,* 17-24. doi.10.1037/a0022181

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929. doi.10.1097/CHI.0b013e318179964f

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Phenomenological analysis. Theory method & research*. London: Sage.

Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities, 122*(1), 49-61. Doi.10.1352/1944-7558-122.1.49

Table I: Participant's Demographic Information

Mother	**Age (ys)**	**Ethnicity**	**Occupation**	**Marital Status**	**Child Clinical Diagnosis**	**Gender of child**	**Age of child (yrs)**	**Age of child at ASD diagnosis**	**Severity of Diagnosis**	**Schooling**	**Mental Health Service involvement**	**Self-harming behaviour**
Amy	*41*	*White British*	*Teacher*	*Married*	*ASD*	*M*	*12*	*9*	*HFA, Verbal,*	*Mainstream*	*YES*	*YES*
Sam	*45*	*White British*	*Nurse*	*Married*	*ASD*	*F*	*15*	*14*	*HFA, Verbal*	*Online*	*YES*	*YES*
Nicky	*44*	*White British*	*Manager*	*Married*	*ASD*	*F*	*14*	*10*	*HFA, Verbal*	*Online*	*NO*	*YES*
Taney	*47*	*White British*	*Teacher*	*Divorce*	*ASD*	*M*	*11*	*7*	*HFA, Verbal*	*Mainstream*	*NO*	*YES*
Natalie	*34*	*White British*	*Full Time Mum*	*Married*	*ASD*	*F*	*13*	*11*	*HFA, Verbal*	*Mainstream*	*YES*	*NO*
Wendy	*44*	*White British*	*Office manager*	*Married*	*ASD* *OCD*	*F*	*12*	*11*	*HFA, Verbal*	*Mainstream*	*YES*	*NO*
Pippa	*44*	*White British*	*Specialist ADHD coach*	*Married*	*ASD* *ADHD*	*M*	*13*	*11*	*HFA, Verbal*	*Specialist provision*	*YES*	*YES*

Table II: The Interview Schedule

Interview Schedule
1. Can you tell me when you began to realise your child might be struggling with their mood and wellbeing? (Prompts: emotions/behaviour?) 2. What helped or hindered your own confidence in supporting your child's mental health? 3. Can you tell me about what you did and who helped you manage your child's mental health before you sought professional help 4. Can you tell me about your journey in accessing specialist professional support to help understand and manage your child's emotional wellbeing? 5. Before you were referred to mental health services, what was your experience of the help and knowledge of those you first spoke to? (GP, School, Health visitor; access to materials) 6. What was it like waiting for support before accessing more specialist services? (Prompts: impact on family/you/child) 7. Following your referral, what was helpful and unhelpful in the initial assessment of your child's experiences? 8. What did you find helpful or unhelpful in the follow up appointments you accessed via the mental health services? (Prompts: for your child/for you as a carer) 9. Can you tell me your hopes and fears for your child's future mental health needs and the support that might be available for them (Prompt: confidence in accessing the right support?) 10. What advice would you give to parents just beginning this journey (prompts: how to access services, or support their child whilst they wait for an appointment?)

Table III: Master and Subthemes

Master Theme	**Subthemes**
Psychological impact on Caregiver	Aloneness
	Feeling Guilty
	Vicarious Traumatisation
Negative experience accessing Mental Health Services	A waiting game
	A sense of rejection
	Fighting to be heard
Breakdown in relationships with professionals	Lack of Trust in the professionals
	Feeling blamed