

Exploring Autism Spectrum Disorders Project

Background Information

There is considerable debate in the literature about the core features of Asperger's syndrome (AS). This leads to confusion about diagnosis amongst professionals and consequent delays for families and individuals seeking understanding about their own or their child's differences. In addition, this confusion creates barriers for research.

There is a lack of valid and reliable questionnaires for measuring the core features of AS, and for differentiating AS from autism, and from conditions that may superficially resemble AS. Valid and reliable questionnaires are invaluable for clinicians to assist with assessing signs and symptoms of AS, assessing severity of AS, pinpointing important areas for therapy, and monitoring therapeutic change.

We know that more people with autism spectrum disorder (ASD, e.g. Asperger's syndrome, autism) experience anxiety and depression than people who do not have ASD. We do not know whether having anxiety and/or depression makes the signs and symptoms of ASD worse.

We do not know why people with ASD generally experience more anxiety and depression than people who do not have ASD. There is some research to show that there is a genetic link. It is also likely that the social environment within which the person lives would have an impact. For example, it is likely that a person in a supportive family environment may experience less anxiety and depression, or that a person who is bullied and teased at school may experience more anxiety or depression. There is very little research to inform us about the influence of the family and peer environments on the psychological health of the person with ASD.

Aims of the Programme of Research

The research that you kindly contributed to had the following aims:

- (1) To determine the core characteristics of AS, to assist in determining the most accurate definition of AS;
- (2) To develop a valid and reliable questionnaire to assist in the measurement of ASD;
- (3) To determine if there is a relationship between severity of ASD and levels of anxiety and depression in children and adolescents aged 6 – 19 years old, i.e. does severity of AS increase with higher levels of anxiety and depression?;
- (4) To examine the relationships between severity of ASD, levels of anxiety and depression, and peer and family influences.

Method

Ethical clearance was sought and granted. Michelle and Tony developed a new questionnaire for ASD: The Australian Scale for Asperger's Syndrome – Revised (ASAS-R). The new measure contained over 200 questions. 865 families who had attended an appointment with either Michelle or Tony were invited via a telephone call to participate. Of these 860 agreed to participate. Nearly 50% of these families kindly donated their time to complete the ASAS-R and a number of other questionnaires either via a secure website or paper questionnaires. Their answers were downloaded

and all identifying information was removed. In addition, a smaller number of families with a typically developing child (i.e. a child not on the autism spectrum) were invited to participate.

Results

(1) Core characteristics of AS

The results of the study identified five core dimensions of AS and the relative weighting of each. These dimensions, in descending order of relative importance, were:

- (i) difficulties with the ability to consider another's perspective during social interactions (Perspective-taking);
- (ii) difficulty accepting change (Rigid adherence to routine);
- (iii) a different sensory processing system observable by sensitivity to certain noises, lights, aromas and/or touch (Sensory sensitivity);
- (iv) difficulty with 'reading' emotion in others, and in expressing emotion appropriately (Understanding and expressing emotion);
- (v) a thinking style that is oriented toward facts, information and detail (Fact-oriented).

Other symptoms of AS known to commonly occur with AS did not emerge as core characteristics of AS, and may represent additional conditions rather than being part of AS. These included: motor clumsiness and 'executive functioning' problems, e.g. difficulties with organization, planning, concentration, time management.

Of interest was that all of the core dimensions identified as being part of AS in this study, except one, have been discovered to be core characteristics of AS in other studies, thus the current results were consistent with previous research. The one exception to this was Sensory Sensitivities. One of the recommendations of this research was that Sensory Sensitivities be incorporated in the diagnostic criteria for AS in future editions of the International Diagnostic texts.

(2) A Valid and Reliable Questionnaire

Results of the study confirmed that the new questionnaire, the ASAS-R, is a reliable and valid measure for AS. Using 46 items, the ASAS-R could differentiate children and adolescents with AS from children who did not have ASD on every dimension of AS. The ASAS-R could differentiate children with AS from those with autism and from children who were referred to an ASD clinic but who did not receive a diagnosis.

The ASAS-R will be published in the near future in a form that is accessible and affordable to clinicians, teachers and parents.

(3) The Relationship between ASD and Anxiety/Depression

Results indicated that there is an association between anxiety/depression and ASD, where the more depressed and/or anxious the person, the more severe their symptoms of ASD. The research could not determine whether high levels of anxiety/depression worsened ASD, or if more severe ASD worsened anxiety/depression.

Knowing that there is an association between AS and anxiety/depression is important for families and clinicians. An implication of this finding is that treatment of anxiety and depression is likely to lead to reductions in severity of ASD. Fortunately, there are programmes available to assist in treating anxiety and depression in children and adolescents with ASD that already have research evidence for their effectiveness, e.g. cognitive behaviour therapy.

(4) The Influence of Peers and Families

We know that ASD is caused by genetic transmission and/or structures in the brain that are working slightly differently. Peer and family environments cannot cause ASD. However, we know that family and peer environments can have a significant impact on the psychological health of children who do not have ASD. One purpose of the current research was to determine if the same is true for children and adolescents with ASD.

We found that both family conflict (for example, consistent openly expressed anger amongst family members) and bullying by peers were related to psychological health. Increased levels of family conflict were associated with increased levels of anxiety/depression for the person with ASD. The more the person with ASD was bullied by peers, the more symptoms of anxiety/depression they experienced. There was also a small but significant relationship between being bullied by peers and experiencing more severe symptoms of ASD.

Interestingly, we found that having peer support did not affect levels of anxiety/depression, or symptoms of ASD, in the children we studied. Having family support was helpful in that it decreased the likelihood of experiencing family conflict.

Implications for Families:

The results of this research suggest that it is very important to know if your child is experiencing name-calling, cruel teasing, rejection or physical bullying by his or her peers, either at school or in another environment. If this is occurring your child is at risk for experiencing symptoms of anxiety and depression, which may worsen his/her symptoms of ASD.

In addition, it is important for you to know if your child is being subject to family conflict. Family conflict is linked to anxiety and depression in children and adolescents with ASD. We do not know why this is the case. It may be for reasons that children without ASD are affected, i.e. the conflict threatens their sense of security and safety. Or it may be because of their ASD profile, for example, the loud noise of an argument may cause distress due to their sensitivity to noise, or the conflict may disrupt their routine and sense of predictability, or the strong emotions cause confusion and distress because they do not know how to deal with them, or what to do. In the children studied, family conflict levels were, on average, at the level of nondistressed families with children without ASD, so it appears that even low to average levels of conflict can be distressing for children with ASD.

In summary, protecting your child from peer bullying and working on decreasing family conflict may directly help your child by decreasing their risk of developing anxiety and depression. There is an excellent article written by Tony and available on the Minds and Hearts website (www.mindsandhearts.net) about how to reduce peer bullying within the

school environment. There are many free services in the community for investigating strategies for reducing family conflict (e.g. Relationships Australia, Centacare). Minds and Hearts has excellent psychologists available for this purpose.

Increasing family closeness also seems important. For the person with ASD this may include increasing all family members' understanding of ASD, and incorporating changes to the person's environment specific to his or her profile, for example, providing predictability as much as is possible, providing mentorship and guidance to understand social situations and emotions, allowing some solitude etc. Peer support did not emerge as being important for protecting the person from experiencing anxiety/depression or more severe symptoms of ASD in this study, however, this is only one study and more research is needed. For example, we know that having friends protects a child/adolescent against bullying, hence assisting your child to develop friendships may be important in helping to guard against anxiety and depression.

Limitations of Research

The research was conducted using one source of information (parental report) only and all data was taken at one point in time. Parental report was deemed to be the most important since, arguably, the parent knows the child better than anyone, and is most informed to provide answers about the child. Nevertheless it would be useful in future research projects to also collect information about peer relationships from peers and teachers at school. Collecting data at one point in time meant that it was not possible to draw conclusions about causal relationships, i.e. that one thing causes another. Future research to answer these questions could usefully incorporate data collection over time.

Strengths of Research

The study incorporated a large sample of children with AS, autism and other conditions affecting social and emotional functioning. Diagnoses were confirmed by experts, and clear diagnostic definitions were used. The use of parent-report data was advantageous.

Further Questions/Referral

Should you have any further questions with regard to these findings please do not hesitate to contact Minds and Hearts (email: info@mindsandhearts.net or Tel.: 07 3844 9466). Whilst Michelle is on maternity leave, Julie Fox will be assisting with any enquiries. If, as a result of reading these results you need a referral to assist you, your child, or your family, please do not hesitate to contact Minds and Hearts, either Beverlee or Katherine will work to help you find the service or professional, you are looking for.

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