Brief report: Investigating the impact of anxious symptomatology in autistic children

Jac den Houting, Dawn Adams, Jacqui Roberts and Deb Keen.

Abstract

Symptoms of anxiety are common in autistic children. In non-autistic children, anxiety can have considerable negative impact across various life domains. To date, there has been limited investigation of the impact of anxiety symptoms on the lives of autistic children and their families. In order to explore the impact of anxiety symptoms, the Child Anxiety Life Interference Scale (CALIS) and Spence Children's Anxiety Scale (SCAS) were administered to 30 autistic children and their parents. Children and parents reported high levels of anxiety-related life impact across all life domains assessed. Parents reported higher levels of impact than children. Both parents and children indicated that school performance is the life domain most impacted by anxiety symptoms. Findings indicate that anxiety symptoms have considerable negative consequences for autistic children and their parents. Further research exploring the impact of anxiety symptomatology in this population is required.

Keywords: Autism, anxiety, impact, impairment, Child Anxiety Life Interference Scale

Impairing levels of anxious symptomatology are highly prevalent within the autistic¹ community, with approximately 40% of autistic children experiencing clinically significant symptoms of anxiety (van Steensel, Bogels, & Perrin, 2011). Despite the high prevalence of anxiety symptomatology in autistic children, there are very few anxiety assessment measures considered reliable and valid for use with autistic children (Grondhuis & Aman, 2012; Wigham & McConachie, 2014). Accurate assessment of anxiety symptomatology in autistic children can be challenging, as growing evidence indicates that the phenomenology of anxiety symptomatology may differ between autistic and non-autistic children (Kerns & Kendall, 2012; Kerns et al., 2014). In addition, there are often similarities between the behavioural indicators of anxiety, and the core behavioural characteristics of autism. For example, an autistic child who avoids social interaction may be perceived to be disinterested in social communication or lacking social communication skills; however, the child's avoidance of social interaction may in fact be due to a fear of negative evaluation by peers, indicating social phobia. Without nuanced assessment, this distinction may be overlooked. Recent efforts to address this concern have resulted in the development of two separate scales for the assessment of anxiety symptomatology in autistic children: The Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD, Rodgers et al., 2016), and the Parent-Rated Anxiety Scale for Youth with Autism Spectrum Disorder (PRAS-ASD, Scahill et al., 2019).

Although the development of these scales marks valuable progress towards understanding anxiety symptomatology in autistic children, it is notable that research in this area to date has focused primarily on the identification of anxiety symptomatology, with few studies examining the consequences of such symptomatology. It has been suggested that the

¹ *Autistic person* (as opposed to “person with autism”) is the preferred language of many individuals on the spectrum (see Kenny et al., 2016), and will therefore be used throughout this paper.

characteristics of autism may interact with symptoms of anxiety to produce a more significant functional impact than would otherwise be expected, implying that the impact of anxiety may be more significant for an autistic individual than a non-autistic individual (Kerns et al., 2014). Some authors have suggested that anxiety is associated with poorer individual and family outcomes for autistic children (MacNeil, Lopes, & Minnes, 2009; van Steensel et al., 2011), but empirical research investigating the specific effects of anxiety on functioning and outcomes for autistic children and their families remains limited.

Co-occurring emotional and behavioural conditions (including depression, anxiety, and ADHD) have been found to limit autistic children's participation in daily activities, with a higher number of co-occurring conditions associated with greater impact on daily activities (Dovgan & Mazurek, 2019). Regarding anxiety specifically, parents of autistic children have reported increases in their own level of anxiety in response to their child's anxiety symptoms (Ozsivadjian, Knott, & Magiati, 2012). Importantly, many parents have indicated that anxiety symptomatology rather than autistic characteristics had a more significant negative impact on their child's quality of life and family functioning (Ozsivadjian et al., 2012). More recently, Kerns et al. (2015) found that autistic youth with co-morbid anxiety disorders had significantly higher rates of parent-reported self-injurious behaviour, depressive symptoms, and parental stress compared to non-anxious autistic youth.

In non-autistic children, anxiety disorders are associated with substantial impact across various life domains including peer relationships, family relationships, and school performance (Lyneham et al., 2013). Anxiety disorders in childhood are a significant predictor of adult anxiety disorders (Gregory et al., 2007), and childhood anxiety disorders in non-autistic youth have also been associated with later substance use disorders and increased risk of suicidal behaviour (Woodward & Fergusson, 2001). Given that anxiety disorders are known to be associated with considerable negative impact for non-autistic children, it is

important to investigate whether similar consequences exist for autistic children. In a previous Australian study investigating a cognitive-behavioural therapy program for the treatment of anxiety in autistic children, pre-treatment scores on a measure of anxiety-related life interference (the Child Anxiety Life Interference Scale [CALIS]) were similar to the scores of non-autistic clinically anxious children. This suggests that anxiety may produce similar levels of impact for autistic and non-autistic children (Lyneham et al., 2013; Ohan et al., 2016). If, as suggested by Ozsivadjian et al. (2012), anxious symptomatology has a greater detrimental impact on the lives of autistic children than the core characteristics of autism, then successful amelioration of anxiety symptoms may prove more beneficial for this population than interventions aimed at reducing the core characteristics of autism.

The current study aimed to investigate the extent and types of life interference and impact resulting from anxious symptomatology, in a sample of autistic children. Data from the CALIS were used to explore:

- (1) The extent to which autistic children and their parents report experiencing anxiety-related life interference and impairment;
- (2) The domains of daily life which children and parents report are most significantly impacted by anxious symptomatology;
- (3) Whether levels of anxiety-related life interference and impact are associated with severity of anxious symptomatology.

Method

Ethics

Ethical approval was obtained from <institution name retracted> University Human Research Ethics Committee.

Participants

Participants for this study were recruited from a longitudinal study of autistic children (see <citation retracted>). The full recruitment procedure for this study is described in <citation retracted>. Briefly, email invitations were sent to 54 families located in Queensland, Australia, with at least one autistic child. Of these, 32 (59%) families agreed to participate in data collection. Two families were excluded due to scores below the chosen cut-off of 11 on the Social Communication Questionnaire (SCQ), resulting in a total sample of 30 families. Participant children were aged between 9 and 12 years, and 25 (83%) were male. Two children were unable to complete the self-report assessments, therefore only parent-report data was available for these families. Demographic information for the participant group is shown in Table 1.

++ Insert Table 1 here ++

Measures

The Child Anxiety Life Interference Scale (CALIS; Lynham et al., 2013) assesses life interference and impairment associated with anxious symptomatology and is available in both child-report (CALIS-CV) and parent-report (CALIS-PV) versions. The CALIS-CV consists of 10 items: one measuring overall distress resulting from anxious symptomatology, eight measuring the level of life interference across different life domains, and one measuring the impact of a child's anxious symptomatology on others (i.e., parents, teachers, peers). The CALIS-PV consists of two subscales. The Child Interference Subscale measures the impact of anxiety on the child's own life and consists of nine items; one measuring overall distress resulting from anxious symptomatology, and eight measuring the level of life interference

across different life domains. Items in the Child Interference Subscale of the CALIS-PV correspond with items in the CALIS-CV. The Family Interference Subscale measures the impact the child's anxiety has on their family, and consists of nine items measuring the level of interference caused by a child's anxiety across different domains of the parent's life.

All items on the CALIS are measured on a five-point scale ranging from not at all (0) to a great deal (4). The CALIS has been found to have good psychometric properties in a sample of children with anxiety disorders (Lyneham et al., 2013). In the current study, Cronbach's alpha indicated that internal consistency was acceptable for the CALIS-CV ($\alpha = .71$), and good to excellent for the CALIS-PV Child Interference Subscale ($\alpha = .85$) and Family Interference Subscale ($\alpha = .94$).

The Spence Children's Anxiety Scale (SCAS; Spence, 1998) is a well-established measure for the assessment of anxious symptomatology in children, available in both child-report (SCAS-CV) and parent-report (SCAS-PV) versions. Both versions consist of 38 items, measured on a four-point scale ranging from never (0) to always (3). Both the SCAS-CV and SCAS-PV have a maximum possible score of 114, and t-scores of 60 or above indicate significant symptoms of anxiety. The SCAS has been found to have good psychometric properties in a sample of non-autistic children (Nauta et al., 2004), and has been identified as a promising measure for the assessment of anxiety symptomatology in autistic children and youth (Grondhuis & Aman, 2012; Wigham & McConachie, 2014; Zainal et al., 2014). In the current study, Cronbach's alpha indicated excellent internal consistency for both the SCAS-CV ($\alpha = .93$) and the SCAS-PV ($\alpha = .94$).

Data Analyses

The CALIS-CV and CALIS-PV scores were explored at total scale, subscale, and item level. Data screening was conducted on all CALIS raw score scales and subscales, and both SCAS

t-score scales. Screening showed normal distribution of scores (skewness and excess kurtosis within the range ± 1) for all total scales and subscales, with the exception of the CALIS-PV Family Life Interference Subscale which was slightly platykurtic (skewness .03, excess kurtosis -1.09). Given that Pearson's correlations have been found robust in slightly to moderately nonnormal distributions (Bishara & Hittner, 2012), parametric analyses were used in this paper.

Pearson's correlations were calculated between CALIS-CV and CALIS-PV scores, to investigate any relationship between child-report and parent-report; and between SCAS t-scores and CALIS raw scores, to identify any association between level of anxiety symptomatology and level of anxiety-related life interference. As this was an exploratory study, an alpha level of .05 was used (Perneger, 1998).

Results

Profile of scores on the CALIS-CV

Total scores on the CALIS-CV ranged from 1 to 24, out of a possible total of 40. The mean score was 11.21 (SD = 6.48, $n = 28$). Of the 28 participants who completed the CALIS-CV, 17 (61%) produced a score of 10 (the mean score for a clinical population, Lyneham et al., 2013) or higher.

As shown in Figure 1, children endorsed items on the CALIS-CV at high rates. Half (50%) of the participants indicated that they are upset by fears or worries at least sometimes, and only two children (7%) indicated that they are never upset by fears or worries. The most frequently endorsed item on the CALIS-CV related to schoolwork, with 57% of children indicating that they experience difficulty completing schoolwork due to anxiety at least sometimes. Seventy nine percent of children reported a belief that their anxious

symptomatology has a negative impact on the lives of those around them, including parents, teachers, and / or peers.

++ Insert Figure 1 here ++

Profile of scores on the CALIS-PV

Scores on the CALIS-PV Child Interference Subscale ranged from 3 to 32, out of a possible total of 36. The mean score was 20.40 (SD = 7.27, $n = 30$). Of the 30 participants who completed the CALIS-PV, 22 (73%) produced a score of 16 (the mean Child Interference Subscale score for mothers of children in a clinical population, Lyneham et al., 2013) or higher.

Parents generally endorsed items on the CALIS-PV Child Interference Subscale at considerably higher rates than children (see Figure 1). The majority (60%) of parents indicated that their child is upset or distressed by anxious symptomatology “quite a lot” or “a great deal”. Consistent with child-report, only two parents (7%) indicated that their child is never upset or distressed by anxiety. Also consistent with child-report, the item relating to classroom performance was most frequently endorsed by parents, with 87% of parents reporting that their child’s classroom performance is impacted by anxiety at least sometimes, and 43% of parents indicating that this occurs “a great deal”.

Scores on the CALIS-PV Family Interference Subscale ranged from 0 to 36, out of a possible total of 36. The mean score was 17.87 (SD = 9.83, $n = 30$). Of the 30 participants, 23 (77%) produced a score of 9 (the mean Family Interference Subscale score for mothers of children in a clinical population, Lyneham et al., 2013) or higher.

Consistent with their responses to items on the Child Interference Subscale, parents also endorsed high rates of life impact and interference on the Family Interference Subscale,

as shown in Figure 2. Eighty three percent of parents indicated that their child's anxious symptomatology had at least some impact on parental stress levels. Half (50%) of parents indicated that their child's anxious symptomatology had "quite a lot" or "a great deal" of impact on the parent's career.

++ Insert Figure 2 here ++

Comparison of scores on the CALIS (CV and PV) and SCAS (CV and PV)

The profile of scores on the SCAS-CV and SCAS-PV for this participant sample has been previously reported elsewhere <citation retracted>. As shown in Table 2, child responses to the CALIS-CV were significantly, moderately correlated with SCAS-CV scores, but not SCAS-PV scores; and parent responses to the CALIS-PV were significantly, moderately correlated with SCAS-PV scores, but not SCAS-CV scores. The two subscales of the CALIS-PV were significantly correlated with each other and the CALIS-PV total scale, however the CALIS-CV was not significantly correlated with either subscale or the total score on the CALIS-PV.

++ Insert Table 2 here ++

Discussion

This study explored anxiety-related life impact in a sample of autistic children and their parents. High rates of life interference and impact were reported, with both children and parents reporting anxiety-related life interference at levels similar to those reported by a clinically anxious population. Parents reported higher levels of life interference and impact than children, which is consistent with findings in non-autistic participant groups (Lyneham et al., 2013).

Findings from this study indicate that anxiety has a high level of impact across all areas of daily life for autistic children and their parents. Autistic people as a population tend to experience poorer outcomes than non-autistic people, across a range of domains (Howlin & Magiati, 2017); the current finding suggests that autistic children with co-occurring anxiety symptomatology also experience considerable negative consequences as a result of anxiety symptomatology, potentially placing them at risk of even poorer outcomes. Alternatively, given the very high rates of anxiety symptomatology in autistic children, it is worth considering the notion that the poor outcomes commonly seen in autistic people may not be a direct consequence of autistic characteristics, but instead a reflection of the impact of anxiety and other co-occurring mental health conditions.

In the current participant group, anxiety symptoms (SCAS) were significantly correlated with impact of anxiety (CALIS) within informants, indicating that higher levels of anxious symptomatology are associated with higher levels of anxiety-related life interference. This finding suggests that the CALIS was, as intended, measuring life interference caused by anxiety symptoms as opposed to life interference resulting from autistic characteristics or other sources. Although further investigation is required to confirm the reliability and validity of the CALIS for use with autistic children, the findings from this study suggest that the CALIS may be a useful screening instrument for identifying the impact of anxiety symptoms in autistic children. It is worth noting, however, that anxiety symptoms were not significantly correlated with impact of anxiety across different informants in this study, suggesting that an individual's perceived level of anxiety-related life interference is associated with their own, but not others' perception of anxious symptomatology. This highlights the importance, from both a research and clinical perspective, of gathering data on these topics from multiple informants.

The high levels of anxiety-related life interference identified in this participant group also suggest that appropriate treatment for anxious symptomatology in autistic children is a priority. School performance was reported as being the domain most impacted by anxious symptomatology, thus support for managing anxious symptomatology in the school environment may be beneficial in facilitating classroom success. Parents' lives were also highly impacted by their child's anxious symptomatology, particularly in relation to stress levels and career, therefore parents may benefit from increased support relating specifically to their child's anxious symptomatology.

Limitations

To our knowledge, this is the second study to utilise the CALIS with an autistic participant group (the first being Ohan et al., 2016), and the first to provide a profile of item-level responses. It is important to note that the CALIS was not designed for use with autistic children, and therefore the findings of this study must be interpreted with caution. However, in the current study, the CALIS was found to have acceptable psychometric properties in a sample of autistic children. Participants' scores were similar to those of a clinically anxious non-autistic sample (Lyneham et al., 2013), and also similar to the pre-treatment scores of autistic children participating in an anxiety intervention program (Ohan et al., 2016), providing support for the use of this measure with autistic children.

Both parents and children were asked to specifically consider only the impact of anxiety when responding to items in the CALIS. However, it is often difficult to differentiate symptoms of anxiety from characteristics of autism, and it is also likely to be difficult to distinguish the impact of anxiety from the impact of autism. It is therefore possible that participants may have inadvertently reported life impact as resulting from anxiety when this impact may be better explained as resulting from autism. Given that the CALIS is a brief self-

and informant-report assessment, the scale provides an overview of anxiety-related life interference, but does not allow for a detailed investigation of such impacts. Future studies may benefit from pairing the CALIS with a more in-depth qualitative exploration of anxiety-related life interference.

Additionally, this study included both child-report and parent-report measures of each child's anxious symptomatology, but parents' own anxious symptomatology was not assessed. It is possible that parents' ratings, particularly on the Family Interference subscale of the CALIS-PV, may have been impacted by parents' own anxious symptomatology.

Conclusion

The current study investigated anxiety-related life interference and impact in a sample of autistic children. Results revealed high rates of child- and parent-reported anxiety-related life interference, across all life domains assessed. Addressing anxious symptomatology in autistic children is therefore likely to have beneficial effects across many aspects of daily life, both for the children and for their families. Findings suggest that the CALIS may be a useful screening instrument for identifying anxiety-related life interference in autistic children, although should be used with caution pending further validation in this population.

References

- Bishara, A. J., & Hittner, J. B. (2012). Testing the significance of a correlation with nonnormal data: Comparison of Pearson, Spearman, transformation, and resampling approaches. *Psychological Methods, 17*(3), 399-417. doi:10.1037/a0028087
- Dovgan, K., & Mazurek, M. O. (2019). Impact of multiple co-occurring emotional and behavioural conditions on children with autism and their families. *Journal of Applied Research in Intellectual Disabilities, 32*(4), 967-980. doi:10.1111/jar.12590
- Gregory, A. M., Caspi, A., Moffitt, T. E., Koenen, K., Eley, T. C., & Poulton, R. (2007). Juvenile mental health histories of adults with anxiety disorders. *American Journal of Psychiatry, 164*(2), 301-308.
- Grondhuis, S. N., & Aman, M. G. (2012). Assessment of anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*(4), 1345-1365. doi:10.1016/j.rasd.2012.04.006
- Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinions in Psychiatry, 30*(2), 69-76. doi:10.1097/YCO.0000000000000308
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. doi:10.1177/1362361315588200
- Kerns, C. M., & Kendall, P. C. (2012). The presentation and classification of anxiety in autism spectrum disorder. *Clinical Psychology: Science and Practice, 19*, 323-347. doi:10.1111/cpsp.12009
- Kerns, C. M., Kendall, P. C., Berry, L., Souders, M. C., Franklin, M. E., Schultz, R. T., . . . Herrington, J. (2014). Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(11), 2851-2861. doi:10.1007/s10803-014-2141-7

- Kerns, C. M., Kendall, P. C., Zickgraf, H., Franklin, M. E., Miller, J., & Herrington, J. (2015). Not to be overshadowed or overlooked: Functional impairments associated with comorbid anxiety disorders in youth with ASD. *Behaviour Therapy*, 46, 29-39. doi:10.1016/j.beth.2014.03.005
- Lyneham, H. J., Sbrulati, E. S., Abbott, M. J., Rapee, R. M., Hudson, J. L., Tolin, D. F., & Carlson, S. E. (2013). Psychometric properties of the Child Anxiety Life Interference Scale (CALIS). *Journal of Anxiety Disorders*, 27(7), 711-719. doi:10.1016/j.janxdis.2013.09.008
- MacNeil, B. M., Lopes, V. A., & Minnes, P. M. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3(1), 1-21. doi:10.1016/j.rasd.2008.06.001
- Nauta, M. H., Scholing, A., Rapee, R. M., Abbott, M. J., Spence, S. H., & Waters, A. M. (2004). A parent-report measure of children's anxiety: Psychometric properties and comparison with child-report in a clinic and normal sample. *Behaviour Research and Therapy*, 42(7), 813-839. doi:10.1016/s0005-7967(03)00200-6
- Ohan, J. L., Sng, A., Russell-Smith, S., Maybery, M. T., Pestell, C., Whitehouse, A. J., . . . Egan, S. (2016). *Autism, anxiety and school functioning: Improving school functioning by reducing anxiety in children on the spectrum*. Brisbane, Australia: Cooperative Research Centre for Living with Autism (Autism CRC).
- Ozsivadjian, A., Knott, F., & Magiati, I. (2012). Parent and child perspectives on the nature of anxiety in children and young people with autism spectrum disorders: A focus group study. *Autism*, 16(2), 107-121. doi:10.1177/1362361311431703
- Perneger, T. V. (1998). What's wrong with Bonferroni adjustments. *British Medical Journal*, 316(7139), 1236-1238. doi:10.1136/bmj.316.7139.1236

- Rodgers, J., Wigham, S., McConachie, H., Freeston, M. H., Honey, E., & Parr, J. R. (2016). Development of the Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD). *Autism Research*, 9(11), 1205-1215. doi:10.1002/aur.1603
- Scahill, L., Lecavalier, L., Schultz, R. T., Evans, A. N., Maddox, B., Pritchett, J., . . . Edwards, M. C. (2019). Development of the Parent-Rated Anxiety Scale for Youth with Autism Spectrum Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, advance online publication. doi:10.1016/j.jaac.2018.10.016
- Spence, S. H. (1998). A measure of anxiety symptoms among children. *Behaviour Research and Therapy*, 36(5), 545-566. doi:10.1016/S0005-7967(98)00034-5
- van Steensel, F. J. A., Bogels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, 14(3), 302-317. doi:10.1007/s10567-011-0097-0
- Wigham, S., & McConachie, H. (2014). Systematic review of the properties of tools used to measure outcomes in anxiety intervention studies for children with autism spectrum disorders. *PLoS ONE*, 9(1), 1-17. doi:10.1371/journal.pone.0085268
- Woodward, L. J., & Fergusson, D. M. (2001). Life course outcomes of young people with anxiety disorders in adolescence. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(9), 1086-1093. doi:10.1097/00004583-200109000-00018
- Zainal, H., Magiati, I., Tan, J. W.-L., Sung, M., Fung, D. S. S., & Howlin, P. (2014). A preliminary investigation of the Spence Children's Anxiety Parent Scale as a screening tool for anxiety in young people with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(8), 1982-1994. doi:10.1007/s10803-014-2075-0

Tables

Table 1. *Participant Demographic Information*

	$\bar{x}$ / n	SD / %
Child's age	11.23	0.62
Child's gender (male)	25	83%
SCAS-CV ² total score	36.57	18.95
Above clinical cut-off on SCAS-CV	13	46%
SCAS-PV ³ total score	40.30	19.28
Above clinical cut-off on SCAS-PV	24	80%
Additional diagnoses (parent-report)		
Any additional diagnosis	20	67%
ADHD / ADD	10	33%
Anxiety	7	23%

² Spence Children's Anxiety Scale – Child Version

³ Spence Children's Anxiety Scale – Parent Version

Table 2. *Pearson's Correlations Between SCAS (T-Scores) and CALIS (Raw Scores)*

	SCAS-PV total t-score (n = 30)	SCAS-CV total t-score (n = 28)	CALIS-PV Child Interference Subscale (n = 30)	CALIS-PV Family Interference Subscale (n = 30)	CALIS-PV total score (n = 30)
SCAS-CV total t-score (n = 28)	.41*	-			
CALIS-PV Child Interference Subscale (n = 30)	.61***	.16	-		
CALIS-PV Family Interference Subscale (n = 30)	.65***	.37	.69***	-	
CALIS-PV total score (n = 30)	.69***	.30	.89***	.94***	-
CALIS-CV total score (n = 28)	.23	.53**	.25	.26	.28

* $p < .05$ ** $p < .01$ *** $p < .001$

Figure Captions

Figure 1. CALIS-CV and CALIS-PV Child Interference Subscale endorsements

Figure 2. CALIS-PV Family Interference Subscale endorsements