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ORIGINAL PAPER

The Impact of Anxiety on the Participation of Children on the Autism Spectrum

Kathryn Ambrose[1,3,4] · **Kate Simpson**[1,2,3] · **Dawn Adams**[1,2,3]

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Abstract

Anxiety is common in children on the autism spectrum, however its impacts are not fully understood. Participation is an important outcome, linked to the health and wellbeing of children. This study examined the relationship between anxiety and participation using parent reports for 131 children on the autism spectrum, aged 6–13 years. Hierarchical multiple regressions explored child and family factors in relation to participation in Home and Community settings. Anxiety was a unique, significant predictor of the frequency of children's participation (but not involvement in activities) in both settings, when controlling for autism characteristics, communication skills and family income. Anxiety symptomatology may contribute to the less frequent participation of children on the autism spectrum in home and community activities.

Keywords Autism · Anxiety · Participation · Home · Community · Mental health

Autism is a lifelong neurological condition that affects approximately 1% of the population (Australian Bureau of Statistics, 2015), characterised by differences in social communication skills, and the presence of restricted/repetitive behaviours (American Psychiatric Association, 2013). Children on the autism spectrum are at risk of poorer outcomes in many areas, including academic performance, physical health, and participation (Garcia & Hahs-Vaughn, 2020; Mayes et al., 2019; Ratcliff, Hong, & Hilton, 2018). Participation, defined as 'involvement in life situations' (WHO, 2007), is considered one of the essential domains for child and youth health. As well as being an important component of quality of life, participation has been linked to social and psychological wellbeing (Kawachi & Berkman, 2001), and the development of skills such as communication (Mactavish & Schleien, 2004). In children on the autism spectrum, more frequent participation has been associated with a higher number of friendships (Dovgan & Mazurek, 2018), improved wellbeing and personal development (Weiss & Burnham Riosa, 2015), and decreased challenging behaviour (Howells et al., 2020). As such, participation is not only a desirable outcome in itself, but may have a broad and important influence on children's health, development and wellbeing.

Children on the autism spectrum are reported to have lower levels of participation compared to their peers who are not on the autism spectrum. For example, they participate less frequently than children with language impairments or a learning disability (Shattuck et al., 2011), and participate in less diverse activities and environments than their typically developing peers (Potvin et al., 2013). These lower rates of participation of children on the autism spectrum are reported across a wide range of life situations and environments, including sports and leisure (Arnell, Jerlinder, & Lundqvist, 2018; Little et al., 2014; Ratcliff et al., 2018; Reynolds et al., 2011; Ryan, Fraser-Thomas, & Weiss, 2018), community and social activities (Orsmond, Krauss, & Seltzer, 2004; Rodger & Umaibalan, 2011), and education (Falkmer et al., 2012; Mâsse et al., 2013; Saggers, Hwang, & Mercer, 2011). Considering the central role of participation in the development of children, these reduced rates

✉ Kathryn Ambrose
Kathryn.ambrose@griffithuni.edu.au

1 Autism Centre of Excellence, Griffith University, Messines Ridge Road, Mt Gravatt, Brisbane, QLD 4122, Australia

2 Griffith Institute for Educational Research, Griffith University, Messines Ridge Road, Mt Gravatt, Brisbane, QLD 4122, Australia

3 The Co-operative Research Centre for Living with Autism (Autism CRC), PO Box 6068, St Lucia, QLD 4067, Australia

4 School of Education and Professional Studies, Griffith University, Mount Gravatt Campus, 176 Messines Ridge Rd, Brisbane, QLD 4122, Australia

of participation in children on the autism spectrum warrant further investigation.

Although the reasons for lower participation rates in children on the autism spectrum are not fully understood, child and family factors may play a role. In the broader literature regarding children with disabilities, functional skills including cognitive, physical, and social skills have been found to have a greater influence on the frequency of participation and level of involvement than the type of diagnoses in children with a range of medical and developmental conditions (Law et al., 2006). In children on the autism spectrum, social communication skills have been linked to participation in sports, leisure activities, self-care, and social activities (Askari et al., 2015; Gan et al., 2014; Ryan et al., 2018; Shattuck et al., 2011). There has also been a suggestion that other autism characteristics (e.g. sensory sensitivity) and co-occurring conditions (e.g. motor coordination difficulties) may also impact participation of children on the autism spectrum (see review by Askari et al., 2015). Amongst family factors, income has been identified as an important predictor in the frequency of participation in children on the autism spectrum in home, school, and community settings (Anaby et al., 2014; Shattuck et al., 2011).

A potentially important factor that has not yet been examined in relation to participation of children on the autism spectrum is anxiety. Approximately 40% of children on the autism spectrum meet the criteria for a clinical diagnosis of anxiety (van Steensel, Bogels, & Perrin, 2011), and a further 30% experience anxiety symptoms that effect their daily activities (Kaat, Gadow, & Lecavalier, 2013). For individuals on the autism spectrum, anxiety that begins in childhood will persist through adolescence, and into adulthood (Gotham, Brunwasser, & Lord, 2015). While previous research has examined the prevalence and presentation of anxiety in children on the autism spectrum, and it has been acknowledged that anxiety may present an additional risk of impairment across a wide range of functions (Belardinelli, Raza, & Taneli, 2016), the potential impacts of elevated anxiety are relatively unexplored.

Although not explored directly, there are indications of a relationship between anxiety and participation in children and youth on the autism spectrum warranting examination. For example, parent reports of youth on the autism spectrum suggest increased internalising symptoms are associated with reduced social activities (Lounds Taylor, Adams, & Bishop, 2017), and youth on the autism spectrum themselves have reported in interviews that anxiety limits their physical activity participation (Arnell et al., 2018). Anxiety has also been linked to poorer quality of life in social, emotional, physical, and school functioning domains (Adams, Clark, & Keen, 2019a; Adams, Clark, & Simpson, 2019b; Adams, Simpson, & Keen, 2019c; Kuhlthau et al., 2018). Further exploration of the relationship between anxiety and participation will enhance our understanding of the factors that influence participation and clarify the potential impact of anxiety on the outcomes of children on the autism spectrum. These insights can support increased awareness of the challenges, capabilities, and experiences of children on the autism spectrum and inform the development of supportive environments that maximise the participation, and therefore the health and wellbeing, of children on the autism spectrum.

The current study was designed to firstly investigate the relationships between child anxiety and participation of children on the autism spectrum in home, community, and school settings. Further to this, the study will specifically examine whether anxiety explains any additional variance in the participation scores of children on the autism spectrum, over and above other child and family factors that have been identified within the literature as relevant to the participation of children on the autism spectrum. In order to achieve these aims, the following research questions were posed:

1. Is the level of child anxiety for children on the autism spectrum correlated with participation (frequency or level of involvement) in home, school, or community settings?
2. Is elevated anxiety related to the participation (frequency or level of involvement) of children on the autism spectrum in home, school, or community settings?
3. Does anxiety predict any additional variance in the participation scores in home, community, and school settings above that explained by child and family factors?

Based on the literature, the following hypotheses are made:

1. In-line with previous work (Arnell et al., 2018; Lounds Taylor et al., 2017), it is hypothesised that higher anxiety scores will be correlated with decreased participation frequency and involvement across the three settings.
2. Based on the broader literature regarding children with disabilities that has linked psychological functioning to participation (Maciver et al., 2019; Mâsse et al., 2013), and indications that anxiety impacts the school, social and physical participation, and quality of life domains of children on the autism spectrum (Adams et al., 2019a, b, c; Arnell et al., 2018; Lounds Taylor et al., 2017), it is hypothesized that when controlling for the child (autism characteristics, adaptive communication skills) and family (family income) factors, anxiety will make a unique and significant contribution to the participation scores of children across all settings.
3. As anxiety levels in children on the autism spectrum vary across settings (Adams et al., 2019a, b, c) and impact different aspects of quality of life differently

(Adams et al., 2019a, b, c), it is hypothesised that the amount of variance in participation scores explained by anxiety will vary across the home, community and school settings.

Methods

This study utilises data collected as part of the Longitudinal Study of Australian Students with Autism (LASA). The aims of the LASA are to investigate the educational and participation outcomes of students on the autism spectrum in two age cohorts (aged 4–5 years and 9–10 years at time of recruitment) across 6 years. Data are collected from parents and caregivers of children on the autism spectrum annually via an online questionnaire. Ethical approval for this study was obtained from all participating universities and health authorities. Informed consent was obtained from all parents in the study.

For a full description of the recruitment process for the LASA, refer to Roberts et al. (2018). In summary, parents of children on the autism spectrum were recruited via a range of autism organisations, service providers, and social media sites. To confirm eligibility for inclusion in the study, parents were requested to provide copies of the child's diagnostic reports and complete the Social Communication Questionnaire (SCQ; Berument et al., 1999). Due to the size and geographical reach of the sample, direct assessments (e.g., ADOS, IQ) were not conducted for the full participant sample.

Participants

Participants for this study were selected from the third year of the LASA [the year at which all children met the minimum age criteria of 5 years and above for the Participation and Environment Measure-Child and Youth–Parent version (PEM-CY) measure]. From a pool of 220 participants who responded at this time point, two participants were excluded as the child's SCQ score was below the cut-off of 15 and a report confirming their community diagnosis of autism was not available. Missing data on the Vineland Adaptive Behaviour Scale-second edition (VABS-II) Communication domain and anxiety measure were imputed in concordance with the published manuals. After this, 87 participants were excluded due to missing data for one or more of the independent or dependent measures (PEM-CY Home or Community subscales, Anxiety Scale for Children with Autism Spectrum Disorder: Parent version (ASC-ASD-P), family income, VABS-II Communication domain). There were no significant differences between included and excluded participants on child gender [$\chi^2(1, 220) = 1.42$, $p = .234$], parent report of 1+ co-occurring conditions (χ^2 (1, 220) = 0.66, $p = .415$), parent-reported anxiety disorder [$\chi^2(1, 220) = 2.76$, $p = .097$], parent-reported sensory problems [$\chi^2(1, 220) = 2.04$, $p = .652$], caregiver education ($\chi^2 = 1.01$, $p = .605$), or caregiver employment ($\chi^2 = 3.18$, $p = .204$). There was a significant difference for co-occurring diagnosis of ADHD, where 33.6% of included participants had a diagnosis of ADHD, compared to 20.2% of excluded participants [$\chi^2(1, 220) = 4.68$, $p = .031$].

The final sample of participants included in this study was parents or caregivers of 131 children on the autism spectrum. Demographic characteristics can be viewed in Table 1. The majority of the parents were educated at tertiary level or above (80.2%) and were employed or studying (79.4%). The age range of children for the sample was 72–161 months (mean 117.5, standard deviation 31.01), and 80.9% of children of the participants were male. Parents reported that 95 (72.5%) of children were diagnosed with at least one co-occurring condition, of which the most frequently reported were anxiety, ADHD, and sensory problems.

Table 1 Participant characteristics based on parent report (N = 131)

		N	%
Gender	Male	106	80.9
	Female	25	19.1
Co-occurring conditions	Any co-occurring condition	95	72.5
	Anxiety	51	38.9
	ADHD	44	33.6
	Sensory problems	39	29.8
Educational setting	Mainstream	101	77.1
	Special setting	21	16.0
	Other	5	3.8
	Attends school, type not specified	4	3.1
Parental education	Secondary or below	26	19.8
	Tertiary or above	105	80.2
Parental employment	Employed	89	67.9
	Studying	15	11.4
	Unemployed	27	20.6
Family income	0–$18,200	2	1.5
	$18,201–$37,000	8	6.1
	$37,001–$80,000	28	21.4
	$80,001–$180,000	73	55.7
	$180,000 and over	20	15.3

Measures

Participation and Environment Measure: Child and Youth–Parent Version (PEM-CY; Coster et al., 2012)

The PEM-CY is a measure of participation for children as reported by caregivers across three environments. The questionnaire comprises 25 items, divided into three settings: Home (10 items), Community (10 items) and School (5 items). Each item refers to an activity that a child might typically participate in, caregivers are asked to rate the frequency that a child participates in the activity and the level of involvement of the child in that activity. Examples of items on the Home subscale include 'household chores' and 'indoor play and games', the Community subscale includes 'neighbourhood outings' and 'organisation, groups, clubs, and volunteer or leadership activities', and the School subscale includes 'classroom activities' and 'special roles at school' (see Coster et al., 2012 for a full description). This study uses informant ratings of the child's frequency of participation on an eight-point scale, ranging from *never* (0) to *daily* (7), and level of involvement in the activity on a five-point scale, from *minimally involved* (1), to *very involved* (5), for each of the three environment subscales. Due to differing numbers of items in the Home, Community and School subscales, mean (per item) frequency scores are calculated by calculating the subscale total score for the subscale divided by the number of items on the subscale. Mean involvement scores are calculated by dividing the subscale total score by the number of items that had a corresponding frequency score of 1–7, indicating the level of involvement in items that the child participated in at least once in the previous 4 months. The PEM-CY is designed for children aged 5–17 years and has been previously used to assess the participation of children on the autism spectrum (Simpson et al., 2017). It has demonstrated adequate test–retest reliability (0.58 and above) (Coster et al., 2011). Cronbach α coefficients in this sample for the Home and Community settings for "frequency" were .70 and .64, and for "involvement" were .78 and .68, respectively. Cronbach α coefficients for the School setting (.27 for frequency and .59 for involvement) indicated that the internal consistency for this scale in this sample of children on the autism spectrum is poor, therefore the School setting subscale was removed from subsequent analyses.

Social Communication Questionnaire: Lifetime Version (SCQ; Berument et al., 1999)

The SCQ was administered to parents/caregivers upon entry to the longitudinal study. It comprises a 40-item checklist regarding the child's social skills, communication, and behaviour. A higher score represents a higher number of behaviours that may be considered indicative of autism. Initial analysis of the SCQ reported good psychometric properties, with an α coefficient of .90, and sensitivity of .96, and specificity of .80 for identifying children with an autism spectrum disorder (Berument et al., 1999). It is a well-researched measure, with a meta-analysis concluding it is an acceptable screening tool for autism characteristics (Chesnut et al., 2017). Within this study, the SCQ was initially used to confirm the presence of autism characteristics (in addition to parent-reported diagnosis and community diagnostic reports where available) before then being included as an independent variable in regression models.

Anxiety Scale for Children with Autism Spectrum Disorder: Parent Version (ASC-ASD-P; Rodgers et al., 2016)

This measure was adapted from the Revised Child Anxiety and Depression Scale (Chorpita et al., 2000) and was developed to document anxiety symptoms in children on the autism spectrum. The ASC-ASD-P comprises 24 items scored on a 4-point Likert scale, with possible responses of *never*, *sometimes*, *often*, and *always* corresponding to a score of 0–3. Scores can be calculated as total score (maximum 72) or can contribute to one of four subscales: Performance Anxiety (5 items), Anxious Arousal (6 items), Separation Anxiety (5 items), and Uncertainty (8 items). The authors have suggested that a total anxiety score > 24 indicates "more specific indication of significant anxiety", therefore as per Adams et al. (2019a, b, c), this threshold was used in this study to identify children with elevated anxiety for group comparisons.

The ASC-ASD-P has good psychometric properties including good internal consistency, validity, and 1 month test–retest reliability ($r = .84$) (Belardinelli et al., 2016; Rodgers et al., 2016), convergent reliability with other established measures of anxiety (den Houting et al., 2018), and divergent reliability with measures of autism characteristics (Keen et al., 2019). Adams, Simpson and Keen (2018) report that the Proportional Reduction in Mean Score Error (PRMSE) values were larger for ASC-ASD-P subscales than the $PRMSE_{TOT}$ value, confirming value of reporting the ASC-ASD-P scores at subscale level. The internal consistency for this sample, calculated using Cronbach's α, was .94 for total anxiety score, .88 for Performance Anxiety, .87 for Anxious Arousal, .84 for Separation Anxiety, and .89 for Uncertainty.

Vineland Adaptive Behaviour Scale-II (VABS-II; Sparrow, Cicchetti, & Balla, 2005): Communication Domain

This subscale of the widely used measure of adaptive functioning asks parents rate their child's functional speaking, listening, reading and writing skills. It can be used across

the lifespan and is appropriate for assessing children with a wide range of ability levels (Kenworthy et al., 2010) including children on the autism spectrum (Lopata et al., 2013; Yang, Paynter, & Gilmore, 2016). In this study, the VABS-II Communication subscale was included as an independent variable within the regression models, as functional skills have previously been identified as predictors of participation in children on the autism spectrum (Gan et al., 2014; Little et al., 2015). The VABS-II demonstrates good internal consistency in the Communication domain (α = .84–.93), and test–retest reliability of 0.88–0.92 (Sparrow et al., 2005).

Data Analyses

Data was screened for missing data prior to analyses. Missing data were handled in accordance with the manual for the VABS-II Communication Standard score, and only complete data sets were used for the other measures of interest. Distribution of data were screened using a Kolmogorov–Smirnov test, and skew and kurtosis for the ASC-ASD-P total and subscale scores, and the PEM-CY frequency and involvement scores in each environment. As none of the measures were normally distributed, non-parametric tests were utilised where appropriate. Spearman's correlations were conducted between independent variables (see Table 2) to screen for collinearity (r > .80, all VIFs between 1.21 and 2.64). As no collinearity was detected, all variables were retained. Data were examined for outliers, normality, linearity, homoscedasticity and independence of residuals, and no violations of these assumptions were found.

To explore the relationships between child anxiety, and participation, Spearman's correlations were conducted. To explore potential differences on the frequency and involvement of the PEM-CY Home and Community subscales between those with and without elevated anxiety, total ASC-ASD-P scores were coded into elevated and non-elevated anxiety (based on the cut-off score of 24), a series of Mann–Whitney U tests were conducted. Effect sizes are reported as *r*, with .10–.30 indicating a small effect, .30–.50 a medium effect and ≥ .50 a large effect size.

To investigate the unique and combined contributions of child and family factors on participation, and to identify whether adding anxiety into predictive models significantly increases the level of variance on participation explained, a series of hierarchical multiple regressions (HMR) were conducted. These were conducted separately for the mean frequency and involvement scores on the PEM-CY Home and Community subscales as the dependent variables. Variables were entered in the following four steps in all models, based upon the following rationale. As functional ability has been previously found to influence participation, over and above diagnosis of a medical condition or disability, the VABS-II Communication standard score was entered at Step 1. As

Table 2 Spearman's correlations between PEM-CY and independent variables

	Mean[a] (s.d.)	2	3	4	5	6	7	8	9	10	11	12
1. PEM-CY Home frequency[a]	5.55 (1.03)	.37***	.39***	.32***	− .16	.34***	.23**	− .11	− .07	− .24**	− .09	− .16
2. PEM-CY Home involvement[a]	3.52 (0.61)	–	.14	.48***	− .14	.35***	.16	− .01	.11	− .07	.03	− .06
3. PEM-CY Community frequency[a]	2.07 (0.89)		–	.32***	− .24**	.27**	.01	− .20	.02	− .23**	− .13	− .26**
4. PEM-CY Community involvement[a]	3.49 (0.76)			–	− .16	.39***	.01	− .10	.06	− .11	− .13	− .14
5. SCQ score	20.07 (6.44)				–	− .41***	− .25**	.20*	.09	.18*	.18*	.23**
6. VABS-II Communication standard score	82.87 (20.04)					–	.24**	− .14	.08	− .18*	− .20*	− .17*
7. Income	NA						–	− .09	− .19*	− .11	− .02	− .06
8. ASC-ASD-P total score	22.96 (14.49)							–	.73***	.80***	.81***	.91***
9. ASC-ASD-P Performance[a]	1.08 (.84)								–	.47***	.44***	.51***
10. ASC-ASD-P Anxious Arousal[a]	0.53 (.59)									–	.63***	.72***
11. ASC-ASD-P Separation[a]	0.88 (.79)										–	.67***
12. ASC-ASD-P Uncertainty[a]	1.24 (.72)											–

*p < .05; **p < .01; ***p < .001

[a]Mean score per item reported

children on the autism spectrum have been noted to have lower participation scores than typically developing children (Potvin et al., 2013), and children with language impairments and learning disabilities (Shattuck et al., 2011), it was hypothesised that autism characteristics may be a significant factor in participation, and therefore SCQ score was entered in Step 2. Participation in the home and community has been previously linked to family income, therefore income was entered in Step 3. Finally, to examine the unique contribution of anxiety to participation over and above the child and family factors, the four anxiety subscales of the ASC-ASD-P were entered simultaneously in Step 4.

As the current study was a novel exploration of the impact of anxiety and other factors on child participation and is aimed at highlighting areas for in-depth investigation in future research, increased risk of Type 1 errors was considered less of a concern than Type 2 errors. Although the design required multiple analyses, which potentially raised the possibility of increased Familywise error, Bonferroni correction was considered too conservative (Perneger, 1998). Thus, the decision was made a priori to retain an α-value of 0.05 across analyses.

Results

Correlations Between Child Anxiety and Participation

As seen in Table 2, higher scores on the Anxious Arousal subscale score were significantly correlated lower frequency of participation in both Home and Community settings. Higher total anxiety scores and Uncertainty subscale scores were weakly (but significantly) associated with lower frequency of participation in the Community setting.

Levels of Participation in Those With and Without Elevated Anxiety

Elevated anxiety (based on the ASC-ASD-P total score) was identified in 50 (38.2%) of the sample. Mann–Whitney U tests, with each participation subscale as the dependent variable and elevated/non-elevated anxiety as the independent variable, indicate that children with elevated anxiety participated significantly less frequently in activities in the Home and Community settings than those with non-elevated anxiety (see Table 3). There was a medium effect size for frequency of participation in the Community ($r = 0.31$) and a small effect size for frequency of participation in the Home ($r = 0.18$). There was no significant difference between those with and without elevated anxiety for the level of involvement in home or community activities.

Hierarchical Multiple Regression Analyses

A series of HMR were conducted, with PEM-CY mean frequency and involvement scores in Home and Community settings as the dependent variables (see Table 4). The independent variables (VABS-II Communication standard score, SCQ score, income, and anxiety subscale scores) were entered into the models as described in the Data Analysis section.

PEM-CY Home Subscale

The PEM-CY Home frequency model at Step 1 [$F(1, 129) = 22.49$, $p < .001$], Step 2 [$F(1, 128) = 12.20$, $p < .001$] and Step 3 [$F(1, 127) = 8.47$, $p < .001$] were significant. The addition of SCQ score (Step 2) and family income (Step 3) did not explain a significant amount of additional variance. At all three steps, VABS-II Communication standard score was identified as a unique significant predictor, and explained 14.8%, 9.7% and 7.8% of the overall variance respectively. The model at Step 4 was significant [$F(4, 123) = 29.39$, $p < 0.001$] and explained 27.4% of the variance. The addition of the anxiety subscales at Step 4 added an additional and significant 8.9% to the variance explained. VABS Communication standard score ($\beta = .27$) and the Anxious Arousal subscale ($\beta = -.39$) were both identified as unique and significant contributors to the model, explaining 5.4% and 6.5% of the variance respectively.

The HMR for PEM-CY Home involvement was significant at Step 1 [$F(1, 129) = 21.90$, $p < .001$], Step 2 [$F(1, 128 = 14.86$, $p < .001$], Step 3 [$F(1, 127 = 10.10$, $p < .001$]

Table 3 Group differences in participation for those above and below the ASC-ASD-P total score cut-off

PEM-CY subscale	Non-elevated anxiety N = 81 Median	Elevated anxiety N = 50 Median	*U*	*z*	*p*	Effect size (*r*)
Home frequency	5.7	5.5	1601	−2.01	.044*	0.18
Home involvement	3.6	3.5	1969	−.266	.791	0.02
Community frequency	2.2	1.6	1288	−3.345	<.001***	0.31
Community involvement	3.6	3.3	1720	−1.449	.147	0.13

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

Table 4 Hierarchical multiple regression analyses for PEM-CY subscale scores

PEM-CY subscale	Step	Predictor	β Step 1	β Step 2	β Step 3	β Step 4
Home Frequency	1	VABS-II Communication	.39***	.34***	.31**	.27**
	2	SCQ		−.18	−.08	−.04
	3	Income			.17	.15
	4	Performance Anxiety				.19
		Anxious Arousal				−.39**
		Separation anxiety				.12
		Uncertainty				.02
ΔR^2			.15***	.01	.02	.09**
R^2			.15	.16	.19	.27
Home Involvement	1	VABS-II Communication	.43***	.41***	.40***	.37***
	2	SCQ		−.06	−.04	−.06
	3	Income			.07	.09
	4	Performance Anxiety				.11
		Anxious Arousal				.05
		Separation anxiety				.10
		Uncertainty				−.13
ΔR^2			.19***	.00	.00	.02
R^2			.19	.19	.19	.21
Community Frequency	1	VABS-II Communication	.26**	.21*	.22*	.19
	2	SCQ		−.14	−.15	−.09
	3	Income			−.06	−.06
	4	Performance Anxiety				.13
		Anxious Arousal				−.12
		Separation anxiety				.13
		Uncertainty				−.29*
ΔR^2			.07**	.02	.00	.07*
R^2			.07	.08	.09	.16
Community Involvement	1	VABS-II Communication	.41***	.39***	.40***	.38***
	2	SCQ		−.06	−.08	−.06
	3	Income			−.10	−.08
	4	Performance Anxiety				.07
		Anxious Arousal				.10
		Separation anxiety				.03
		Uncertainty				−.23
ΔR^2			.17***	.00	.01	.02
R^2			.17	.17	.18	.20

*p < .05; **p < .01; ***p < .001

and Step 4 [F(4, 123) = 4.74, $p < 0.001$]. At each step, VABS-II Communication standard score was the only significant predictor, explaining 18.6%, and 14.1%, 12.8% and 10.4% of the variance respectively.

PEM-CY Community Subscale

Similar to previous HMRs, the PEM-CY Community frequency model at Step 1 [F(1, 129 = 9.47, $p = .003$], Step 2 [F(1, 128 = 5.86, $p = .004$] and Step 3 [F(1, 127 = 4.04, $p = .009$], were significant but the addition of SCQ score (Step 2) and family income (Step 3) did not explain a significant amount of additional variance. At all three steps, VABS-II Communication standard score was identified as a unique significant predictor, explaining 6.8%, 3.7.% and 4% of the overall variance respectively. At Step 4, the overall model was significant [F(4, 23) = 3.25, $p = .003$] and explained 15.6% of the overall variance of Community frequency scores. The anxiety subscales added to the model at this step explained an additional and significant 6.9% of the variance of the model. The Uncertainty subscale (β = .22) was identified as the only unique, significant predictor of the final model, explaining 3.2% of the variance at Step 4.

The HMR for PEM-CY Community involvement was significant at Step 1 [$F(1, 129) = 25.72$, $p < .001$], Step 2 [$F(1, 128 = 13.00$, $p < .001$], Step 3 [$F(1, 127 = 9.17$, $p < .001$] and Step 4 [$F(4, 123) = 4.41$, $p = .001$]. At each step, VABS-II Communication standard score was the only significant predictor, explaining 16.6%, 12.6%, 13.4% and 10.9% of the variance respectively.

Discussion

Although anxiety is continuously identified as one of the most common co-occurring conditions in children on the autism spectrum, little is known about its impact. As the first study to statistically explore the impact of anxiety on children's participation (both frequency and involvement) in home and community activities, two key findings address this research gap. Firstly, children on the autism spectrum who are experiencing elevated anxiety are reported to participate less frequently in home and community-based activities than those without elevated anxiety, but when they do attend, they are not less involved than children without elevated anxiety. Secondly, when child language ability, autism characteristics and family income are controlled for, anxiety explains additional variance in the frequency, but not involvement, of participation of children on the autism spectrum.

The use of HMR allowed for previously identified factors impacting participation to be explored in Steps 1–3 of each model. Prior to the inclusion of the anxiety subscales, the VABS-II communication standard score, which measures functional speaking, listening, reading and writing skills, was as a unique significant predictor in the HMR models of Home frequency and involvement, and Community involvement. There are several pathways by which these communication skills may influence the participation of children on the autism spectrum. Communicative ability impacts children's learning, independence, competence, and positive social interactions (Almqvist & Granlund, 2005; Potvin et al., 2013; Reynolds et al., 2011). Adaptive communication skills may influence the (perceived or actual) ability of adults to facilitate the inclusion of children, especially in community environments (Grandisson et al., 2012; Shields & Synnot, 2014; Shields & Synnot, 2016). There may of course be a cyclical relationship; reduced participation may also impact the opportunities for children to practice and develop communication skills across environments (Little et al., 2019; Pfeiffer et al., 2017). While findings of this cross-sectional study preclude drawing causal inferences, longitudinal studies in future would help clarify the direction of this relationship.

The addition of the four anxiety subscales in Step 4 of the HMR significantly increased the amount of variance explained for the frequency of participation in Home and Community activities. In Step 4, for the frequency of home participation, the significant predictors were VABS-II Communication and ASC-ASD Anxious Arousal subscale and for the Community it was the ASC-ASD Uncertainty subscale. Whilst these results of the HMR indicate that anxiety does impact upon how often children participate, further (qualitative) work is required to find out about how and why this occurs. It may be that anxiety increases the likelihood of children disengaging or withdrawing from activities and environments that heighten their anxiety in order to control their anxiety symptoms (Hofmann & Hay, 2018). In addition, the presentations of anxiety in autism, including changes in vocalisations, affect, and movements, and behaviours that may be challenging (Adams et al., 2018) may make it more difficult for children to attend and engage in activities, and for adults to support them (Howel & Pierson, 2010).

Anxiety, Communication, and Home Participation

HMR analyses of Home participation revealed that both adaptive Communication skills and Anxious Arousal symptoms significantly predict higher frequency of participation in activities in the home. As well as the potential for Communication skills and anxiety to independently influence the participation of children, Communication skills and anxiety are closely associated in children on the autism spectrum. For example, communication influences the manifestation of anxiety symptoms (Davis et al., 2011), and anxiety predicts communication impairments over time (Duvekot et al., 2017), although this may not explain why Communication and Anxious Arousal specifically predict participation in the Home and not other settings. It may be that different adjustments or accommodations are made for children with high anxiety and poorer communication skills in the home environment, enabling children to use more withdrawal and avoidance strategies to manage their anxiety (Adams & Emerson, 2020).

The findings of this study highlight the potentially important role of Anxious Arousal symptoms in the outcomes of children on the autism spectrum. Consistent with other studies that utilise the ASC-ASD measure (Adams et al., 2019a, b, c; Adams & Emerson, 2020; den Houting et al., 2018), and the documented challenge for parents in identifying the signs of physiological arousal in their children on the autism spectrum (Helverschou & Martinsen, 2011), the Anxious Arousal subscale was the least frequently endorsed subscale in this study. Despite the less frequent reporting of these physiological signs of anxiety, Anxious Arousal has been linked to poorer quality of life for children on the autism spectrum in the areas of social, emotional, and school functioning (Adams et al., 2019a, b, c), poorer adaptive social skills (Keen et al., 2017) and now less frequent participation in the home. Two independent traits that relate to identifying and understanding physiological states, interoception

(Nicholson et al., 2019) and alexithymia (Kinnaird, Stewart, & Tchanturia, 2020), may affect the ability of some children on the autism spectrum to manage their Anxious Arousal symptoms (Milosavljevic et al., 2016; Palser et al., 2018). Furthermore, sensory over-responsivity, which is indicated in approximately 70% of children on the autism spectrum (Ben-Sasson et al., 2007) has been proposed as both a cause and a consequence of anxiety in children on the autism spectrum (Green & Ben-Sasson, 2010; Williams, Campi, & Baranek, 2021) and has been linked to reduced participation (Little et al., 2015). Differences in processing the physiological symptoms of anxiety may contribute to avoidance of activities or environments that induce anxiety for children on the autism spectrum, thereby reducing their participation.

Anxiety and Community Participation

Scores on the Uncertainty subscale were the only unique, significant predictor of frequency of Community participation in our model. The Uncertainty subscale of the ASC-ASD comprises eight items that the scale authors identify as anxiety signs related to autism characteristics in the restricted and repetitive behaviours domain, particularly insistence on sameness and sensory issues. It is conceivable that anxiety related to uncertainty is heightened in community settings because they are generally less predictable and more varied than the home environment. As anxiety was a stronger predictor of participation than autism characteristics in this study, it is possible that autism-related anxiety symptoms, rather than autism characteristics themselves, contribute to the lower participation rates of children on the autism spectrum, and these relationships are an avenue for further research. These findings linking anxiety on the Uncertainty subscale with frequency of Community participation also suggest that changes in community participation may be a useful outcome measure for interventions that focus on symptoms related to Uncertainty, such as the CUES© program (Rodgers et al., 2016).

When the standardised β for each variable in Step 4 of the HMR for the frequency of Community participation are examined, it suggests that the relationship between anxiety and participation differs for different subscales; the β is positive for Performance Anxiety and Separation Anxiety but negative for Anxious Arousal and Uncertainty. The Performance Anxiety items on the ASC-ASD-P include items with a social evaluation component, for example *My child worries when he/she thinks he/she has done poorly at something in case people judge him/her negatively.* It has been suggested that children with higher Anxious Arousal and Uncertainty symptoms may find participation in less predictable community settings anxiety-provoking, and if they also experience low Performance Anxiety, their anxiety-related behaviour may not be moderated by social inhibition (Adams & Emerson, 2020). This combination of factors may exacerbate parental fears about how others perceive their child's behaviour and influence parental support of their child's participation in the community (Adams & Emerson, 2020). The potential mechanisms explaining the relationship between this profile of anxiety symptomatology and child outcomes warrant further investigation.

The Impact of Other Child and Family Factors in Participation of Children on the Autism Spectrum

Autism characteristics (as measured by the score on the SCQ) were only correlated with PEM-CY Community frequency scores and when entered into the HMR, did not explain significant levels of variance of any of the participation scores. This finding aligns with previous work suggesting that functional skills are more predictive of participation than a diagnosis on the autism spectrum (Askari et al., 2015; Gan et al., 2014; Little et al., 2015; Ryan et al., 2018). Although children on the autism spectrum have been reported to have lower participation rates than typically developing children (Potvin et al., 2013) or children with language impairments or a learning disability (Shattuck et al., 2011), the findings of this study suggest complex interactions of factors within a child's profile which contribute to the participation of children on the autism spectrum. For example, children on the autism spectrum participate in less diverse ways than their peers who are not on the spectrum (Potvin et al., 2013; Ratcliff et al., 2018; Shattuck et al., 2011), which may reflect not only a preference for routine that is characteristic of autism, but also anxiety about new environments and activities.

One unexpected finding in this study was that family income was only correlated with frequency of participation in the Home setting and was not a unique predictor of any participation subscales in regression analyses, in contrast to previous studies of children on the autism spectrum and those with a range of disabilities (Anaby et al., 2014; Khetani et al., 2014). One factor that may have considerable relevance to this finding is the National Disability Insurance Scheme (NDIS), which was introduced in Australia in 2013 and provides government funding to support access to community and in-home supports for children with disabilities. The NDIS may substantially reduce financial barriers to participation in community activities reported in previous studies, highlighting the need for country-specific studies.

Limitations and Areas for Further Development

Consistent with other studies that have utilised measures of participation at school (Simpson et al., , 2017, 2019), the internal consistency on the PEM-CY School frequency

and involvement subscales in this sample were low, suggesting that this subscale does not accurately describe the construct of school participation for children on the autism spectrum. As meaningful participation may vary in children on the autism spectrum (Falkmer et al., 2012; Lami et al., 2018), future investigations may examine reliable, autism-specific measures of participation in the school environment. The purpose of this study was to identify the relationship between anxiety and participation in children on the autism spectrum. To further understand how other factors may influence this relationship, future studies may consider the role of additional variables, such as behavioural challenges, sensory sensitivity, and cognitive and motor skills (Askari et al., 2015), and other co-occurring conditions.

The use of parent report enabled the collection of anxiety and participation data from children with a wide range of communicative abilities, however, parent views may not necessarily reflect the subjective experiences of children. Using child self-report to investigate the views of children regarding the impact of anxiety and communication skills on their participation would provide further, valuable information on these relationships. The participant sample in this study was self-selecting which may introduce bias in participant characteristics such as income and parent education. However, the median income of families in this sample was AUD$80,001–$180,000, in line with the median income of families of AUD$90,168 in Australia according to 2016 census data. As there was a broad battery of measures collected by the LASA, participants were not recruited for the purpose of gaining information regarding their child's anxiety specifically, and therefore a strength of the study may be that the sample may include participants who do not have a specific interest in, or experience of, anxiety in the child on the autism spectrum.

Conclusion

The findings of this study highlight a relationship between elevated anxiety and lower frequency of participation of children on the autism spectrum in their home and community. Anxious Arousal symptoms, and anxiety related to Uncertainty, were identified as unique predictors of frequency of participation in our models, and these symptoms may be useful targets for anxiety interventions. Children with better adaptive communication skills also participate more frequently in the home and community, and are more involved in activities at home. Participation may be enhanced for children on the autism spectrum through the provision of environmental supports to accommodate different communicative styles and elevated anxiety.

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Declarations

Conflict of interest The authors declare no conflict of interest with respect to the research, authorship, or publication of this article.

Ethical Approval Ethical approval for this study was obtained from all participating universities and health authorities.

Informed Consent Informed consent was obtained from all parents in the study.

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