

A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder

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Background: Psychoeducation is an essential component of postdiagnostic care for people with ASD (autism spectrum disorder), but there is currently no evidence base for clinical practice. We designed, manualised and evaluated PEGASUS (psychoeducation group for autism spectrum understanding and support), a group psychoeducational programme aiming to enhance the self-awareness of young people with ASD by teaching them about their diagnosis. **Methods:** This single-blind RCT (randomised control trial) involved 48 young people (9–14 years) with high-functioning ASD. Half were randomly assigned to PEGASUS, administered in six weekly group sessions, with the others receiving no additional intervention. ASD-related self-awareness, the primary outcome, was evaluated using the bespoke Autism Knowledge Quiz (AKQ). Secondary outcome measures included the Rosenberg Self-Esteem Scale. All measures were collected during home visits and scored by researchers blind to group assignment. The trial is registered on ClinicalTrials (NCT01187940, <http://www.clinicaltrials.gov>) and was funded by the Baily Thomas Charitable Trust. **Results:** Bootstrap multiple regression showed ASD knowledge ($\beta = .29$, $p < .001$, 95% CIs [0.13, 0.44]) and ASD self-awareness ($\beta = .42$, $p = .001$, 95% CIs [0.17, 0.67]), measured by number of ASD-related personal strengths and difficulties listed by participants, increased for those who attended PEGASUS ($n = 24$) compared with controls ($n = 24$). There was no effect of PEGASUS on self-esteem by self-report ($\beta = .10$, $p = .404$, 95% CIs [-0.14, 0.35]) or parent report ($\beta = .12$, $p = .324$, 95% CIs [-0.12, 0.36]). **Conclusions:** After PEGASUS, participants had more general knowledge about ASD, and showed a greater awareness of their collection of unique strengths and difficulties associated with ASD. Psychoeducation did not lower self-esteem. This RCT provides initial evidence for PEGASUS's efficacy as a psychoeducation programme for people with ASD. **Keywords:** Autism spectrum disorder, psychoeducation, postdiagnosis, self-awareness, group intervention, randomised control trial.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition, characterised by atypical social interaction and communication, and inflexibility (American Psychiatric Association, 2013). It occurs in approximately 1.5 per cent of the population (Centres for Disease Control and Prevention [CDC], 2014), emerging early in development and persisting across the life span. Around two thirds (69%) of people with ASD have an IQ over 70, outside the intellectual disability range (CDC, 2014). In several developed countries, there has been a concerted effort to improve the recognition of ASD, to ensure that a high proportion of cases are identified in childhood (e.g. Johnson, Myers & American Academy of Pediatrics Council on Children with Disabilities, 2007; NICE, 2012).

Such policy has potential to benefit young people with ASD, by identifying their needs, and suggesting appropriate interventions. Furthermore, having accurate knowledge of an ASD diagnosis can foster self-awareness in a way that minimises self-criticism (e.g. Hurlbutt & Chalmers, 2002). However, the

assignment of an ASD diagnosis does not necessarily confer such benefits, and it can be associated with costs. Ruiz Calzada, Pistrang, and Mandy (2012) interviewed young people with high-functioning ASD, and discovered that most were keen to distance themselves from their diagnosis, reporting shame at being 'not normal', and reporting that they received few additional services or other benefits after diagnosis. Many knew little about ASD, having actively avoided information on the disorder, and most held negative stereotypes about people on the autistic spectrum (Ruiz Calzada et al., 2012). These findings accord with those from youths with other neurodevelopmental disorders (e.g. Singh, 2011), and remind us that such diagnoses can have negative, as well as positive effects, including exposing a person to stigma and lowering his or her self-esteem (Jutel & Nettleton, 2011).

One way to counter the phenomenon of young people feeling disengaged from, or even diminished by, their ASD diagnosis is to offer them psychoeducation. Whilst no universal definition exists, we delineate psychoeducation as the provision of information about a mental disorder. We distinguish between 'level one' and 'level two' psychoeducation. Level one psychoeducation involves teaching facts

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about a disorder. Level two psychoeducation is a more intensive process that aims at psychological change by facilitating persons with a mental disorder to take in information about that disorder *and apply it to themselves*. Level two psychoeducation aims to increase the utility of diagnosis, by encouraging people to use information about their condition to understand themselves better. Both level one psychoeducation and level two psychoeducation have the potential to minimise potential costs and maximise strengths of diagnosis, by countering the negative views of a disorder and emphasising strengths.

Psychoeducation has been shown to improve outcomes for children with non-ASD neurodevelopmental conditions such as Tourette's syndrome and attention-deficit/hyperactivity disorder (Nussey, Pistrang, & Murphy, 2013), and is recognised as a *sine qua non* of good postdiagnostic care in ASD (e.g. Johnson et al., 2007; NICE, 2012). Despite this, there is currently no grounding for evidence-based practice in this area: we know of no investigations of the efficacy of psychoeducation for young people with ASD. Given that most people with ASD are capable of participating in some form of psychoeducation, this is a significant lacuna in the clinical literature that limits effective, client-centred care after diagnosis.

We designed and manualised a programme to teach young people with ASD about their diagnosis (level one psychoeducation) and to help them use this information to develop insight into their own unique collection of strengths and difficulties (level two psychoeducation). This programme is called 'PsychoEducational Groups for Autism Spectrum Understanding and Support', or PEGASUS. PEGASUS has a strong focus on strengths, encouraging young people to focus on their capacities as well as their difficulties, and strongly conveying the message that having ASD involves being different from, but not inferior to, people without ASD.

After piloting PEGASUS, we tested its efficacy by conducting a randomised controlled trial, comparing it with management as usual (MAU). We predicted that PEGASUS would outperform MAU in terms of increasing young peoples' knowledge about ASD (level one psychoeducation); and by improving their capacity to apply this knowledge to themselves to understand their own strengths and difficulties (level two psychoeducation, our primary outcome). Given the concerns of some theorists that teaching children about their ASD could lower self-esteem by emphasising their limitations and abnormality (e.g. Jutel & Nettleton, 2011), we also tested whether there was an effect of PEGASUS on self-esteem.

Methods

Trial design

This was a randomised controlled trial (RCT) with two equally sized arms: (a) the PEGASUS condition, in which child and

parent(s) were invited to attend the PEGASUS programme; and (b) the control condition, where the child received management as usual (MAU), with no additional intervention. The trial is registered on ClinicalTrials (NCT01187940, <http://www.clinicaltrials.gov>). In the current report, we present child outcomes from this project, including some secondary outcomes, such as self-esteem and psychopathology, which were measured by self- and parent report.

Participants and randomisation

The study was approved by the National Research Ethics Service (North West London REC 2). Recruitment was achieved through advertisement in the hospital where this research was based, in a special educational needs magazine and via ASD support groups in the Greater London area. To participate, young people gave informed assent and their parent gave informed consent.

Inclusion criteria were: (a) received an ASD diagnosis from a NHS child and adolescent psychiatrist, clinical psychologist or paediatrician; (b) meets criteria for ASD on the Developmental, Dimensional and Diagnostic Interview – short version (3Di-sv; Santosh et al., 2009); (c) aware of ASD diagnosis; (d) aged between nine and 14 years inclusive; (e) IQ above 65; (f) shows evidence of ability to function in a small group; (g) speaks English.

Initially, potential participants were telephone screened by the research coordinator (KG). Those who passed were then visited by KG at their home for further screening, including an IQ test. For children who met study criteria, this home visit also involved the collection of baseline data. Randomisation was achieved as follows. A consecutive series of unique participant identification numbers (PINs) was generated. These PINs were then randomly ordered using the website www.random.org. The first half of this randomly ordered list of PINs was allocated to the PEGASUS condition and the second half to the control condition, thus randomly assigning each PIN to either the PEGASUS or the control condition whilst ensuring that equal numbers of PINs would be in each condition. The PINs were then returned to their original sequence, and allocated to participants meeting inclusion criteria in the exact temporal order they entered the study by passing the inclusion criteria screen. The list of randomised PINs was generated and held by WM, who had no direct involvement in screening or recruiting participants for the study.

All baseline visits were double blind, as neither the assessor nor the participant knew which condition they would be assigned to. Postintervention visits were single blind, as the participant, but not the assessor, knew whether they had been in the PEGASUS or the control condition. Postintervention home visits were conducted on average 12.5 weeks after baseline assessment.

In the absence of any directly relevant literature, we reasoned that we were interested in discovering whether PEGASUS had clinically significant (i.e. substantial) impact, and hence powered this study to detect large effects (Cohen's $d = .9$), but not medium or small effects, giving a required sample size of 42. We aimed to recruit an additional six individuals as we anticipated some dropout.

Psychoeducational intervention

PEGASUS is administered to groups of up to six young people and their parents over six parallel young person and parent sessions. It aims to provide information about ASD (level one psychoeducation), and to help young people make use of this information to gain insight into their unique collection of autistic strengths and difficulties (level two psychoeducation). Sessions are weekly and last for 1.5 hr. Young people's and parents' sessions are separate, each conducted by two facili-

tators, involving short presentations of information; group discussions; and educational games. Young people's sessions were designed to be comfortable, fun and accessible to people with ASD. They make use of visual aids and worksheets and are predictably structured, whilst also being playful in tone and content. In addition, young people are given 'home tasks' to complete between sessions, to consolidate learning. Table S1 (available as supplement online) summarises the content and aims of each session.

Fundamental to the PEGASUS ethos is the idea that young people can assimilate information about their diagnosis in a constructive and positive way, in a manner that promotes realistic insight without depleting their self-esteem. This is done through the provision of positive information about celebrated people with special needs; consistent presentation of materials about strengths as well as difficulties associated with ASD; and facilitators focusing group discussion on participants' strengths. The parents' group is designed to empower participants to support their child's learning; to encourage discussion of child strengths; and also to help parents cope with the impact of the diagnosis on the family system.

In the current study, facilitators were fully qualified clinical psychologists. In addition, the child group was joined by a helper, who was a psychology graduate with experience of working clinically with children.

Participants in the control group received no intervention from the research team. All participants in the PEGASUS and control groups were able to continue any existing interventions throughout the study, such as psychological therapy, speech and language therapy, occupational therapy, activity groups for children with ASD or other special educational needs. The PEGASUS and control groups did not differ at baseline ($p = .54$) or postintervention ($p = .24$) in terms of the number of additional services they were accessing.

Outcomes

Psychoeducational outcome measures. Our primary outcome concerned level two psychoeducation; namely whether PEGASUS helps young people to use information about ASD to understand themselves better. We call the result of this process 'ASD self-awareness'. We also wanted to test whether level one psychoeducation had occurred, by assessing changes in our participants' knowledge about ASD. No means of assessing ASD self-awareness and ASD knowledge are described in the literature, hence during a pilot study prior to the current study, we developed the Autism Knowledge Quiz (AKQ) for this purpose. The AKQ is a self-report measure, which has two sections: (a) a short structured interview; and (b) a 15-question multiple-choice quiz testing knowledge of ASD. The first part, designed to measure ASD self-knowledge, consists of open questions to elicit from young people lists of their strengths and difficulties. The second part, designed to measure general knowledge about ASD, includes questions on the nature, prevalence and causes of ASD; strengths and difficulties commonly observed in people with ASD; and associated features of ASD such as anxiety.

Participant responses to part one of the AKQ were transcribed and subjected to content analysis (Barker, Pistrang, & Elliott, 2002). A sample of 30 randomly selected transcripts was used to generate a coding frame, which enabled raters to classify whether each strength or difficulty listed by the young person was specific to ASD. For example, if a child listed 'being good at cricket' as one of their strengths this would not be considered specific to ASD. If they named 'having good attention to detail' as a strength, this would be counted as being ASD-specific. Once all transcripts had been coded, we counted the number of ASD-specific strengths and ASD-specific difficulties listed by each child, at baseline and postintervention. PEGASUS was designed primarily to increase

children's ASD self-awareness. We reasoned that an increased reporting of ASD-specific strengths and difficulties would indicate such a change. Therefore, in line with the study hypothesis that PEGASUS would increase ASD self-awareness, we predicted that between baseline and postintervention assessments there would be a greater increase in the number of reported ASD-specific strengths and difficulties in the PEGASUS children compared with those who did not attend PEGASUS.

All 96 transcripts from the AKQ (i.e. baseline and postintervention for each participant) were coded twice, by independent raters who were blind to the identity and group allocation of participants. Interrater agreement on the key outcome variable (number of ASD strengths and difficulties) was high, with an intraclass correlation coefficient of .90.

Part two of the AKQ, which used a multiple-choice format to measure ASD knowledge, was scored by summing the number of correct answers, yielding a scale with a maximum score of 15.

Psychopathology and adaptation. The Developmental, Dimensional and Diagnostic Interview – Short Version (3Di-sv; Santosh et al., 2009) was used to confirm the diagnoses that participants had received from NHS clinicians. This computerised parent-report interview has 53 items, which are summed to yield dimensional autistic trait scores, and to provide categorical diagnoses based on DSM-IV criteria. It possesses strong reliability, and criterion validity with respect to the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and the long version of the 3Di (Skuse et al., 2004) is also excellent (Santosh et al., 2009).

The Strengths and Difficulties Questionnaire (SDQ) is a behavioural screening tool and dimensional measure of psychopathology and adaptation for children and adolescents (Goodman & Goodman, 2009), which is valid in young people with ASD (Simonoff et al., 2013). We administered both self- and parent-report versions.

The Rosenberg Self-Esteem Scale (Rosenberg, 1965) is a ten-item self-report measure with responses captured by a four-point Likert scale ranging from strongly agree to strongly disagree. It is considered a reliable and valid quantitative tool for measuring self-esteem (Robins, Hendin, & Trzesniewski, 2001) and has been used with young people with ASD in previous research studies (Shipman, Sheldrick, & Perrin, 2011). We also asked parents to report on how they perceived their own child's self-esteem by asking them to complete an adapted version of the Rosenberg Self-Esteem Scale.

Analysis

Initially, we compared the PEGASUS and control groups on demographic and clinical variables at baseline, to test whether random assignment had yielded well-matched groups. This was done using t-tests for continuous data, Mann-Whitney tests for ordinal data and two-tailed Fisher's exact tests for nominal data. Group differences for outcomes were tested using linear regression, with the postintervention outcome variable regressed on group and the variable at baseline. For all relevant analyses, the assumption of heterogeneity of regression slopes was met, but some outcome variables deviated from normality. Therefore, to ensure robustness of our analyses by avoiding the normality-based assumption associated with the t-distribution used in standard linear regression, we used bootstrap regression based upon 1000 random samples (with replacement) of size $N = 48$. In addition to these group analyses, we also conducted individual analyses for our main outcome measures (ASD self-awareness and ASD knowledge), using the methodology of Jacobson and Truax (1991) to generate a reliable change index for each participant, to identify people for whom a statistically reliable change had occurred.

Results

Recruitment and participant flow

Recruitment began in October 2010 and the last postintervention assessments were completed in September 2012 once adequate sample size was achieved.

Figure 1 describes the flow of participants through the study. Sixty-seven families contacted the study for information, but did not progress to receiving a home visit. Of these, 41 decided not to participate after being given information about the study, and a further 26 were found not to meet inclusion criteria during the telephone screen. Of the 17 children who passed the telephone screen, but who subsequently failed to meet full inclusion criteria, eight scored below 65 on the IQ test and seven were deemed unsuitable for group work due to challenging behaviour and/or hyperactivity. For two children, it emerged that, in contrast to their parents, they had negative attitudes to participating in the study, hence they were excluded for ethical reasons, as it was not considered possible to attain true assent from them, independent of parental pressure. Another child withdrew shortly after his home visit, having met inclusion criteria, due to a change in family circumstances. Forty-eight children took part in this RCT, after passing inclusion criteria and being randomly assigned to either the control or PEGASUS condition.

All of the 48 people who met inclusion criteria and received a baseline visit also completed a postinter-

vention assessment. All 24 young people who started PEGASUS completed the programme. Sixteen children attended all six sessions and the remaining eight attended five sessions.

PEGASUS Participant satisfaction and homework completion

Participants completed satisfaction questionnaires at the end of their last session. Two participants were unable to attend their last PEGASUS session, due to parental commitments elsewhere, and so we do not have satisfaction data for them. The responses of the rest of the sample suggest they mostly valued their participation in PEGASUS. All but one found PEGASUS to be either 'quite enjoyable' ($n = 4$, 18.2%) or 'extremely enjoyable' ($n = 17$, 77.2%). Over half ($n = 12$, 54.5%) of the young people who completed the satisfaction survey found PEGASUS 'extremely helpful' and a further third ($n = 7$, 31.8%) found it quite helpful. Most ($n = 21$, 95.5%) reported that PEGASUS increased their knowledge about ASD, with the same proportion ($n = 21$, 95.5%) stating that it helped them to understand themselves better. PEGASUS participants are asked to complete five homework tasks during the programme. Most (91.7%, $n = 22$) did at least four of these, but two participants did not do any homework.

Adherence

To measure adherence to the manual, 19 sessions were recorded and rated by a researcher who had not been involved in the development or implementation of the PEGASUS programme. The researcher listened to each session and recorded which of the aims and activities, as stated in the manual, were covered in the session. Each session has an average (mode) of 4 aims and 8 activities. For each of the 19 sessions, 100% of aims were achieved and in 17 out of 19 sessions, 100% of activities were completed. On two occasions (one young person group and one parent group), time ran out before all session content was covered, with 80% (8 out of 10) of activities completed in each instance.

Baseline comparability

Table 1 shows that PEGASUS and control groups were matched on a range of clinical and demographic variables. Table 2 shows baseline scores on outcome measures. There were no differences at baseline for knowledge about ASD, $t(46) = 0.15$, $p = .884$, self-reported ASD strengths and difficulties, $t(46) = 0.06$, $p = .949$, self-reported ASD strengths, $t(46) = 0.40$, $p = .691$, or self-reported ASD difficulties, $t(46) = -0.36$, $p = .720$. Also, groups did not differ by self-report, $t(46) = 0.00$, $p = 1.000$, or parent report, $t(46) = -0.59$, $p = .554$, on level of co-occurring psychopathology

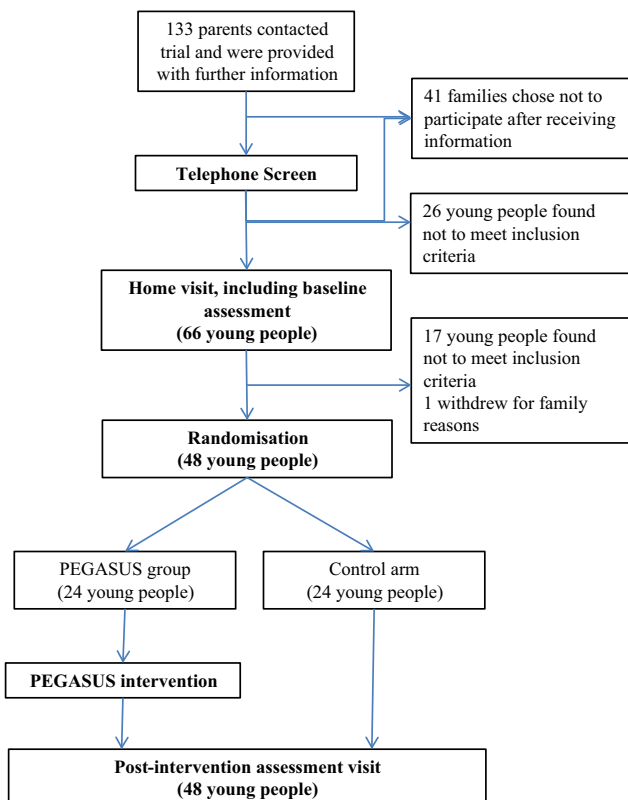


Figure 1 Flow of participants through the trial

Table 1 Characteristics of the sample

	Whole sample (<i>N</i> = 48)	PEGASUS group (<i>n</i> = 24)	Control group (<i>n</i> = 24)	Comparison of PEGASUS and control groups
Males/females	40/8	18/6	22/2	<i>p</i> = .121
Mean age in years (SD)	11.45 (1.55)	11.74 (1.66)	11.15 (1.42)	<i>p</i> = .197
Age range in years	9.05 to 14.81	9.15 to 14.81	9.05 to 14.34	–
IQ				
Mean FSIQ	104.58 (16.63)	105.04 (17.59)	104.13 (15.97)	<i>p</i> = .851
Mean verbal <i>t</i> -score	51.73 (10.88)	51.33 (11.32)	52.13 (10.65)	<i>p</i> = .804
Mean performance <i>t</i> -score	52.73 (10.43)	53.17 (10.88)	52.29 (10.18)	<i>p</i> = .774
Autistic symptomatology – 3Di domain scores ^a				
Reciprocal social				
Interaction	16.87 (4.23)	17.05 (4.39)	16.69 (4.15)	<i>p</i> = .776
Communication	16.91 (3.13)	17.15 (3.26)	16.68 (3.05)	<i>p</i> = .611
Repetitive/stereotyped behaviour	7.86 (2.21)	7.85 (2.29)	7.88 (2.17)	<i>p</i> = .964
Ethnicity				
Asian British	1	0	1	<i>p</i> = .561
Black British	3	3	0	
Black other	1	1	0	
Chinese	1	1	0	
European other	2	1	1	
Mixed heritage	9	3	6	
Other	1	0	1	
White British	27	12	15	
White other	2	2	0	
None provided	1	1	0	
ASD diagnosis				
Autism	19	9	10	<i>p</i> = 1.0
Asperger Syndrome	28	14	14	
Atypical autism	1	1	0	
Mean time since diagnosis in months (SD)	4.53 (3.17)	4.50 (3.57)	4.56 (2.79)	<i>p</i> = .949
Additional diagnoses				
ADHD	3	1	2	<i>p</i> = 1.0
Dyslexia	1	0	1	<i>p</i> = 1.0
Dyspraxia	2	0	2	<i>p</i> = .489
Anxiety or depression	8	5	3	<i>p</i> = .701
Tics	1	0	1	<i>p</i> = 1.0
Sensory processing disorder	1	0	1	<i>p</i> = 1.0
Educational placement				
Mainstream	43	21	22	<i>p</i> = .609
Specialist unit within mainstream	1	0	1	
Specialist school	4	3	1	
Mothers' qualification level				
Postgraduate	13	5	8	<i>p</i> = .249
Bachelor's level	19	9	10	
A level	8	5	3	
GCSE/O level	7	4	3	
No formal education	0	0	0	
None given	1	1	0	

^aThresholds for clinical range: Reciprocal social interaction = 11.5; Communication = 8; Repetitive/stereotyped behaviour = 5.5 FSIQ, full-scale IQ; 3Di-sv, Developmental, Dimensional and Diagnostic Interview – Short Version; ASD, autism spectrum disorder; ADHD, attention-deficit/hyperactivity disorder.

as measured by the SDQ total problem score. There were no baseline differences between groups in self-esteem by self-report, $t(46) = 0.96$, $p = .340$ or parent report, $t(46) = 1.62$, $p = .112$.

Level one psychoeducation: does PEGASUS increase knowledge about ASD?

Bootstrap multiple regression, controlling for ASD knowledge at baseline, showed a significant effect of

group on ASD knowledge postintervention, $\beta = .29$, $p < .001$, 95% CIs [0.13, 0.44].

Level two psychoeducation: does PEGASUS increase ASD self-awareness?

Our primary outcome was ASD self-awareness, measured by the AKQ. There was a significant and substantial effect of group on the combined number of ASD-related personal strengths and difficulties

Table 2 Outcome measures at baseline and postintervention assessment

	Baseline			Postintervention		
	Control	PEGASUS	Cohen's d	Control	PEGASUS	Cohen's d
Knowledge about ASD						
Mean	8.71	8.88	.04	9.25	11.17	.64
SD	3.92	3.98		3.53	2.51	
Range	0–15	1–15		1–14	5–15	
Self-reported ASD strengths and difficulties						
Mean	2.42	2.45	.02	2.67	4.71	.92
SD	1.83	2.58		1.71	2.71	
Range	0–8	0–13		0–6	0–12	
Self-reported ASD strengths						
Mean	1.13	1.29	.12	1.08	2.25	.92
SD	1.33	1.56		.88	1.65	
Range	0–5	0–7		0–3	0–7	
Self-reported ASD difficulties						
Mean	1.29	1.17	-.07	1.58	2.46	.69
SD	1.04	1.34		1.21	1.38	
Range	0–4	0–6		0–4	0–5	
Self-reported self-esteem						
Mean	18.75	20.38	.28	19.88	21.45	.35
SD	6.10	5.57		4.84	4.30	
Range	5–30	9–30		11–27	13–29	
Parent-reported young person self-esteem						
Mean	14.58	16.75	.48	15.45	17.58	.50
SD	4.07	5.12		4.12	4.50	
Range	6–22	9–28		8–23	10–26	
Self-reported SDQ total problems						
Mean	15.13	15.13	.00	13.83	14.33	.10
SD	6.19	6.38		4.82	5.57	
Range	4–32	4–29		6–21	1–23	
Parent-reported SDQ total problems						
Mean	18.33	17.83	-.18	18.5	16.83	-.29
SD	6.21	5.37		7.02	4.61	
Range	7–32	10–30		8–36	8–25	

ASD, autism spectrum disorder; SDQ, strengths and difficulties questionnaire.

listed by participants postintervention, controlling for this measure at baseline, $\beta = .42$, $p = .001$, 95% CIs [0.17, 0.67]. This reflected a higher number of both ASD strengths ($\beta = .41$, $p = .002$, 95% CIs [0.15, 0.67]) and ASD difficulties ($\beta = .34$, $p = .001$, 95% CIs [0.08, 0.60]) listed by PEGASUS participants at postintervention assessment.

Secondary measures: does PEGASUS change self-esteem or co-occurring symptoms of psychopathology?

Controlling for baseline measures there was no effect of PEGASUS on self-esteem by self- ($\beta = .10$, $p = .404$, 95% CIs [-0.14, 0.35]) or parent ($\beta = .12$, $p = .324$, 95% CIs [-0.12, 0.36]) report. PEGASUS did not change SDQ total problem score, by self- ($\beta = .05$, $p = .671$, 95% CIs [-0.18, 0.27]) or parent ($\beta = .08$, $p = .429$, 95% CIs [-0.12, 0.29]) report.

Reliable change index analysis

In addition to testing the efficacy of PEGASUS using significance testing of group differences, we conducted individual-level analyses to capture individual variability of response. Each participant's ASD

knowledge (AKQ section two) and ASD self-awareness (AKQ section one) scores were used to calculate reliable change indices (RCIs) for these constructs. The RCI is a standardised score designed to identify changes over time that are unlikely merely to reflect fluctuations resulting from measurement error (Jacobson & Truax, 1991). For a given outcome measure, any individual with a reliable change index (RCI) ≥ 1.96 was classed as showing statistically reliable improvement between baseline and postintervention assessment. RCIs ≤ -1.96 signified decline, with participants who showed an RCI between 1.96 and -1.96 classified as showing no statistically reliable change. In the current study, reliable change in ASD knowledge equated to a shift of at least three points on the AKQ's 15-item multiple-choice quiz, on which each correct answer earns one point. Reliable change for ASD self-awareness equated to a child naming at least three more, or three fewer, ASD strengths and difficulties postintervention compared with baseline.

In PEGASUS, 10 (42%) participants improved their ASD knowledge, whilst the remaining 14 (58%) did not show statistically reliable change. In the control condition, four (17%) improved their ASD knowledge, 17 (71%) showed no change and 3 (13%) demonstrated less knowledge postintervention than at base-

line. A two-tailed Fisher's exact test revealed that the groups differed significantly ($p = .046$) in their pattern of individual response for ASD knowledge.

There were also significant group differences in the pattern of individual response in terms of ASD self-awareness ($p = .002$). Ten PEGASUS (42%) participants showed improved ASD self-awareness, as measured by a statistically reliable increase in the number of personal ASD-related strengths and difficulties they listed during the AKQ. Twelve (50%) showed no change and two (8%) showed a reduction in ASD self-awareness. Only one participant (4%) in the control group had increased ASD self-awareness, with 22 (62%) demonstrating no change and one (4%) showing a decline.

Discussion

Psychoeducation following a diagnosis of ASD is recognised as an essential element of good-quality care, but currently there is little empirical evidence on which to base clinical practice. We designed and manualised a group psychoeducation programme for young people with ASD and their parents, called PEGASUS, which aims to increase ASD-related self-awareness as well as knowledge about ASD.

The findings we present from a randomised controlled trial offer initial support for the efficacy of PEGASUS. Postintervention, ASD knowledge was significantly higher in the PEGASUS group compared with the control group, controlling for baseline ASD knowledge level. Crucially, our measure of ASD self-awareness, the primary outcome for this study, was significantly and substantially (Cohen's $d = .92$) higher in the PEGASUS group postintervention compared with the control group, again controlling for baseline levels. This reflected the fact that after PEGASUS, when asked to describe their own strengths and difficulties, young people named more autism-related personal strengths as well as autism-related difficulties compared with controls.

Other findings suggest the potential value of PEGASUS as a component of clinical care. Young people reported good levels of satisfaction with and enjoyment of PEGASUS. This may partly account for the lack of any dropout from PEGASUS in this study, and for the high rates of homework completion. Some theorists argue that teaching young people about their neurodevelopmental disorder diagnosis, and encouraging them to use this knowledge to understand themselves, could be harmful, leading to self-stigma and a reduction in self-esteem (e.g. Jutel & Nettleton, 2011; Singh, 2011). We did not observe this phenomenon: participants in PEGASUS did not show any reduction in self-esteem, either by self- or parent report. This is reassuring, and may reflect the PEGASUS approach of emphasising strengths as well as difficulties associated with ASD. Nevertheless, we used a measure of global self-esteem, which

might have been insensitive to changes in specific subtypes of self-esteem. Educating people about their ASD could make them more aware of their social difficulties, so it will be valuable to monitor self-esteem in the social domain during future trials of PEGASUS.

We calculated reliable change indices (RCIs; Jacobson & Truax, 1991) for our main primary and secondary outcomes, ASD self-knowledge and ASD knowledge, to examine the impact of PEGASUS on individual participants. In line with our group-level analyses, the RCI analyses showed that in PEGASUS more children showed a positive change in terms of ASD knowledge and self-knowledge and fewer children showed a decrease or no change, compared with the control group. Nevertheless, these analyses highlighted that around 60% of young people who received PEGASUS did not show statistically reliable change in their ASD self-awareness. The proportion of our sample showing definite improvement according to this rigorous criterion is comparable to that found in other trials of efficacious psychological treatments (e.g. Wong, 2008). Nevertheless, our RCI analyses highlight the need for further development of PEGASUS to ensure that positive effects will be experienced by a greater proportion of participants.

Future research should be sufficiently powered to investigate moderators of treatment efficacy, by identifying differences between people who do and do not show reliable change as a result of PEGASUS. For example, it is possible that child characteristics, such as IQ and baseline level of self-awareness, and parental variables, such as maternal insightfulness (Siller, Hutman, & Sigman, 2013) or ASD knowledge, could influence the impact of PEGASUS. Furthermore, it will be interesting to discover how adherence, as indexed by rates of homework completion and attendance, relates to outcome. Such findings could be used to reform the intervention, and to identify subgroups that require bespoke treatments and an increased intervention dose.

The following limitations of the current study will need to be addressed in future work. First, the use of a management as usual (MAU) control group limits interpretation of the findings, so that it is currently unclear which aspects of the PEGASUS group brought about change in ASD self-awareness and knowledge. The PEGASUS effect may have arisen from some or all of: the didactic parts of the programme; the experience of being in a group of peers with ASD; contact with clinically knowledgeable facilitators; the homework tasks; or indirect effects resulting from the parallel parent sessions. Future studies should use more active control conditions (e.g. a group that does not include teaching about ASD, or a child group without a parallel parent group) to delineate more precisely the active ingredients of PEGASUS. Also, qualitative investigations will be useful to generate hypotheses about processes that may drive positive change in

PEGASUS. Second, there are no previous quantitative investigations of ASD self-awareness, hence it was one of the major challenges of the current project to operationalise and measure this construct, which is the primary outcome in this trial. The instrument we designed to measure ASD self-awareness, called the AKQ, possesses good reliability, but further work is required to test fully its psychometric properties. Third, we have not yet studied the extent to which PEGASUS outcomes are sustained after the termination of treatment. Fourth, we tested PEGASUS on a high-functioning sample, having excluded young people with intellectual disability and/or significant conduct problems. Furthermore, two thirds of the young people in our study had a mother who had a university degree, which suggests that our sample may be biased towards people with higher socioeconomic status. This limits the generalisability of our findings, and underscores the need for the development of psychoeducational programmes for those with more severe difficulties; and for investigation of whether PEGASUS works for families with limited socioeconomic resources.

Conclusion

In summary, we found evidence of PEGASUS's efficacy for increasing ASD knowledge and ASD self-awareness in young people with high-functioning ASD. Efficacy should be further investigated through attempted multisite replication, and

effectiveness will need to be tested in a range of real-world settings. It will be essential to discover whether PEGASUS has benefits beyond increased knowledge and understanding in terms of trajectory and long-term outcomes for individuals and their families. Finally, we emphasise that PEGASUS did not reduce levels of comorbid psychopathology in our study: it is a psychoeducational programme and should not be used in place of targeted treatment for specific clinical problems.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1. Summary of content of the PEGASUS programme.

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Key points

- Psychoeducation is recognised as a *sine qua non* of good postdiagnostic care for people with ASD
- To date, there has been no evidence base for clinical practice in this domain.
- We designed, manualised and evaluated PEGASUS, a group psychoeducational programme for young people with ASD.
- The PEGASUS psychoeducation group enhanced children's knowledge about ASD, as well as their awareness of their own ASD strengths and difficulties.

References

- American Psychiatric Association (2013). *Diagnostic and statistical manual*, (5th edn). Washington, DC: Author.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology*. Chichester, UK: John Wiley and Sons.
- Centres for Disease Control and Prevention (2014). Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR. Surveillance Summaries*, 63(SS02), 1–21.
- Goodman, A., & Goodman, R. (2009). Strengths and difficulties questionnaire as a dimensional measure of child mental health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48, 400–403.
- Hurlbutt, K., & Chalmers, L. (2002). Adults with autism speak out: perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities*, 17, 103–111.
- Jacobson, N.S., & Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*, 59, 12–19.
- Johnson, C.P., Myers, S.M., & American Academy of Pediatrics Council on Children With Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120, 1183–1215.
- Jutel, A., & Nettleton, S. (2011). Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine*, 73, 793–800.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659–685.
- NICE. (2012). CG128 Autism in children and young people: NICE guideline. NICE. Guidance/Clinical Guide-

- lines. Retrieved November 12, 2013, from <http://www.nice.org.uk/>
- Nussey, C., Pistrang, N., & Murphy, T. (2013). How does psychoeducation help? A review of the effects of providing information about Tourette's syndrome and attention-deficit/hyperactivity disorder. *Childcare, Health and Development*, 39, 617–627.
- Robins, R.W., Hendin, H.M., & Trzesniewski, K.H. (2001). Measuring global self-esteem: Construct validation of a single-item measure and the Rosenberg Self-Esteem Scale. *Personality and Social Psychology Bulletin*, 27, 151–161.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.
- Ruiz Calzada, L., Pistrang, N., & Mandy, W.P.L. (2012). High-functioning autism and Asperger's disorder: utility and meaning for families. *Journal of Autism and Developmental Disorders*, 42, 230–243.
- Santosh, P.J., Mandy, W.P.L., Puura, K., Kaartinen, M., Warrington, R., & Skuse, D.H. (2009). The construction and validation of a short form of the developmental, diagnostic and dimensional interview. *European Child & Adolescent Psychiatry*, 18, 521–524.
- Shipman, D.L., Sheldrick, R.C., & Perrin, E.C. (2011). Quality of life in adolescents with autism spectrum disorders: Reliability and validity of self-reports. *Journal of Developmental and Behavioral Pediatrics*, 32, 85–89.
- Siller, M., Hutman, E., & Sigman, M. (2013). A parent-mediated trial to increase responsive parental behaviors and child communication in children with ASD: A randomized clinical trial. *Journal of Autism and Developmental Disorders*, 43, 540–555.
- Simonoff, E., Jones, C.R.G., Baird, G., Pickles, A., Happé, F., & Charman, T. (2013). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 54, 186–194.
- Singh, I. (2011). A disorder of anger and aggression: Children's perspectives on attention deficit/hyperactivity disorder in the UK. *Social Science & Medicine (1982)*, 73, 889–896.
- Skuse, D., Warrington, R., Bishop, D., Chowdhury, U., Lau, J., Mandy, W., & Place, M. (2004). The developmental, dimensional and diagnostic interview (3di): A novel Computerized assessment for autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43, 548–558.
- Wong, D. (2008). Cognitive and health-related outcomes of group cognitive behavioural treatment for people with depressive symptoms in Hong Kong: randomized wait-list control study. *The Australian and New Zealand Journal of Psychiatry*, 42, 702–711.

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