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The effects of autistic traits in adolescents on the efficacy of paediatric Intensive Interdisciplinary Pain Treatment (IIPT)

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ABSTRACT

Autistic adolescents are at greater risk of chronic pain, but it is unclear how autistic features may relate to individual aspects of chronic pain. As autism traits exist in the general population as well, it is important to know if autistic traits could impact how effective chronic pain management is for adolescents. Here we examined autistic traits in 112 patients (12–18yrs) recruited from a UK national specialist adolescent pain rehabilitation programme. Participants completed screening questionnaires for autistic traits upon entry to the programme, as well as clinically recognised pain measures before and after the 3-week treatment program. Autistic traits predicted greater psychological challenges at treatment onset. Critically, autistic traits were not related to the magnitude of improvement in pain measures during the pain management program. Our study suggests that adolescents with greater autistic traits may benefit from existing pain rehabilitation programs at similar rates to their peers. Additionally, these data suggest no reason for therapeutic pessimism for autistic pain patients. We do however acknowledge that these data may differ in populations with an autistic diagnosis, and that barriers may still exist for autistic people in treatment for pain.

Perspective: Autistic traits were explored in patients undergoing an Intensive Interdisciplinary Pain Treatment (IIPT). Higher autistic traits correlated with more pain related psychological difficulties at intake. Autistic traits were not related to the magnitude of improvement following IIPT. Our data therefore suggests that autism should not be a barrier to IIPT.

Data availability: Data is held in the PAIRED Pain Rehabilitation Database: Bath and Bristol, individual data used in the current analyses are therefore not available.

Introduction

Chronic pain is a common experience in adolescence,¹ with many adolescents reporting substantial pain-related impacts on their lives such as impairments in school engagement, emotional, cognitive, social, developmental, and physical functioning.^{2–7} Interdisciplinary management of chronic pain (Interdisciplinary Intensive Pain Treatment, IIPT) in adolescents, has been established to be effective in treating various domains of adolescent functioning, including affect, social functioning, and family functioning.^{8–10} A number of demographic features have

been shown to alter the efficacy of many aspects of pain management including patient race,¹¹ and sex,¹² however other features have not been considered, including divergent neurotypes, i.e. autism.

There is increasing evidence that autism is related to childhood pain. In a US National Survey 15.6–19.9% of autistic children had recurrent or chronic pain in the last year compared to 8.2% of non-autistic children in the study.¹³ Furthermore, recent adolescent pain services audits have suggested a clinically significant level of autistic traits in as many as 14% of adolescent patients presenting with chronic pain,¹⁴ significantly higher than the current population prevalence estimates of 1.85%.¹⁵ In

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spite of this increased prevalence, little is known about how autistic people experience and express pain.¹⁶ There is also reason to suspect that, in addition to difficulties in eliciting healthcare support in the autistic population, aspects of how autistic people may experience pain may leave them more vulnerable, for example in a systematic review of neurocognitive function in adults with chronic pain, several studies documented struggles with cognitive or mental flexibility,¹⁷ which also appears to be higher in autistic populations.¹⁸ This knowledge is further hampered by challenges that autistic females, who might be at greater risk of pain,¹⁴ are diagnosed much later than males and are more likely to not have received a diagnosis until adulthood,¹⁹ therefore necessitating more flexible approaches to examining these questions in this population. Further, autistic adolescents have reported additional challenges associated with chronic pain and pain management, including overstimulation and perceptions of difference to non-autistic adolescents in pain.²⁰ As such, evaluation of autistic traits in the general population, which can often include undiagnosed autistic individuals, can provide insight into associations between pain and autism.

Currently unknown is the effectiveness of typical psychological management for chronic pain in autistic adolescents, or how features associated with autism might relate to interdisciplinary treatment. Indeed, little is known about psychological traits associated with pain in autistic adolescents. Previous research has established that autistic adults might experience a significantly greater degree of pain anxiety than their neurotypical peers.²¹ The efficacy of CBT for anxiety in autistic adolescents²² also may be reduced, with recommendations for modifications showing benefit from CBT for affective conditions,²³ social anxiety,²⁴ general anxiety²⁵ and depression.²⁶ Given the paucity of research about how autistic traits may impact interdisciplinary pain treatment efficacy, we first assessed the efficacy of non-adapted pain management intervention. In this study we first sought to examine how social and cognitive features associated with autism, related to the presentation of pain, within a chronic pain service. To achieve this, we used two measures of features which might be associated with autism, namely the Social Communication Disorders Questionnaire, to consider the social and communicative differences often observed in autistic populations,²⁷ and the Detail and Flexibility Questionnaire (DFlex),²⁸ to measure neurocognitive features associated with cognitive rigidity and attention to detail, which have been suggested to be particularly relevant to processing styles in autistic populations.¹⁸ We then explored if the magnitude of reductions in pain intensity, pain disability and pain affect, following a standard, un-adapted IIPPT programme, differed in relation to autistic features.

Methods

One hundred and twelve consecutive patients (88 female, 19 male, 5 did not state their sex, participants were not asked about their identifying gender) and their accompanying parents were recruited from a UK national specialist residential adolescent pain rehabilitation programme. Participants were aged between 12 and 18 years at the time of their first visit (mean 15.8yrs, SD=1.63). Participants were predominantly of white race (88%), with no other racial group being represented by more than 3 patients. Participants self-described a range of diagnoses, which have been summarised into categories used in previous research. This, and further demographic information is present in Table 1.

Intensive Interdisciplinary Pain Treatment (IIPPT) programme

Participants in this study comprised adolescents, and one accompanying parent, who completed an intensive three-week residential pain rehabilitation programme. This type of programme, also known as an Intensive Interdisciplinary Pain Treatment (IIPPT), is a standard approach for treating young people who present with chronic pain and high levels of pain related disability.²⁹ This particular clinical programme has

Table 1

Demographic information about participants at intake.

	Male	Female	Not reported
Sex	19	88	5
Family history of pain	Yes 41	No 38	Unknown 6
	Mean (SD)		
Age (years)	15.8 (1.6)		
Age at pain onset (years)	11.0 (3.5)		
Weeks absent from school	32.7 (49.7)		
Diagnosis	Diffuse / localised idiopathic pain		39%
	Complex Regional Pain Syndrome		22%
	Back Pain		15%
	Pain associated with hypermobility		13%
	Abdominal / pelvic pain		4%
	Other		6%
Race	White		88%
	Black		2%
	Chinese		2%
	Indian		1%
	Pakistani		1%
	Any mixed background		3%
	Other ethnic group		1%

previously been described in detail elsewhere, and has been shown to be clinically effective across nearly all outcome domains, including physical functioning, social functioning and several domains of mood.^{30–32}

Entry criteria for the clinical service meant that all participants were 11–18yrs and had enduring chronic pain that was functionally disabling and refractory to standard treatment in their local services (i.e. adolescents had withdrawn from traditional education and/or were unable to engage with their daily activities). Adolescents underwent a full medical and rehabilitation assessment before being enrolled onto the programme. Exclusion was a decision of the assessing clinicians and as such there were no universal criteria; in practice, exclusion was usually due to severe mental health problems, child protection concerns, or lack of willingness to undertake demanding rehabilitation.

The programme aimed to help adolescents to restore everyday functioning and to improve mood in the face of ongoing pain that was not expected to change during treatment. Adolescents received daily physiotherapy, psychological intervention and skills-based work. Parents participated in most adolescent sessions and also received a number of parent-only sessions with a Psychologist. Further details are available in Kemani et al.³². Of note, the programme was relatively intensive, including >80 h of input.

Materials

Detail and Flexibility Questionnaire (DFlex)

The DFlex is a measure of neurocognitive features associated with cognitive rigidity and attention to detail, these features have been suggested to be particularly relevant to processing styles in autistic populations¹⁸ and were therefore considered relevant within the current study. Adolescents' self-reported features of cognitive rigidity and attention to detail were measured using the DFlex.²⁸ The DFlex is a 24 item self-report questionnaire evaluating two aspects of cognitive profile and their correlates in daily life. The DFlex comprises two subscales measuring flexibility/cognitive rigidity (12 items) and attention to detail/weak central coherence (12 items), for example, "I get very distressed if plans change at the last minute". Higher scores indicate greater perceived difficulties, or alternatively a larger number of features of an autistic processing style. The DFlex was developed in an adult population, and chosen for this study due to the face validity of the items in detecting autistic processing styles in high functioning individuals. In the original version, Cronbach's alphas were 0.91 and 0.88 for the DFlex Rigidity and DFlex Attention to Detail, respectively.^{28,33} As this measure was not initially used with an adolescent population, we also calculated Cronbach's Alpha based on our sample; here, alphas were .85 and .90 for

the DFlex Rigidity and DFlex Attention to Detail respectively.

Social and Communication Disorders Checklist (SCDC)

The Social and Communication Disorders Checklist (SCDC) is a parent-reported screening tool for autism-like features in the young person. Twelve items ask the parent to report on the accuracy of a range of autistic behavioural features as ‘not true’, ‘quite or sometimes true’ or ‘very often true’. For example, “Does not pick up on body language”. The SCDC has been shown to be reliable ($\alpha = .93$) to screen effectively for autism, and to have good discriminant validity in discriminating these features from other clinical groups.²⁷ A group cutoff score of 8 on the SCDC has been shown to have a sensitivity of .90 and a specificity of .75 for ASC, and a score of 9 has a sensitivity of .87 and a specificity of .82 for ASC when compared to a neurotypical comparison group.³⁴ As previous research has found that the SCDC might be somewhat prone to over inclusion of people meeting the cutoff for autism, we selected the higher score of 9 when exploring potential presentation rate of autism within chronic pain services. Further, given that this measure is non-diagnostic, here we chose to use the full range of scores within our analyses to explore the relationships between autistic traits and chronic pain presentation. The SCDC has been generally considered a good screening tool in population studies and was included in the ALSPAC dataset.³⁵ The SCDC has also been used recently in the context of other health related conditions, for example showing a relationship to symptoms of eating disorders in a study exploring the relationship between autistic presentation and eating behaviours.³⁶ The SCDC has also been shown to correlate with scores on the on ADI-R, however correlations with the ADOS were non-significant.³⁷

Bath Adolescent Pain Questionnaire (BAPQ)

The Bath Adolescent Pain Questionnaire (BAPQ) was used to measure physical and psychological pain functioning before and after treatment. The BAPQ is a self-report instrument that comprises seven subscales that index various aspects of the impact of pain on an adolescent; specifically, social functioning, physical functioning, depression, general anxiety, pain anxiety, family functioning, and self-rated social development.³⁸ Subscales range from 6–12 items in length and adolescents are asked to indicate the frequency that they are able to perform various activities (i.e. “I walk normally”), or the frequency with which they experience distress (i.e. “Pain scares me”) on a five point Likert scale (“never” to “always”) for six of the seven subscales. The development subscale requires adolescents to compare their developmental progress on a particular task with that of their pain-free peers using a five-point scale ranging from ‘very behind’ to ‘very ahead’. Higher scores indicate worse functioning on all subscales. The seven BAPQ scales have good internal consistency in pain management and paediatric rheumatology populations ($\alpha = 0.80$ – 0.85 in pain population) and generally adequate test–retest reliability.³⁸

Pediatric Quality of Life Questionnaire (PedsQL)

The Pediatric Quality of Life Questionnaire (PedsQL) was used to measure psychosocial and physical quality of life before and after the IIPT. The PedsQL is a widely-used 15 item index of health-related paediatric quality of life.³⁹ Here, we used the PedsQL 4.0 SF15 Short-form Generic Core Scales for Teens. Questions address how often a teen has a problem in the areas of health and fitness, feelings, social relationships and experiences at school (i.e. “walking more than one block”, “getting along with other teens”, “paying attention in class”). This measure generates two subscale scores, (1) psychosocial quality of life and (2) physical quality of life, both rated from 0 – 100 where 100 equals perfect health-related quality of life.

Functional Disability Inventory (FDI)⁴⁰

The Functional Disability Inventory (FDI) was used to measure the level of disability experienced by adolescents before and after the IIPT. The FDI is a 15 item children’s self-reported instrument to measure

difficulty in physical and psychosocial functioning due to their physical health. The FDI measures perceptions of activity limitations during the past 2 weeks with greater scores indicating greater disability (i.e. “Being at school all day”). Items are scored from 0 (“no trouble”) to 4 (“impossible”) and alpha was reported at .92 in the original validation paper.

Procedure

Research ethical approval was attained for this overall study from the relevant health related (20/NW/0296) and university organisations (20–205). Ethical approval was also gained for the Research Database that provided the data (17/SW/0002).

All patients enrolled into the intensive adolescent pain rehabilitation programme, and their accompanying parent, were invited to give written, informed consent to have their standard clinical data (including the measures described in this study) stored in an anonymised format on a formal Research Database (PAIRED Pain Rehabilitation Database: Bath and Bristol). A range of clinical measures were completed at the beginning and end of the 3-week programme, both by the adolescent and parent. The SCDC, a parent report of autistic traits in the child, was only administered at the beginning of treatment, as it was not considered likely to change over 3 weeks. Data for this study were taken from the PAIRED database.

The study was registered on the Open Science Framework ahead of data collection and analyses. The protocol can be found here: <https://osf.io/cs8uw/>.

Analysis

All anonymised data were transferred to SPSS 25⁴¹ for analysis. Data were first examined for missing values for each of the measures, where fewer than 15% of items were identified as missing on a single measure, this was replaced with mean value replacement. For both the DFlex and SCDC, a number of participants were missing either at baseline or at the end of treatment for these measures. At the pre-assessment period there were 13 participants with missing data for the DFlex and 4 participants with missing data for the SCDC (all of whom were included in those missing for the DFlex). Post testing there were no data missing from the SCDC or from the DFlex. For those with only one timepoint, this was used as a measure of autism traits. Nineteen participants were removed due to having more than 15% of data missing on at least one measure.

Total scale and sub-scale scores were calculated for each measure based on published guidelines.^{27,28,38,39,40} Data were assessed for outlying scores (mean scores greater than three standard deviations above/below the group mean,⁴² here single outlying values were identified for the change scores for BAPQ social, BAPQ depression, BAPQ general anxiety, BAPQ developmental, PEDs QOL physical, FDI, and SCDC total. Following removal of participants, we had a final sample of 89 participants (17 male, 71 female, 1 missing) with a mean age on intake of 15.68 yrs (SD=1.61). Data were also examined for normal distribution based on Skewness statistics between -2.56 and 2.56 (Clark-Carter, 2004); here all data were found to be normally distributed.

Given the novelty of the current analyses and fitting with the pre-registered analysis plan, we adopted an exploratory approach. First, we used Pearson’s Product Moment Correlation to examine if patients with greater autistic features might differ to those with fewer features in how they experience pain, and function in the face of pain, prior to treatment. We then used repeated measures t-tests to assess the effectiveness of the IIPT overall. To examine if the magnitude of improvement from treatment was related to our measures of features associated with autism, a series of ANCOVA analyses were conducted. Given that the primary question of interest here is how measures associated with autism might interact with the magnitude of improvement in pain, interpretation of variables were focused on these findings. For each

outcome an ANCOVA was conducted with time (pre-post) as a within subjects factor, total scores for Dflex, as well as the parent-reported SCDC, were entered as 'covariates'. Alpha was set to.05.

Results

Our first analysis was performed to examine the percentage of patients within the IIPT who might meet clinically significant numbers of autistic traits. Based on the SCDC measure, a cut-off of 9 has been proposed.²⁷ Within our sample 23/94 (24.5%) participants met this criterion, suggesting a high number of our sample may benefit from assessment for an autism or other neurodivergent diagnosis. Given the previous findings of a particular over-representation of pain in women¹⁴ who have high autistic traits, we examined the relationship between sex and our above cut-off/below cut-off using a 2x2 Chi² analysis. Here 12 males and 58 females were below the cutoff and 6 males and 17 females were above the cutoff, this revealed no relationship between sex and 'autism group' X²(1)=.887, p=.346.

To examine the relationship between autistic features and pain-related symptoms at intake to IIPT, bivariate Pearson's Product Moment Correlation were used (see Table 2). Adolescent patients who reported greater cognitive rigidity and attention to detail (associated with autism) on the DFlex, also reported more challenges with social functioning, depression, general anxiety, family functioning and greater pain related anxiety on the BAPQ. Additionally, results relating to the DFlex indicated that higher self-reported cognitive rigidity and attention to detail, associated with autism, also related to poorer psychosocial Quality of Life (PedsQL). Critically here, cognitive rigidity and attention to detail did not relate to physical functioning on the BAPQ, or physical quality of life, nor did they relate to functional disability or current or past weeks' pain intensity or levels of fatigue. This therefore suggests that a cognitive processing style associated with autism does not appear to be related to the physical features of pain, however the psychological and psychosocial functioning of patients might be related to autistic features, with those with greater processing style associated with autism, having greater difficulties.

When considering the parent report of autistic features on the SCDC however, fewer effects were observed, here greater autistic traits were associated with greater challenges with family functioning and greater social challenges.

Next, we examined the efficacy of IIPT on pain related variables for all participants with repeated measures t-tests (see Table 3). Here it can be seen that the IIPT was a success in improving all aspects of functioning, except family functioning, as measured by the BAPQ. Participants also improved on physical quality of life and functional disability, though not in psychosocial QoL. The programme also did not improve self-reported pain intensity or fatigue. These data suggest that overall, the participants enrolled into the IIPT benefited from their treatment.

To examine if the magnitude of improvement from treatment was related to our measures of features associated with autism, a series of ANCOVA analyses were conducted with time as a between subjects factor and our two measures related to autistic traits as 'covariates'. For all BAPQ variables (social functioning, physical functioning, depression, general anxiety, pain anxiety, family functioning, social development), there were no interactions between time and scores on the DFlex as a covariate (all F<1.2, all p >.1 & and P eta²<.02) or for SCSD as a covariate (all F<1.2, all p >.1 & and P eta²<.03). There were also no interactions between time and scores on the DFlex as a covariate (all F<2.6, all p >.1 & and P eta²<.03) or on the SCDC as a covariate (all F<1, all p >.1 & and P eta²<.01) for all Peds QoL measures.

For scores on the Functional Disability Inventory there were no interactions between time and scores on the Dflex (F(1,95)=.103, p=.749, P eta²=.001) or scores on the SCDC (F(1,95)=.006, p=.940, P eta²<.001). For current pain there were no interactions between time and scores on the DFlex as a covariate (F(1,89)=1.962, p=.203, P eta²=.018) or scores on the SCDC as a covariate (F(1,89)=.102, p=.750,

Table 2 Correlation matrix showing Pearson's r between scores on measures associated with autistic features (DFLEX and SCDC) and scores on the subscales of the Bath Adolescent Pain Questionnaire, Pediatric Quality of Life Questionnaire, Functional Disability Questionnaire, measures of average and current pain intensity and average fatigue.

	BAPQ Social	BAPQ Physical	BAPQ Depress	BAPQ Anxiety	BAPQ Pain Anx	BAPQ Family	BAPQ Develop	BAPQ Total	PEDS QoL Psychosocial	PEDS QoL Physical	PEDS QoL Total	FDI	Avg Pain	Current Pain	Avg Fatigue
Dflex Cog	.25*	.07	.44***	.46***	.20	.26*	.09	.40***	-.400***	.02	-.35	.04	-.01	.22*	.01
DFlex	.22*	-.01	.34***	.33***	.20	.21*	.09	.31**	-.39***	.08	-.29	.01	-.03	.07	-.03
Attention	.25*	.04	.41***	.42***	.21*	.25*	.10	.37***	-.41***	.03	-.34***	.03	-.02	.15	-.01
DFlex total	.30**	.07	.07	.12	.11	.30**	.15	.27*	-.24	.01	-.20	-.02	-.03	>.01	.14

* = p<.05
 ** = p<.01
 *** = p<.001

Table 3

Means (Standard deviations) and t-statistics for the change in Bath Adolescent Pain Questionnaire, Pediatric Quality of Life Questionnaire, Functional Disability Questionnaire, measures of average and current pain intensity and average fatigue before and after completing the adolescent Intensive Interdisciplinary Pain Treatment (IIPT).

	Potential Range	Pre treatment	Post treatment	t-statistic	Effect size (d)
BAPQ Social	0–36	19.19 (5.89)	16.25 (5.40)	5.55***	.60
BAPQ Physical	0–36	12.21 (4.07)	10.71 (3.89)	4.10***	.60
BAPQ Depression	0–24	14.26 (4.39)	12.50 (4.38)	4.91***	.39
BAPQ Anxiety	0–28	15.62 (5.31)	14.49 (4.94)	2.95**	.33
BAPQ Pain Anxiety	0–28	15.30 (5.24)	12.73 (4.97)	5.47***	.52
BAPQ Family	0–48	18.53 (6.16)	19.20 (6.55)	1.30	.14
BAPQ Develop	0–44	26.65 (5.93)	24.86 (6.03)	4.43***	.46
BAPQ Total	0–244	121.76 (23.62)	110.74 (23.92)	5.50***	.56
PEDS QoL Physical	0–100	49.69 (15.49)	50.31 (15.16)	.520	.32
PEDS QoL Psychosocial	0–100	23.76 (17.54)	34.72 (19.76)	6.08***	.89
PEDS QoL Total	0–100	41.05 (12.19)	45.14 (12.72)	3.41**	.62
FDI	0–60	28.40 (8.77)	25.30 (9.94)	2.92**	.17
Average Pain	0–10	7.11 (1.29)	7.28 (1.30)	1.08	.31
Current Pain	0–10	6.45 (1.83)	6.52 (1.94)	.35	.21
Average Fatigue	0–10	6.67 (1.83)	6.98 (1.80)	1.44	.37

*= $p < .05$

**= $p < .01$

***= $p < .001$

$P \eta^2 = .001$). For average pain there were also no interactions between time and scores on the DFlex as a covariate ($F(1,87) = .126$, $p = .724$, $P \eta^2 = .001$) or scores on the SCDC as a covariate ($F(1,87) = .063$, $p = .802$, $P \eta^2 = .001$). Finally for fatigue there were no interactions between time and scores on the DFlex as a covariate ($F(1,88) = .044$, $p = .835$, $P \eta^2 < .001$) or scores on the SCDC as a covariate ($F(1,88) = .233$, $p = .631$, $P \eta^2 = .003$).

Discussion

The purpose of this study was to examine the relationship between (1) cognitive and social traits associated with autism and (2) pain intensity, pain disability and pain affect in adolescents experiencing chronic pain. Further this study is the first to examine how these features associated with autism may affect the magnitude of changes in pain related constructs following adolescent IIPT. We found that almost a quarter of the participants within a specialist chronic pain service scored above the cut-off on the SCDC for autism. Scores on the SCDC were related to poorer social and family functioning at baseline. Scores on the DFlex were related to generally poorer quality of life, greater psychosocial disability and more affective challenges, as well as social and family functioning. This finding suggests that autistic adolescents, or adolescents with cognitive rigidity and attention to detail potentially associated with autism, might arrive at a chronic pain clinic with greater psychological symptoms that require management during IIPT.

Overall, IIPT improved most aspects of pain related mood and functioning; however, it did not reduce pain intensity, which is congruent with other IIPT treatment research.³¹ Critically, features associated with autism did not alter the magnitude of improvement in pain related factors from baseline to post treatment, suggesting that IIPT may be as effective for autistic adolescents as for neurotypical individuals. There are however outstanding questions that our data cannot answer, although those with greater features of autism may benefit from treatment, we cannot say if they feel they are benefiting or perceive that their treatment is addressing their greatest needs. Further, given that having more autistic features is associated with greater challenges at intake, it is unclear if the IIPT is sufficient to allow these patients to return to a rewarding life in the context of pain. Moreover, those patients who take up an IIPT are not representative of the wider autistic community; how a more heterogenous autistic population might respond is unknown. It might also be that programs to prepare these young people for pain services might help to reduce anxiety and promote equity at service entry.

The current study supports the findings that autism (here defined as a score above cutoff on the SCDC) may be over represented in adolescent chronic pain services.¹⁴ Within Lipsker et al.'s¹⁴ study, approximately 14% of service users were above cut-off for autism on the Social Responsiveness Scale. The current study found a greater percentage scoring above cut-off with almost a quarter of adolescent in an IIPT scoring above cut-off on the SCDC. It is however important to acknowledge here that the SCDC has greater sensitivity than the SRS but the SRS has greater specificity³⁴ meaning that the measurement tool may be a factor in these findings. However, both studies indicate that autism appears overrepresented within tertiary chronic pain services. These data however, did not support Lipsker et al.'s observations of a particular over representation of female patients presenting with pain, scoring high in traits of autism. It is therefore clear that sex/gender differences in presentation of pain in autism require further research.

These data support recent research indicating that pain related psychological features might be particularly problematic for autistic adolescents. Autistic traits are related here to greater anxiety and depression as well as poorer psychosocial functioning. These findings replicate recent data from psychophysical examinations which showed greater levels of pain related anxiety in autistic adults.²¹ Systematic reviews have also established greater levels of affective symptoms associated with both anxiety and depression in autistic populations compared to non-autistic populations.⁴³ Given the role of these affective symptoms in understanding pain processing and response, it is evident that the management of affective challenges in autistic individuals are likely to be central in ensuring optimal outcomes.

Importantly, previous data have suggested that autistic adolescents are overrepresented within paediatric chronic pain services.¹⁴ Our data suggest that although processing styles associated with autism might predispose more complex needs prior to treatment, they do not prevent individuals from gaining the benefit from psychologically-oriented IIPT. These findings support other recent studies which have found that, when modified for an autistic population, the management of mental health challenges can be efficient and effective for managing social anxiety,²⁴ general anxiety²⁵ and depression.²⁶ Although our data suggests that current best practice is effective in managing pain related symptoms in individuals with processing styles more common in autistic populations, this does not mean that this process cannot be made more optimal. Specifically, a recent interview study sought to understand the experience of autistic adolescents who had undergone IIPT.²⁰ Here autistic adolescents reported that the sensory sensitivities associated with autism, often further triggered both mental health challenges, as well as

making pain feel worse. They also reported that they felt doubly different to their non-autistic peers, and that core elements of IIPT were less accessible to them. For example, the use of metaphors was challenging to engage with, as were wider challenges associated with mindfulness practice. Although our cohort showed a good treatment response, they are a cohort of the “treatment willing”; they had been willing to approach pain services, go through a long assessment, and consent to, and complete a long and demanding treatment. It seems possible, and indeed likely, that there are other young people who are less willing and more disengaged as described in the qualitative research. Changes to practice may support more reluctant autistic young people to engage with pain services and thus to access effective treatment.

Furthermore, given that features associated with autism appear to predict greater problems at intake, autistic patients presenting with pain may start at a disadvantage and need further support to return to optimal functioning/ to prepare for IIPT. Here we propose that more research is required to consider how autistic individuals will best respond to pain management to optimise their outcomes. Challenges with expressing emotion and being appropriately believed during mental health treatment have been linked to poorer perceived outcomes in autism.⁴⁴ Furthermore, continuity of care may be particularly important for autistic individuals who may find it challenging building a rapport with a neurotypical therapist, as well as challenging the therapist building a relationship with a patient with a different world view, often referred to as the double empathy problem.⁴⁵

In the current study, although features associated with autism were measured, we were not able to engage in a diagnostic process for autism. Autism diagnosis was not recorded within the service, however a small number of patients did disclose an autism diagnosis and more reported being on the diagnostic pathway for autism. A further challenge presented here is that the population in this study were among those with minimal support needs and generally had both high intellectual and verbal communication capacity. How to best manage persistent pain in those who might struggle to engage with such a programme is a question which needs to be considered in future research. There are ongoing research programmes seeking to understand the best ways to manage pain in populations with intellectual disabilities,⁴⁶ here a range of issues are being considered ranging from diagnosis, causes of pain, pain measurement, as well as how to best manage these patients’ pain. Differences in how verbal communication is used present a particular challenge and can result in a temptation to draw more heavily of pharmacological management, however with sensible adaptation and the use of technology, it might be that non-pharmacological approaches can be accessible to these populations.⁴⁷ At present these tools have not been explicitly adapted for autistic populations, and it is still unclear how the intersection of needs between these two aspects might work. This is of particular relevance as it must also be noted that the DFlex measures constructs around attention to detail and cognitive rigidity, and although there are established studies showing that these features are common in autistic populations,¹⁸ it should also be noted that cognitive flexibility may also associated with chronic pain in general.¹⁷ It is therefore unclear how ‘autism’ per se may predict pain in the current study, and the challenges with diagnostic overshadowing remain within this population.

The pain programme studied here was highly intensive, including >80 h of treatment in a residential setting. Whilst it was reassuring that individuals with more autistic traits benefited, this finding may not extend to less intensive or specialist settings, where there are fewer hours of treatment and autistic individuals have less time to form relationships with therapists.

This study has clear clinical implications. Here we show that those in adolescent tertiary pain services report greater numbers of autistic traits, if this is reflective of other services, then a clear strategy to support autistic people in pain is needed. We do however establish that autistic traits are not prohibitive to benefitting from a IIPT. With further

understanding and other modifications identified in future research, this process might be even easier for both patients and professionals. Autism should not be a barrier to appropriate, high quality, pain management.

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Author contributions

All authors were involved throughout the process of this research from conceptualisation, development of methodology, analysis, writing and editing. DM led the writing of this manuscript and the data was collected as a part of an ongoing research database (PAIRED Pain Rehabilitation Database: Bath and Bristol).

Declaration of Competing Interest

The authors have no conflict of interest in this manuscript.

References

- Gobina I, Villberg J, Välimaa R, et al. Prevalence of self-reported chronic pain among adolescents: evidence from 42 countries and regions. *European Journal of Pain*. 2019;23(2):316–326. <https://doi.org/10.1002/ejp.1306>.
- Jones A, Caes L, McMurtry CM, Eccleston C, Jordan A. Sociodevelopmental challenges faced by young people with chronic pain: a scoping review. *Journal of Pediatric Psychology*. 2021;46(2):219–230. <https://doi.org/10.1093/jpepsy/jsaa101>.
- Jordan A, Family H, Forgeron P. Interpersonal relationships in adolescent chronic pain: a qualitative synthesis. *Clinical Practice in Pediatric Psychology*. 2017;5(4):303. <https://doi.org/10.1037/cpp0000215>.
- Ayonrinde OT, Ayonrinde OA, Adams LA, et al. The relationship between abdominal pain and emotional wellbeing in children and adolescents in the Raine Study. *Scientific reports*. 2020;10(1):1–11. <https://doi.org/10.1038/s41598-020-58543-0>.
- Groenewald CB, Tham SW, Palermo TM. Impaired school functioning in children with chronic pain: a national perspective (DOI): *The Clinical Journal of Pain*. 2020;36(9):693–699. <https://doi.org/10.1097/AJP.0000000000000850>.
- Rabbitts JA, Holley AL, Karlson CW, Palermo TM. Bidirectional associations between pain and physical activity in adolescents (DOI): *The Clinical Journal of Pain*. 2014;30(3):251. <https://doi.org/10.1097/AJP.0b013e31829550c6>.
- Caes L, Dick B, Duncan C, Allan J. The cyclical relation between chronic pain, executive functioning, emotional regulation, and self-management. *Journal of Pediatric Psychology*. 2021;46(3):286–292. <https://doi.org/10.1093/jpepsy/jsaa114>.
- Claus BB, Stahlschmidt L, Dunford E, et al. Intensive interdisciplinary pain treatment for children and adolescents with chronic noncancer pain: a preregistered systematic review and individual patient data meta-analysis (DOI): *Pain*. 2022;163(12):2281–2301. <https://doi.org/10.1097/j.pain.0000000000002636>.
- Claus BB, Stahlschmidt L, Dunford E, et al. Intensive interdisciplinary pain treatment for children and adolescents with chronic noncancer pain: a preregistered systematic review and individual patient data meta-analysis (DOI): *Pain*. 2022;163(12):2281–2301. <https://doi.org/10.1097/j.pain.0000000000002636>.
- Shulman J, Conroy C, Cybulski A, et al. Does intensive interdisciplinary pain treatment improve pediatric headache-related disability? *Disability and Rehabilitation*. 2022;44(2):194–201. <https://doi.org/10.1080/09638288.2020.1762125>.
- Campbell CM, Edwards RR. Ethnic differences in pain and pain management. *Pain Management*. 2012;2(3):219–230. <https://doi.org/10.2217/pmt.12.7>.
- Boerner KE, Eccleston C, Chambers CT, Keogh E. Sex differences in the efficacy of psychological therapies for the management of chronic and recurrent pain in children and adolescents: a systematic review and meta-analysis (DOI): *Pain*. 2017;158(4):569–582. <https://doi.org/10.1097/j.pain.0000000000000803>.
- Whitney DG, Shapiro DN. National prevalence of pain among children and adolescents with autism spectrum disorders. *JAMA pediatrics*. 2019;173(12):1203–1205. <https://doi.org/10.1001/jamapediatrics.2019.3826>.
- Lipsker CW, Bölte S, Hirvikoski T, Lekkander M, Holmström L, Wicksell RKJ. Prevalence of autism traits and attention-deficit hyperactivity disorder symptoms in a clinical sample of children and adolescents with chronic pain. 2018;11:2827. <https://doi.org/10.2147/JPR.S177534>.
- Knopf A. Autism prevalence increases from 1 in 60 to 1 in 54: CDC. *The Brown University Child and Adolescent Behavior Letter*. 2020;36(6). <https://doi.org/10.1002/cbl.30470>.
- Moore DJ. Acute pain experience in individuals with autism spectrum disorders: a review. *Autism*. 2015;19(4):387–399. <https://doi.org/10.1177/1362361314527839>.
- Higgins DM, Martin AM, Baker DG, Vasterling JJ, Risbrough V. The relationship between chronic pain and neurocognitive function: a systematic review (DOI): *The Clinical journal of pain*. 2018;34(3):262. <https://doi.org/10.1097/AJP.0000000000000536>.

18. Landry O, Mitchell P. An examination of perseverative errors and cognitive flexibility in autism. *Plos one*. 2021;16(1), e0223160. <https://doi.org/10.1371/journal.pone.0223160>.
19. Lockwood Estrin G, Milner V, Spain D, Happé F, Colvert E. Barriers to autism spectrum disorder diagnosis for young women and girls: a systematic review. *Review Journal of Autism and Developmental Disorders*. 2021;8(4):454–470. <https://doi.org/10.1007/s40489-020-00225-8>.
20. Jordan A, Parchment A, Gauntlett-Gilbert J, et al. Understanding the impacts of chronic pain on autistic adolescents and effective pain management: a reflexive thematic analysis adolescent-maternal dyadic study. *Journal of Pediatric Psychology*. 2024;49(3):185–194. <https://doi.org/10.1093/jpepsy/jsae004>.
21. Failla MD, Gerdes MB, Williams ZJ, Moore DJ, Cascio CJ. Increased pain sensitivity and pain-related anxiety in individuals with autism (DOI:) *Pain Reports*. 2020;5(6), e861. <https://doi.org/10.1097/PR9.0000000000000861>.
22. Attwood A. *The complete guide to Asperger's syndrome*. Jessica Kingsley Publishers; 2006.
23. Kester KR, Lucyshyn JM. Cognitive behavior therapy to treat anxiety among children with autism spectrum disorders: a systematic review. *Research in Autism Spectrum Disorders*. 2018;52:37–50. <https://doi.org/10.1016/j.rasd.2018.05.002>.
24. Bemmer ER, Boulton KA, Thomas EE, et al. Modified CBT for social anxiety and social functioning in young adults with autism spectrum disorder. *Molecular Autism*. 2021;12(1):1–15. <https://doi.org/10.1186/s13229-021-00418-w>.
25. Wood JJ, Kendall PC, Wood KS, et al. Cognitive behavioral treatments for anxiety in children with autism spectrum disorder: a randomized clinical trial. *Jama Psychiatry*. 2020;77(5):474–483. <https://doi.org/10.1001/jamapsychiatry.2019.4160>.
26. Menezes M, Harkins C, Robinson MF, Mazurek MO. Treatment of depression in individuals with autism spectrum disorder: a systematic review. *Research in Autism Spectrum Disorders*. 2020;78, 101639. <https://doi.org/10.1016/j.rasd.2020.101639>.
27. Skuse DH, Mandy WP, Scourfield J. Measuring autistic traits: heritability, reliability and validity of the social and communication disorders checklist. *The British Journal of Psychiatry*. 2005;187(6):568–572. <https://doi.org/10.1192/bjp.187.6.568>.
28. Roberts ME, Barthel FM-S, Lopez C, Tchanturia K, Treasure JL. Development and validation of the detail and flexibility questionnaire (DFlex) in eating disorders. *Eating behaviors*. 2011;12(3):168–174. <https://doi.org/10.1016/j.eatbeh.2011.04.001>.
29. Hechler T, Kanstrup M, Holley AL, et al. Systematic review on intensive interdisciplinary pain treatment of children with chronic pain. *Pediatrics*. 2015;136(1):115–127. <https://doi.org/10.1542/peds.2014-3319>.
30. Eccleston C, Malleon P, Clinch J, Connell H, Sourbut C. Chronic pain in adolescents: evaluation of a programme of interdisciplinary cognitive behaviour therapy. *Archives of disease in childhood*. 2003;88(10):881–885. <https://doi.org/10.1136/adc.88.10.881>.
31. Gauntlett-Gilbert J, Connell H, Clinch J, McCracken LM. Acceptance and values-based treatment of adolescents with chronic pain: outcomes and their relationship to acceptance. *Journal of pediatric psychology*. 2013;38(1):72–81. <https://doi.org/10.1093/jpepsy/jss098>.
32. Kemani MK, Kanstrup M, Jordan A, Caes L, Gauntlett-Gilbert J. Evaluation of an intensive interdisciplinary pain treatment based on acceptance and commitment therapy for adolescents with chronic pain and their parents: a nonrandomized clinical trial. *Journal of Pediatric Psychology*. 2018;43(9):981–994. <https://doi.org/10.1093/jpepsy/jsy031>.
33. Tei S, Fujino J, Hashimoto R-i, et al. Inflexible daily behaviour is associated with the ability to control an automatic reaction in autism spectrum disorder. *Scientific reports*. 2018;8(1):8082. <https://doi.org/10.1038/s41598-018-26465-7>.
34. Bölte S, Westerwald E, Holtmann M, Freitag C, Poustka F. Autistic traits and autism spectrum disorders: The clinical validity of two measures presuming a continuum of social communication skills. *Journal of autism and developmental disorders*. 2011;41:66–72. <https://doi.org/10.1007/s10803-010-1024-9>.
35. Golding Pembrey, Team AS. ALSPAC—the avon longitudinal study of parents and children. *Paediatric and perinatal epidemiology*. 2001;15(1):74–87. <https://doi.org/10.1046/j.1365-3016.2001.00325.x>.
36. Schaumberg K, Zerwas SC, Bulik CM, Fiorentini C, Micali N. Prospective associations between childhood social communication processes and adolescent eating disorder symptoms in an epidemiological sample. *European child & adolescent psychiatry*. 2021;30:1929–1938. <https://doi.org/10.1007/s00787-020-01655-9>.
37. Skuse D, Warrington R, Bishop D, et al. The developmental, dimensional and diagnostic interview (3di): a novel computerized assessment for autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2004;43(5):548–558. <https://doi.org/10.1097/00004583-200405000-00008>.
38. Eccleston C, Jordan A, McCracken LM, Sled M, Connell H, Clinch J. The bath adolescent pain questionnaire (BAPQ): development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *Pain*. 2005;118(1-2):263–270. <https://doi.org/10.1016/j.pain.2005.08.025>.
39. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the pediatric quality of life inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical care*. 2001:800–812.
40. Walker LS, Greene JW. The functional disability inventory: measuring a neglected dimension of child health status. *Journal of pediatric psychology*. 1991;16(1):39–58. <https://doi.org/10.1093/jpepsy/16.1.39>.
41. IBM. *SPSS Statistics for Windows, Version 25.0*. IBM Corp.; 2017.
42. Stevens J. *Applied multivariate statistics in the social sciences: 3rd edition*. LEA; 1996.
43. Hollocks MJ, Lerh JW, Magiati I, Meiser-Stedman R, Brugha TS. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological medicine*. 2019;49(4):559–572. <https://doi.org/10.1017/S0033291718002283>.
44. Camm-Crosbie L, Bradley L, Shaw R, Baron-Cohen S, Cassidy S. 'People like me don't get support': autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*. 2019;23(6):1431–1441. <https://doi.org/10.1177/1362361318816053>.
45. Milton DE. On the ontological status of autism: the 'double empathy problem'. *Disability & Society*. 2012;27(6):883–887. <https://doi.org/10.1080/09687599.2012.710008>.
46. El-Tallawy SN, Ahmed RS, Naguib MS. Pain management in the most vulnerable intellectual disability: a review. *Pain and therapy*. 2023;12(4):939–961. <https://doi.org/10.1007/s40122-023-00526-wa>.
47. McManus S, Treacy M, McGuire B. Cognitive behavioural therapy for chronic pain in people with an intellectual disability: a case series using components of the Feeling Better programme. *Journal of Intellectual Disability Research*. 2014;58(3):296–306.