The Occurrence of Mood and Anxiety Difficulties in Males and Females with Pervasive Developmental Disorders

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Overview

The Literature Review discusses the issue of co-morbid mood and anxiety difficulties in individuals with Pervasive Developmental Disorders (PDD). This begins with a review of the literature examining relative prevalence rates of such difficulties in PDD before addressing the diagnostic validity of psychiatric co-morbidity in PDD. The assessment of anxiety and mood difficulties in PDD is then considered, particularly with regards to PDD individuals' ability to introspect and report on cognitive and affective states. Finally, ideas about the possible etiology of mood and anxiety difficulties in PDD are discussed, with a particular focus on self-concept. The Empirical Paper involves a comparison of levels of internalising behaviours in a child and adolescent PDD sample with that of a typically developing sample, using parental report questionnaires. It also extends beyond the issues covered in the Literature Review by considering sex differences in PDD, both in terms of levels of internalising behaviours and PDD severity ratings. The relationship between levels of internalising behaviours and PDD severity is also examined. The Critical Appraisal considers in some detail the recruitment process and selection of appropriate measures, with personal reflections upon the experience. The strengths and weaknesses of the study are discussed and suggestions for further analyses are made. The clinical implications of the study are also considered.

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Acknowledgements

Part One: Literature Review

The Occurrence of Mood and Anxiety Difficulties in Individuals with Pervasive Developmental Disorders

Abstract

An emerging literature consistently shows that individuals with Pervasive Developmental Disorder (PDD) experience higher rates of mood and anxiety difficulties than typically developing populations. The current review considers the evidence for the increased relative prevalence rates and addresses the queried validity of such diagnoses in PDD populations. The complex issue of assessment in this population, particularly with regards to self-report, is discussed. The evidence that psychiatric co-morbidity forms part of the broad autism phenotype is also reviewed. Possible etiological factors are then explored, including the hypothesised role of self-concept and friendships. The implications of these findings for the understanding of and assessment of PDD are presented.

Introduction

The nature of Pervasive Developmental Disorders (PDD) is such that the individual will understand and interact with the world in ways that differ significantly from those without PDD. Their representations of self, others, the world, and the three in relation to each other are likely to vary in many respects. They will also elicit quite different responses from others, and may experience the task of functioning in a predominantly non-PDD world as confusing and demanding. It would therefore be surprising if PDD populations experienced exactly the same prevalence of mood and anxiety symptoms as typically developing populations. However, the issue of co-morbidity has been relatively neglected in the PDD literature, resulting in a poverty of understanding of the occurrence and manifestation of mood and anxiety symptoms in PDD. This has considerable theoretical and clinical implications, including diagnostic, assessment and treatment issues.

Recently this issue has received increasing empirical attention, and it appears that PDD populations suffer from higher rates of psychiatric disorder, and that this is particularly marked for anxiety and mood difficulties. Although this conclusion must be considered within the context of methodological and assessment limitations, it is also important to note the *consistency* of these findings. Overall, there is more consistency than inconsistency in the literature.

The current review is concerned with this emerging literature and will address not only the question of relative prevalence rates but also the important issue of diagnostic validity and boundaries. It will also consider the possible etiology and

maintenance of mood and anxiety difficulties in PDD, with a particular focus on self concept in this population. The relatively small size of the literature, as well as the often shared methodological limitations, means that this review will explore many of the studies in some depth.

Diagnostic Criteria

PDD encapsulates a range of disorders of varying severity. Table 1 presents the DSM-IV diagnostic criteria for Autistic disorder in which impairment is demonstrated in all three of the PDD domains (American Psychiatric Association, 1994; see Table 1). Other classifications include Atypical Autism, also known as Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) in which significant impairments are demonstrated but symptoms are sub-threshold in at least one domain of impairment. The PDD literature is mixed with regards to whether Aspergers Syndrome (AS), another PDD classification, should be considered to be a distinct disorder from High Functioning Autism (HFA - high functioning referring to autistic individuals with IQ in the normal range), the main difference being that in AS the onset of language development occurs at the normal age. However, in the current review, no such distinction will be made. Although some studies in the literature have been concerned with examining differences between PDD sub-types, this issue will not be addressed here, and the review will consider the full range of presentation in terms of severity in the three domains of impairment.

Table 1: Diagnostic & Statistical Manual of Mental Disorders-IV Diagnostic Criteria for Autistic Disorder

A.	A total of six (or more) items from (1), (2) and (3), with at least two from (1) and one each from (2) and (3):

	(1) qualitative impairment in social interaction, as manifested by two of the following: (a) marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction (b) failure to develop peer relationships appropriate to developmental level (c) a lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g. by a lack of showing, bringing, or pointing to objects of interest) (d) a lack of social or emotional reciprocity
	(2) qualitative impairments in communication as manifested by at least one of the following: (a) delay in, or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture and mine) (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others (c) stereotyped and repetitive use of language or idiosyncratic language (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
	(3) restricted repetitive and stereotyped patterns of behaviour, interest and activities, as manifested by at least one of the following: (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus (b) apparently inflexible adherence to specific non-functional rituals or routines (c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements) (d) persistent preoccupation with parts of objects
B.	Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
C.	The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

Most of the PDD literature has involved child and adolescent populations and the co-morbidity literature is no exception. The co-morbidity literature has also predominantly examined HFA samples rather than PDD samples with IQs below the normal range. Thus, unless otherwise specified, PDD samples referred to in this review will be children and adolescents with IQs within the normal range.

Prevalence of Mood and Anxiety Symptoms in PDD

Whilst the diagnostic criteria for PDD is well defined, a range of behavioural disturbances over and above these is commonly observed. However, a diagnosis of PDD is often considered to be an exclusion criterion for other psychiatric disorders. Whilst it is not uncommon for psychiatric medication to be prescribed for the treatment of problematic externalising behaviour in PDD, such as hyperactivity, internalising behaviours such as anxiety and mood difficulties are much less likely to be identified or treated in the clinical context. This may because these behaviours share characteristics with the core PDD symptomatology and because they are relatively less 'problematic', in terms of the impact of such behaviours on others.

Although in the last twenty years the issue of co-morbidity has gradually begun to be addressed empirically, the early literature mainly involved case series and did not include comparisons with typically developing controls (e.g. Ghaziuddin & Tsai, 1991; Rumsey, Rappoport and Sceery, 1985; Szatmari, Bartolucci, Bremner, Bond, Rich,1989; Wing, 1981). It is important to address whether the presentation of psychiatric syndromes in this clinical group is similar to that observed in typically

developing populations and whether the prevalence and severity of symptoms is comparable. Recent years have seen an emergence of studies concerned with this issue. They have generally approached the question by employing measures developed for use in typically developing populations and compared the scores on these measures in PDD, typically developing and clinical (i.e. individuals with psychiatric or developmental disorder diagnoses) samples. Without exception, when compared to typically developing controls, PDD samples demonstrated a higher prevalence of many psychiatric difficulties, particularly anxiety and mood difficulties. In addition, some studies report that the PDD samples demonstrated symptom severity equal to or greater than clinical samples.

In the largest study of psychiatric co-morbidity in PDD populations, Gadow, Devincent, Pomeroy and Azizian (2005) compared symptom severity for a range of psychiatric disorders in primary school aged PDD, clinical and typically developing community children. They found that the PDD sample scored significantly higher than the community controls for all diagnostic categories except conduct disorder (CD). The clinical and PDD samples demonstrated comparable severity for depression, Generalised Anxiety Disorder (GAD) and separation anxiety, whilst for social phobia, OCD and tics, the PDD sample had higher severity scores than the clinical controls. Examination of the prevalence rates demonstrated that 6% and 12% of the PDD sample scored over the cut-off for depression and dysthymia, respectively, compared to 0% and 1.6% of typically developing controls. For GAD, the discrepancy in prevalence rates was even more marked: 25% for PDD compared to 3% for the controls. The authors utilised the same methodology in a younger age range (3-5 years old) with a comparably smaller (but still considerable relative to the

rest of the literature) sample. Gadow, Devincent, Pomeroy and Azizian (2004) reported very similar results, with the PDD sample demonstrating greater severity for all diagnostic categories except conduct disorder. However, the question of the diagnostic validity of such disorders in this age range is debatable. Although the authors state that the behavioural symptoms do not constitute clinical diagnosis, for example, it could be argued that measures of emotional difficulties would have been more appropriate than a collection of behavioural symptoms equivalent to a diagnosis of depression.

In another, earlier study which considered a range of psychiatric disorders in PDD children, Kim, Szatmari, Bryson, Streiner and Wilson (2000) reported similar results to the Gadow *et al* (2004; 2005) studies with the PDD sample demonstrating significantly higher scores than the typically developing population norms for all measures except conduct disorder. Kim *et al* (2000) found that 17% of the PDD sample demonstrated clinically significant depression scores (defined as two standard deviations above the community population mean) and 13.6% for the measure of generalised anxiety. Thus, as in Gadow *et al* (2005), anxiety and mood disorders were particularly apparent in the PDD sample.

In a slightly different approach, Green, Gilchrist, Burton and Cox (2000) used a CD comparison group in their study of psychiatric co-morbidity. They reported particularly high prevalence rates, with 65% of the PDD sample meeting the criteria for an emotional disorder. On the whole, for both the parent and child interviews, the prevalence of psychiatric symptoms was similar for the PDD and CD groups, although in some cases the PDD group demonstrated greater severity (e.g. 35% of

the AS sample met criteria for GAD compared to 5% of CD). This demonstrated that, even when compared to a sample with a comparable externalising problem presentation, the PDD group appeared to suffer from higher rates of anxiety.

Other studies in the literature have not considered such a wide range of psychiatric presentations, rather they have addressed the issue of prevalence and severity of more specific psychiatric disorders. Gillott, Furniss and Walter (2001) focussed on anxiety symptoms, their results demonstrating that the PDD sample scored significantly higher than typically developing and specific language impairment samples for levels of overall anxiety. Additionally, half of the PDD group scored within the clinically significant range. The same pattern of results was found for both self and parent report, although the parent report results demonstrated larger effect sizes. This result was replicated in a similar study by Russell and Sofronoff (2005), in which the PDD sample was rated as significantly more anxious than typically developing controls across a range of anxiety disorders, according to both parent and self-report. They also scored either comparably or higher than a clinically anxious sample. Hill, Berthoz and Frith (2004) reported that 22% of their adult PDD group were in the clinical depression category, whilst none of the typically developing controls reached this cut-off. Additionally, 75% of the PDD sample demonstrated some degree of depression, compared to 17% of the controls (in both cases the results were statistically significant).

It is important to note that the co-occurrence of PDD and OCD specifically has received considerable interest in the literature. Many researchers (e.g. Rumsey *et al*, 1985) have noted high rates of compulsive behaviours in PDD and have noted the

high degree of overlap in symptomatolgy between OCD and the repetitive and stereotyped behaviours domain of PDD. However, some investigators (e.g. Baron-Cohen, 1989) have concluded that the two are not equivalent and that important differences exist. Although this is a relevant and related literature, it is beyond the scope of the current review, and it will therefore not be concerned with studies specifically investigating OCD.

There is some variation in the literature with regards to the magnitude of severity and prevalence rates, relative to both typically developing population norms and clinical controls. This is unsurprising considering the wide variation in age range, measures and type of comparison samples. However, what is interesting is the degree of consistency in that all of the quantitative research has demonstrated prevalence rates to be higher than in typically developing populations. This is particularly marked for anxiety and mood symptoms, with levels of severity often in the clinically significant range.

The Diagnostic Validity of Psychiatric Co-Morbidity in PDD

Arguably, one of the main reasons that the issue of psychiatric co-morbidity has been neglected is the inherent difficulty encountered in attempting to discriminate additional psychiatric symptoms from those of PDD itself. Are the symptoms in question simply behavioural manifestations of the underlying PDD or can they be considered to be the same discrete, classifiable disorders observed in typically developing populations? Differential diagnosis therefore requires an extremely

thorough assessment, ideally involving a combination of standardised semi-structured parental interviews (e.g. The Autism Diagnostic Interview (Le Couteur *et al*, 1989)), standardised direct observational measures (e.g. the Autism Diagnostic Observational Schedule, Lord, Risi & Lambrecht, 2000) and the clinical judgement of experienced clinicians. Crucially, this type of assessment considers not only the current presentation of the individual, but also their early development. It is in this respect that individuals with PDD stand apart from those with other psychiatric presentations, as PDD is, by definition, a developmental disorder. It is accepted that early development of PDD individuals would deviate from normal development in a characteristic way (although the degree of deviation and age at which it becomes clearly apparent may vary) and in a manner which cannot simply be attributed to temperamental or environmental factors. Once a diagnosis of PDD has been made, it is common for any 'problematic' symptoms to be attributed to PDD. The likely result of this is that many mood and anxiety symptoms experienced by individuals with PDD remain undiagnosed and untreated.

In terms of the overt behavioural manifestation of many psychiatric symptoms, there can be considerable overlap with the core features of PDD. For example, a relative dearth of social relationships, or outright social avoidance is central to PDD, however, this type of presentation may also be observed in a range of psychiatric disorders including social anxiety and depression. Features of the restricted interests and repetitive behaviours domain of the PDD triad of impairment may also overlap with symptoms of various anxiety disorders, especially OCD (Rumsey *et al*, 1985).

Despite the difficulties encountered in attempting differential diagnosis, there are data which support the diagnostic validity of mood and anxiety symptoms in PDD populations. For example, one line of argument proposes that there are factors associated with the occurrence of mood and anxiety symptoms which are observed in both typically developing and PDD populations. For example, typically developing populations often experience an excess of negative life events prior to the onset of depression. Ghaziuddin, Alessi and Greden (1995) investigated whether the same association between life events and depression could be observed in an PDD sample and found that 82% of depressed PDD participants had experienced a recent negative life event, compared to 45% of non-depressed PDD participants. The authors also posited that the experience of stressors such as bereavement could potentially be particularly difficult for individuals with PDD due to their difficulty in adjusting to change more generally.

Ghaziuddin and Greden (1998) found an increased prevalence of depression in the first degree relatives of individuals with PDD and depression, compared to a control group of participants with PDD alone. The authors interpreted these results in light of the pattern demonstrated in typically developing populations, in which there is a higher incidence of depression in the relatives of depressed individuals. They conclude that this provides support for the diagnostic validity of depression in PDD populations.

Lainhart and Folstein (1994), in a review of 17 published case studies (involving mainly adults, with IQs both within and below the normal range), used the criterion of a *change* in predominant mood, self perception and appearance of vegetative

symptoms as indicative of a diagnosis of affective disorder in addition to PDD. In all cases a change in mood was apparent to others, including, for example, increased lability of mood or frequent crying. This is a significant observation considering the fact that a common feature of PDD is impairment in the expression of affect. A change in self attitude or attitude towards others was implied by overt behaviour such as a decline in self care, a decrease in social interaction or a decrease in co-operativeness. Vegetative symptoms were reported in all cases including changes in sleep, appetite and level of activity. In three cases an increase in "autistic" behaviours was observed (e.g. stereotypies). The authors also noted that, as in typically developing populations, these changes in behaviour were usually episodic. The observation that all of the cases had reported at least partial response to pharmacological treatment for depression was also cited by the authors as further evidence for the diagnostic validity of affective disorder in PDD.

If one accepts the argument that anxiety and mood symptoms do *not* constitute separate, independent disorders in this population, and rather, are expressions of the PDD itself, one might predict that the severity of anxiety or depressive symptoms would be positively correlated with the severity of autistic symptoms. Kim *et al* (2000) addressed this issue, specifically hypothesising that the stereotyped and repetitive behaviour domain may reflect a temperamental disposition to anxiety. However, in fact, they found no correlation between scores on any of the three autism domains and ratings of anxiety or mood symptoms. Further, Gadow *et al* (2005) reported that the severity of certain anxiety and mood disorders *was* associated with PDD severity, but that the correlation was negative rather than positive. Specifically, they found that participants with diagnoses of AS and PDD-

NOS scored significantly higher on measures of depression, dysthymia and obsessionality than those with Autism diagnoses (with Autism constituting a more severe PDD presentation). However, this was not a consistent finding, varying according to the informant, and the authors acknowledged that it may have also related to the differing verbal abilities (and hence ability to express their affective experience) of the different PDD sub-types.

In conclusion, therefore, there does appear to be evidence to support the diagnostic validity of psychiatric symptoms differentiable from the behavioural disturbances attributable to PDD.

Assessment Issues

If psychiatric co-morbidity in PDD is diagnostically valid, then a closely related issue concerns how this may be assessed. The following section will argue that, although relative to their typically developing peers, PDD individuals have difficulty reflecting and reporting their covert cognitive and affect states, this should not necessarily render self report data invalid.

Assessment of the presence of mood and anxiety symptoms in children and adolescents from parent report typically involves questions relating to overt, observable behaviour such as avoidance, activity levels and biological functions such as sleep. However, it is also important to consider the child's covert affective and cognitive experience, for example, feeling sad, engaging in rumination or having low

self-esteem. In the case of PDD, assessment in this respect may be problematic due to PDD individuals' relative difficulty with self-reflection and emotional understanding. For example, Hill *et al* (2004) suggested that the empirically well established PDD feature of impairment in mentalising (also known as theory of mind) could be associated with a similar difficulty in understanding and describing one's own mental states. They utilised a self report questionnaire which measures the 'alexithymia construct', characterised by impairments in identifying and describing feelings, distinguishing emotions from the physical manifestation of affective arousal, impaired symbolisation and concrete thought. In their comparison with a normal sample the authors found that the PDD group did indeed demonstrate greater impairment on this measure. However, the small sample size meant that statistical comparisons were made only for the overall score, rather than the three subcomponents (i.e. difficulty identifying feelings, difficulty describing feelings, and externally orientated thinking), meaning that it was not possible to examine whether the PDD sample were significantly impaired in all of these domains. However, these results suggest that PDD populations (even high functioning ones) may experience greater difficulty in understanding and reflecting upon their mental states than their typically developing peers. Interestingly, the authors also interpret the results as providing evidence against the idea that PDD populations are unable to provide adequate responses to such questionnaires. They noted that no PDD participant had asked questions about the meaning of items, and that the frequency of missing items was equivalent to the normal sample. However, whether this does indeed reflect their understanding, or is more related to factors around compliance is not clear.

The issue of the degree to which self report data from PDD (or, specifically, HFA) populations represents a valid measure of their mental states is pertinent in the case of Gillott *et al* (2001) and Russell and Sofronoff (2005). Russell and Sofronoff (2005) found that parent ratings on the Spence Children's Anxiety Scale (SCAS; Spence, 1997) were significantly higher than self-report for the social phobia, generalised anxiety and separation anxiety sub-scales. The authors interpreted this result as demonstrating that the PDD sample lacked insight into their own difficulties. However, relatively low concordance between parent and child report is a well established phenomenon in typically developing samples (De Los Reyes & Kazdin, 2005). This is particularly the case for internalising symptoms in which, sometimes covert, behaviour is the subject of assessment. Although concordance is generally consistently low to moderate, the direction of disagreement varies, and the literature is mixed with regards to which informant is more reliable. Multiple variables have been proposed to account for the discrepancy, and it is therefore unwise to attribute the lower self-report scores in this case simply to a lack of insight. It is also possible that additional factors come into play with PDD populations, such as parental expectation that, for example, their child might be worried about what others think of them, due to their awareness of their child's PDD-related impairments.

However, it is important to note that, despite the discrepancy, the PDD self-report scores were still significantly higher than those of the typically developing controls, and were comparable to the scores of a clinically anxious sample. The same was found in the Gillott *et al* (2001) study. Many of the items which contribute to the SCAS scores require the respondent to reflect upon covert cognitive states, such as

whether they engage in rumination. The fact that the PDD group scored higher than the controls on many of these items suggests that they are able to introspect for the purposes of a questionnaire. Also of note was the finding by Russell and Sofronoff (2005) that the one SCAS sub-scale for which the self-report scores were significantly higher than the parents' was for OCD. About half of the OCD items refer to compulsive behaviours, which may have some overlap with PDD symptomatology (and also, presumably, be more apparent to parents). However, the other items refer to obsessive cognitions, such as whether they are disturbed by intrusive thoughts or images. Again, this presents a challenge to the idea that PDD individuals cannot reflect upon and report such mental states.

In terms of ability to understand and report on affective states, there is evidence to suggest, at least in HFA populations, that they are able to talk about their experiences of both simple emotions, such as happiness, and complex ones, such as pride (Capps, Yirmiya & Sigman, 1992). Lee and Hobson (1998), in a qualitative study of self-understanding, reported that, contrary to their hypothesis, the PDD group were comparable to typically developing controls in terms of the frequency of psychological self-statements and references to emotional states. However, they did observe that the PDD group differed in terms of the quality of such understanding. It is important to note that this study involved a low functioning sample (with verbal age as low as four years) and it is possible that a high functioning sample may have demonstrated superior ability in communicating self concept and affective experience.

As in typically developing children, a thorough clinical assessment interview which involves both the parent and child (as well as other sources) and which also considers whether there has been *change* in the child's behaviour, is likely to be the most reliable approach to diagnosing mood or anxiety disorders. However, this method has rarely been employed in the literature which has primarily involved questionnaires. This approach also accommodates the possibility that anxiety or mood disorders may present in PDD populations as an increase in 'autistic' behaviours, for example, an exacerbation in ritualistic behaviours or preoccupations. Such behaviours may provide the PDD individual with a means of expressing or releasing feelings of anxiety or distress. However, it is worth bearing in mind that relying on the criterion of change can also have its limitations, for example, anxiety disorders may have a very gradual period of onset, be difficult to discriminate from underlying personality characteristics, and may not necessarily be episodic.

In conclusion, it appears that although there are limitations to utilising self-report measures, high functioning individuals, at least, are able to introspect to some degree and have sufficient understanding of their own affective and cognitive states to complete measures of anxiety and affective disorders. However, it is important to be mindful of the fact that their abilities in this respect are impaired relative to typically developing populations.

Methodological Issues

In addition to the issue of co-morbidity assessment validity and reliability, many of the studies in the literature share further methodological limitations. The following section will consider different aspects of methodology in turn.

Sample size

One of the major limitations of the literature has been the tendency to use relatively small sample sizes. Kim *et al* (2000) and Russell and Sofronoff (2005) had larger sample sizes than most, with PDD groups of 65 and 68 respectively. However, to date, the largest samples recruited have been those of the Gadow *et al* (2005) and Gadow *at al* (2004). In the former, a primary school aged sample, 301 PDD children were involved, whilst in the latter, pre-school sample, 182 PDD children were recruited. The reduced statistical power resulting from small sample size is a particularly pertinent concern as the vast majority of studies in this field have also used multiple measures as well as considering multiple sub-scales in the analyses. It is rare in the literature for statistical corrections to be made when making large numbers of comparisons, although there are rare exceptions (e.g. Russell & Sofronoff, 2005). Even when the sample size has clearly precluded statistical analyses of certain results, some studies have used descriptive data from sub-scales in their interpretation of the results (e.g. Gillott *et al*, 2001).

Comparison samples

Some studies have been limited by their use of normative data for comparison purposes. For example, Gadow *et al* (2004) and Gadow *at al* (2005) employed two newly developed questionnaires, the Early Childhood Symptom Inventory (ESI-4; Gadow & Sprafkin, 1997) and the Child Symptom Inventory (CSI-4; Gadow & Sprafkin, 2002), which have been normed on community samples of 507 and 446 children, respectively. The demographic profiles of these normative samples differed significantly in a number of respects, most notably in terms of the gender ratio, which was roughly equal for the normative samples, but demonstrated the usual male bias in the case of the PDD samples. The two groups also differed significantly in terms of IQ and socio-economic status (SES). The authors suggested that, overall, age, gender, SES and IQ were only minimally associated with scores on the measures. However, it is possible that these analyses missed out on small but potentially relevant differences between the groups, and closer matching between samples would have been preferable. Kim *et al* (2000) used normative data from the Revised Ontario Child Health Study (OCHS-R), a parent report questionnaire adapted from the Child Behaviour Checklist. This was standardised on a community sample of 1751 children and adolescents (Boyle *et al*, 1993). However, in this case the authors did not report on the demographic profile of this sample. The PDD sample was compared to age and gender norms but it was not clear whether the PDD group was adequately matched in terms of other variables such as IQ and SES, variables which are associated with mood and anxiety symptoms. It was also not clear whether the procedure for administration of the measure had been equivalent in the two groups. Russell and Sofronoff (2005) similarly did not report on any

demographic comparisons made between the normative data for the Spence Children's Anxiety Scale (SCAS; Spence, 1997) and the PDD sample. In addition, in the case of their other measure, the Spence Social Worries Questionnaire (SWQ; Spence, 1995), the typically developing child comparison data were from the typically developing sample used in the Gillott *et al* (2001) study. This approach was limited not only by the relatively small sample size in the latter study (N=15) but by the differing demographic characteristics, including age range, in the two studies, which was not controlled for in the analyses.

Recruitment

Generally, the PDD samples have been recruited either from specialist developmental disabilities or communications clinics or from psychiatric outpatient settings. As a result, most of the participants in the PDD samples have undergone thorough diagnostic assessments for PDD, often including standardised measures. However, one limitation of this method of recruitment concerns the possible referral bias involved, with clinic samples demonstrating potentially higher rates of co-morbidity, or more complex PDD profiles, thus meaning that they may not be fully representative of PDD populations. It may be argued that children diagnosed at earlier ages in more generic paediatric settings, would be more representative. However, it is also important to be aware that most studies have primarily been concerned with and involved higher functioning PDD participants, who often do not receive diagnoses at such an early age, or may require more specialist assessments.

A further bias may have arisen in the studies of Ghazuiddin *et al* (1995) and Ghaziuddin and Greden (1998). Their method of recruitment may have influenced the results obtained in that their depressed and non-depressed PDD samples were both recruited from inpatient settings. The authors do not report on the reasons for the non-depressed PDD samples' admission to this setting, however, this appears to be an important question, which would have implications for the representativeness of the participants as 'non-depressed PDD'. Green *et al* (2000) similarly reported that 40% of their PDD sample had had an inpatients admission in the past, again, raising questions about how representative this sample was.

Russell and Sofronoff (2005) report that their PDD sample was recruited from a study evaluating the efficacy of an anxiety intervention (Sofronoff, Attwood & Hinton, 2005). The recruitment for this latter study was through advertisements in newspapers and local support groups, and the authors had specifically screened for the presence of anxiety. It is therefore questionable whether this constitutes a representative sample. Although the authors report that they did not include participants with a diagnosis of anxiety disorder, the recruitment method implies that they would have been expected to have demonstrated at least some anxious behaviour.

It is worth considering that most of the literature has involved child and adolescent populations, which may have implications for the generalisability to adult populations. It is not yet clear whether the prevalence of mood and anxiety symptoms in PDD would demonstrate the same variation across the life span as in typically developing populations. It is possible that some of the typical changes with

age (for example, moving out of the parental home) may be particularly challenging for PDD individuals.

Psychiatric Co-Morbidity as Part of the Broad Autism Phenotype

Research, including twin and family studies, suggests that PDD is strongly genetically influenced (e.g. Bailey *et al*, 1995). In relatives of individuals with PDD, there is not only a higher prevalence of PDD but also of more subtle abnormalities characteristic of PDD (e.g. social difficulties), often termed the 'broad autism phenotype' (Bailey *et al*, 1998). What has not been fully established is whether additional psychiatric disorders constitute part of this broad autism phenotype. If this were the case, then it could be argued that co-morbidity in PDD populations could be attributed to a shared genetic liability, rather than being secondary to environmental factors. This would provide a challenge to the idea that depression and anxiety symptoms in PDD constitute discrete disorders.

Yirmiya and Shaked (2005) conducted a meta-analysis of the few studies which have addressed this issue. They reported that parents of children with PDD demonstrated more psychiatric problems than controls. However, the composite mean effect size was small and not homogenous, with the type of comparison group being particularly important. The results were more homogenous for depression and anxiety specifically, with parents of PDD children demonstrating higher rates than parents of typically developing and Down's Syndrome (DS) controls. However, they did not

differ significantly from parents of children with learning disabilities (LD) or psychiatric disorders.

An important issue in the interpretation of these results concerns the appropriateness of the comparison groups. Although parenting a child with DS, LD or psychiatric disorders will present a range of difficulties and sources of stress, the symptoms characteristic of PDD arguably present unique challenges (Dumas, Wolf, Fisman & Culligan, 1991). Thus, the elevated rates of depression and anxiety in parents may be attributed to the burden of raising a child with PDD. However, Bolton, Pickles, Murphy and Rutter (1998) and Micali, Chakrabarti and Fomonne (2004) provide evidence against this hypothesis. In both studies mothers of children with PDD demonstrated higher rates of anxiety and/or affective disorders (Bolton *et al* (1998) measured affective disorders only) than DS controls, however, the levels were elevated even *prior* to the PDD child's birth. On the other hand, Bolton *et al* (1998) did find that there was an association between the rate of depression in first degree relatives and the level of behavioural abnormalities in the child, a result which could be interpreted as providing some support for the burden hypothesis.

The hypothesis that these disorders constitute part of the broad autism phenotype also does not receive much support. Bolton *et al* (1998), Micali *et al* (2004) and Piven and Palmer (1999) all report that in parents of children with PDD there is no association between depression and/or anxiety symptoms and behavioural abnormalities associated with the broad autism phenotype and that the pattern of familial aggregation is inconsistent with the hypothesis. For example, the prevalence of affective disorders was higher in female relatives, in contrast to the pattern of

inheritance of the autism phenotype, which is more common in male relatives (Bolton *et al* (1998), Micali *et al* (2004)).

Thus, although the evidence is relatively consistent, demonstrating that parents of children with PDD have elevated rates of depression and anxiety, the mechanism for the association is unclear. Although the burden of raising a child with PDD may play a role in maintaining these problems, it cannot be considered to be the sole etiological factor. Equally, depression and anxiety do not appear to form part of the broad autism phenotype. Further research is required to determine what alternative mechanism may explain this relationship. However, these findings may have important implications for the understanding of co-morbidity in PDD. If the parents suffer from an increased incidence of mood and anxiety disorders this may contribute to the child's mental health, either via a shared genetic liability or the psychological impact of having a depressed or anxious parent.

Etiology

If we are to accept that the prevalence of mood and anxiety disorders is elevated in PDD populations, albeit with the caveat that accurate measurement of the magnitude of this is difficult, then it is both theoretically and clinically important to explore possible explanations. As in typically developing populations, a multitude of interacting factors are likely to be involved in the etiology and maintenance of anxiety and mood disorders in PDD. Genetic, temperamental and familial variables would be expected to all play a role to some extent. Some of these issues have been

mentioned previously, for example, Ghaziuddin and Greden (1998) demonstrated that a genetic predisposition to depression may play a part, and Ghaziuddin, Alessi and Greden (1995) illustrated that depression may be triggered by stressful life events. Both of these examples suggest that PDD individuals share commonalities with typically developing populations.

As discussed previously, the parents of children with PDD experience elevated rates of depression and anxiety. Although the mechanism for this association is not established, it is important to consider that this may play a role in the etiology of the child's depression and anxiety, not just in terms of shared genetic liability, but also the impact of having a depressed or anxious parent on the child's development. Thus far, no studies have investigated whether there is an association between the occurrence of depression and anxiety in parents and their PDD children, however, this potential relationship would mirror that observed in typically developing populations.

It is also important to consider how the lives of individuals with PDD differ from typically developing children, both in terms of their internal worlds and the reality of their day to day lives and relationships. These differences may influence the development of mood and anxiety difficulties. For example, one neglected aspect of the literature is that of familial relationships and the impact of these on PDD mental health. There are some data to suggest that individuals with PDD do demonstrate attachment behaviour and that there are more similarities than differences in terms of the quality of this attachment, as compared to that of developmentally delayed control samples (e.g. Rogers, Ozonoff & Maslin-Cole, 1993). However, as yet, this

field of research does not address whether these factors impact upon PDD mental health in the same way as in typically developing or developmentally delayed individuals.

Self Concept, Friendships and Association with Mood and Anxiety

Self concept, and specifically self-worth, is a construct which is widely considered to be associated with the occurrence of depression in typically developing populations. Self worth relates to the self in relation to others, and may be developed by gaining a sense of approval from others or from a sense of achievement in relation to others (Gilbert, 2000). In developing a sense of the self in this way, social comparison often plays an important role. From an early age self-concept is developed through comparison with others, with the focus of these comparisons changing with age, for example, from more physical to psychological terms (Lee & Hobson, 1998). Thus, if an individual judges his self-representation to compare unfavourably with that of others, it may lead to negative affect and a host of associated cognitive and behavioural responses.

The issue of self-representation in PDD has received very little empirical attention in the literature. Lee and Hobson (1998) administered a semi-structured interview with a low functioning PDD sample and learning disabled controls. Their results indicated that the PDD group had developed a sense of self which included constructs such as desires, preferences and an awareness of physical and psychological attributes. The authors acknowledged that the sample's ability to communicate this sort of self

understanding suggested that they had developed a sufficient 'theory of mind' to be able to reflect on themselves in relation to others. However, the PDD sample differed in that they demonstrated a relative poverty in their concept of the interpersonal self, that is, their tendency to refer to themselves in the context of social interactions or relationships. This qualitative study, although limited by a small sample size and a wide age range, makes an important contribution to the understanding of PDD self-concept, and further research, of both of a qualitative and quantitative nature is certainly warranted.

If it is the case that PDD (or, at least, HFA) individuals are able to reflect on their own self-concept, as well as introspect on internal mental states, then measures of self-competence and self-worth arguably can be validly utilised in this population. Capps, Sigman and Yirmiya (1995) employed a self-report questionnaire which measured perceived self-competence in cognitive, social and physical domains, as well as general self-worth. They found that a HFA group (well matched to typically developing controls) rated themselves significantly lower in all domains except cognitive competence. The effect size was particularly large in the social competence domain. The finding that the sample did not demonstrate the same pattern for the cognitive competence domain is important as it suggests that the result is not simply attributable to response bias. If they had scored consistently lower on all scales, this could potentially be an explanation for the results, however, the HFA group appeared to be aware that they were functioning at the same level as their peers, cognitively. This may be a judgement which could be confirmed by relatively objective information (e.g. grades at school) which lends itself well to direct comparison. Additionally, the fact that the PDD sample did not consider themselves to be less

cognitively competent, but did have lower general self worth, suggests that social and physical domains must be partly contributing to this scale.

Bauminger, Shulman and Agam (2004) administered a standardised self-report questionnaire to their HFA sample which measured self-perception across six domains including: social acceptance; scholastic competence; athletic competence; physical appearance; behavioural conduct; and general self worth. The authors pointed out that their questionnaire, unlike that used by Capps *et al* (1995), also incorporated items relating to self-perception of physical attractiveness and awareness of behavioural peculiarities. The latter in particular may be significant in this sample, as it could provide a measure of the HFA child's insight into their 'odd' or inappropriate behaviour (and thus their ability to engage in social comparison in this regard). However, it is unclear whether this sub-scale of the questionnaire is an appropriate measure in this respect as the authors did not provide detailed information with regards to the types of items contributing to this domain. The questionnaire was designed for use with typically developing children, and therefore would be unlikely to contain questions relating specifically to PDD-type behavioural abnormalities. It is also not apparent whether the social acceptance domain is concerned simply with whether the respondent perceives himself, for example, to be generally liked by others, or whether it taps attributions relating this to social skills. Thus, for example, if a respondent perceived himself to be generally rejected by others, would he attribute this to his difficulties in socialising or to the hostility of others?

In fact, the results provided only partial support for Capps *et al* (1995) finding that the HFA sample differed only in the social acceptance and athletic competence domains, in which they rated themselves significantly lower. Considered together, the findings of the two studies suggest that PDD children and adolescents are aware that their social functioning is impaired relative to their peers. They may also be aware that their social interaction skills are relatively poor, that others recognise this, and that they ignore, reject or even persecute them as a consequence.

In contrast, Green *et al* (2000), found that although the AS sample could identify their social difficulties, in a way that mirrored those reported in parental observations, they were impaired in terms of their understanding of their own role in their social difficulties. Thus, it appears that they may have made external attributions for the problems they experienced in social relationships, or simply failed to reflect upon the causes at all. They also reported that a minority of the sample had an accurate perception of the nature of their autistic disability or an awareness of why others thought them to be different. It appears that there is an important distinction to be made in such research relating to the attribution made regarding one's difficulties in forming and maintaining relationships. It would be important to distinguish whether individuals recognise that others are responding to their impaired social skills (and other PDD related disabilities) or if they simply perceive others to be hostile or unfriendly.

One factor which would inform an individual's perception of their own social functioning in relation to others, and the development of self concept, more generally, is the quantity and quality of friendships. Bauminger *et al* (2004)

investigated how the concepts of friendship, loneliness and self worth related to each other in HFA children compared to typically developing controls. Comparison of HFA and typically developing children's scores on a standardised self report questionnaire of perceived friendship quality demonstrated that the HFA sample considered their friendships to be relatively poorer across various domains except 'closeness'. This finding replicated that of an earlier study which had used the same measure (Bauminger & Kasari, 2000). A complex picture of correlations between the different friendship domains and self-competence ratings emerged from the results of Bauminger *et al* (2004), however, overall there was a trend towards HFA children with a more positive self concept also perceiving their friendships to be higher in quality. This included friendship quality being associated with a greater sense of self-worth.

Two studies investigated loneliness, utilising a standardised questionnaire, with good psychometric properties (Bauminger & Kasari, 2000; Bauminger *et al*, 2004). The results were consistent in demonstrating that the HFA groups considered themselves to be more lonely than the typically developing controls. However, the two studies differed when correlations between loneliness and friendship quality were examined. Bauminger *et al* (2004) found that HFA ratings of loneliness were highly negatively correlated with friendship quality in most domains (except 'conflict'). Bauminger and Kasari (2000), on the other hand, reported that total loneliness ratings were *not* associated with any of the friendship quality domains. These inconsistent findings are also more difficult to interpret if one considers the results for the typically developing controls. In both studies this sample did not demonstrate any significant correlations between friendship and loneliness, with the exception of a negative

association in the case of 'closeness' domain in the Bauminger and Kasari (2000) study (in contrast to the later study in which this correlation was extremely low). If we understand loneliness as being an absence of relationships which provide attributes such as companionship and closeness, then it should arguably be expected that if one perceives one's friendships to be 'better' then one would experience less loneliness. Why it should be that a HFA sample did make this connection, whilst two typically developing samples generally did not, is difficult to explain.

The relationship between loneliness and self-concept was examined by Bauminger *et al* (2004). They found that HFA children with a higher perception of themselves in the social, academic, athletic and general self-worth domains also experienced less loneliness. Interestingly, Bauminger and Kasari (2000) found that HFA and typically developing children's definitions of loneliness did not differ in terms of locus of control. Thus, HFA children were comparable with regards to their tendency to attribute their loneliness to internal factors (e.g. not knowing how to make friends) as opposed to external (e.g. because other children are mean). This is a significant finding as it supports the idea that HFA can relate their experience of loneliness to self-competence or self-attributes, rather than simply making external attributions which may not impact upon self-concept in the same way.

Overall, the findings from these two studies suggest that HFA population's apparent low sense of self worth and competence, may be, at least in part, related to their greater sense of loneliness and their perception of their friendships as poorer in quality. Crucially, what both of these studies were lacking was a more objective measure of the quality of the children's friendships. A combination of parent and

teacher reports, as well as observational measures would be valuable in providing further insight into the relationship between self-concept and social relationships in this population.

There is evidence to suggest that HFA individuals *do* have a desire to be involved in social relationships, and that they can recognise a lack of and/or poverty in such relationships. It also appears that this can impact on their self-concept. However, what has not been established is whether any of these factors contribute towards the development of mood or anxiety symptoms, as they would be expected to do in typically developing populations. Bauminger *et al* (2004) found the understanding of loneliness in their HFA sample differed significantly from controls in that their definitions were less likely to involve an affective component, for example, indicating that loneliness involves feeling sad or afraid. However, their understanding did not differ in the social-cognitive domain, for example, social exclusion or unfulfilled or unsatisfying relationships. These results can be interpreted as indicating that, whilst HFA children can engage in the process of social comparison and self-evaluation in order to develop an understanding that loneliness involves being alone, whilst desiring fulfilling relationships with others, they do not necessarily relate this to negative affect.

What is unclear is whether the lack of an *explicit* understanding of the connection between aloneness and emotions necessarily means that HFA individuals do not experience negative affect in response to loneliness. Given that emotional understanding is impaired in HFA, it would not be surprising if they also find it more difficult to attribute their experience of negative affect to particular causes. In this

respect, it would therefore have been interesting if the studies had included additional measures of mood and anxiety symptoms. Capps *et al* (1995) addressed whether there was an association between self worth and affective experience. They administered a parent report questionnaire which asked parents to rate how often they had observed their child exhibiting particular behaviours related to specific affect states, within a given time period. This included behaviours such as facial expression and tone of voice. The results showed that lower self worth was associated with *less* sadness and fear, as observed by parents. This result runs contrary to the idea that lower self worth would result in lower mood and/or anxiety symptoms, and therefore poses a challenge to the hypothesis that, although PDD individuals do not make this connection explicitly, it would be implicit in their behaviour. However, it is important to bear in mind that this measure is limited in that it relies on the parent's ability to infer their child's affective experience based on behavioural manifestations. Data suggests that the expression of affect in PDD, such as facial expressions, is impaired or abnormal, and therefore may not be as reliable an index of emotion experience as in typically developing individuals (Travis & Sigman, 1998). It would be important to see if this result could be replicated with a larger sample, inlcuding self-report of affective experience.

In conclusion, there is a small but important literature which suggests that, at least in HFA populations, PDD individuals *do* experience lower self worth, particularly in the social domain, and that this may be associated with poorer friendship quality and loneliness. How these variables impact upon affective experience remains unclear. Although all of these studies share many of the methodological limitations of the co-morbidity literature, they provide important pointers for potential further research

which may elucidate the relationship between self concept and mood and anxiety symptoms in PDD.

Etiology of Anxiety in PDD

Consideration of the possible causal factors involved in the apparent higher prevalence of anxiety and mood disorders in PDD has thus far focused on variables which may impact on the individual's sense of self. In typically developing populations self concept is related to the occurrence of depression and some anxiety disorders. However, anxiety disorders may be related to a range of other factors, including the perceived likelihood of and ability to cope with threat. One common feature of PDD is resistance to change, which may be related to a difficulty in understanding events in the environment, resulting in a perceived lack of control. Therefore, change, or potential change, may be experienced as threatening, and thus, anxiety provoking to PDD individuals. Change, or unpredictability may encompass a variety of domains, including changes in routine, plans, physical environment or social interactions which may be perceived to be unpredictable.

A further common feature of PDD which may result in anxiety is heightened sensory awareness. For example, the sound of other children in a classroom may be perceived by a PDD individual to be excessive and overwhelming and they may have a lower threshold for tolerating 'unpleasant' sensory stimulation. This sense of being overwhelmed by sensory experience may be extremely distressing for the individual and could also impair their ability to attend to and concentrate on the task at hand. In

addition, this may make the individual more sensitive to unexpected environmental stimulation, and increase the perceived need to control their environment. One way of dealing with uncertainty may be the engagement in the obsessive, ritualistic, repetitive and stereotyped behaviours, which allow the individual to exert a sense of control and predictability. As such, an increase in such behaviours may be considered as an index of a corresponding increase in anxiety. Prevention of engagement in these activities may result in heightened anxiety.

Russell and Sofronoff (2005) and Gillott *et al* (2001) examined the manifestation of anxiety symptoms in PDD with a view to developing an understanding of the factors contributing to anxiety in this population. Russell and Sofronoff (2005) investigated scores on the different subscales of the SCAS and reported that PDD children rated themselves as just as anxious as clinically anxious controls for Panic/Agoraphobia, Social Phobia, Separation Anxiety, GAD and Total Anxiety. They scored higher in the case of OCD and physical injury fears. The authors attribute the former finding to the overlap between PDD and OCD symptomatology and the latter result to their increased sensitivity to touch. While Gillott *et al* (2001) reported similar results, their sample size was too small to statistically examine the individual sub-scales. These results are interesting as they demonstrate that anxiety in PDD presents in a similar range of symptoms to that observed in clinically anxious and typically developing controls. Items included on the SCAS e.g. 'I worry about things' and 'When I have a problem I feel shaky', suggest that PDD individuals can reflect upon their anxiety states and engage in some level of cognitive processing of these states, as opposed to automatically engaging in e.g. avoidance or stereotyped behaviours as a means of anxiety relief without any awareness of the source or meaning of their anxiety. It also

suggests that the content of their anxious thoughts may be similar to typically developing children.

A further interesting result reported by Russell and Sofronoff (2005) was that there was a discrepancy between PDD scores on the SWQ (self-report version) and the Social Phobia sub-scale of the SCAS, with the sample endorsing less of the social worries included in the SWQ. The authors point out that the Social Phobia sub-scale contains items relating to covert internal states such as worries about social evaluation while the SWQ is concerned with worries relating to overt action, such initiating social contact. This may suggest that PDD individuals have thoughts relating to how they are perceived by others and experience anxiety or other negative affect in response to their perception of rejection. However, they may not make the link between these concerns and their relatively impaired social skills. The authors suggest that this explicit connection may be made later in development (their sample were aged 10-13 years old). However, it is also important to note that parents rated their PDD children higher on the SWQ, and Gillott *et al* (2001) found that their sample scored higher than controls on the self-report version of the SWQ. All together, these results suggest that for PDD individuals, the content of anxiety is often concerned with the social world,   and these thoughts seem to be concerned with how they are perceived by others, rather than being solely attributable to concerns about the unpredictability of social contact and demands.

The understanding of anxiety in PDD may potentially benefit from consideration of theories of PDD which view executive function, attention and/or arousal as primary deficits in PDD (e.g. Dawson & Lewy, 1989; Ozonoff, 1995). Although impairments

in these domains result in characteristics which are not necessarily present in many anxiety disorders (OCD being an exception), their presence in an individual could arguably make them more vulnerable to developing and maintaining anxiety symptoms. For example, a difficulty in shifting one's attention may result in excessive rumination.

The literature addressing anxiety in PDD will need to investigate issues such as whether a deterioration in anxiety symptoms, or of repetitive and stereotyped behaviours, is generally preceded by a period of change, or threat of change. Our understanding of anxiety in this population would also benefit from a detailed examination of the typical triggers and content of worries and rumination.

Conclusion

This review has presented the generally consistent finding that many PDD individuals demonstrate symptoms which appear similar to those observed in mood and anxiety disorders and that the prevalence is greater than in typically developing populations and often comparable to clinical populations. It has concluded that, despite the diagnostic overlap with PDD itself, there is evidence for the diagnostic validity of mood and anxiety co-morbidity in PDD. However, assessment remains a complex task, the nature of PDD being such that both behavioural observation and self report may be less valid measures than in typically developing populations. The current review also considered the evidence suggesting that mood and anxiety symptoms do not constitute part of the broad autism phenotype. The small co-

morbidity literature has yet to fully address the question of possible etiology. A related literature suggests that PDD populations may have an awareness of the differences between themselves and others and that this may impact on their sense of self. However, an important omission has been exploration of how this may influence mood and anxiety difficulties.

The various diagnoses which fall within the PDD spectrum demonstrate great heterogeneity in terms of symptom range and severity, level of functioning and IQ. Additionally, there can be considerable change in symptomatology and functioning across development. Thus classification is far from straightforward, even without the necessity to consider potential psychiatric co-morbidity. Meaningful assignment of diagnoses would require some degree of hierarchical decision making with regards to shared symptoms, however, the vast majority of the PDD literature has tended to ignore altogether the possibility of co-morbidity in their samples. Arguably, this trend has been to the detriment of the research involved. When presented with behaviours which would otherwise be considered to demonstrate mood or anxiety symptoms, the researcher is forced to make a rather arbitrary judgement of whether those behaviours represent PDD symptomatology. It is also important to consider the possibility that additional mood or anxiety symptoms may acerbate underlying PDD symptomatology, which has implications for the assessment of severity of PDD. A lack of consensus with regards to classification in this respect has implications for both validity and reliability of findings in the literature, and thus also for theory.

There are similar implications for the clinical sphere, both in terms of individual diagnosis and treatment plans and the larger scale evaluations of interventions. Both

the research and clinical fields would benefit from the development of assessment tools which include questions relating to a wider range of symptoms and are also concerned with *change* in symptomatology. One approach may be to consider the degree of pervasiveness of a behaviour or impairment across contexts and time. For example, there has been some evidence to suggest that a substantial proportion of PDD individuals experience a deterioration in cognitive function during adolescence, which in many cases resolves itself within a relatively brief time period (Mesibov & Handlan, 1997) and it is possible that these periods represent undiagnosed episodes of depression. Arguably, the literature provides further evidence supporting the need for in-depth individual case formulations, which look beyond a simple diagnosis of PDD. Interventions could then be tailored to individuals which take into consideration the full range of presentation, and which attempt to explore the possible association and primacy of different symptoms. Developments in the literature with regards to the validity of self report will also be very helpful, both in terms of potentially providing a further source of information, and an additional means of evaluating outcomes.

The theoretical implications of the existence of co-morbidity in PDD will become clearer as our understanding of its manifestation and etiology develops. However, as things stand, it is important to be mindful that not all PDD individuals present with additional mood and anxiety symptoms. Arguably, one implication of the literature is that it increases the degree of heterogeneity in the population, thus further complicating the task of developing a unified theory to explain the full spectrum of behaviours and impairments characteristic of, and associated with, the disorders.

From a developmental psychopathology perspective, the occurrence of additional mood and anxiety difficulties in PDD would be likely to contribute to increased multifinality, that is, increased diversity in outcomes and developmental pathways. The idiosyncratic behavioural, psychological and functional profile of a given individual with PDD, and the degree of stability of this profile over their life-span would be the result of complex interrelations between that individual and their environment. Longitudinal designs are particularly important when attempting to elucidate complex developmental pathways, an approach rarely utilised in the PDD literature. However, Sigman (1998) has demonstrated that some early achievements in communication and social skills in PDD can predict later capacities and level of functioning. It is important to determine what aspects of the child and their environment foster the development of particular skills, or deficits, in order to inform both the theoretical and clinical fields. Mood and anxiety difficulties may be considered to be factors which contribute to such variation in outcomes. Similarly, the characteristic deficits of PDD may be seen as enduring risk factors for the development of mood and anxiety disorders. Dynamic transactions occur between the individual in their environment in which they exert a reciprocal influence on each other. For example, the increased levels of mood and anxiety difficulties in the parents of PDD children may be expected to increase the risk of the child developing their own mood and anxiety difficulties via the same mechanisms implicated in typically developing populations, such as shared genetic liability and parenting style. However, the behaviour of the PDD child may further amplify this maladaptive pattern by, for example, increasing the practical and emotional demands on the parent and thus intensifying their mood and anxiety symptoms. Similarly, from this transactional perspective, social avoidance resulting from a difficulty in

understanding social communication may be reinforced if the individual's attempts at interacting with others are repeatedly met with negative and rejecting responses. Social anxiety may be more likely to develop in this context, maintained by avoidance.

The complexity of these interrelationships means that it is difficult to know to what degree the risk and resilience factors identified for mood and anxiety disorders may be equally relevant in individuals who are also PDD. Additionally, PDD individuals may respond differently to particular developmental challenges, such as puberty and their vulnerabilities to certain disorders may emerge in different contexts or developmental periods than in typically developing populations. Longitudinal designs could be employed in contrasting the presentation and course of PDD individuals with and without co-morbid psychiatric difficulties across maturational stages and life events.

Despite the complexity of elucidating these factors and the inherent difficulties involved in the empirical study of co-morbidity in PDD, the potential utility of such research for both the theoretical and clinical fields would be invaluable.

Link To Empirical Paper

The following Empirical Paper will aim to expand the understanding of the occurrence of mood and anxiety difficulties in PDD by investigating sex as a possible factor. It will examine whether there are any differences in levels of mood and anxiety difficulties in male and female PDD participants and will also look at whether sex differences are present in PDD severity ratings. In addition, it will investigate whether any association exists between mood and anxiety difficulties and PDD severity, across the three domains of impairment.

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Part Two: Empirical Paper

Sex Differences in Internalising Behaviours and Pervasive Developmental

Disorder Symptoms in Children and Adolescents with Pervasive Developmental

Disorders

Abstract

Individuals with Pervasive Developmental Disorders (PDD) are increasingly recognised as suffering from elevated levels of anxiety and mood difficulties but sex has received little empirical attention as a possible factor. The present study examined levels of parental ratings of internalising behaviours in a child and adolescent (aged 3 to 16 years) high functioning PDD sample (n = 62) as compared to an age and verbal IQ matched typically developing sample (n = 62). Sex differences were investigated in terms of both levels of internalising behaviours and PDD severity ratings. Parental report questionnaires were used as measures of internalising behaviours and scores obtained from a computerised diagnostic parental interview were used as a measure of PDD severity across the three domains of impairment. The PDD group demonstrated significantly higher levels of parent rated internalising behaviours than controls. PDD females were found to have significantly higher internalising scores than PDD males, a sex difference not apparent in the control sample. No sex differences were demonstrated in PDD severity in the PDD sample. Some associations were found between the measures of internalising behaviours and PDD severity ratings. These results suggest that PDD females may be even more vulnerable to developing additional internalising behaviours than their male counterparts.

Introduction

Co-morbidity of Mood and Anxiety Disorders in PDD

Pervasive Developmental Disorder (PDD) is a group of disorders characterized by qualitative abnormalities in (a) reciprocal social interactions, (b) in patterns of communication, and (c) by a restricted, stereotyped, repetitive repertoire of interests and activities (World Health Organisation, 1992). Subtypes include: autism, in which abnormality is demonstrated in all three domains; Aspergers syndrome (AS), which differs from autism in that there is no general delay in language or cognitive development; and, atypical autism in which the diagnostic threshold is met in only two of the three domains (World Health Organisation, 1992). The term 'high functioning' denotes an IQ above 70.

A range of behavioural and psychological difficulties may be observed in addition to the core features of PDD but once a diagnosis of PDD has been given, further problematic symptoms are usually attributed to the PDD. However, there is an emerging literature concerned with the identification and understanding of mood and anxiety disorders in PDD. Earlier studies mainly involved case series or did not include comparisons with typically developing controls (e.g. Ghazziuddin & Tsai, 1991; Rumsey, Rappoport & Sceery, 1985) but recently, larger scale, empirical studies have consistently demonstrated the prevalence rates of mood and anxiety symptoms to be elevated in PDD relative to typically developing controls, with levels often comparable to clinical samples (Gadow, Devincent, Pomeroy & Azizian, 2004;

Gadow, Devincent, Pomeroy & Azizian, 2005; Gillott, Furniss & Walter, 2001; Hill, Berthoz & Frith, 2004; Green, Gilchrist, Burton & Cox, 2000; Kim, Szatmari, Bryson, Streiner & Wilson, 2000; Russell & Sofronoff, 2005).

Diagnostic and Assessment Issues

An important concern is the diagnostic validity of psychiatric co-morbidity in PDD. Can symptoms of anxiety and depression be considered to represent discrete, classifiable disorders or are they simply manifestations of the underlying PDD? Evidence for the former argument includes the finding that some factors associated with the occurrence of mood and anxiety disorders are apparent in both typically developing and PDD populations. For example, Ghaziuddin, Alessi and Greden (1995) reported that, as in typically developing populations, a PDD sample with apparent co-morbid depression had experienced significantly more negative life events prior to onset than a non-depressed PDD control group. A depressed PDD sample was also found to have significantly higher rates of depression in their first degree relatives than a non-depressed PDD group (Ghaziuddin & Greden, 1998), a pattern also observed in typically developing populations. Additionally, if mood and anxiety symptoms are simply manifestations of PDD then one may expect a large correlation between PDD severity scores and mood and anxiety symptoms. In the only study to directly address this issue, Kim et al (2000) reported that contrary to their hypothesis, this association was not demonstrated for any of the three PDD domains. In a similar vein, Gadow et al (2005) examined the variation in scores for internalising disorders according to PDD subtype and found that the Aspergers and atypical autism groups demonstrated greater severity for some internalising

disorders. However, it should be noted that PDD subtype diagnosis is not analogous to severity of PDD.

Discrimination between PDD and mood and anxiety symptomatology is complicated by the diagnostic overlap between mood and anxiety disorders and PDD (e.g. social avoidance). The task of differential diagnosis is complex and no formal guidelines or recommendations exist regarding assessment. Lainhart and Folstein (1994) approached this issue by utilising the criterion of *change* in presentation as indicating the onset of mood disorder in their review of 17 published case studies. However, most of the literature has employed parental, teacher and/or self-report questionnaires developed for typically developing populations as measures of mood and anxiety symptoms. Although these measures have not been developed or standardised for use in PDD populations, in the absence of alternatives they remain important research tools. For example, although there are limitations in the use of self-report measures, it appears, at least in high functioning PDD individuals, that they are able to introspect and have sufficient understanding of their own affective and cognitive experience to respond to these measures. However, their abilities in this respect are likely to be impaired relative to typically developing populations (e.g. Capps, Yirmiya & Sigman, 1992; Gillott *et al*, 2001; Hill *et al*, 2004; Lee & Hobson, 1998; Russell & Sofronoff, 2005).

Co-Morbidity and IQ

There is some inconsistency in the literature with regards to the association between prevalence rates and IQ. However, overall, in contrast to the literature in learning

disabilities, in which lower IQ seems to be associated with higher rates of mood and anxiety problems, in PDD the opposite appears to be the case (Kim *et al*, 2000). This finding may be attributed to higher functioning individuals' greater ability to articulate their difficulties to others. However, other authors have suggested that higher functioning individuals may be more vulnerable to developing anxiety and mood problems due to increased awareness of their difficulties relative to others. This idea is supported by the finding that higher functioning individuals consider themselves to be less competent and to have lower self worth (Capps, Sigman & Yirmiya, 1995). There also appears to be an association between the ability to understand others and a negative view of the self (Sigman *et al*, 1997).

Sex Differences in the Prevalence Rates of PDD

A further relatively neglected area in the PDD literature has been that of sex differences. PDD has consistently been shown to demonstrate a male preponderance, with a sex ratio in the range of 4:1 to 7:1 (Rutter, Caspi & Moffitt, 2003). Some studies have suggested that females may be disproportionately represented at the lower end of the IQ range (Lord, Schopler & Revikci, 1982; Wing, 1981). In addition to the issue of relative prevalence rates, other authors have queried whether there are sex differences in the severity or distribution of PDD symptoms. McLennan, Lord and Schopler (1993) and Pillowsky, Yirmiya, Shulman and Dover (1998) both compared scores on the Autism Diagnostic Interview (ADI) (Lord, Rutter & Lecouteur, 1994) for males and females and found few significant differences of note. However, Szatmari (2002) found that females demonstrated significantly lower

symptom severity. An important consideration is whether the pattern of symptomatology differs between the sexes, and may therefore necessitate different diagnostic criteria for males and females (Rutter *et al*, 2003 and Pilowsky *et al*, 1998). However, research aiming to answer this particular question has been limited by the prohibitively low numbers of females in most clinical samples.

Sex Differences in Mood and Anxiety Symptoms in PDD

Thus, sex differences have rarely been considered in relation to mood and anxiety symptoms in PDD. Lainhart and Folstein (1994) noted that females were disproportionately represented (47%) in their case study review of individuals with PDD and affective disorders, however, the absence of matched typically developing controls meant that it was difficult to ascertain whether this simply mirrored the higher incidence of depression in typically developing females. Gadow *et al* (2004) and Gadow *et al* (2005), with large sample sizes included sex as a variable (136 males, 36 females and 242 males, 42 females respectively). They proposed that if the distribution of symptoms in males and females was similar for PDD and comparison groups then this provided further support for the idea that additional psychiatric symptomatology in PDD represented true psychiatric syndromes. Gadow *et al* (2005), in their sample of 7-10 year olds, reported a complex picture of sex differences which varied by informant (ie whether parent or teacher report), but overall there were few sex differences within the PDD groups. Interestingly, this contrasted with the typically developing sample, in which males tended to score higher for externalising disorders. A similar pattern of results was demonstrated in 3-5 year olds (Gadow *et al*, 2004). However, it is important to note that these studies

employed a questionnaire which produced scores for psychiatric categories (e.g. GAD, dysthymia) rather than being a more general measure of internalising behaviours. This is arguably an inappropriate for pre-school samples in which the validity of such psychiatric categories has not yet been established. Additionally, the samples were restricted in age ranges and may therefore not be generalisable to older children and adolescents.

Despite the absence of sex differences in mood and anxiety symptoms demonstrated in the above studies, consideration of findings from the typically developing sex differences literature suggests that PDD females might arguably be expected to experience a greater degree of these symptoms relative to PDD males.

The Potential Role of Parenting Factors

A relatively consistent and robust finding within the typically developing literature is that females develop language and social skills earlier than males, and this is attributed to a combination (and interaction) of biological and socialisation factors (Keenan & Shaw, 1997). Parents of children as young as two years have differing expectations for the behaviour of their sons and daughters and demonstrate different parenting approaches accordingly. For example, empathy and prosocial behaviour are encouraged more in daughters than sons even at this young age (Keenan & Shaw, 1997). In this respect, the behaviour of a young PDD female would deviate from gender norms to a greater extent than that of a PDD male and an important question concerns how parents might respond to this deviation.

There is strong evidence, at least in typically developing populations, that child-rearing practices are associated with the development of internalising behaviours in the child. Specifically, controlling and rejecting parenting styles are associated with anxiety and depression respectively (Rapee, 1997). There is also some evidence to suggest that parents are more likely to adopt a protective and controlling parenting style with their daughters than with their sons (e.g. Pomerantz & Ruble, 1998). There are no studies which address whether PDD females are treated any differently by their parents than PDD males. However, it is possible that behaviour which is perceived to be even more 'unusual' relative to same-sex peers would be more likely to elicit a rejecting or controlling response from parents.

The Potential Role of Peer Relations

In typically developing populations, particularly from middle childhood, rejection (including victimisation) by peers and internalising behaviours are strongly associated (Deater-Deckard, 2001). However, this relationship has not been directly established in PDD populations. It could be argued that, as PDD individuals are less socially orientated and experience difficulties in understanding others' behaviour, peer rejection would have little impact upon their sense of well-being or behaviour. However, Capps *et al* (1995) found that a high functioning PDD sample reported lower general self worth and self competence than typically developing controls and this was particularly marked for their self-perception of social competence. Interestingly, their self perception of cognitive competence did not differ from the controls, suggesting that this finding was not simply attributable to response bias. Similar results were reported by Bauminger, Shulman and Agam (2004), who also

found that a more negative self-concept was associated with greater self-reported loneliness and self-perception of poorer friendship quality. This suggests that PDD individuals can recognise an absence and poverty of relationships and that this impacts upon their self-concept. Low self-esteem is generally associated with low mood in typically developing populations, but this relationship has yet to be established in PDD populations.

Although Capps *et al* (1995) and Bauminger *et al* (2004) did not address sex differences, it is possible that PDD females are more likely to experience rejection by peers. Deviation from sex norms may be responded to negatively by peers as well as by parents, for example, prosocial behaviour is favoured by peers in both sexes, however, females may be expected to exhibit such behaviours to a greater degree (Deater-Deckard, 2001). Female relationships become relatively more relationally orientated through childhood and adolescence, demanding a sophistication in social interaction skills and understanding which would place PDD females at a greater disadvantage. Indeed, it appears that PDD females have significantly fewer friendships than their male counterparts (McLennan *et al*, 1993). In typically developing populations, having at least one close friend has been found to be an important protective factor both in terms of risk and consequences of victimisation (Deater-Deckard, 2001). A further important consideration is hormonal influences, specifically oxytocin, whose increased levels in adolescent females is thought to intensify the drive for attachment and affiliation (Cyranowski, Frank, Young & Shear, 2000). There is no reason to expect that these same biological factors are not

active in PDD females, resulting in an increased desire for social relationships coupled with an impaired ability to develop or sustain them.

Additionally, by adolescence, a tendency to pursue stereotypically male interests or activities is associated with rejection by female peers (Nolen-Hoeksema & Girgus, 1994). PDD individuals characteristically demonstrate preoccupation, often to an obsessive degree, with a relatively narrow range of interests. Orsmond, Krauss and Seltzer (2004), found that PDD friendships were typically focused on such shared and circumscribed interests, with little social interaction involved. Many interests, hobbies and activities, for example, computer games or collecting objects, may be considered to be stereotypically 'male', and thus viewed as odd or inappropriate by peers and even family of PDD females. The higher incidence of PDD (and PDD traits) in males may also mean that it is easier for PDD males to find a like-minded companion in their school or community. A final consideration is that the unequal sex ratio in PDD may also contribute to the perceived peculiarity of PDD females, not only in comparison to typically developing females, but also to PDD males.

The present study involves participants who have received a diagnosis of either autism or atypical autism. The adoption of wider inclusion criteria will go some way to addressing the concerns relating to the applicability of the current PDD diagnostic criteria to females.

Hypotheses

The first hypothesis of the present study was that the PDD group would demonstrate higher scores on the three internalising sub-scales (Anxious-Shy, Psychosomatic and Emotion) than typically developing controls. The second hypothesis was that PDD females would score higher on the internalising sub-scales than PDD males, and that the magnitude of this sex difference would be greater than that for the typically developing group. The third hypothesis was that there would not be any association between scores on the internalising sub-scales and severity of PDD across the three domains. Finally, the study aimed to explore whether PDD males and females differ with respect to severity of PDD symptoms.

<u>Method</u>

Sample

The PDD sample involved children and adolescents, aged 3 to16 years old, who had been seen at a specialist PDD assessment clinic between 1999 and 2006 and who had received a diagnosis of autism, AS or atypical autism. Assessments included the administration of a detailed, semi-structured parental interview, the Developmental, Dimensional and Diagnostic Interview - "3di" (Skuse *et al*, 2004) by a clinician qualified in its use. This standardised computerised assessment produces scores indicating degree of impairment in the three PDD domains (Reciprocal Social

Interaction, Use of Language and Other Social Communication Skills, Repetitive and Stereotyped Behaviour). In addition, the final diagnosis was confirmed by informal observation of the child during the assessment process by a team of psychiatrists and psychologists. Parents also completed a wide range of questionnaires relating to their child's behaviour prior to attending the clinic. The majority of children underwent a neuropsychological assessment, either in their home or in the clinic, in order to ascertain IQ. Tests employed for this purpose were, in most cases, the British Picture Vocabulary Scale (BPVS; Dunn, 1982) and the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). The assessment clinic was part of a national children's hospital, with referrals coming from across the UK and it was therefore a heterogeneous sample in terms of ethnicity and socio-economic status.

31 females met the inclusion criteria. These were: (a) scores above the diagnostic threshold in at least two of the three PDD domains (b) verbal IQ within the normal range (i.e. 70-130), and (c) complete data available for the two questionnaire measures. A sample of 31 males who also fulfilled the inclusion criteria was matched to the females for chronological age and verbal IQ scores.

The typically developing sample were recruited from mainstream schools and nurseries within London and were screened to ensure the absence of clinically significant PDD symptoms. A final sample of 31 males and 31 females was matched to the clinical sample for chronological age and verbal IQ.

Group characteristics are presented in Table 1. Examination of verbal IQ distributions revealed a slight negative skew for all four groups, which reflects the

verbal IQ distribution of PDD females involved in this study . However, the skewness and kurtosis values demonstrated that the skew was non-significant for all four groups for both IQ and age. One way ANOVAs were carried out for both age and IQ. No significant differences were found between the four groups for either variable, demonstrating that they are well matched. A balanced group design was used.

Measures

Two of the questionnaires completed by parents as part of the assessment process at the PDD assessment clinic were employed in the present study as measures of internalising behaviour. One was the Conners Parent Rating Scale-Revised (CPRS-R; Connors, Sitarenios, Parker & Epstein, 1998) a questionnaire of parental report of childhood behaviour problems. It is a measure widely used in research and clinical settings, which demonstrates adequate psychometric properties overall. In terms of reliability the coefficient alphas range from .75 to .94 for the seven sub-scales. Test-retest reliability ranges from .13 to.78. Sensitivity is 92.3%, specificity 94.5% and kappa .87 (Connors *et al*, 1998). It includes seven sub-scales, however, only two of the sub-scales were of interest in the present study, namely 'Anxious-Shy' and 'Psychosomatic'. Examples of items include "Timid, easily frightened" and "Aches and pains" for 'Anxious-Shy' and 'Psychosomatic' respectively. It is scored on a four point Likert scale with a maximum score of 24 for each sub-scale. The questionnaire was adapted for the purposes of the current study to exclude questions

from the externalising sub-scales. This was negotiated with the publishers of the CPRS-R.

The second measure used was the Strength and Difficulties Questionnaire (SDQ; Goodman, 1997), a brief measure of psychopathology and adjustment in children and adolescents. It is a widely employed clinical and research tool which demonstrates good psychometric properties. Internal consistency is satisfactory with a mean Chronbach's alpha coefficient of .73 and retest stability is .62. Scores above the 90th percentile were associated with a substantial increase in psychiatric risk with an odds ratio of 15 (Goodman, 2001). In the current study the entire questionnaire was administered to parents but only the 'Emotion' sub-scale results were used. An example of one of the five questions contributing to this sub-scale is "Often unhappy, downhearted or tearful". It is scored on a three point Likert scale and the maximum score of the 'Emotion' sub-scale is 10.

The typically developing sample was screened for PDD symptoms using the Social and Communication Disorders Checklist (SCDC; Skuse, Mandy & Scourfield, 2005). This is a brief rating scale, designed as a screening tool for PDD traits in individuals with IQs in the normal range and can be completed independently by parents. Internal consistency is high with a Cronbach's alpha coefficient value of .93 and retest stability is .81. In terms of discriminant validity, a cut-off score was identified with sensitivity of .90 and specificity of .69. Criterion validity was modest at .38 but was significant (Skuse *et al*, 2005). It is scored on a three point Likert scale with a maximum score of 24, an example of an question from the 'Emotion' sub-scale is "Not aware of other people's feelings". The recommended cut-off score

indicative of a *possible* PDD diagnosis was utilised in the current study with participants in the typically developing sample scoring above this excluded from the study.

The assessment of verbal IQ in the typically developing sample involved the administration of the 'Vocabulary' sub-scale of the WASI for participants aged between six and sixteen years old. For younger participants the BPVS was employed. For the purposes of the current study only *estimates* of verbal IQ were required, and it was not presumed that either the 'Vocabulary' sub-scale or the BPVS represented a complete and accurate measure of verbal IQ.

Table 1. Sample Characteristics

	PDD Females (N=31)	PDD Males (N=31)	Typ.Devel. Females (N=31)	Typ.Devel. Males (N=31)
VIQ (M/SD)	96.2 (10.5)	97.0 (11.6)	94.6 (13.2)	96.1 (12.6)
VIQ Range	76 – 121	76 – 122	73 –124	71 – 118
Age (M/SD)	9.3 (3.5)	9.3 (3.5)	9.7 (3.5)	10.0 (3.2)
Age Range	3.0 – 16.5	3.4 – 16.2	3.5 – 16.7	3.4 – 16.7

Procedure

Ethical approval for the study was sought and granted by University College London Ethics Board.

The typically developing sample was recruited in three ways. One involved re-contacting control participants (i.e. recruited from mainstream schools) who had been involved in previous research carried out in the academic department associated with the PDD assessment clinic. The previous study had involved the children being administered sub-scales from the WASI in their schools and this data is held on a database. The parents of children who met inclusion criteria in terms of age and verbal IQ were contacted by post and, in some cases, by phone and asked if they would be interested in participating in the current study. Those who gave written consent were sent the three questionnaires to complete in their own time. Parents were encouraged to contact the author should they have any questions relating to the questionnaires or the study itself.

The second method involved recruiting families directly through their school or nursery. Information sheets and consent forms were distributed by the teachers to parents and when written consent was obtained, children were seen individually in a separate classroom for the neuropsychological assessment. Parents were then sent the questionnaires in the post, as above. Finally, a small number of the participants involved in the above methods of recruitment had siblings who were assessed in their own homes. In these cases the parents completed the questionnaires in the presence of the researcher.

Analyses

The SPSS statistical package was used for all analyses. The planned analyses were as follows: A multivariate analysis of variance was performed to address the first two hypotheses as there was more than one dependent variable (Anxious-Shy, Psychosomatic and Emotion) which could not simply be combined. It is also a test which enables identification of interactions among two independent variables (Group and Sex). Subsequent univariate analyses were planned in the event of a significant effect in order to examine the three Internalising sub-scales independently. Bivariate correlations were planned in order to examine possible associations between the three Internalising sub-scales (Anxious-Shy, Psychosomatic, Emotion) and the three PDD domains (Reciprocal Social Interaction, Use of Language and Other Social Communication Skills, Repetitive and Stereotyped Behaviour) for the PDD sample only. Finally, sex differences within the PDD sample were examined across the three PDD domains using a MANOVA, and this was followed up with independent samples t-tests looking at sex differences within the three PDD domains.

Post-hoc analyses were carried out in order to examine whether Internalising scores were influenced by age. Bivariate correlations were carried out for each of the three Internalising sub-scales for each of the four groups (i.e. PDD males and females and typically developing males and females).

Finally, a post-hoc power analysis was carried out to determine whether the study had sufficient power to detect an interaction between Group and Sex.

Results

The first hypothesis was that the PDD group would demonstrate higher parental ratings of internalising behaviours than typically developing controls. The second hypothesis was that PDD females would score higher on the internalising measures than PDD males, and that the magnitude of this sex difference would be greater than that for the typically developing group. The third hypothesis was that there would not be any association between scores on the internalising measures and severity of PDD across the three domains. The final hypothesis involved identifying whether PDD males and females differ with respect to severity of PDD symptoms. In addition two post-hoc analysis were carried out, one examining associations between age and internalising scores and the other a post-hoc power analysis of the interaction between group and sex.

The response rate for the return of the questionnaires in the typically developing sample was as follows: the first method of recruitment resulted in a 31.4% response rate and the second method resulted in a 13.3% response rate. The third method, which involved further participation by a small number of families who had already completed questionnaires had a 100% response rate.

A significant main effect for Group confirmed, in line with the first hypothesis, that the PDD group demonstrated more Internalising behaviours than the typically developing group ($F = 14.2$ (3, 118), $p < .001$). Follow up tests revealed that the PDD group scored higher for the Anxious-Shy ($F = 35.5$ (1, 120), $p < .001$),

Psychosomatic ($F = 28.9$ (1, 120), $p < .001$) and Emotion ($F = 34.7$ (1, 120), $p < .001$) sub-scales. The effect size for overall Internalising behaviours was 0.54 (medium). For the Anxious-Shy, Psychosomatic and Emotion sub-scales the effect sizes were 0.47 (medium), 0.39 (small) and 0.45 (medium) respectively.

With regards to the second hypothesis, although there was no significant main effect for Sex, there was a significant interaction between Group and Sex for the combined Internalising scores ($F = 3.17$ (3, 118), $p = .03$). Follow up tests showed that the Group x Sex interaction was significant for the Psychosomatic sub-scale ($F = 6.3$ (1, 120), $p = .01$) with PDD females scoring higher than PDD males. The same applied for the Emotion sub-scale ($F = 6.0$ (1, 120), $p = .02$). The effect sizes for Emotion and Psychosomatic were small (0.10 in both cases). Although PDD females scored higher on the Anxious-Shy sub-scale than PDD males, the interaction did not reach significance. See Table 2.

Table 2. Mean Internalising Sub-Scale Scores (and Standard Deviations)

	PDD Females	PDD Males	Typ. Devel. Females	Typ. Devel. Males
Anxious-Shy	10.1 (6.9)	8.4 (5.9)	3.3 (3.9)	3.6 (4.4)
Psychosomatic	6.7 (5.0)	4.1 (3.4)	1.6 (1.8)	2.3 (3.3)
Emotion	5.5 (3.3)	3.6 (2.6)	1.7 (1.9)	2.1 (2.2)

The third hypothesis concerned the possible associations between the three Internalising sub-scales and the three PDD domains (see Table 3.). The only significant correlations were between Anxious-Shy and the Reciprocal Social

Interaction domain (r = .36, p = .004) and between Anxious-Shy and the Repetitive

and Stereotyped Behaviour domain (r = .27, p = .03). The results for the fourth

hypothesis demonstrated that within the PDD group there were no sex differences in

the scores of any of the three PDD domain scores.

Table 3. Correlations Between the Internalising Sub-Scales and PDD Domains

	Reciprocal Social Interaction	Use of Language and Other Communication Skills	Repetitive and Stereotyped Behaviours
Anxious-Shy	0.36 **	0.11	0.27 *
Psychosomatic	0.20	0.13	0.24
Emotion	0.20	0.02	0.09

** Correlation is significant at the 0.01 level (2-tailed).
 * Correlation is significant at the 0.05 level (2-tailed).

A post-hoc analysis examined whether there was an association between age and

Internalising scores. For each of the four groups bivariate correlations were carried

out between age and each of the three Internalising sub-scales. None of these

correlations reached significance.

Finally, A post-hoc power analysis was carried out using the G*Power3 program

(Faul, Erdflder, Lang & Buchner, in press). Data inputted included the effect size for

the interaction (0.08), an alpha value of 0.05, the total sample size (124) and the

number of predictors and dependents (two and three). According to this program, the

study had 93% power to detect an interaction between Group and Sex.

Discussion

The current study found that participants with PDD scored higher on parental ratings of internalising behaviours than typically developing participants. Females with PDD were found to score higher on overall internalising scores than males with PDD, a sex difference which was not demonstrated in the typically developing sample. Specifically, PDD females scored higher for Psychosomatic and Emotion but did not differ from the PDD males in their Anxious-Shy scores. With regards to associations between scores on the three Internalising scales and the three PDD domains, the only significant associations were between Anxious-Shy and Reciprocal Social Interaction and between Anxious-Shy and Repetitive and Stereotyped Behaviours. No sex differences were found in the severity scores of the three PDD domains. A post-hoc analysis showed that there was no association between age and Internalising scores within any of the groups. Finally, a post-hoc power analysis demonstrated that there was sufficient power to detect the interaction between Group and Sex.

The current study provided further support for the consistent finding that individuals with PDD score higher on measures of internalising behaviours than typically developing controls (Gadow *et al*, 2004; Gadow *et al*, 2005; Gillott *et al*, 2001; Hill *et al*, 2004; Green *et al*, 2000; Kim *et al*, 2000; Russell & Sofronoff, 2005). Within this high functioning sample, according to parental observation, emotional and anxious behaviour appeared to be elevated. Items contributing to these scales included consideration of fearfulness, avoidance, low mood and somatic symptoms. Of particular interest was the finding that two of the internalising sub-scales, Emotion and Psychosomatic were not significantly correlated with any of the three

PDD sub-domains. This result replicated that of Kim *et al* (2000) who reported that anxiety levels were not associated with scores of PDD severity. This is an important finding as it addresses a commonly cited limitation of the co-morbidity literature, namely, that internalising behaviours may simply be a manifestation of PDD symptomatology. However, if this were the case, one might expect a very high correlation between the two factors. The absence of an association for the Emotion and Psychosomatic scales suggests that these elevated scores cannot simply be attributed to the severity of PDD symptomatology. Although causal factors cannot be inferred from the present design, it is possible that, in this high functioning group, the presence of clinically significant PDD symptoms, regardless of severity, is enough to mark a child out as different to others. If the child has an awareness of this difference it may impact upon their self-esteem, resulting in low mood, anxiety and the manifestation of somatic symptoms.

However, the findings of Kim *et al* (2000) were not fully supported, in that the Anxious-Shy sub-scale did demonstrate a significant moderate correlation with two of the PDD domains. The association between the Anxious-Shy sub-scale and the Reciprocal Social Interaction domain may be understood by considering the degree of overlap between the types of behaviours contributing to the two scales. For example, Anxious-Shy items include reference to withdrawn, socially anxious behaviour and difficulties in forming and maintaining friendships. These types of difficulties are characteristic of the Reciprocal Social Interaction domain. With regards to the association between Anxious-Shy and Repetitive and Stereotyped Behaviour, may be that ritualistic and obsessive behaviour is a manifestation and/or means of managing underlying anxiety. The resistance to change and unpredictability

in the environment characteristic of many individuals with PDD may underlie this association. Thus, engagement in behaviours which enable the individual to exert some sense of control over his/her environment, may provide relief from underlying anxiety and may even address the source of the anxiety. Considering the overlap in symptoms and close inter-relationship between the Anxious-Shy sub-scale and the above PDD domains it is perhaps unsurprising that correlations should exist. However, understanding the relationship between these three factors remains a complex task, and is beyond the scope of the current design.

The present study employed broader diagnostic boundaries than many in the PDD literature by including atypical autism. This arguably better equipped the study to address the question of sex differences in PDD symptomatology. Some authors (e.g. Rutter *et al*, 2003) have questioned the applicability of the existing diagnostic criteria for PDD females, suggesting that the pattern or severity of symptoms may differ. The finding that no sex differences were demonstrated in PDD severity across the three domains does not provide support for this hypothesis, replicating the findings of McLennan *et al* (1993) and Pilowsky *et al* (1998). However, although the study's design allows for examination of severity and pattern of symptoms in terms of comparison across the three PDD domains, it did not explore the distribution of symptoms within the domains. Additionally, although the inclusion criteria were broader, it still could be argued that females require different diagnostic criteria and that those included in the sample are therefore not representative of PDD females in the general population. The issue of referral bias is also very relevant in this respect and will be discussed in more depth below.

The current study contributes to the PDD co-morbidity literature by investigating sex as a factor in internalising behaviour. PDD females were found to demonstrate higher parental ratings of overall internalising behaviours than PDD males, a sex difference not present in the typically developing sample. Closer inspection of the results revealed that PDD females' higher internalising scores were restricted to the Psychosomatic and Emotion sub-scales, with Anxious-Shy scores not differing significantly between PDD females and males. The finding that PDD females score higher than PDD males for parental ratings of overall internalising behaviours is consistent with the study's hypothesis. It has been suggested here that this result can be attributed to the greater discrepancy between the behaviour of PDD females and typically developing females relative to PDD males and typically developing males. PDD females' more pronounced deviation from gender norms may result in a more rejecting and controlling parent style and increased rejection by peers. Both of these factors may contribute to the development of internalising behaviours in PDD females. This could particularly be the case for higher functioning individuals who are more likely to comprehend how they differ from others, perceive their rejection and understand the relationship between the two.

However, why it should be the case that PDD females' increased internalising is restricted to behaviours in the Emotion and Psychosomatic sub-scales is less clear. It is worth considering that Anxious-Shy correlated with two of the PDD domains and that no sex differences were demonstrated in PDD severity. It may be that the high degree of overlap between items contributing to the Anxious-Shy sub-scale and the two PDD domains mask small sex differences in anxiety behaviour.

It is not clear why the sex difference in internalising scores demonstrated here was not apparent in Gadow *et al* (2004) and Gadow *et al* (2005). It is possible that this could be attributed to the wider age range employed in the current study, the types of behaviour addressed in their measure or differences in the PDD sample profiles. However, it is interesting to note that in the Gadow *et al* (2005) study the PDD males did not demonstrate higher externalising behaviour scores than the PDD females, a difference which was present in their typically developing sample. This suggests that the PDD females presented with higher levels of externalising behaviour than might be expected. The current study did not include measures of externalising behaviour, however, it is important to consider that anxiety and emotional distress may also be expressed in this form of behaviour. Externalising behaviours are often more apparent to parents, more readily identified as problematic and considered to be more characteristic of boys (Crick & Zahn-Waxler, 2003). It is possible that within the context of a female demonstrating a range of PDD symptoms, additional anxiety or mood problems are less likely to be identified by parents than are externalising behaviours.

An important consideration in relation to the finding of sex differences in internalising behaviour is that this difference may reflect the different manifestation of PDD in females. As discussed above, PDD females may present with a different pattern of symptoms than males, perhaps even with additional symptoms. It is possible that as part of the female profile of PDD there is a greater propensity for expression of the disorder in internalising symptoms, specifically, in emotional or somatic symptoms. However, testing this specific hypothesis is far from straightforward. The absence of an established genetic marker (or markers),

neurological or neurochemical basis with which to definitively identify individuals with PDD means that diagnosis relies on presenting symptomatology. Thus, large scale, epidemiological studies are required to clarify the issue of potential sex differences in PDD.

In Lainhart and Folstein's (1994) review of, mainly adult, depressed PDD case studies almost half of the cases were female. It was hypothesised by the authors that the sex difference in internalising behaviours may become more pronounced in adolescence and adulthood (as in typically developing populations). The post-hoc analysis included in this study aimed to address this question, but found no association between age and internalising scores. However, it is important to note that the present sample included few adolescents, with only eight out of 31 in each group being 12 years or older. It is possible that a significant association may have been found if there had been more adolescents involved.

Limitations

The study's clinical sample was recruited from an assessment clinic which receives referrals from across the UK. Some of these originate from parts of the country where there is a shortage of staff qualified to make a diagnosis, however, others concern more complex cases in which a specialist assessment is deemed necessary. It is therefore important to consider that the PDD sample may not have been fully representative, an issue which has important implications for the interpretation of the results. It is possible that more internalising behaviours may have resulted in the

participants missing out on an earlier diagnosis as they presented with a more complex picture of symptomatology. Thus, the increased levels of internalising behaviours could arguably be attributed to sample characteristics. However, another important feature of the sample was that they all had IQs in the normal range. Although high functioning autistic individuals are increasingly being identified and diagnosed in clinical settings, it remains that they often present a somewhat different picture to low functioning individuals, which may result in confusion, delayed diagnosis or misdiagnosis by less experienced and specialised clinicians.

Similarly, the typically developing sample may not be considered to be fully representative. The low response rates, particularly for the second method of recruitment, are a concern. It is possible that there are important differences between those participants who chose to take part and those who did not and that these differences may have influenced the findings of the study.

The validity of parental report in the case of the behaviour of PDD individuals is debatable. Both overt and covert manifestations of anxiety and mood difficulties may be difficult to discern in PDD as individuals are impaired in the expression and understanding of affective and cognitive states. Additionally, the measures utilised here had not been standardised for use in this population. However, although this is an important limitation, it is also one which is shared by most of the literature and until new measures, techniques and diagnostic criteria are developed for the assessment of additional mood and anxiety symptoms in PDD it will be necessary to rely on such measures.

Finally, the sex of the parent and that of the child they are rating has been shown to be influence their perception of the child's behaviour and how 'problematic' it is considered to be (e.g. Luoma & Tamminen, 2004). However, the current study did not record whether the mother or father had completed the questionnaires and it was therefore not possible to control for this variable or examine its effect on the results. Future studies may benefit from adding parental sex as an additional variable.

Suggestions for Further Research

The finding that PDD females demonstrate increased internalising behaviours relative to PDD males is an interesting one which warrants replication in a larger sample. Larger scale research involving longitudinal designs could also allow for the examination of possible causal factors such as awareness of difficulties relative to typically developing peers, degree of actual or perceived rejection, parenting style and the possible protective role of friendships. This may also go some way to clarifying whether increased levels of internalising behaviours in PDD females are secondary to some of the above factors or reflect a differing pattern of PDD symptomatology in females.

Further research could also incorporate self-report measures as a means of obtaining information about the more covert experience of internalising behaviours . Although, as mentioned above, there are some limitations to the use of such measures in PDD populations, this may be minimised to some degree by using high functioning samples. It would be interesting to examine the content or focus of anxiety or low

mood, for example, whether females are more concerned with social worries such as peer rejection. Qualitative approaches could be employed in order to address the absence of measures for use specifically in this population and could provide more in-depth information about their internal experience.

Conclusion

The current study provided further support for the finding that PDD individuals demonstrate higher parental ratings of internalising behaviours than their typically developing counterparts. Within this high functioning, child and adolescent sample, there was a mixed picture with regards to the association between internalising scores and severity ratings across the three PDD domains. However, it appeared that the elevated internalising scores in PDD could not simply be considered as manifestations of the underlying developmental disorder. Sex differences were also investigated, both in relation to PDD severity and to internalising scores. PDD females were found to have higher overall internalising scores. Although no sex differences were apparent in PDD severity it remains to be established whether PDD males and females differ with respects to the pattern of PDD symptomatology and whether the sex differences in internalising behaviours are related to this.

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Part Three: Critical Appraisal

Overview

The following critical appraisal will review and evaluate the research process as a whole. It begins by reflecting upon my personal experience of the research process, specifically focusing on issues related to the selection and development of appropriate measures and to the recruitment process. In this respect it will address some of the strengths and weaknesses of the research study as they unfolded and consider the lessons I have learned and what, in hindsight I might have done differently. It will then discuss the strengths and weaknesses of the design of the study, the measures used and aspects of the samples and recruitment. Some consideration will then be given to possible further analyses and finally it will discuss some of the clinical implications of the findings.

Personal Reflections on the Research Process

Choice of Measures

One of the measures used with the PDD sample was the Conners Parent Rating Scale-Revised (CPRS-R; Connors, Sitarenios, Parker & Epstein, 1998). Clinically, the full range of presenting difficulties had been of interest, however, for the purpose of the present study, only measures of internalising behaviours were required. The CPRS-R includes seven sub-scales with 80 individual items and the length of the questionnaire was a concern in terms of the possibility of reducing the response rate. In contrast, 26 items relate to internalising behaviours, an arguably less intimidating

number of questions which fit neatly onto one side of paper. I therefore decided to investigate the possibility of excluding the four externalising sub-scales entirely. Thus ensued a lengthy process of negotiation with the publishers of the CPRS-R, primarily through email communication. Although they did not object to the proposed adaptation of their questionnaire, the process of producing a final, usable and approved measure took several months. This involved communication with various departments including the legal department.

Although I still believe that the reduced length of the questionnaire probably resulted in an improved response rate, in hindsight I think that perhaps sticking with the original questionnaire would have been a wiser decision. I had not anticipated the length of time the whole process would take and it did delay data collection significantly. Also, during this time I decided that one of the internalsing sub-scales – Perfectionism – shared so many features with the Repetitive and Stereotyped Behaviour PDD domain that its inclusion was not necessary or useful. This could have reduced the length of the adapted measure further but as the decision was made late in the negotiating process I decided not to remove this sub-scale. Although the entire experience was a frustrating one I also feel that it was important and useful in terms of learning about the often convoluted processes involved in dealing with big publishers and issues of copyright.

The vast majority of studies in the PDD literature do not use screening instruments to exclude PDD symptomatology in their typically developing control samples. However, in the case of the present study it was considered to be an important consideration. This related to the inclusion of Atypical Autism in the PDD sample, a

diagnostic category which may considered to be closer to 'normality' on the PDD

spectrum. Indeed, many of the PDD sample attended mainstream schools and had

remained undiagnosed for many years. It was considered likely that even within a

mainstream setting a number of the sample may present with some degree of PDD

traits. For the purpose of the present study I wanted to be able to exclude these

participants. However, when it came to the decision of which measure to utilise in

order to screen out significant PDD traits in the typically developing sample it

became apparent that there was no single measure which fulfilled all of the

requirements of the study.

The Gilliam Autism Rating Scale (GARS; Gilliam, 1995) was initially recommended

to me as an easy to use behavioural checklist for use by parents, which is suitable for

use in both research and clinical settings. I was unable to access a copy of the

questionnaire itself or the manual and so decided to order a copy (which the

publishers provide free for those carrying out dissertations) in order to examine the

individual items and instructions for use. However, at this point several limitations to

the potential use of the measure in the present study became apparent. The most

obvious one concerned the use of language in the questions, for example, "speaks or

signs with flat tone, affect, or dysrhythmic patterns". I was unsure whether parents

would be able to understand such psychological jargon, and indeed, after piloting

some of the questions on non-psychologist friends it became clear that many of the

questions were indeed difficult to comprehend. Additionally, many of the questions

were quite long and complicated, for example, using double negatives, and it struck

me that this could be very off-putting to some parents. Consultation of the manual

left me unclear about the degree of independence parents were intended to have

when completing the measure. It stated that during the standardisation process participants completed the forms independently in the presence of researchers, but did not refer to the type of information or instruction provided prior to or during administration. I therefore contacted the publishers directly, resulting in an experience not dissimilar to that encountered with the CPRS-R (for example, a focus on copyright issues which required consultation with the legal department). It also failed to completely clarify exactly how much and what sort of instruction I should give to the parents and whether I would be able to provide advice or information over the phone to parents should they need it.

A further concern related to the scoring of the GARS, in which a raw score of 0 (never observed) is described as 'you have *never* seen the individual behave in this manner', whilst 1 (seldom observed) is described as 'individual behaves in this manner 1-2 times in a 6 hour period'. There is no option of behaviour seen rarely, which seemed strange as many of the items could arguably be occasionally observed in non-autistic children e.g. "withdraws, remains aloof, or acts stand-offish in group situations" or "behaves in an unreasonably fearful, frightened manner", especially as the data is not age normed. It seemed to me that it would be quite likely that some typically developing children would score over the diagnostic cut-off, for example, only two of the fourteen items would need to be considered to be 'seldom observed' for them to score in the 'possibly' autistic range. Finally, the distinction between a screening and a surveillance tool was highlighted in the South *et al* (2002) study involving the investigation of the utility of the GARS. They cited (Baird *et al.*, 2001): '*Screening* refers to the use of specific tests to identify an unrecognized disorder in general groups (e.g., for all children in a given region), whereas

surveillance refers to the systematic collection of relevant diagnostic data for individuals at-risk or suspected of having the disorder'. South *et al* (2002) considered the GARS to be in the surveillance category as it had been developed as a measure for discriminating between children with autism and those with other developmental disorders. Thus, for all of the above reasons it was decided that the GARS was an unsuitable measure for use in the current study.

Another measure which was considered for use was the Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles & Bailey, 1999). This is a 40 item questionnaire designed to be understandable to non-professionals, including parents. Although in this respect it demonstrated advantages over the GARS it is an instrument which is primarily used in lower functioning PDD individuals. Additionally, the authors themselves point out that it had not been developed as a screening measure for use in the general population and therefore caution against its use in this context. The Social and Communication Disorders Checklist (SCDC; Skuse, Mandy & Scourfield, 2005), on the other hand, *was* designed to be a screening instrument. Although a measure of autistic traits as opposed to a diagnostic tool, it demonstrated an advantage over the previous two measures in being designed for use in children with no learning disability. It is also designed to be easily understood by parents and to be completed independently. A further advantage is its brevity (12 items), which, in combination with its easy to understand questions, suggested that it may be much less likely to result in non-completion or partial completion by participants. However, this measure was not without its own disadvantages. One related to the age range employed in the standardisation of the measure. Although the PDD and clinical control groups ranged between two and

eighteen years old the typically developing group ranged between seven and seventeen years old. This was a concern considering the fact that the current study involved participants as young as three years. A further weakness of the SCDC was the criterion validity, assessed by comparing its scores with scores on the 3di the computerised parental diagnostic interview (Skuse *et al*, 2005). The correlations, although significant, were modest, for example, the correlation between the two instruments' total scores was 0.38. The authors point out that the SCDC was designed to measure autistic traits rather than for diagnostic purposes. However, despite the limitations of the SCDC it was decided that overall, weighing up the individual strengths and weaknesses of each questionnaire, that the SCDC was the most appropriate for the purposes of the current study. Crucially, the GARS and the SCQ had been developed for the purpose of discriminating between individuals with possible PDD or other clinical presentations, whereas the SCDC was more relevant for use in a typically developing population.

The issue of measure selection and development has been considered in some detail here as it represented an important learning experience for me. As well as the issues of psychometric validity and reliability it also highlighted the issue of the real world application of such measures. For example, it was striking that, in the absence of access to copies of the questionnaires or manuals it must be very difficult for researchers to select the most appropriate measure. Details about the content, scoring and administration of questionnaires is often absent in validation studies or other readily available data. This makes the job of thinking about how useful or relevant the measure may be for your own study more difficult. The effect upon response rate is also a very real concern and one which may be highly influenced by the ease of

comprehension and completion of the instrument. My experience of communication and negotiation with the publishers of both the GARS and the CPRS-R was also an important learning experience in terms of the convoluted process involved in either clarifying details about the use or administration of measures or any proposed adaptations. I imagine that this could be off-putting to many researchers, particularly those with limited time and resources. This may thus particularly impact upon those working in smaller scale and/or clinically based research and this could be to the detriment of the quality of their work, for example, in using less appropriate measures (or using them incorrectly). It is interesting to contrast my experience with the above questionnaires with the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), the third measure used in my study. This questionnaire is freely available on the internet to any member of the public and this includes access to normative data and published studies. It is also available in many languages and in parental, teacher and self-report versions. Scoring aids are even provided on-line for ease of administration and scoring. Perhaps as a consequence this instrument is widely used both clinically and in research. This has resulted in a broad research base demonstrating how scores may vary across many demographic and clinically significant variables, information which is valuable in the clinical setting.

Recruitment

One of the great advantages of the current project was that I was able to use existing PDD data from previous research. This meant that I was able to ask questions in my project which would otherwise have been beyond the scope of a DClinPsy project as PDD females are potentially a very difficult population to access and recruit. Thus,

the main data collection task was to recruit a typically developing comparison sample. However, as these were to be matched for both age and IQ and the PDD sample included a wide age range this task was not necessarily a straight forward one. An additional appeal of the project was that I was given access to a database of typically developing children and adolescents who had been involved in previous research in which IQ data had been collected. At the time of choosing a project, developing the hypotheses and writing the proposal I was of the understanding that this database included over 500 participants, for whom the addresses and phone numbers were available to contact them and ask if they would be interested in participating in further research. Given their willingness to participate in prior research, I estimated that the response rate from this sample should be more than sufficient for the matching purposes of my project. However, once the proposal and ethics had been approved and I came to the data collection stage I discovered that the majority of the participants' consent forms (which included the contact details) were missing and I was left with the contact details of only 156 participants. After a long process of attempting to recruit this remaining group by post and on the phone 49 in total returned their questionnaires.

I therefore needed to recruit a new set of participants, for whom I would need to collect not only questionnaire but also IQ data. I did so by contacting some of the schools who had been involved in the previous study and a nursery which was also involved in some of the departmental research. The nursery and one school responded, the former giving me a list of participants whose parents had agreed to take part and the latter agreeing to distribute information sheets and consent forms to parents. In the case of the nursery participants ten consent forms were returned to me

and of the ten children I then assessed I received nine completed questionnaires. In the case of the school, approximately 150 information sheets and consent forms were distributed to parents via their childrens' homework bags. I tested the 33 children for whom I received consent forms but only 20 of these returned their questionnaires. The 78 participants for whom I had both IQ data and completed questionnaires were not matched closely enough in terms of age so I re-contacted some of the families by phone to ask if they had other children of the appropriate ages who might also be willing to participate. I obtained a further ten participants in this manner and as they were assessed at home whilst the parent filled in the questionnaires.

Overall, the experience of data collection taught me several lessons. Firstly, the importance of actually confirming the existence of available data before commencing on a project which in large part relies on it. The apparent availability of the contact details of over 500 research friendly participants was not an insignificant factor in my decision to choose this particular design. I had also not considered that recruiting this sample would be quite so laborious and time consuming as the process of obtaining 49 questionnaires from a sample of 156 took a considerable number of mail outs and follow up telephone calls. The experience of recruiting from this initial sample and the fresh recruitment from the school also taught me that recruiting a typically developing sample was not actually as straight forward as many had suggested to me.

In hindsight, although I do feel that the results of the study were important and interesting, I may have been more inclined to have designed a study which involved re-contacting the PDD sample. I initially had been put off this idea by the advice that

recruiting a clinical sample is much more difficult than recruiting a typically developing one. However, during the process of developing my hypotheses and writing the literature review I was frequently frustrated by the limitations of the existing questionnaire data I had from the PDD sample. Although I acknowledge the importance of having a typically developing control group, I do believe that many interesting findings could have resulted from a design which involved administering more in-depth measures of mood and anxiety problems to the PDD sample, possibly involving a qualitative approach.

Strengths and Limitations of the Study

Samples

Although certainly not a limitation restricted to the current study, the issue of representativeness of both samples is a pertinent consideration. With regards to the typically developing sample, the above details of the recruitment process illustrate that the response rate was low, even in the case of participants who had previously agreed to take part in prior research. One can only speculate as to the different characteristics of those who had chosen to participate and those who had not, however it is very possible that these differences are significant and would have implications for how 'typically developing' the sample should be considered to be.

The question of the representativeness of the PDD sample was addressed in the empirical paper, where it was highlighted that, as a specialist assessment clinic, the

children seen may not have been completely representative of general PDD populations. However, although many of the participants presented with a more complex picture of symptomatology, resulting in confusion about the diagnosis, many also presented with a much more typical PDD picture. Set in a National children's hospital, the clinic also received many referrals from parts of the country which were under resourced in terms of their capacity to make PDD diagnoses.

However, an important point, which was raised in the empirical paper, is that the PDD sample included in the study were all high functioning. Indeed, the clinic tended to receive more referrals for children with IQs in the normal range, perhaps reflecting the diagnostic confusion resulting from the differing presentations of those with low functioning and high functioning PDD. Many clinicians may have had training or experience predisposing them to recognise features of PDD in low functioning individuals whilst attributing PDD symptoms in high functioning PDD to other factors. For example, in Aspergers Syndrome, individuals may not present with the same developmental delay, for example, characteristically developing language at a normal age. Thus, although presenting with a range of unusual behaviours, these characteristics may be too subtle to be picked up by health or educational workers until much later on (if at all). Although unusual in quality, their ability to adequately communicate their needs and desires may make some of the more challenging behaviours typically seen in low functioning individuals unnecessary. Thus the current sample may actually be reasonably representative of a high functioning PDD sample (though probably not of low functioning individuals).

One further issue with regards to the PDD sample concerns the possible impact of a delayed diagnosis. The fact that many of the sample had not received a diagnosis until late childhood or even adolescence may be pertinent. Considering the current study's focus on anxiety and mood difficulties it may be important to think about how the children and their parents may have understood their difficulties prior to receiving a diagnosis. Although the meaning and impact of a PDD diagnosis is likely to vary between individuals, it remains that in the absence of one, these children and their families may have still been aware that something was different about them.

The issue of matching is also an important consideration. Age and verbal IQ were chosen as matching characteristics as both are commonly found to be factors affecting levels of internalising behaviours in typically developing populations. For the purposes of the current study, an estimate of verbal IQ was considered to be adequate and verbal IQ rather than performance IQ was chosen, as this is arguably a more important variable in PDD populations in which communication is often impaired. An additional variable which ideally would have been employed for matching purposes was Socio-Economic Status (SES). Leventhal and Brooks-Gunn (2000) in their review of large scale national and regional studies found that SES was associated with both academic achievement and behavioural and emotional problems. There was a positive association in the former case and an overall negative association for the latter, although they reported that the findings were less consistent for internalising than externalising behaviours. The mechanism by which SES may be associated with emotional and behavioural problems in children is likely to incorporate multiple factors including the availability of institutional, community and home based resources and parental characteristics (Leventhal & Brooks-Gunn,

2000). Thus, for example, access to quality schools, childcare and medical facilities may impact upon child development and be associated with SES. Similarly for resources available in the home environment such as space and books. SES may also be associated with parent characteristics such as mental and physical health. For example, financial difficulties may result in parental stress and depression which may in turn affect parenting behaviour. The authors also point to the mediating effect of crime and violence in low SES neighbourhoods on maternal warmth and controlling parenting style. The potential influence of SES is therefore pertinent in the case of the current study, however, SES information was not collected for the PDD sample. Although it was also not collected for the typically developing sample it is worth noting that they were recruited from mainstream state schools in relatively deprived areas of London.

The sample size was arguably a strength of the study. The inherent difficulty involved in accessing and recruiting PDD females means that the current N of 31 was actually quite a respectable number, especially when one considers that they were high functioning and covered such a wide age range. Indeed, the power analysis demonstrated that the sample size was sufficient for detecting an interaction.

Measures

The current study employed parental report as the measure of internalising behaviours, an approach which has several limitations. Ideally, any assessment of child behaviour or difficulties would include parental and teacher report, child self

report and direct observation of the child. However, within the context of the constraints of psychological research, the thoroughness of such assessment is typically compromised. Questionnaires are often employed rather than interviews or direct observation and it is often not possible to administer parental, teacher and child questionnaires. The limitations of the use of questionnaires in general are numerous and I will not review all of them here, however, the limitations of parental report in particular is an important consideration.

The concordance of parent and child report of psychiatric symptoms has been consistently found to be low, with externalising behaviours typically demonstrating greater parent-child agreement than internalising (Karver, 2006). Several characteristics of the behaviours in question have been identified as factors determining concordance rates. One of the most important is the saliency of the behaviours to the child and parent, that is, the objectivity, perceivability, seriousness and observability of the behaviours (Karver, 2006). Thus, externalising symptoms are likely to be more salient to the parent, as they may be more objectively apparent, more socially undesirable and easily identifiable as unusual or problematic. Internalising symptoms, on the other hand, are more subjective and may be outside of parental awareness. However, internalising symptoms may be more salient to the child as they represent their internal experience and may be a source of distress. Parent-child agreement is higher for more observable internalising symptoms (Cromer & Kendall, 2004), however, covert, internal experiences such as rumination or negative self-worth may often not be noticed by parents. The child may lack the capacity or the desire to communicate such experiences to their parent or the parent may be unavailable or unreceptive to the child's attempts to communicate them.

Willingness to report particular symptoms also influences both parent and child report (Karver, 2006), both of whom may be concerned with issues of social desirability or the sharing of the information with known others. For example, an anxious child may worry about how others might evaluate them based on their responses (Cromer & Kendall, 2004). Consistency of behaviours across time and context appears to be a factor with a more mixed influence on concordance, for example, a more inconsistent behaviour may appear more unusual to parents and thus appear more salient (Karver, 2006). However, particularly in the case of internalising behaviours, parents may be unaware of behaviour which occurs outside of the home. For example, Cromer and Kendall (2004) found that there was less parent-child agreement about school based behaviours.

The above points would apply both to typically developing and PDD populations, however, in the latter case there are additional limitations to parental report. The expression, understanding and communication of affective experience is impaired in PDD. As such, the parent's capacity to understand their child's experience of mood or anxiety difficulties would be similarly impaired. Although an important limitation, it is interesting to consider the fact that despite these likely difficulties, the parents involved in the current study were able to report on such aspects of their child's behaviour. And indeed, they reported levels of these behaviours as being higher than did the control group.

An additional limitation, which may be particularly pertinent in the case of PDD populations is that of the influence of the parent's own psychological state. Mood or anxiety problems in the parent may result in them taking a more negative view of

their child's behaviour, or making more negative interpretations. Commonalties in parent and child symptoms may also make them more salient to the parent. However, the parent's own difficulties may also make them less sensitive to their child's behaviour. Either way, it may result in a distorted measure of the child's presentation (Richters, 1992). The increased rates of depression and anxiety disorders in parents with PDD may mean that such a distortion is likely to be more pronounced in this population.

The current study's reliance on parental report also meant that it was not possible to address some of the hypothesised causal factors involved in the increased rates of internalising behaviours in PDD. Self report measures which address the focus of low mood or anxiety would have provided very useful information, such as whether the sex differences related specifically to social concerns or aspects of self concept.

The study had several strengths in terms of its use of measures. One is the number of measures and sub-scales which it included in the analyses. As only three internalising variables and three PDD variables were used it reduced the likelihood of type I error. In many respects it would have been interesting to have examined correlations and sex differences in relation to more specific and detailed aspects of PDD presentation, and to have examined some of the externalising behaviours. However, I decided that it was more important to retain the statistical strengths of the study and keep the hypotheses focused.

A further strength was its screening of the typically developing sample with a PDD screening measure. This aspect of the design is rarely included the PDD literature,

although it appears to be an important consideration. Also, despite the limitations to the use of parental questionnaires, a strength of the study was its use of widely used, psychometrically sound measures. Finally, the investigation of whether PDD severity was a factor in relation to internalising scores has often been neglected in the literature. With the exception of Kim *et al* (2000) the two have not been considered in relation to each other, an omission which has meant that criticisms levelled at the literature in terms of the validity of co-morbidity diagnosis in PDD cannot be addressed.

Ethical Considerations

One aspect of the study which has important ethical implications was the offer to parents to provide feedback regarding their responses to the questionnaire. The decision to do so was made at an early stage, the rationale being that it would be likely to increase the response rate from potential participants. The idea was that once the study was complete the parents would be informed of their child's results, if they had indicated that they wished to receive this on the consent form. The feedback was planned to be very brief and non-specific, for example, stating that their child scored within or out of the normal range expected for their age. Although it is not typical for such feedback to be offered to participants, it was approved by the ethics committee. However, as the study progressed I became more aware of the potential difficulties involved in this plan. One concerned what action should be taken if the parents wanted advice with regards to what they should do about a child who was scoring within a clinically significant range. Through consultation with my

supervisors and course staff it seemed that in this case it would be most useful for me to advise them as to which CAMHS service to be referred to, if this seemed appropriate. A further issue was that of the PDD screen and what to do if a child was found to be scoring above the cut-off. The SCDC is not designed to be a diagnostic measure for PDD, but rather a screening tool for PDD *traits*. Although sufficient in this respect for the purposes of the current study, it is therefore not a measure which can be used for diagnostic purposes. The authors of the SCDC identified a cut-off of *possible* PDD, however, as a new and in many respects limited measure, I felt that the potential harm of providing feedback (e.g. causing unnecessary and unfounded distress or anxiety to parents) outweighed the possible benefits. For all of the above reasons, when it came to the second phase of testing I decided to omit the offer of feedback from the consent forms. It was interesting to note that this did not appear, on the surface at least, to be influencing participants' decisions to participate. For example, this was never mentioned by parents when I spoke to them on the phone. This was a valuable learning experience as I think that I would be unlikely to offer participants feedback on their responses in the future. This experience has highlighted to me the potentially difficult ethical issues facing studies involving normal control samples, particularly with children.

Consideration of issues related to ethics also came into play at an early stage when I decided not to follow up the original clinical sample. The process of applying for ethical approval for a clinical population is a much more complicated and lengthy one, and, in view of the time frame of the project I decided that the existing data for this sample would suffice. A further issue is that of consent on the part of the children assessed for IQ. Although it is likely that many would have been asked by

their parents whether they would be willing to participate, it is equally likely that some, especially younger ones, may have felt pressured to take part against their wishes. However, it was made clear on the consent forms that the child could choose to cease testing at any point, and indeed, if I had perceived any child to have been unduly distressed or anxious during testing then I would have stopped immediately (this was never the case).

Possible Further Analyses and Investigations

The issue of the possible relationship between externalising behaviours and PDD severity was not addressed in the current study. The decision not to include this was made very early on in the project development. This was for two main reasons, firstly to try to minimise the number of variables being investigated, thus minimising the possibility of type I error. Secondly, I wanted to remain focused on one main body of literature in order to be able to investigate it in more depth. The literature on externalising behaviours and PDD is more extensive than that in internalising, perhaps because their management is such a significant concern for families and services. I was more interested in focusing on internalising behaviours, although I was aware that they could not be considered to be completely independent and unrelated to externalising behaviours. As a consequence I decided to omit the externalising items from the CPRS-R. However, I did collect this data for the SDQ and one possibility for further investigation would be to examine the inter-relationships between externalising behaviours, internalising behaviours, PDD severity and sex differences.

The question of whether age is a factor in internalising behaviours, PDD severity or sex differences is also an interesting one. Indeed, initially the design of my project had involved this being a factor in the analyses. However, I decided to remove this as a factor for two reasons. One was as a result of the reading I did for both the literature review and empirical paper. My initial hypothesis has been that the sex differences in internalising behaviours in PDD would not come into play until late childhood/ adolescence. Although there is variation across diagnostic categories, overall levels of internalising behaviours are generally found to be similar in typically developing boys and girls during childhood. During adolescence, on the other hand, internalising behaviours in females exceeds that in males (e.g. Keenan & Shaw, 1997; Crick & Zahn-Waxler, 2003). Some of the factors thought to be involved in this sex difference change at adolescence, such as hormonal factors, may be expected to be shared by PDD females. However, my original hypothesis was that some of the additional pressures of adolescence may be particularly challenging for PDD females, for example, the increasing social complexity of female relationships and pressure to engage in gender consonant interests and activities. I therefore hypothesised that the sex difference in internalising behaviours in PDD would become apparent in adolescence, over and above the sex difference present in a typically developing sample. However, my reading and thoughts on the possible impact of further factors led me to re-consider this hypothesis. For example, the greater deviation from gender norms in even very young PDD females may be hypothesised as eliciting more rejecting or controlling responses from parents. Rapee (1997) points to the association between such parenting styles and the development of depression and anxiety and it is therefore possible that sex differences in

internalising behaviours may be apparent from an early age. Another important consideration was that some of the variables thought to be playing a role in the increased levels of internalising behaviours in typically developing adolescent females may not be as pertinent in the case of PDD females. For example, one theory is that typically developing females' increased internalising in adolescence is due to their superior empathsising and socialisation which predisposes them to more guilt and responsibility (Nolen-Hoeksema & Girgus, 1994). PDD females' relative deficits in empathising abilities and possibly reduced susceptibility to socialisation may mean that the discrepancy between internalising behaviour levels in childhood and adolescence are not as pronounced.

Another reason for not investigating age as a main factor was that the size of my sample was not really sufficient for an analysis comparing children and adolescents (only eight of 31 were twelve years or older). Thus, although it was interesting to note a lack of an association between age and internalising scores, it is possible that this may have been found if there had been more adolescents in the sample. Further research involving adolescents and adults would be interesting.

Clinical Implications

The assessment and diagnostic implications of co-morbid mood and anxiety problems in PDD was discussed in some detail in the literature review. However, another important clinical implication of the finding of increased rates of internalising behaviours in PDD is for treatment. Where psychological treatment is

concerned, questions of diagnostic boundaries or validity arguably become less of a concern. Provided the clinician involved has a sound understanding of PDD itself (and can therefore include this understanding within the case conceptualisation), mood or anxiety related behaviours identified as problematic may be the focus of treatment, whether they are attributed to the PDD itself or considered to be independent syndromes. What does need to be explored further is what the most useful interventions may be. For example, for an individual who suffers from social anxiety, would a behavioural, exposure based approach and teaching of anxiety management strategies be most useful or should the treatment aim to increase social skills and understanding. Is greater insight into one's own deficiencies in relation to others necessarily beneficial for mental health? How important is the perceived ability to change? If PDD individuals do engage in social comparison and this does impact upon their self concept, then is there utility in exposing those in mainstream schooling to others with PDD? There are certainly more questions than answers, as yet, in this field, but the single study (Sofronoff *et al*, 2005) which has been concerned with psychological treatment of anxiety in PDD has reported promising results.

Conclusions

The process of carrying out this study has been a great learning experience, and has highlighted many of the important factors and potential difficulties to be considered when planning any future research. In particular the importance of the choice of measures and recruitment sources stood out and I learned the valuable lesson of

never to underestimate how long both of these processes can take. It has also been useful in terms of experiencing first hand the real world compromises which have to be made in attempting to design and produce a good piece of research. During the process of writing the literature review it was quite easy to find weaknesses of other studies or limitations in their ability draw particular conclusions. Overcoming such weaknesses in developing my own study was a lot more difficult. Overall, however, despite the multitude of limitations of the study and its potential conclusions, I do feel that it produced some interesting results, with valuable conclusions which are well worth further investigation and expansion.

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Appendix A

Ethical Approval Letter

UCL GRADUATE SCHOOL
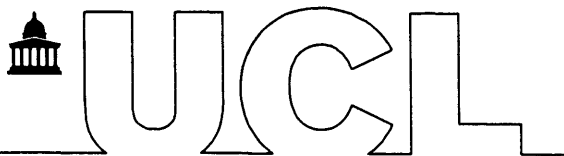
Professor J
Clinical Health Psychology Sub-Department
UCL
Gower Street
London
WC1E 6BT

30 September 2005

Dear Professor (

Re: Notification of Ethical Approval

Re: Ethics Application: 0529/001: Are girls with Autism at more risk of depression and anxiety than boys?

The above research has been given ethical approval following review by the Chair of the UCL Committee for the Ethics of non-NHS Human Research for the duration of the project subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: http://www.grad.ucl.ac.uk/ethics/ and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

3. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events.
For non-serious adverse events you will need to inform Ms   _   Ethics Committee Administrator   within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events
The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

UCL Graduate School, North Cloisters, Wilkins Building
University College London Gower Street London WC1E 6BT
Tel: +44 (0)20 7679 7844   Fax: +44 (0)20 7679 7043

www.ucl.ac.uk/gradschool

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely

{

Chair of the UCL Committee for the Ethics of Non-NHS Human Research

Cc: Motchila Innocente, Clinical Health Psychology Sub-Department, UCL

Appendix B

Phase One Informed Consent Letter

Institute of Child Health

and Great Ormond Street Hospital for Children NHS Trust

UNIVERSITY COLLEGE LONDON

Informed Consent Form

Please take time to read and answer *all* of the following questions by ticking either 'yes' or 'no'.

	Yes	No
Have you read the Participant Information Sheet?		
Do you understand that if you would like further information about the study then you can contact the research team?		
Do you understand that you are free to withdraw from the study at any stage?		
I consent to participating in the completion of questionnaires		
I consent to .... brother/sister between the age of three and eight years old doing some games and puzzles		
I wish to receive feedback about my participation		
I wish to receive feedback about the findings of the study		

Please sign and complete the following details:

Signed:.. Date:...

Full Name in Capitals: ....

Full Name of Child in Capitals ....

Contact Telephone Number ....

Thank you for taking the time to complete the Informed Consent Form. Please return this form using the enclosed prepaid address label and envelope.

THE QUEEN'S
NNIVERSARY PRIZES
HIGHER AND FURTHER EDUCATION

2000

Behavioural and Brain Sciences Unit
Neurosciences and Mental Health Directorate
Head of Unit: Professor David Skuse
Professor Peter Hobson Dr Tony Charman
Unit Administrator: Marta Salamonowicz

UCL

Appendix C

Phase Two Informed Consent Letter

Institute of Child Health

and Great Ormond Street Hospital for Children NHS Trust

UNIVERSITY COLLEGE LONDON

The
child
first
and
always

30 Guilford Street
London
WC1N 1EH
Tel. No: 020 7831 0975
Fax. No: 020 7831 7050

Informed Consent Form

Please take time to read and answer *all* of the following questions by ticking either 'yes' or 'no'.

	Yes	No
Have you read the information about the research included in the letter?		
Do you understand that if you would like further information about the study then you can contact the research team?		
Do you understand that you and your child are free to withdraw from the study without penalty at any stage?		
I consent to participating in the completion of questionnaires		
I consent to my child doing some games and puzzles		
I wish to receive feedback about the findings of the study		

Please sign and complete *all* of the following details:

Full Name (of parent) in Capitals:..

Full Name of Child in Capitals: ....

Child's Date of Birth: .... Child's Class: ....

Address: ....

....

....

Contact Telephone Number: ....

Signed:.. Date:................................

Thank you for taking the time to complete the Informed Consent Form. Please return this form to your child's class teacher.

Appendix D

Phase One Participant Information Sheet

Participant Information Sheet

Are Girls with Autism at More Risk of Depression and Anxiety Than Boys?

What is the purpose of this study?

Previous research suggests that people with Autism are more likely to suffer from additional mental health problems, such as depression, or anxiety, than people without Autism. However, relatively little is known about why this may be, and what factors might determine whether an individual with Autism develops further problems. This is an important issue which has implications for both the prevention and treatment of mental health problems in Autism. We know that your child does not have Autism but your participation is very important.

The present study aims to contribute to this understanding of Autism by addressing the question of whether girls with Autism are more likely to suffer from problems such as depression and anxiety than boys with Autism. In order to answer this question, it is necessary to compare levels of mood and anxiety in children with Autism with that of children without Autism. The purpose of your participation would therefore be to provide important information about anxiety and mood in children without Autism. This study will involve about seventy families of children without Autism, and seventy families of children with Autism.

Whilst there are no immediate benefits for those people participating in the study, it is hoped that this work will make a valuable contribution to our understanding of the mental health problems experienced by many people with Autism. This growing understanding may lead to the development of therapies and preventative interventions specifically tailored for individuals with Autism.

Is my participation voluntary?

Participation in this research study is completely voluntary. Additionally, it would be your right as a research participant to withdraw from the study at any time and for any reason.

What would my participation involve?

Participation in the study would involve you completing three questionnaires about your child. These questionnaires ask about how your child is getting along. All three questionnaires simply require you to tick boxes and should take no longer than half an hour. We would send these questionnaires to you by post and provide a prepaid self addressed envelope for you to return them to us.

As part of the study we will also be using IQ (general intelligence) data. As you may be aware, we have already gathered this information as part of the previous study. If you chose to participate in the present study we would request your permission to use that existing data.

Invitation for younger children to take part in the study

Lastly, we would like to see additional children aged between three and eight. If you have any children of this age, we would like to invite them to do some games and puzzles, in order to measure general intelligence in this, younger age group. The puzzles usually take only about twenty minutes and would be conducted in your home. You are free to withdraw your child at any time.

Would I receive feedback about my participation?

Upon completion of the study, it is possible to provide feedback to participants regarding the responses given in the questionnaires. We can also provide feedback regarding the findings and conclusion of the research.

Will you guarantee confidentiality?

All questionnaire and IQ data will be collected and stored in accordance with the Data Protection Act (1998). Information stored on computer databases would be secured with passwords and all questionnaire and IQ data would be stored in locked cupboards. The information collected is confidential, and no details of identity such as names would be accessible to persons outside of the research team. This research has been approved by University College London's Committee on the Ethics of Non-NHS Research. In accordance with their requirements for research involving children, all researchers have undergone a criminal records check.

Appendix E

Phase Two Recruitment Letter and Participant Information Sheet

Institute of Child Health

and Great Ormond Street Hospital for Children NHS Trust

UNIVERSITY COLLEGE LONDON

The
child
first
and
always

30 Guilford Street
London
WC1N 1EH
Tel. No: 020 7831 0975
Fax. No: 020 7831 7050

22nd February 2006

Dear parent/guardian,

We would like to invite you and your child to take part in research being carried out by the Institute of Child Health, Great Ormond Street Hospital. Please take time to read the following information about the research study. If you think that you would be interested in taking part, please complete the Informed Consent form included with this letter, and return it to your child's class teacher.

What is the purpose of this study?
Previous research suggests that people with Autism are more likely to suffer from additional mental health problems, such as depression, or anxiety, than people without Autism. However, relatively little is known about why this may be, and what factors might determine whether an individual with Autism develops further problems. This is an important issue which has implications for both the prevention and treatment of mental health problems in Autism. We know that your child does not have Autism but your participation is very important.

The present research study aims to contribute to this understanding of Autism by addressing the question of whether girls with Autism are more likely to suffer from problems with mood and anxiety than boys with Autism. In order to answer this question, it is necessary to compare the behaviour of children with Autism with that of children without Autism. The purpose of your participation would therefore be to provide important information about the behaviour of children without Autism.

What would my participation involve?
The study would involve the participation of both your child *and* either parent (or guardian). It is important for the study that both the child and a parent take part, and, as such, we would not be able to use any information unless *both* participate.

Your child
Your child's participation would involve him/her completing some puzzles and word games together with a researcher. This should take about 10-20 minutes and would happen during school time, in a separate classroom. Your child would be free to withdraw from testing at any time.

THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION

2000

Behavioural and Brain Sciences Unit
Neurosciences and Mental Health Directorate
Head of Unit: Professor David Skuse
Professor Peter Hobson Dr Tony Charman
Unit Administrator: Marta Salamonowicz

UCL

Parent/guardian
Participation in the study would involve you completing three short questionnaires about your child. These questionnaires ask about how your child is getting along. All three questionnaires simply require you to tick boxes and should take a maximum of 15 minutes to complete, in your own time. We would send these questionnaires to you by post and provide a prepaid self-addressed envelope for you to return them to us.

Will you guarantee confidentiality?
The information collected is confidential, and no details of identity such as names would be accessible to persons outside of the research team. This research has been approved by University College London's Committee on the Ethics of Non-NHS Research. In accordance with their requirements for research involving children, all researchers have undergone a criminal records check.

We would like to thank you for considering taking part in this research. If you have any questions, please do not hesitate to contact Motchila Innocente on 07813 793 899.

Yours Sincerely.

	Motchila Innocente
MD FRCP FRCPsych FRCPCH	Trainee Clinical Psychologist
Professor of Behavioural Sciences	

Appendix F

Phase One Recruitment Letter

Institute of Child Health

and Great Ormond Street Hospital for Children NHS Trust

UNIVERSITY COLLEGE LONDON

The child first and always

30 Guilford Street
London
WC1N 1EH
Tel. No: 020 7831 0975
Fax. No: 020 7831 7050

Parent/guardian of «first_name» «surname»
«add_1»
«add2»
«add3»
«postcode»

26th November 2005

Dear Parent/guardian of «first_name» «surname»,

As you may recall, you had kindly agreed in the past for «first_name» to participate in research being carried out by the Institute of Child Health, Great Ormond Street Hospital. «first_name»'s participation at that time made an invaluable contribution to the research, and was greatly appreciated.

I am writing to you now to ask if you would consider participating in another research project being conducted in our department. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed Participant Information Sheet carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

If you do chose to participate in this research, please complete, sign and return the enclosed Informed Consent Form using the prepaid label and envelope included. You will be given a copy of this consent form to keep for your own records. This letter may be followed up with a phone call in order for you to have an opportunity to ask any questions you may have.

If you have any further questions you wish to ask about the research or the rights of the participant, please do not hesitate to contact:
Motchila Innocente, Trainee Clinical Psychologist, on 07813 793 899.

We greatly appreciate you taking the time to consider participating in this research.

Yours Sincerely,

MD FRCP FRCPsych FRCPCH
Professor of Behavioural Sciences

Motchila Innocente
Trainee Clinical Psychologist

Behavioural and Brain Sciences Unit
Neurosciences and Mental Health Directorate
Head of Unit: Professor David Skuse
Professor Peter Hobson Dr Tony Charman
Unit Administrator: Marta Salamonowicz

UCL

Appendix G

Connors Parent Rating Scale – Revised
(Version Adapted for the Purposes of the Current Study)

Appendix H

Strengths and Difficulties Questionnaire

Appendix I

Social Communication Disorders Checklist