

An Investigation into the Communication Development and General Communication of children with Pathological Demand Avoidance Syndrome

Charlotte Graham-White

Early Years Diagnostic Centre, Nottingham

Introduction

Pathological demand avoidance syndrome (PDA) was identified by Newson in 1980, as a potential subgroup within the Pervasive Developmental Disorders (PDD). Newson (2000) has outlined the atypical development of children with PDA in detail, and suggested that the underlying deficit in PDA is a lack of social identity (Newson 2000). This is theorised to create major difficulties with social responsibility and obligation and, therefore, a lack of the social need to comply. Evidence for this deficit is apparent from the children's difficulties with their own identities; for example, lability of mood, little expression of pride or shame. It is also apparent from the children's difficulties with other people's identities; for example, difficulty in recognising status and authority, and problems with gender identification. Recent research has found that a presence or absence of social identity is a successful discriminator between Asperger's Syndrome (AS) and PDA; children with AS were found to have fewer problems with social identity than children with PDA (Graham-White, 2001).

If accurate, the proposal that the underlying deficit in PDA is a lack of social identity has substantial implications for both the syndrome and for research into children's social development. Newson (1995) notes that the sense of self is crucial to development, and removal of this sense must be seen as "destructive" (pg. 2). Shatter (1998) defines possessing a social identity as "knowing where I stand in

relation to others around me within a particular...'moral world' of possibilities" (pg.272). He describes lacking a social identity as lacking "an evaluative orientation in a 'moral world'... a grasp of what precisely my doings are doing...in relation to my current social surroundings" (pg.272). It is possible that lacking a social identity and therefore having difficulty understanding other people's identities results in difficulty, not with understanding how people think and feel, but with understanding how people exist and interact. This may manifest in the appearance of the child not understanding how other people feel, when actually they do not understand, or attribute to themselves, the impact of their actions on others.

To progress in understanding this complex syndrome, it is important to undertake research into how exactly a lack of social identity causes atypical development. Examining communication and particularly communication development is important as there is a deficit in knowledge about this aspect of PDA (Graham- White, 2001) and because understanding the presence of any communication deficits within a developmental disorder enables better diagnosis of the disorder, better understanding of the disorder and improved intervention for the disorder (Bishop, 1997). Cohen, Paul and Volkmar (1997) describe the understanding of language and its dysfunctions as vital in the understanding of how mental processes develop. A clear example of how having a comprehensive understanding of the communication difficulties of a developmental disorder can lead to better understanding of that disorder is that of Asperger's Syndrome (AS). One of the most handicapping aspects of AS is impairment in the social use of language (pragmatics), which has become a hallmark of the syndrome (Baron-Cohen, 1988). The impairment is more striking when compared to the fact that actual speech production in AS is not affected. Understanding the difficulties children with AS have with pragmatics, but not with speech production, has clarified that the underlying deficit is one of difficulty empathising with other people, or a lack of 'theory of mind' (Happe, 1997).

Existing research has already indicated that the communication development and general communication of children with PDA is atypical. Newson (1996) described a high proportion of children with PDA as having speech delay and abnormal speech

content, although non-verbal communication was Jess affected. These findings were added as criterions for the diagnosis of PDA in the second revision of the diagnostic criteria (Newson, 2000). The pragmatics of language have been described as rarely significantly affected (Newson and Je Maréchal, 1998). However, recent research has found that children with PDA have difficulties with understanding metaphorical speech and using and understanding humour (Graham-White, 2001).

The salient question is one of how exactly an impairment in social identity might impact on communication development and general communication. Locke (1996) stressed the importance of speech in infants as an unconscious desire to identify with other people; this may explain the high level of speech delay in children with PDA. Dunn (1988, cited in Shotter 1998) outlines two essential communication skills as "understanding the relations between others and comprehending the sanctions, prohibitions and accepted practices of their world" (pg.5). It is possible that this may be lacking in children with PDA.

Further evidence for possible difficulties in communication caused by social identity is found from Bishop's (1997) observation that effective interpersonal communication depends on developing a sensitive differentiation between people that is achieved by using social stereotypes. It is plausible that this is reliant on being able to understand social identity and it can therefore be expected that children with PDA would find this difficult.

This study aimed to comprehensively describe the communication development and general communication of children with PDA. It then aimed to relate this description to the proposed social identity deficit within PDA. It did not aim to provide a detailed analysis of the language of children with PDA, but instead was an exploratory study to investigate in greater depth the anomalies of the communication of children with PDA and to lay the foundations for future research into this area of the syndrome.

Method

The design of this study was divided into two parts. The first part of the study had a descriptive design that involved archival research. This comprised collating information from 58 case files of children diagnosed with PDA held at the Early Years Diagnostic Centre, Nottingham (EYDC). The criterion for a case file being selected for use in this study was that it described a child between the ages of 5-12 years who had been diagnosed as having PDA by the EYDC in the years 1994-2001. The 58 case files selected involved children with an age range of 5 years 0 months to 11 years 9 months and there were 32 males and 26 females.

Two data collection forms were used to collate information from each case file. The first form focused on the child's early communication development between the ages of 0-5 years and the second form focused on the child's speech and communication at the time of their diagnosis. Data was collated from the case files over a period of four weeks; each case file comprised clinical and educational reports and a detailed diagnostic assessment report from which the majority of information was collated. An independent student completed both data collection forms for approximately 10% of the total sample (6 case files) to provide inter-rater reliability.

The second part of the study comprised a between-subjects design involving analysis of audio recordings of children's speech; the independent variable was the diagnosis of the child on three Levels - PDA, AS or control group (no diagnosis needed). The dependent variable was the speech content recorded. However, due to an extremely low participant response, the two recordings received (both of children with PDA) were used as case studies. Informed consent was gained from the parents/guardians of the children previously to the audio recordings being analysed.

Data Analysis

Information from the 58 case files was used to complete 58 case-specific 'Early Communication Development 0-5 years' and 58 case-specific 'General Speech and Communication at Diagnosis' data collection forms from which the results are collated. To gain descriptive percentages each category on the data collection forms, e.g. 'Echolalia' was divided into likely sub-categories i.e. present 1-3yrs, present 3yrs+, absent. The information from the data collection forms was then recorded into the subcategories using a computerised spreadsheet. The number of case files in each sub-category were counted and used to produce a descriptive percentage. The descriptive percentages were used to create an Early Communication Profile and a General Speech and Communication Profile.

If the case file contained no information on a particular behaviour, this was recorded as Nil and a percentage was calculated of how many files did not contain information on that particular category. If over 75% of the total case files did not contain information on the category, then the sample was considered too small to provide any conclusive results.

Description and discussion of Profiles

Early Communication Profile

The communication development of children with PDA suggested by the results appears unique when compared to other related PDD's e.g. autism, AS, and it also appears atypical. Over two-thirds of infants with PDA were generally described as 'smiley', however, the majority of the children studied showed difficulties with joint focus of attention, pointing and engaging in pre-verbal conversations. These behaviours appear delayed or do not emerge at all during the child's early development. In concurrence with these delays in pre-verbal communication, it appears that children with PDA show a generalised delay across all aspects of speech development. Babbling and first words are delayed in the majority of the children studied, as are two word utterances and key word sentences. Interestingly, physical developmental milestones did not show a similar pattern of delay to these communication milestones; this indicates that the communication delay is specific rather than part of a global developmental delay.

Although there appears to be a clear delay in the speech development of children with PDA, it is less clear how deviant this speech development is. Loss of speech, abnormal grammar development, echolalia and pronoun reversal were not present in the speech development of the majority of the children studied. However, abnormal vocabulary was more salient a feature. Two-thirds of the sample attended Speech and Language Therapy (SALT), and of this sample, the majority attended before the age of 4 years. Almost all of the children were described as experiencing difficulties such as being avoidant, inattentive or upset; it is possible that these difficulties impacted on the effectiveness of the SALT for the child.

This early communication profile is informative with regards to the underlying deficit within PDA. The delay/absence of pre-verbal communication indicates early difficulties with social consciousness and a sense of awareness of self and others. It is notable that this pattern of pre-verbal communication development in children with PDA is very similar to that of children with autism or AS. Within autism, it is taken as a sign of difficulty in developing a 'theory of mind' and is supported by other deviant development such as lack of imaginative play, social naivety (Baron-Cohen, 1988). It is therefore interesting to consider whether the delay/absence of pre-verbal communication in children with PDA can also be seen as a difficulty in developing a 'theory of mind' when this proposal is not supported by later development; children with PDA show no difficulty in developing imaginative play and are described as socially manipulative from a young age. It is possible that the delay/absence of pre-verbal communication is a general indicator of difficulty with social awareness, rather than an indicator of a specific 'theory of mind' deficit as hypothesised in children with autism and AS.

Further clarification of the similarities and differences in communication development between PDA, AS and autism is provided by the information on children with PDA's speech development. Unlike the similarities to autism and AS in pre-verbal communication, the speech development of children with PDA is not similar to these disorders. The lack of deviant features e.g. pronoun reversal, echolalia contrasts to the speech development of AS, where these features are more common (Newson, Dawson and Everard, 1982). Research has also shown that speech delay is not a major feature of AS (Gilchrist, Green, Cox, Burton, Rutter and Le Couteur, 2001). It is possible that, during speech development, the distinctly different social impairments in PDA and AS begin to have contrasting effects on development. This is perhaps not surprising considering that this same pattern is found when comparing autism and AS; pre-verbal communication development is similar, however, speech development shows clear differences due to the different severity levels of the underlying impairment (Szwarc, Archer, Fisman, Strien and Wilson, 1995).

General Communication Profile

The profile of the general communication of children with PDA suggested by the results is one with considerable variation in some areas and several salient areas of anomalies. The expressive speech profile of the children studied shows that the majority have normal grammar and vocabulary, although word-finding difficulties are apparent. Unusual semantic content is a prominent feature, particularly repetitive speech and bizarre content. Although normal articulation and intonation were observed in a high proportion of the sample, immature pronunciation was also a strong feature, indicating possible difficulties with age identification. A number of the children studied also showed anomalies with volume of speech that may have been related to lability of mood; for example, sudden loudness due to anger, frustration or excitement.

A striking feature of the expressive speech of children with PDA appears to be the impact of demand avoidance on different areas within speech; this appears to become more sophisticated with age. Further evidence for the pervasiveness of the demand avoidance within the expressive speech of children with PDA is found from the results regarding the children's use of speech. The majority of the children studied were described as using speech to direct, avoid, protest or distract.

The majority of the sample were described as having fluent conversational ability and no difficulty with social timing. Non-verbal communication was shown to be generally normal; most of the children studied had no difficulties with gesture or facial expression. Interestingly, the results for literality showed that a large proportion of children with PDA have difficulty in understanding non-literal speech or with understanding teasing or sarcasm.

Analysis of the audio recordings of the two children with PDA provided some supporting evidence for the general communication profile; however, the audio recordings proved quite difficult to analyse without the additional presence of any reliable comparative data. However, it was possible to identify from the recordings that the children had very little difficulty with conversational speech or social timing. A sudden variation in volume of voice was consistent for both children. Use of speech for demand avoidance was noticeable; for example, "Two minutes? But you said three minutes ... Can you just watch me swimming ... I just need to get wet", "I can't talk because I'm a statue". Grammar and vocabulary were not clearly disordered and both children did not seem to have difficulty understanding other people's speech or any obvious problems with literality or inferential communication.

The profile of the general communication of children with PDA is again informative when attempting to understand the underlying deficit within PDA. The profile suggests that children with PDA do not have difficulty using speech and non-verbal communication to communicate; this implies that children with PDA do not have difficulty with social empathy in the same way that children with AS do. However, lack of social identity in children with PDA can be seen to produce speech anomalies due in part to demand avoidance, but also involving lability of mood. A lack of social identity may also cause some pragmatic difficulties, although it is not clear how these difficulties differ from those of AS. It is possible that lacking a social identity can cause specific difficulties with understanding inferential communication, potentially because it involves social identification of some sort i.e. an awareness of the speakers personality, age and status.

Improvements, further research and conclusions

This study could have benefited from several expansions and improvements. A reoccurring difficulty during data collection was missing information from the clinical files. Although all the clinical files originated from the same style of diagnostic assessment, and the diagnostic assessment reports had a consistent structure, differences in content and style existed due to the seven-year time period within which the diagnostic clinics had taken place. It is also unfortunate that difficulty in gathering audio recordings meant that no exact comparisons could be drawn between children with PDA, children with AS and a control group. Further research could focus on actively arranging these recordings to study these important comparisons.

The results of this study have indicated several areas that would benefit from additional research. Further research to determine how exactly communication development is delayed and/or deviant would be useful, particularly if it utilised interviews with parents/guardians. Possible topics could include pre-verbal and verbal imitation; a large proportion of files did not contain any information on this topic. If infants with PDA do not identify with their caregivers or their environment then it is plausible to expect imitation to be affected.

An aspect of communication that has again been highlighted as a potential problem within children with PDA is specific difficulties with pragmatics of speech such as literality, communicative intent and metaphor. Research that investigated these difficulties, in comparison to the similar pragmatic difficulties of children with AS, would assist in clarifying why these particular aspects of the pragmatics of speech cause difficulties for children with PDA.

In conclusion, this study has shown that the communication development and general communication of children with PDA is both unique and atypical. Examining the early communication profile and the general communication profile together suggests that the communication of children with PDA is initially delayed but then develops to a normal or good standard with some salient anomalies. There are striking similarities to autistic children and AS in pre-verbal communication, although development of speech is very different. The study has also shown that the general communication of children with PDA has abnormalities in content and certain characteristics that are related to a lack of social identity i.e. high degree of demand avoidance, lability of mood. Apart from those features, speech is not noticeably deviant and the pragmatics of speech are mainly normal, although some aspects of pragmatics generate difficulties. The communication of children with PDA is an important aspect of the syndrome, and one that a better understanding of provides supporting

evidence for the underlying deficit within the syndrome. Improved understanding and diagnosis of this complex and challenging syndrome is vital for the children and families who have to cope with its pervasive effects.

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