Training programmes for parents of children with autism spectrum disorder: the benefits of a psycho-education model

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Abstract

Children with autism spectrum disorder often exhibit problematic behaviour, which can place parents under great stress. A pilot study was performed to evaluate the effectiveness of an existing parent training programme. Parents were asked to set their own goals before attending the group. Self-ratings of parent stress and self-efficacy were completed before and after the intervention. Parents were also asked whether the training met their goals. Both individual session evaluations and an overall evaluation of the intervention were completed by the parents to determine whether the group had met their expectations. The ratings revealed no significant differences in parenting stress following the group work. Self-efficacy, however, was found to be statistically significantly improved. The perceived ability of parents in attaining their goals was also improved. Overall, parents reported the group as being helpful in generating ideas and meeting expectations in learning about their child's condition. They had the opportunity to consider the behaviours that were consistent with their child's condition and adjust their style of managing them. Psychoeducation programmes for parents should be considered as an early intervention and preventative approach to reduce the need for mental health interventions. The approach encourages the parent to become the expert on their child's difficulties.

Behavioural problems

Children with autism spectrum disorder (ASD) frequently display challenging behaviour (1). There are several possible causes of such behavioural problems, including difficulties in understanding social situations, picking up social cues, understanding language and coping with change. These difficulties can result in frustration and anxiety. The high state of anxiety can often manifest as defiant behaviour or aggression. A large proportion of children with ASD also have attention deficit hyperactivity disorder (2), which can add to their difficulties and result in challenging behaviour.

Parental stress

The impairments in ASD can place considerable stress on parents, both directly and indirectly (3). Parent-child interactions may be perceived by the parents as being unrewarding. Parents may feel overwhelmed by guilt when these difficulties are encountered. Lecavalier et al. (4) found that behavioural problems in children with ASD had a higher impact on parental stress than any other characteristic of the child or parent.

Self-efficacy

Self-efficacy may be defined as the perception of one's abilities and sense of confidence in any given area (5). Sofronoff and Farbotko (1) defined self-efficacy as the level of confidence that parents feel in terms of their ability to manage their child's behaviour. They concluded that low parental self-efficacy can result in depression and lower levels of satisfaction in the role as a parent. Self-efficacy was found to be an important predictor of parenting stress (5). The stresses in parenting children with ASD are being recognised increasingly (6). In other disorders in which behavioural problems are common, for example in ADHD, NICE guidelines (7) currently recommend that parents be offered a parenting

group as a first approach. The Carers and Disabled Children Act (2000) (8) made it compulsory for local councils to support carers and provide direct services to them. The Department of Health Autism Working Group (2002) also recognised parental stress in children with ASD; they recommended the use of educational programmes to empower and support parents and carers.

Parenting groups for ASD

Several parent training programmes to support carers of children with ASD are available. For example, the Earlybird and Earlybird Plus programmes (www.nas.org.uk) provide training courses to parents/carers. For parents/carers to have access to these programmes, the child needs to have a diagnosis of ASD and be in receipt of specialist education provision. This excludes many families who have a child with high functioning ASD who is attending a mainstream school. These programmes also exclude families who do not have a diagnosis but are struggling to manage behaviours suggestive of a significant social communication difficulty.

Pilot study of parent training programme

The author of this paper was keen to explore the benefits of a parent training programme that filled gaps in local service provision. The Milton Keynes CAMHS parent training programme which is piloted in this paper was developed and evaluated by the Sofronoff and Farbotko psycho-education approach (1). The Sofronoff and Farbotko programme consisted of six sessions, which included psycho-education about the condition, management of behavioural problems, understanding your child's communication style, and anxiety management. Parents were encouraged to choose which sessions to attend or could book themselves onto the whole block of six. Although their child did not need to have a formal diagnosis of ASD, for parents to access this training, the child did need to have some level of social communication difficulties and challenging behaviours that were consistent with these difficulties. This approach ensured that those families who would usually fall between the gap of service provision by not meeting strict referral criteria would be able to attend. The pilot appeared to be very successful.

Following the apparent success of the pilot, the counselling psychologist at the specialist CAMHS service in Milton Keynes, Buckinghamshire, England, further developed and coordinated a parent training programme for this client group. The parent group was run over eight weeks and was based on the manual developed by Sofronoff and Farbotko (1). Additional sessions were added to the programme following a parental survey. The programme was also designed to promote joint agency working. Presenters were recruited from within existing local authority and child health agencies.

The sessions included the following.

1. What is ASD? Understanding the behaviours consistent with this condition. Multidisciplinary diagnostic investigations according to the National Autism Plan.

2. Communication styles. How to use comic strip conversations and social stories. Enhancing communication with your child. Interpreting behaviour as a form of communication.

3. Anxiety, obsessive-compulsive and ritualistic behaviours. CAMHS interventions. The role of psychotropic medication. Environmental manipulation to reduce anxiety.

4. Relationships and sexuality issues in ASD. Social awareness versus sexualised deviant behaviour. Puberty and sexual identity. Reluctance to change and transition to adulthood.

5. Understanding and managing challenging behaviour.

6. Agencies and services. The role of community paediatricians. Medical investigations and interventions.

7. Special education needs. Support available within schools, including transition to adulthood. The special educational needs statement process and relevant laws.

8. Caring for the carers. Pamper and relaxation session. Community agencies were invited to inform parents of local and national support services.

Each session was taught by a different professional who had expertise in that area. The group was attended by parents and carers of children with ASD, although a prior diagnosis of this condition was not a requirement of attendance. Some parents may have accessed CAMHS previously for support. Parents were able to choose which sessions to attend and re-attend for refresher sessions in the future. They were also encouraged to bring co-parents and child minders.

Aims of the study

The aims of this study were to determine whether the parent training programme contributed to a reduction of parental stress and whether it improved self-efficacy in managing difficult behaviours.

A further aim was to determine whether the programme contributed to an increased understanding of the difficult behaviours in children with ASD.

It was anticipated that the results of the study might help in making decisions about whether future programmes should be offered and might also indicate how to design future programmes by revealing which parts of the programme were most helpful.

Research questions

Are self-ratings of parental stress for managing a child with difficult behaviour different after the training programme?

Are self-ratings of efficacy in managing difficult behaviours different after the programme?

Are self-ratings of understanding difficult behaviours different after the programme?

Did the programme meet the expectations and goals of parents?

Design

This study consisted of two components. The first of these involved examining questionnaires before and after attending the programme. These were analysed for statistically significant differences and reliable change index. The second component involved completing weekly session evaluation forms to determine satisfaction with the programme.

Participants

The participants in this study were parents and carers who accessed the parent training programme for managing difficult behaviour in children with ASD. It was an open referral system. Parents or carers could refer themselves to the group and choose which sessions they attended. Numbers attending varied from session to session. Leaflets advertising the programme were available in schools, clinics, doctor's surgeries and on the local authority website.

Forty-three parents were invited to be participants in the study. Thirteen completed the pre-group measures. Eight completed both pre-group and post-group measures; only these were used in the analysis. Six of the eight were mothers of a child with ASD. One was a father. One was a stepfather. The age of the children ranged from 4 to 16 years with an average age of 10.75 years. All the participants had seen professionals, for example psychologists and family therapists, previously for help with their

child's behaviour. Four parents were receiving ongoing support from these professionals. Two parents had attended parenting groups before. Six of the eight participants were White British; one parent was African and one Indian. The children had the same ethnicity as the parents. All the children had been diagnosed as having ASD. The age of the child at the time of diagnosis ranged from 3 to 15 years (mean 9.29 years).

No demographic data were collected in the session evaluation forms; it cannot be assumed that this sample had the same characteristics as those of the parents who completed the pre-group and post-group measures. The number of questionnaires completed after each session varied from 7-25 (mean 14.25).

Measures

1. A general information questionnaire was given, asking parents to choose three goals they would like to achieve by attending the group. They were asked to rate their current ability to achieve these goals on a Likert scale from zero (not able to do it) to five (completely able to do it).

2. Parenting stress was measured by the Parental Stress Scale (PSS) (Berry & Jones, 1995 (9)) This measure is designed to identify areas where the parent-child relationship is considered to be dysfunctional and consequently to identify potential stressors on the parent. The PSS has good psychometric properties. The test-retest reliability is 0.81. It is suitable for use in parents of school-aged children and for a broad range of ethnic groups and family compositions (9).

3. An adapted version of the questionnaire used by Sofronoff and Farbotko (1) to measure parental self-efficacy in the management of ASD was also used. The psychometric properties of this questionnaire are not known as it has been tailored specifically for the parent group being evaluated. Parents were asked to indicate the number of difficult behaviours that had occurred in the past month and to rate their confidence in managing this behaviour on a scale from zero (no confidence) to five (complete confidence). An average self-efficacy score was obtained by dividing the total score for confidence by the number of behaviours exhibited by their child. Parents were also asked to rate their understanding of the behaviours on the scale from zero (no understanding) to five (complete understanding). This was used, in a similar way, to calculate an average understanding level.

4. A session evaluation form, designed for the purpose of this group, was distributed after each group session, asking parents which features of the session they felt were most helpful.

5. A further evaluation form, designed for the purpose of this group, was sent with post-group measures. This asked parents which sessions they attended and which they found were most useful. They were also asked to re-rate their abilities in relation to the goals they set prior to the group.

Procedure

The general information questionnaire, PSS and measure of parental self-efficacy were sent to each parent with a covering letter when they booked into the group. Parents were asked to return the questionnaires by post or bring the completed measures to the first session that they attended. An evaluation form was given at the end of every group session. Overall evaluation forms were given to parents at their last session.

Interpretation of results

Although there was no overall statistically significant difference in parental stress (PSS) after the programme, the reliable change index (RCI) indicated that two parents had a significantly lower stress level and two had a significantly higher stress level. It is difficult to interpret these results.

The results of the confidence ratings from the measure of self-efficacy indicated that parents rated

themselves as statistically significantly more confident in managing their child's behaviour following the programme.
Parental ratings of understanding their child's behaviour were found to be statistically significantly higher after the programme.

Parent ratings of their abilities to meet the goals they set prior to the group were significantly higher following the programme. This indicates that parents' goals were at least partly achieved by the group.

Session evaluation forms indicated that session four (relationships and sexuality) met the expectations of most parents. Session evaluation forms from this session indicated that the content of the session, homework given and advice given were the most helpful aspects. As might have been expected, session one, which dealt with what ASD and social communication disorder are, was rated the most helpful overall. Results from the evaluation forms indicated that the most helpful aspects were the information presented, advice and tips, and meeting with other parents. In view of the fact that challenging behaviour often causes major concern in families, it is notable that session five (understanding and managing challenging behaviours) was rated the least helpful and met the least expectations overall. This might be interpreted as indicating that the content and presentation of this session can be reviewed to include more examples of management techniques.

It is difficult to draw conclusions about the correlation between the numbers of sessions attended and how helpful the programme was found to be overall. It is possible that the greater time spent on the programme was helpful but it is also possible that those who attended a greater number of sessions were more committed. Since parents booked the sessions in advance, the latter might be viewed as a more probable explanation.

Limitations

This was a small study (N = 8) and was questionnaire-based. There was no control group, nor was there a treatment-as-usual group. There were no limits placed on how much information parents could obtain from other sources and this may have been a confounding factor. It is also possible that parents gained in confidence simply from meeting other parents in a similar situation. The parents might have been biased in their assessments, especially in view of the fact that they set the goals themselves and might have felt motivated to score their success higher on this basis.

Clinical and service implications

This evaluation is consistent with the findings of Sofronoff and Farbotko (1). The latter study also found that self-efficacy had increased following the programme. Sofronoff and Farbotko carried out a three-month follow-up study to ascertain whether the improvements had been maintained. It is possible that the increased insight into ASD contributed to increased levels of stress

The evaluation questionnaires consistently indicated positive feedback from the parents on many aspects of the programme. The findings also showed that parents were statistically significantly more confident and felt that they had a greater understanding of their child's behaviour following the programme. This suggests that such programmes can be valuable.

Conclusions

The data reflected that this parent training programme was valued by parents. The results indicated that it generated ideas and met expectations. The variability in stress level after the programme may have indicated increased confidence in some parents but increased stress in others in coming to terms with the implications of the diagnosis of ASD. It should be noted that this programme became very popular with parents over a relatively short period of time. This initial programme was piloted in 2008. The Parent training programme has continued to run in Milton Keynes and increased in popularity. There has been a notable shift in the attendance population in the last five years. More fathers and

grandparents are attending the programme. Families have relocated to Milton Keynes on hearing about the parent training programme.
This pilot study and further audits of this programme had been used to secure joint agency NHS/ Local authority funding. The Milton Keynes Specialist CAMHS audits reflected a significant decrease in referrals from this client group, since the start of this programme. Parents of children with difficulties that may be consistent with ASD who contact the CAMHS helpline are now directed to the parent training programme. Post diagnosis, our paediatric colleagues can now invite parents to attend the programme. The increased competence in managing their child's difficulties has also empowered some parents from the groups to set up parent support groups.

The author of this paper was keen to explore further the benefits of a parent training programme that filled gaps in local service provision elsewhere in the country. This programme is now being piloted in Bedfordshire. A programme of a similar nature is also being developed for professionals and siblings.

The popularity might be taken as an independent measure of the value of such a programme. Against this background, serious consideration should be given to providing specific parenting programmes for parents of children with ASD as part of the wider services for families.

GP comment.

What have I learned from this paper?

Clearly it is important to offer support to parents of children with ASD. The Parenting Group in Milton Keynes appears to be meeting a need, in particular helping parents to feel more confident in managing behavioural problems in their children and improving their understanding of ASD. The author notes that the group is now flourishing. The actual evidence presented in this paper is limited by the small sample and it would be interesting to explore further what works and what doesn't in providing practical tips and support for managing problem behaviour. Anything that actually is helpful to parents of children with ASD in helping them manage, and that helps reduce stigma and guilt as well, has to be a good thing and this Parenting Group appears to be a useful and valuable service.

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