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Parent education and home-based behaviour analytic intervention: an examination of parents' perceptions of outcome

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There is convincing evidence that applied behaviour analysis (ABA) offers a highly effective form of intervention for children with autistic spectrum disorder (ASD). There is less evidence, however, about how parents perceive and evaluate ABA programmes. In this paper an examination of parents' perceptions of outcome is reported. Twenty-two questionnaires were completed by two groups of parents. The first group had just completed an introductory

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course in ABA and were in the early stages of implementing ABA programmes with their children. The second group had been involved in ABA education for more than 2 years. Overall, both groups of parents reported a positive impact of ABA on the lives of their children, their family life, and themselves. The long-term group reported that they had achieved complex goals with their children, whilst the short-term group reported an immediate positive impact on child and family functioning and parental self-esteem. Conclusions are drawn in the context of evidence-based practice.

Introduction

In common with many of the other natural sciences, behaviour analysis has a conceptual, an experimental, and an applied strand (Baer, 1997; Chiesa, 1994). In this paper we concentrate on the applied strand of behaviour analysis, that is, applied behaviour analysis (ABA). ABA is defined as the use of knowledge gained within the science of behaviour analysis for the improvement of behaviours that are socially important (Baer, Wolf & Risley, 1968). It is used in many areas such as community development, social work, nursing, industry, education, and medicine. For over 30 years ABA has been employed successfully with children with autism spectrum disorder (ASD) (Matson, Benavidez, Compton, Paclawskyj & Baglio, 1996). It is the aim of this paper to add to the existing knowledge by exploring the views of parents who have been trained in the use of ABA with their own children.

While the exact neurological differences between children with ASD and their typically developing peers remain unclear, the diagnosis generally relies on observations of differences in behaviour. Children are diagnosed with ASD if they engage in specific behavioural excesses (e.g., “stimming”, temper tantrums, stereotypic, emotionless play) and particular behavioural deficits (e.g., lack of language, social interaction, social initiation, and interactive play) (cf. DSM-IV, 1994). In behaviour analysis the term “behaviour” has a wide definition. Anything a person does is regarded as behaviour; this includes publicly observable behaviours as well as “private” behaviours, such as feeling and thinking (Reese, with Howard & Reese, 1978). This holistic perspective on being a person means that the term ASD is viewed as a summary label for publicly observable behaviour patterns as well as private responses (Holth, 2001).

ABA for children with ASD

The best-known applications of behaviour analytic knowledge for children with ASD are discrete trial methods that were initially developed by Lovaas (1987). However, ABA involves a wide range of other strategies, including Picture Exchange Communication System (PECS), precision teaching, shaping and chaining of new behaviours, generalisation and maintenance training to name but a few. It is not the aim of this paper to describe in detail what is involved in a comprehensive ABA programme. Interested readers are referred to the available literature (e.g., Keenan, Kerr & Dillenburger, 2000; Maurice, 1993; Maurice, Green & Luce, 1996; Richman, 2001).

Extensive research over 30 years shows that early intensive behavioural intervention can lead to significant gains in cognitive, social, emotional, and motor functioning that can be generalised to other situations and maintained in the long term (McEachin, Smith & Lovaas, 1993). A review of over 500 studies shows that ABA consistently offers

positive outcomes in terms of educating children with ASD and enhancing life skills (Matson et al., 1996). Even in cases of less intensive parent-managed behavioural intervention, it was found that children were able to live in less restrictive environments than if they had not received behavioural interventions (Bibby, Eikeseth, Martin, Mudford & Reeves, 2002). The level of ABA training and expertise of professionals varies considerably, and ranges from having some training and experience with so-called “Lovaas’ methods” in the 1970s (Jordan, 2001) to rigorous internationally recognised qualifications, such as those offered by the Certification Board for Behavior Analysis.

ABA treatment and parent education

The quality of ABA training is a crucial factor in the determination of treatment outcome. Exact data relating to quality of training are generally unavailable (Bibby et al., 2002) with the exception of one study which found that parent-employed therapists who had received short-term training were less effective than college trained therapists (Smith, Buch & Gamby, 2000). More research has concentrated on the quality of parent training in general (Callias, 1994; O’Reilly & Dillenburger, 1997).

The approach to ABA training for parents differs between programmes (Keenan et al., 2000; Richman, 2001). Some training programmes teach parents the use of distinctive treatment procedures (Boyd & Corley, 2001) while others start by educating parents about general behavioural principles (Keenan, 2001; Keenan & Dillenburger, 2000). The former approach has been criticised as a “cookbook approach to practice” (Bronson & Thyer, 2001, p. 193), likened to giving “recipes” for treatment, a “one fits all” approach. The latter approach offers detailed knowledge of the broad spectrum of behavioural principles so that parents are empowered to adapt interventions to the individual, ever-changing needs of their own child (Webster-Stratton & Herbert, 1994). In the present study the latter approach was used; in other words, parents were educated in general principles of ABA to enable them to design individually tailored treatment programmes for their children.

Parent training in ABA

Education in general principles of ABA begins by giving the parents a basic understanding of the philosophy of the science on which ABA is based, namely, behaviourism (Chiesa, 1994; Keenan & Dillenburger, 2000). Behaviourism encourages the scientist to go to the root of traditional assumptions and beliefs by exposing the futility of mind/body dualism inherent in much of contemporary psychology (Chiesa, 1994). This philosophy of science informs parents so they can recognise the tautology inherent in the term “autism” and avoid the category mistakes (Holth, 2001). From this basis parents are then taught some of the basic principles of behaviour and how these are applied to children with autism (Maurice et al., 1996).

In the present study an introductory course in ABA that ran one evening per fortnight in a local university for an 18-week period was designed for the parents. The topics covered were: the philosophy of applied behaviour analysis, reinforcement, extinction, increasing adaptive behaviours and decreasing maladaptive behaviours, shaping and chaining new behaviours, stimulus discrimination training, observation and data collection, designing and implementing an intervention, and a session dedicated to revision. Parents read assigned chapters from a textbook (Grant & Evans, 1994) in

preparation for each session and were given a multiple-choice questionnaire at the end of each session. The parents then carried out the applied practice of the theoretical skills learned through the course at home as frequently as possible throughout the day. An ABA professional visited each family on a weekly basis for approximately 2 hours to supervise and adjust individualised programmes together with the parents.

Parental perception of outcome

To date there exists only one parental satisfaction survey of early intensive behavioural intervention for young children with autism in a community setting (Boyd & Corley, 2001). In Boyd and Corley's study tutors and supervisors in California were trained in autism and "discrete trial" training; in other words, they were trained in one specific 1:1 treatment procedure (often referred to as Lovaas therapy) rather than in the full range of applications of ABA. Weekly review meetings then were held with parents, tutors, and supervisors. Boyd and Corley reviewed 22 cases (mean length of treatment: 23 months; mean age of child: 41 months). Two children were in home programmes; the remainder received discrete trial training in schools. Boyd and Corley found that although all children had made progress they did not achieve "recovery" (Lovaas, 1987). Parents were generally satisfied or very satisfied with the implementation of their child's programme and outcome.

The study reported here differs in a number of respects. First, parent training did not concentrate on one particular method of intervention. Instead parents were educated in general principles of ABA that enabled them to tailor individual training programmes according to the changing needs of their own children using the full range of strategies developed within ABA. Second, it includes older children. Third, all children were on home programmes; and fourth, the effect of treatment duration was assessed.

Methodology

Sample

A total population of 50 families were actively engaged in home-based ABA programmes in Northern Ireland at the time of the study. All of these families were invited to participate (see procedure). A total of 22 families took part in the study. The length of time they had been involved in ABA training was used to differentiate between two equivalent groups of families. The long-term group (LTG) ($n=12$) had been involved in ABA programmes for an average of 35.5 months (range 18–72 months); the short-term group (STG) ($n=10$) had been involved in ABA programmes for an average of 6.1 months (range 2–12 months). Although the age range of children in both groups was virtually the same (3–12/13 years) more of the older children were in the LTG (mean = 125 months) than in the STG (mean = 52 months). The mean age of children at the start of ABA was 91 months for the LTG and 46 months for the STG.

Parents in the LTG were slightly older (mean age 41 years, range 31–52) than those in the STG (mean age 36.6 years, range 32–43). The groups were equivalent with regard to employment status (8 LTG parents vs. 5 STG parents in employment, the remainder unemployed) and with regard to socio-economic status. The reasons parents were not employed were similar between the two groups and were mainly related to caring for a child with autism.

In regard to gender of parents and children the groups were equivalent (LTG: 5

fathers, 7 mothers, 10 boys, and 2 girls; STG: 3 fathers, 7 mothers, 9 boys, and 1 girl). All families were two-parent families except for one father-led one-parent family in the LTG. All families had other children. In the LTG the average number of other children was 3 (range 1–4) and mean age of other children was 11 years (range 7–19). In the STG the average number of other children was 2.5 (range 1–3) and mean age of other children was 7.1 years (range 1–19). Both groups had one family in which the siblings of the child with autism did not live in the same household. In both cases the father had custody of the child with ASD while the mother had custody of the other siblings. Generally, all parents reported good relationships with their children, although one mother (LTG) stated that she had a strained relationship with her other child “because of the autistic son”.

Procedure

ABA evaluation questionnaires were designed and circulated to the families. The questionnaires evaluated the validity of ABA, including significance of goals of the intervention, appropriateness of the intervention strategies, and importance of the outcomes (Kazdin, 1977; Wolf, 1978). Questionnaires were sent by post to all 25 LTG families who were in receipt of ABA at the time. Twelve of these families returned questionnaires by post in a pre-paid addressed envelope, constituting a return rate of 48%.

Twenty-five STG families were in receipt of ABA education at the time of the study. The questionnaires were distributed at the end of the final ABA training session. Ten of the STG parents completed the questionnaire in the training room and returned it anonymously to a table for collection, constituting a return rate of 40%. While the return rate for postal questionnaires (LTG) is average, the relatively low return rate of collected questionnaires (STG) can be explained by the fact that parents who had just finished a training session were eager to get home to their children rather than fill in questionnaires.

Ethical considerations

Written, informed consent was obtained from parents prior to the study. A letter was given to the parents explaining the purpose of the study and assuring them that their participation was voluntary and that non-participation would in no way affect the services they received. The letter outlined that their response to the questionnaire was confidential and would be used for research purposes only.

Results

Did the intervention make a difference?

Table 1 shows that ABA was perceived to have made a difference to a number of mutually agreed goals, such as independence, quality of life, skills development and maintenance, and interaction in virtually all of the children’s lives. Only one LTG parent, who had stated that ABA made a great difference in the other categories, did not know if ABA had made a difference in the “quality of life” category for her 10-year-old child with a severe disability. One STG parent (who had received ABA education for less than 2 months) reported that ABA had made a difference already in all the categories, apart from her 3-year-old child’s independence. There were no statistically significant differences between LTG and STG parents’ perceptions.

Table 1

Number of parental responses regarding difference that ABA made to a range of child behaviour categories

Behaviour category	Response alternatives											
	Great difference		Some difference		Little difference		No difference		Don't know		Not applicable	
	LTG	STG	LTG	STG	LTG	STG	LTG	STG	LTG	STG	LTG	STG
Independence	3	5	8	4			0	1				
Quality of life	7	8	2	2	1	0			1	0		
Skills development	8	8	3	2								
Skills maintenance	6	6	5	4								
Interaction	6	7	5	3								

One LTG parent did not complete these items.

Effectiveness of the intervention strategies

Table 2 shows that overall the ABA strategies which had been jointly agreed with the parents were effective and had an important impact on the life of all the children. The overall perception of most parents was that ABA was very effective. Only two LTG parents (who had scored high levels of effectiveness in the other categories) found ABA not to have been effective in self-help; one of these parents also did not think ABA had been effective with social skills. One of these was the parent of a 10-year-old boy with profound autism.

Two STG parents did not know if ABA had been effective in terms of self-help; one of these parents was also unsure about the effect on social skills. These were all parents who had commenced ABA education only 3–8 months earlier; one of these parents added the word “yet” to her answer, indicating her expectation that ABA would be effective in this area in the longer term. Only one LTG parent did not know if ABA had been effective in

Table 2

Number of parental responses regarding perceived effectiveness of ABA in a range of child behaviour categories

Behaviour category	Response alternatives									
	Very effective		Effective		Not effective		Don't know		Not applicable	
	LTG	STG	LTG	STG	LTG	STG	LTG	STG	LTG	STG
Self-help skills	6	4	3	4	2	0	1	2		
Social skills	9	4		5	1	0	0	1		
Problem behaviour	9	5	3	5						
Obsessive behaviour	8	4	4	3					0	3
Gross motor skills	9	6	3	3					0	1
Fine motor skills	9	6	3	4						
Communication	9	7	3	3						
Concentration	10	9	2	1						

Table 3***Examples of parents' statements regarding the impact of ABA on family life***

Categories	Examples from LTG parents	Examples from STG parents
Before ABA treatment	Autism equals disruption, loss of a bedroom, wife having to leave work, cannot book holidays ...	
General effect on family life	Made it easier. Immense impact. We are now approaching normal family life. We have a level of reasoning. More manageable.	Time with other children has been reduced although they understand this. Entirely positive. Great impact. Life is a bit calmer.
Effect on family cohesion	We have a level of reasoning. Entirely positive. Brought the family tighter to help child. Great impact, more normal family life.	ABA has improved family life immensely. We have a direction now. Gives us hope. Brought the family together to help child.
Work load	Made it more manageable.	A lot of time and energy used up on implementing ABA programmes.
Structure	More structured than before. It has helped give a focus. Able to deal with difficult situation.	It has put a strain on it to organise sessions.
Finance		Financially very stressful.
Freedom	Made us able to go on more outings.	It has raised expectations of relations.

terms of self-help skills. There was a tendency for LTG parents to evaluate ABA effectiveness somewhat better than STG parents.

Importance of the outcomes in relation to family life

In response to the question "What impact has ABA had on your family life?" parents in both LTG and STG considered that ABA had a positive effect on family life, although one parent drew attention to the amount of work and finance necessary for an intensive ABA programme (Table 3).

Importance of the outcomes in relation to parents

In response to the questions "What impact has ABA had on you/how you feel about yourself?" all parents felt that ABA had positively impacted on them and how they feel about themselves (Table 4).

Importance of the outcomes in relation to the child

In response to the question "What impact has ABA had on the life of your child?" all parents responded that ABA had had a very positive impact on their child's life (Table 5).

Table 4***Examples of parents' statements regarding the impact of ABA on themselves***

Categories	Examples from LTG parents	Examples from STG parents
General impact	Entirely positive. I now feel like a normal person.	ABA works and that impresses me. I feel it is brilliant.
Communication	A good impact through improved communications.	
Confidence	Made me more confident and relaxed. I feel capable of helping my son. It has made me feel confident. Confident as a mother. I feel as if I have done something constructive in helping my child. A sense of control over situations.	Given me confidence to help my child. Gives me a sense of control in my child's life. Feel more focused. I feel more in control. Determination to change things.
Coping	More able to cope with situations at home. It has helped me in everyday situations and can cope better. Enables me to cope with life and not lost as I felt when my son was first diagnosed. Gives me a greater understanding of my son and how to work properly with his needs.	Encouragement of X. I am more hopeful. I feel I am actually doing something to help my child. Given me hope for the future. Has given me the hope that I can improve my daughter's life without being dependent on professionals and their opinion.
Worry/stress	Made me worry less and enjoy my child more. Given hope and reduced stress levels. Given me some hope.	It makes me realise what can be achieved but I sometimes feel inadequate to the task. It has to some extent increased stress but as we become more familiar with the concepts, stress levels are decreasing slowly!
Self-esteem/empowerment	Initially one feels rather inadequate in terms of what we had been doing to help X with his autism. However, undertaking ABA has been a definite step forward and constantly increases self-esteem. Makes me feel more empowered.	It gives me skills. It has given me the ability to help him.

Discussion

In this paper we reported an examination of parents' perceptions of the outcome of home-based ABA programmes. It was found that parents considered ABA to have high effectiveness in facilitating development of their children. In particular they expressed that ABA outcomes were important and had made a substantial difference for the family as a whole and raised the general level of parents' confidence and empowerment. In the context of other similar programme evaluations the findings reported here are noteworthy for a number of reasons.

Prior to the introduction of ABA, only one other treatment approach (Treatment and

Table 5***Examples of parent's statements regarding the impact of ABA on life of child***

Categories	Examples from LTG parents	Examples from STG parents
General demeanour	Has controlled his outbursts and made him a happy child. Improved tasks and difficult issues. Completely back in control and can deal with problem behaviours.	Calming influence, responds well to commands. There has been a very big change in X.
Communication/speech	He is less frustrated and easier to manage.	It has improved his communication hugely. He is more settled, more spontaneous, speech much better. The improvements have been dramatic. Her language and awareness have exceeded all expectations.
Academic skills	I don't believe my child would be at mainstream primary school and coping academically without ABA.	Exceptional results. He has had nothing else. Better concentration and vast improvements in writing, reading and many other areas. He is starting to write/read and is doing things I would never dream he could do.
Independence	Improved. He has learned to be more independent and acquired some basic skills. She has learnt skills she did not have!	He is now toilet trained. Taught my son that we expect him to participate/cooperate/interact/communicate.
Relationships	Not only has it helped my child but also the whole family quality of life has improved dramatically.	ABA has certainly helped modify X's behaviours and has had a positive impact on family life in general. Large impact. Lots of family life changes. Excellent positive effect.

Education of Autistic and Communications Handicapped Children, or TEACCH) (Schopler, Mesibov, DeVillis & Short, 1981) had been available in Northern Ireland. Sines' (2001) evaluation of TEACCH showed that parents were generally satisfied with the service they received for their child, although they were not convinced of the effectiveness of TEACCH in achieving the goals that they were expecting. Data presented here show that, when offered an alternative, parents reported very substantial levels of satisfaction with the significance of goals of ABA intervention, the appropriateness of ABA intervention strategies, and the social importance of ABA outcomes for the child, the parents, and the family as a whole.

When compared with Boyd and Corley's (2001) parental evaluation of ABA programmes in California, findings reported here confirm a high level of parental satisfaction with ABA. The subtle downward shift in terms of parental satisfaction with treatment outcome noted by Boyd and Corley was not detected in this study. As

mentioned earlier in this paper, parent education did not concentrate on one particular method of intervention (e.g., 1:1 discrete trial training); instead, parents were educated in general principles of ABA and then became involved in the development of individually tailored treatment plans that encompassed the full range of methods developed within ABA. It is possible that this difference accounts for the high levels of satisfaction.

Indeed, through this kind of education in ABA it is likely that in general parental interactions with the child change, and that this change affects the child on a 24-hours-a-day/7-days-a-week basis. If this were found to be the case it would have implications for an analysis of treatment intensity. The intensity of behavioural intervention has been found to be important for treatment outcome (Lovaas, 1987). Is it possible that educating parents in ABA achieves increased levels of treatment intensity? Future studies should include direct assessment of parental programme implementation as well as a component analysis of parent education to shed more light on this tentative conclusion.

Previous research had shown that the age of the child at the onset of treatment is an important factor in treatment success (Fenske, Zalenski, Krantz & McClannahan, 1985). Results reported here confirm Eikeseth, Jahr and Eldevik's (1997) findings that, while there may be an optimum age for starting behaviour analytic treatment (STG), late treatment onset (LTG) still has high levels of validity from a parental point of view. Further studies should be conducted with older children who receive home-based ABA interventions based on parent education programmes in order to establish exactly what variables are responsible for the achievement of treatment goals with these children.

Length of treatment is also usually viewed as a decisive factor with long-term treatment achieving better results than short-term treatment (Smith, 1999). Results reported here however, show that parents educated in ABA in the short term can achieve significant changes. The present study was based on the premise that there was no time limit on ABA intervention. Instead the approach was to work with the child as long as it takes to achieve the desired outcomes.

To the authors' knowledge the study reported here is the first examination of parents' perceptions of the outcome of home-based ABA programmes. Usually more rigorous objective scientific research methodologies are harnessed to measure the effect of ABA on various indices associated with a child's development (Keenan, 2003; Keenan et al., 2000). Despite the wealth of quantitative research reported in the literature (e.g., Anderson, Avery, DiPietro, Edwards & Christian, 1987; Smith, 1996, 1999; Weiss, 1999), it is argued by some that the jury is still out on whether ABA is as effective as it is purported to be (Ives & Munro, 2002; Jordan, Jones & Murray, 1998; Task Force Report, 2001). Although the present study did not include evaluative, continuous data on behaviour changes in the child, the tentative findings reported here mean that there is a strong indication that parents are satisfied with the outcomes achieved through basic ABA training. This group of parents was satisfied and perceived ABA to be valid in terms of significance of behavioural goals, appropriate in relation to intervention strategies, and important as regards outcomes for the quality of life for the children, their own confidence and feeling of empowerment, and the impact on family life as a whole.

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