Practical Research

Feasibility of Parents of Children with Autism Using an Applied Behavior Analytic Early Treatment Program: A Preliminary Study in Malaysia

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The purposes of the present study were to investigate the resources for formal and informal support for families of children with autism in Malaysia, and, with those findings, study the possibility of Malaysian parents conducting an applied behavior analysis-based treatment program in their homes. A questionnaire survey was conducted of 119 parents who were members of parents' support groups, and intensive interviews were done with 8 parents who responded to the survey and were already using an applied behavior analytic program. The questionnaire results revealed that most of the parents had learned about applied behavior analysis from books or the Internet and had no formal training, and that they were searching for experts to advise them in its use. During the intensive interviews, all the parents reported that they could learn about teaching methods from an applied behavior analysis program. On the other hand, most of them pointed out difficulties in understanding the contents of the program and in confirming whether they could really communicate with their children. To overcome these difficulties, the parents' support groups provided general information and shared the teaching techniques of applied behavior analysis with their members. However, parents noted that even so, they needed to access information about autism other than just the applied behavior analysis program.

Key Words: parents of children with autism, early treatment program, applied behavior analytic treatment, parent support group, Malaysia

Introduction

After a treatment program for very young children with autism, based on applied behavior analytic (ABA) methods, had been implemented, the children showed marked improvement in their linguistic, cognitive and social skills (Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; Maurice, 1996; Smith, Buch, & Gamby, 2000). Although the program was established first in the United States, it has

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since been applied in many other countries with various cultures.

For such an early treatment program to succeed, it is important to clarify the formal support resources, such as the welfare system and education system, in the country where the program will be used. At the same time, informal supports, such as understanding about autism, the teaching method used in the early treatment program, and information about parents' support groups, also need to be taken into account. Especially in developing countries where formal support systems are often lacking, informal supports for the early treatment program should be clarified in advance.

In Malaysia, some members of support groups for parents of children with autism procured information on autism from the Internet or books, and shared the information with other parents. Other parents from the support groups implemented an applied behavior analytic program as they understood it from reading about it in books.

The present article reports an investigation of the situation of children with autism in Malaysia, done in order to analyze the possibility of implementing an applied behavior analytic program there, that is, in a country where support mechanisms are less formal than in more developed countries.

**Purpose**

The purposes of the present study were (1) to investigate both formal and informal support resources for children with autism in Malaysia, and (2) with the findings, to analyze the possibility of implementing an applied behavior analytic program in other developing countries.

**Method**

Two methods were used in order to assess program needs in Malaysia. One was a questionnaire about the background of children with autism and their families, which also asked how often an applied behavior analytic program was used. The other was an intensive interview, using another questionnaire, in order to establish the feasibility and sustainability of an applied behavior analytic program in places lacking professional support. The questionnaires were developed through discussions with four professionals in special education and members of Parents’ Resource for Autism (PR4A), an autism support group in Malaysia.

Interviewing and data collection were conducted with the cooperation of Parents’ Resource for Autism.

**Sample**

The written questionnaire was sent to 119 parents who were members of parents’ support groups and societies for autism in East and West Malaysia, of whom 92 responded (77% response rate). Of the respondents' children with autism, 37% (33 children) were 5 years old or younger, 50% (45 children) were between 6 and 10 years
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old, 10% (9 children) were between 11 and 15 years old, and 3% (3 children) were between 16 and 19 years old. The intensive interview with its questionnaire was conducted with eight of the parents who responded to the written questionnaire and who had been using an applied behavior analytic program.

Procedure

The written questionnaire was mailed to the following groups through the Parents' Resource for Autism: Parents' Resource for Autism (Kuala Lumpur in West Malaysia), Calvary Autistic Association (Johor Bahru in West Malaysia), Sarawak Autistic Association (Sarawak in East Malaysia), and Cita-Cita Centre for Children with Special Needs (Sabah in East Malaysia). The respondent organizations were chosen randomly from a list of parents' support groups and societies for autism. For the intensive interviews, the respondents were selected by Parents' Resource for Autism, with the condition that the parents selected had responded to the written questionnaire survey and were using an applied behavior analytic program intensively with informed consent.

Method of Analysis

The questions selected for analysis focused on the background of the children with autism and their families, and the feasibility and sustainability of an applied behavior analytic program in localities where professional support was lacking. The responses to each question in the questionnaire survey were totaled. The answers to each question in the intensive interview were recorded on mini-disk and summarized after the interview, and then the summaries were confirmed by the interviewees.

Contents of the Questionnaire and the Intensive Interview Survey

The questionnaire and the intensive interview survey mainly focused on two areas as follows:

(1) Information about the background of the children with autism and their families (3 questions); registration with the Welfare Department, the child's language environment, and utilization of service providers and an applied behavior analytic program.

(2) The feasibility and sustainability of an applied behavior analytic program in a situation where professional support was lacking (3 questions); ability and inability to learn from the applied behavior analytic program, and problems with continuing the applied behavior analytic program.

Survey Schedule

The written questionnaire survey was conducted during July and August, 2000. The intensive interviews were carried out on the 9th of August, 2000.
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**Table 1 Registration with the Welfare Department (N = 90)**

<table>
<thead>
<tr>
<th>Reason for not registering</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>46</td>
</tr>
<tr>
<td>No</td>
<td>44</td>
</tr>
<tr>
<td>Reasons for not registering:</td>
<td></td>
</tr>
<tr>
<td>No benefit (Unsure of their ability to help my child; Feel we can handle him better)</td>
<td>17 (11)</td>
</tr>
<tr>
<td>(Hope child can recover; Do not want to attach permanent stigma to child)</td>
<td>6 (6)</td>
</tr>
<tr>
<td>Time restriction</td>
<td>6</td>
</tr>
<tr>
<td>No knowledge</td>
<td>3</td>
</tr>
<tr>
<td>Other (Reluctant to have another test on the child as he may have an impression that he is sick; Hope that she will be able to overcome it; No one has yet confirmed my son is ADD or has autism; Never get down to do it; Will be doing soon)</td>
<td>10</td>
</tr>
<tr>
<td>No reason given</td>
<td>9</td>
</tr>
<tr>
<td>n.a.</td>
<td>2</td>
</tr>
</tbody>
</table>

Results and Discussion

The results from the written questionnaire are shown in Tables 1, 2, and 3, and Figure 1. The results from the interviews are summarized in Table 4.

**Registration with the Welfare Department**

Of the 92 respondents, only a little more than 50% answered that they had registered with the Welfare Department. The reasons given for not registering were: No benefit (39%; 17 respondents), Time restriction (14%; 6 respondents), No knowledge (7%; 3 respondents) and Other (23%; 10 respondents); for those who answered “other”, their reasons are listed in Table 1. Once registered, families can receive formal support such as tax reductions and monetary benefits (the equivalent of approximately 1,000 to 5,000 per month), but the amount of the benefit depends on the state government and the severity of the child’s disability. Some of the parents replied that the amount of money they would receive was not adequate to compensate them for their child being labeled disabled.

These data suggest that families having children with autism tend to lack adequate support from the government and have to rely on NGOs. Actually, the Malaysian government encourages NGOs to play an important role in providing services to people with disabilities (Mhamad, 1999).
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The Child's Language Environment

With regard to the ethnicity of the respondents, 11% (10 respondents) reported that they were Malay; 75% (69 respondents), Chinese; and 14% (13 respondents), Indian. Even though the Malay language is the national language in Malaysia, English is often used in business there. The most commonly used language in the respondents' homes was English (74%, 68 respondents) (Fig. 1). Most of the parents may already have used English before the birth of the child with autism.

When parents were asked what language they thought their child would need in the future, English (73%, 67 respondents) and Malay (65%, 60 respondents) received almost the same number of responses. On the other hand, many respondents noted that they were already using English to their child and that they required more teaching materials in English (74%, 68 respondents) (Fig. 1).

The fact that many parents preferred English to their national language suggests that they may have felt that the Malay language-teaching environment was not sufficient. During the intensive interviews with Parents' Resource for Autism members, parents said that they faced the dilemma of whether to train their child in basic skills in English or to struggle to develop materials in the Malay language. In Malaysia, the Ministry of Education is responsible for the education of children with mild to moderate disabilities (Mhamad, 1999). Usually, at the time children enter school, they are required to have basic skills necessary for taking care of themselves, such as being able to go to the toilet (Nasuno, 2000). Malay is used in primary school (and even more extensively after primary school), so information and programs now available in English need to be translated into Malay. Alternatively, it should be determined whether children with autism can generalize what they learn in English to a Malay-language situation.

Utilization of Service Providers and Applied Behavior Analytic Programs

The economic status of the families in the sample was relatively high, with 97%...
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**Table 2** Experience Using a Service Provider (*N*=88)

<table>
<thead>
<tr>
<th>Experience</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>At present go to a service provider</td>
<td>37</td>
</tr>
<tr>
<td>At present go to a service provider as well as</td>
<td>15</td>
</tr>
<tr>
<td>in past had gone to another service provider</td>
<td>18</td>
</tr>
<tr>
<td>In past had gone to a service provider</td>
<td>18</td>
</tr>
<tr>
<td>Never been to a service provider</td>
<td>18</td>
</tr>
</tbody>
</table>

**Table 3** Duration of Using a Service Provider (*N*=45)

<table>
<thead>
<tr>
<th>Duration</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 3 months</td>
<td>8</td>
</tr>
<tr>
<td>About 6 months</td>
<td>16</td>
</tr>
<tr>
<td>About 1 year</td>
<td>10</td>
</tr>
<tr>
<td>About 1 and half years</td>
<td>14</td>
</tr>
<tr>
<td>About 2 years</td>
<td>10</td>
</tr>
<tr>
<td>About 2 and half years</td>
<td>2</td>
</tr>
<tr>
<td>More than 3 years</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note.* More than one answer possible.

of the respondents (89 of 92 respondents) stating that the family income was above the average income in Malaysia, and 50% of 92 respondents reporting that they had hired a private caregiver.

Of the 88 respondents, 59% (52 respondents) were using service providers such as centers for autism, private therapists, and hospitals (Table 2). Most respondents had used a service provider for from six months to two years (53 respondents, where more than one answer was possible) (Table 3).

In the intensive interviews, it was discovered that nonprofit centers for autism had been established two years previously, and 30 respondents reported that they were using centers for autism as their service provider. Of those using the centers, 23% (7 respondents) noted that the teachers at those centers were helpful, warm, or committed. On the other hand, 20% (6 respondents) said that the teachers were not well trained or lacked expertise. In other words, some parents appreciate what the service providers do in places offering less formal support, whereas others expect specialists. It has been reported that there are children on the waiting lists for the centers for autism, and that teachers at the centers are not required to have any special qualifications (Nasuno, 2000).

Aside from the families using centers for autism, 17% of the respondents (10 out of 58) have used an applied behavior analytic program intensively in their home. Moreover, 50% of those respondents (6 of 12) reported that some type of applied behavior analytic program was used by their service provider. These parents were trying to get their child into an applied behavior analytic program, but many of them pointed out that parents needed experts to advise them about an applied behavior analytic program. Most of the parents said that they had learned about applied behavior analytic programs through books or the Internet, without going through any formal parent-training or supervision.
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<table>
<thead>
<tr>
<th>TABLE 4 Parents’ Evaluation of the ABA Program (N=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent</td>
</tr>
<tr>
<td>------------</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>B</td>
</tr>
<tr>
<td>C</td>
</tr>
<tr>
<td>D</td>
</tr>
<tr>
<td>E</td>
</tr>
<tr>
<td>F</td>
</tr>
<tr>
<td>G</td>
</tr>
<tr>
<td>H</td>
</tr>
</tbody>
</table>

Note. ABA = applied behavior analysis.

An individualized teaching method is essential for an applied behavior analytic program. Most of the parents who were carrying out such a program had not received any guidance from specialists before they began it.

**Ability to Learn from the Applied Behavior Analytic Program**

In response to the question “what are you able to learn from the applied behavior analytic program?” all respondents mentioned that they could learn about
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teaching methods (including how to modify or improve the child's behavior). Two respondents (C, F) said, "compliance about behavior management or making eye contact, etc." One respondent (E) noted, "teaching tools," and one other (H) mentioned "learning about structured methods in the applied behavior analytic program" (see Table 4).

These respondents spoke English with their children when they used the applied behavior analytic program. From the standpoint of acquiring basic social interaction skills, play skills, and self-help skills at an early age, it could be meaningful for children to learn in English because of the availability of various teaching materials, so long as the parents have ability to practice the program in English. However, in the long run, it might be beneficial for language comprehension and language production to be taught in the national language, Malay.

The respondents to the intensive interview survey included the President and the Secretary of Parents' Resource for Autism. According to them, the parents' support group has been providing general information and sharing the teaching techniques of applied behavior analysis with its members. The other six respondents, who were also members of Parents' Resource for Autism, stated that the information provided by the group was very useful to them in guiding their children. These comments suggest that informal supports are useful in building up fundamental knowledge about child guidance, even if the formal support situation is thoroughly insufficient. Furthermore, the same teaching system as in the United States could be established, if supervision by specialists in early treatment were added to this informal support, which includes written information as well as parents' mutual support.

**Inability to Learn from the Applied Behavior Analytic Program**

Three of the eight interviewees mentioned that it was hard to understand the contents of applied behavior analytic programs. Another three respondents found it difficult to confirm whether they really were communicating with their child. One respondent complained that they were unable to learn from the applied behavior analytic program about the cause of autism, another, that they could not learn about the influence of food, and a third, that they could not learn about behavior caused by physiological factors.

Difficulties in understanding applied behavior analytic programs could possibly be overcome if experts advised parents or held seminars that included demonstrations. In the matter of other information scarcities such as those relating to the causes of autism and the influence of food or other physiological factors, systematic studies and recent information about autism could be provided in a comprehensive support package for the families of children with autism, as a complement to an applied behavior analytic program. This would seem to be especially necessary in countries where information on autism is lacking.

**Problems in Continuing the Applied Behavior Analytic Program**

Four of the eight interviewees said that they had found it difficult to continue
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with the applied behavior analytic program. Moreover, two respondents pointed out that there were insufficient experts, such as therapists or consultants. These problems could be overcome if experts would provide support, such as explaining the content of the program, advising parents with regard to the child’s level of development within the program, and giving further recommendations on the prospects of education for the child. The Internet may be able to provide useful information, advice, or consultation. However, it is more realistic to provide this type of support based on a videotape of the child.

One respondent said there had been no problem in continuing an applied behavior analytic program in the home. But another respondent mentioned that there were other obstacles getting in the way of continuing an applied behavior analytic program, such as the mother’s health problems and pregnancy. These difficulties could occur anywhere and would not necessarily need to be handled exclusively by experts, because the early treatment applied behavior analytic program is designed to be implemented mainly by the child’s parents in their home. Therefore, it is necessary to consider not only the contents of the applied behavior analytic program but also ways to increase local support.

Summary and Conclusions

Based on the results from the present study, we conclude the following:

1) Most of the parents in the sample used teaching materials that were mainly English versions from abroad, rather than local teaching materials (which are yet to be developed). Moreover, parents used English in their home, even though the main language of instruction in the Malaysian school system is Malay.

2) In Malaysia, parents who have children with autism find it difficult to carry out an applied behavior analytic program at home because of the lack of a support system and shortage of professionals, even though parents realize that such a program would be helpful for their child. So far parents have learned structured methods in applied behavior analytic and the teaching methodology of the program (such as how to modify or improve the child’s behavior) from manuals. However, it was found that there are difficulties in continuing to carry out the program. The difficulties include: (a) an inability to know, from written information only, whether the child is really progressing as described in the program, (b) an inability to confirm whether the parents can communicate with their children with autism, and (c) a difficulty in identifying the cause of the child’s behavior.

In order to solve the above-mentioned problems, the following methods would probably be effective for getting precise advice from a specialist, even if the specialist is not nearby:

(a) Based on written information about structured methods in an applied behavior analytic program, the parents or the child’s guidance counselor should list problems currently faced in the program.

(b) Such a list should state the child’s and parents’ needs clearly in prioritized
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order.
(c) An actual scene of guidance, covering the points listed above, should be recorded on video.
(d) The parents should send (b) and (c) to a specialist for analysis and comment, and include any request that the parents have for the specialist. The specialist should give careful consideration to protection of the privacy of this information.

For distant specialists, the parents should as much as possible provide correct and detailed information, so that the specialist can more easily respond with concrete advice. At the same time, the specialist should refer to the written information provided by the parents, using the same textbook as the parents used for reference when making their list, advising parents on which pages they should be referring to, and confirming the parents’ needs.

3) In order to increase local support as well as parents’ mutual support, it might be effective to provide a comprehensive support package to families of children with autism, including diagnostic criteria, a method for assessment of developmental level, description of an intervention program such as applied behavior analysis, and information regarding networking with other parents.

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References


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