

Japanese Parents' Experiences with Home-Based Interventions of Applied Behavior Analysis for Young Children with Autism Spectrum Disorders

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ABSTRACT

This study involved qualitative analyses of the benefits and difficulties of providing home-based Applied Behavior Analysis (ABA) for Japanese parents of young children with autism spectrum disorder (ASD). An open-ended questionnaire survey was administered to 35 parents of children with autism who were implementing home-based ABA. The mean age of the parents was 38.7 years old (SD = 3.80), and the time since initiation of home-based ABA was 25.5 months (SD = 19.58). The mean age of the children with ASD was 64.5 months old (SD = 37.7). Data were analyzed using the KJ method of qualitative analysis. The benefits of implementing home-based ABA were related to growth of the parents themselves and child development. Identified difficulties included balancing work and household responsibilities and psychological problems. These findings were then compared with similar previous studies to discuss support for families implementing in-home ABA programs.

Key words applied behavior analysis; autism spectrum disorders; parents

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder associated with social impairments and repetitive behaviors and interests.¹ Although there is compelling evidence to suggest that Applied Behavior Analysis (ABA) provides a highly effective form of psychosocial intervention for children with ASD, there is little evidence regarding how parents perceive and evaluate ABA programs.² In addition, theories of evidence-based practice suggest that the decision makers' "perception" of evidence is an important factor in the selection of the intervention program^{3–5}; some research on the perceptions of parents implementing home-based ABA has been conducted abroad, but not in Japan. The purpose of this study was to conduct an

open-ended questionnaire survey on the perceptions of parents who have implemented ABA at home in Japan, and the results were analyzed quantitatively using the KJ method.⁶

SUBJECTS AND METHODS

Subjects

This study was conducted in 2014 as a mailed questionnaire survey. Subjects were recruited with the help of a nonprofit organization (NPO) that provides home-based ABA for children with ASD. This NPO provided services to support the implementation of ABA home-based therapy, including the dispatch of ABA therapists, workshops for parents, and consultations. As a result, 35 respondents (34 mothers and 1 father) were obtained. The mean age of the parents was 38.7 years (SD = 3.80) and nine of the 35 respondents were employed. Thirty-four of the children had a diagnosis of ASD and one exhibited ASD characteristics without diagnosis. The children's mean age was 64.5 months (SD = 37.7). Thirty-four respondents lived with their spouses, and one lived alone. Six were additionally living with the children's grandparents.

Home-based ABA

In Japan, visiting therapists are not covered by public subsidies, and parents have to pay their own expenses when hiring a visiting therapist. Therefore, many parents attended workshops provided by NPOs that involved utilizing a textbook created with reference to Lovaas' book,⁷ and spent much of their time implementing ABA at home themselves. The textbook explains the basic principles of ABA, teaching methods, and examples of communication and cognitive tasks. The average duration of home-based ABA was 25.5 months (SD = 19.6). The maximum time spent implementing home-based therapy per week was 15.09 hours (SD = 10.19) and the mean for the shortest week was 4.94 hours (SD = 3.37).

Questionnaire

A face sheet was used to ask about basic attributes of the respondent parents, such as their age, gender, and the age of the subject child, as well as family members

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Abbreviations: ABA, Applied Behavior Analysis; ASD, Autism Spectrum Disorders

living together, and the status of implementation of home-based ABA. The survey items in the questionnaire regarded both the benefits and difficulties of conducting ABA on an at-home basis, to which the respondents were asked to respond in an open-ended format.

Analysis method

The KJ method⁶ is a qualitative inductive analysis method that attempts to grasp the reality of chaotic reality and its essence. While expressing the situation in a concrete way, the level of abstraction is increased step by step to recognize patterns of similarity, and subsequently the whole can be expressed structurally through spatial arrangement guided by the obtained relationships. Finally, the logical structure contained within the phenomenon can be derived from the spatial arrangement. The analysis procedure is as follows.

Procedure

Labeling, grouping, diagramming, and writing were performed according to procedures described according to the KJ method. Within the labeling process, data were divided into the smallest meaningful units, each of which was summarized and described on a label. In grouping, all labels were first spread out to enable a bird's-eye view, and subcategories were created by bundling several labels that were closely related in terms of their content. Next, the labels in the subcategories were read back and their compressed expressions were considered and named. The labels were reviewed by two authors and four graduate students majoring in clinical psychology.

Ethical considerations

This study was approved by the Tottori University School of Medicine Ethics Committee (approval number 2286). Requests for research cooperation took place through written documentation. The study was conducted in accordance with the ethical standards established by the 1964 Declaration of Helsinki.

RESULTS

The labels obtained from the free-text responses to each question were grouped together. The main categories and subcategories, and the number of labels regarding the benefits and difficulties of practicing home-based ABA are presented in Table 1. Sixty-six labels were obtained for the benefits of practicing home-based ABA. In particular, the main category related to "Growth of parents themselves" was extracted from all parents' responses. For "Child development," the main focus was

on the development of communication skills and group adjustment. Other categories such as "Family unity" and "Presence of a support person" were also mentioned. Eighty-three labels were obtained as difficulties with practicing home-based ABA. The most common main category was "Mental stress." Additionally, "Compatibility" of housework, childcare, and work, "Continuation of therapy" regarding the preparation of materials and motivation, and "Financial burdens" were also mentioned. Categories related to understanding the relationship between the couple were provided for both benefits and difficulties.

DISCUSSION

The results were discussed in comparison to the Grindle et al.⁴ study conducted in the United Kingdom (UK), which, like Japan, does not allow direct funding for early ABA intervention in ASD. It was demonstrated that parents had experienced the benefits associated with ABA at home, including positive changes in the children and the parents themselves, as in previous studies. Further, the results for difficulties were similar to those of previous studies, but an original label was extracted: "Compatibility" (balancing treatment and daily life). This may be due to the fact that parents in Japan implement most of the therapy with their children alone, without the help of visiting ABA therapists.

The financial issues related to therapy were also identified in both our study and the UK study, but the content of these issues differed considerably. In particular, it appears that British parents were simultaneously struggling to get the Local Education Authority (LEA) to approve the cost of therapy required by ABA. On the other hand, when Japanese parents hired a therapist, they had to pay almost the entire cost due to institutional problems. Thus, even though the content of therapies and programs were common across countries and cultures, parents faced different challenges regarding implementers and funding due to differences in the laws and systems under which they were provided. Additionally, we believe that the issues of marital incomprehension, absence of counselors, mental health issues, preparation for and stagnation of therapy, and time availability may be common difficulties that arise when considering the continuation of home-based ABA therapy. Family relationships, such as the relationship between husband and wife, may be a common factor that can be both a benefit and a difficulty.⁸ Although this study involved a limited number of subjects, the results suggest the need for professionals and providers in providing psychological support to parents, as well as techniques and materials when offering evidence-based

Table 1. The main categories and subcategories and the number of labels for the benefits and difficulties of practicing home-based ABA

	Main-category	% of parents (<i>n</i> = 35)	Sub-category	Example	Number of labels
Benefits	Growth of parents themselves	100.0	Parenting skills	“I was able to deal with my child calmly.”	9
			Relationships with children	“I was able to communicate with my child.”	11
				“I spend more time with my child.”	
				“I enjoy living with my child.”	
			Understanding children	“I have a better understanding of child.”	11
				“I was able to recognize the growth of my child.”	
	Emotion	“I feel less guilty.”	3		
		“I had hope for the future.”			
	Siblings	“Helped me raise their siblings.”	1		
	Child development	48.6	Child development	“Child’s communication skills have improved.”	15
				“Child was able to adapt in kindergarten.”	
		Child’s emotion	“Child is more pleased.”	2	
	Family unity	11.4	Family united	“I became able to face child-rearing with my partner.”	4
	Presence of a support person	20.0	Supporters	“I met a good supporter.”	3
Child-rearing companion			“I made a child-rearing companion.”	4	
Not good yet	2.9	Not good yet	“Nothing good has happened yet.”	1	
Others	5.7			2	
Difficulties	Compatible	45.7	Therapy time	“I have a hard time finding time for therapy.”	9
			Housework	“I have difficulty balancing housework and therapy.”	4
			Compatibility with sblings’ childcare	“I have difficulty balancing therapy with caring for their siblings.”	2
			Balance with work	“I have difficulty balancing my work and therapy.”	1
	Financial burden	25.7	The cost of therapy	“I find the cost of therapy a huge burden.”	9
	Continuation of therapy	45.7	Motivation	“I have a hard time keeping myself motivated for therapy.”	6
			Child motivation	“Difficulty getting children to participate in therapy.”	4
			Preparation for therapy	“It is difficult to prepare materials and settings for therapy.”	6
	Absence of supporters	25.7	There is no one to talk to	“There is no one to talk to when you need help.”	9
	Mental stress	74.3	Mental burden	“Feeling anxious or impatient.”	8
				“I feel mental vexation.”	
			Therapy impasse	“Therapy gets stuck.”	11
				“Frustration when therapy goes wrong.”	7
	Conflict of between families	11.4	Couple	“The couple had a disagreement.”	3
			Grandparents	“I had a problem with their grandparents.”	1
	Communication with children	8.6	Children have less time to play	“I can’t let my child play.”	2
			Rising hurdles	“Evaluations of the child became more severe.”	1

programs. Factors such as parental income, education, family structure and the severity of the child's ASD have been noted to influence parental ABA therapy choices.³ This study did not examine these factors. Future research should increase the number of case studies and examine the relationship between these factors and parental experiences, which would allow for family support for different parental background factors.

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