Analysis of Research Trends in Parents of Children with Autism Spectrum Disorder in Korea

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Abstract: This study analyzed previous studies to suggest research directions for children with autistic disorders in Korea. In order to achieve this purpose, the general characteristics of parents of children with autistic disorders and research trends according to evidence-based practice were investigated. The literature on analysis related to parents of children with autistic disorder has a total of 24 studies, general characteristics (research target, Independent Variable, Dependent Variable, Research design) and evidence-based actual qualitative indicators were analyzed. Korean journal articles published between 2008 and August 2020 were selected for analysis. The research results are as follows. First, as a result of analyzing the general characteristics of research papers mediated directly by parents of children with autistic disorders, there were three group-designed studies (12.5%) and fifteen single-subject studies (87.5%). The study mainly conducted social interaction training, positive behavior support, complementary and alternative communication tools, central axis response training, sensory integration program, developmental play therapy, and a structured approach in relation to independent variables. Second, looking at the rating table for the qualitative indicators of evidence-based reality, it can be seen that 19 studies that satisfies the information on the subject of study were presented relatively faithfully compared to other items. Therefore, when conducting intervention studies on children with autism disorders, group design studies are also necessary, and evidence-based practical intervention strategies should be presented and implemented.

Keywords: Autism Spectrum Disorder, Disabled Parents, Research Trends, Evidence-based Practice

1. Introduction

1.1 The Need for Research

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with neurobiological causes, characterized by persistent defects in social communication and social interaction limited and repetitive behavior interest or activity[1]. According to the 2019 Statistics Yearbook of Health and Welfare in the Republic of Korea, the number of persons with autism disorders continues to increase, with 11,874 persons in 2007, 16,906 persons in 2012, and 26,703 persons in 2018[2]. In addition, according to the 2020 special education statistics, out of the 95,420 persons subject to special education, 13,917 persons

Received: April 11, 2021; 1st Review Result: May 28, 2021; 2nd Review Result: July 19, 2021

Accepted: August 30, 2021

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with autism disorder special education are 14.6%[3], which is steadily increasing compared to 12.5% in 2016.

Children with autism disorder have a lack of understanding of how to initiate and react to others for common interest, and because they have difficulty understanding the intentions of others expressed through language and gestures, they are unable to interact with others, including their family members. Experience difficulties[4].

It is estimated that the majority of children with autism disorder do not develop functional language[5], and many of these children do not understand oral language well. In particular, children with autism disorder show significant limitations in both the quantity and quality of verbal and non-verbal initiating behaviors compared to those who typically develop[6][7].

This is also supported by a report that the lack of social skills of children with autism disorder negatively affects not only early in their life but also various social relationships they face while growing up[8]. In addition, even if the child's communication ability improved as the child grew, or the acceptance of the child was relatively increased due to the decrease in parents' expectations, it was found that they were still experiencing stress from behavioral problems including aggression of the child[9].

Parents spend the most time with their children during the day to promote their children's development and meet their needs. Furthermore, parents play an important role in maximizing the educational effect of their children through team cooperation with related experts to provide services to their children[10] [11]. Children subject to special education have different types of disabilities and their degrees of disability, and are often not resolved through general developmental stages or educational theories[12], and it is difficult to acquire new skills naturally or independently[13]. In many cases, problematic behaviors appear seriously, leading to difficulties in parenting and education[14].

Recently, access to education for children with disabilities is not limited to only individual children, and awareness of support for children with disabilities and their parents is increasing[15][16]. As social consensus has been reached that the role of parents is very important in the development and education of children with disabilities[17], parental involvement in awareness and education of children with disabilities is becoming important. There is an emphasis on cooperation between parents and teachers. In addition to the active participation of parents in children with disabilities, research is being conducted with increasing interest in the stress and life of parents raising children with disabilities.

Parental participation is very important for early diagnosis and adequate support for children with autism disorders, and it is important to reflect on where each study began, where it is currently located, and where it is heading[18]. Therefore, at the present time when various studies on parents of children with autism disorder are being accumulated, understanding of what has been revealed in the studies related to parents of children with autism disorder to date and the topic and direction of the research that has been focused recently should be prioritized.

Evidence-based practice is a teaching technique that includes research method standards to bridge the gap between the experimental situation and the practice, and to ensure the improvement of students' performance level[19][20]. According to the U.S. Council for Exceptional Children's (CEC) special education evidence-based practice standard, for a research methodologically appropriate study, context and situation, participants, mediation providers, description of practice, mediation fidelity, internal validity, performance measurement/dependent variables, qualitative indicators such as data analysis should be met[21].

Research on evidence-based practice is being actively conducted in the field of special education in Korea[22-26]. The argument that research methods and the quality of research should be improved to meet CEC's evidence-based actual quality indicators is persuasive[20][27][28]. It is necessary to improve the standards and quality of research so that the application of interventions conducted by the parents of children with autism disorders is consistent with evidence-based practice, and to provide information so that the proven effective interventions are applied.

In this study, the factors related to the parents of children with autism are specifically investigated in order to specify the methods and contents for support for parents of children with autism, and the experimental studies conducted by the parents of children with autism are a qualitative indicator of evidence-based practice. Based on this background, this study is aimed to review domestic papers between 2000 and 2020 about the parents of children with autism and examine effective parenting factors for children with autism. In addition, this study systematically categorizes researches on parents of children with autism, and studies the overall flow and pattern, providing a balanced development of research and a direction for future research, which can be helpful to children with autism. In addition, if the main characteristics of intervention studies conducted by parents of children with autism are revealed, research methods in this field can be improved, and it is expected that more effective intervention methods can be applied to the field of special education.

1.2 Research Problem

First, what are the general characteristics of domestic research on parents of children with autism disorders?

Second, what are the characteristics of the evidence-based actual qualitative indicators in domestic intervention studies involving parents of children with autism disorders?

2. Research Method

2.1 Research Design

This study completed research ethics education and received deliberation and approval (1041478-2020-HR-035) from the Nambu University Bioethics Committee according to the research ethics guidelines, and to analyze the research trends of parents with children with autism disorders in Korea. Korean journal articles published between 2008 and August 2020 were selected for analysis. This quailitative study was designed to analyze previous studied related to sutism in Korea, and the analysis conducted by a researcher and two PhDs in special education.

The literature selection criteria for this study are as follows.

First, the study subjects were limited to parents of children with autism disorders, and disability areas other than autism disorders were excluded from the area of disability. Second, all papers published in Korea and searchable through the search DB were included, and studies published before September 1, 2020, when the final search was conducted, were targeted. Third, the research method included all studies of parents of children with autism disorders, and included parents, fathers, and mothers. At this time, research on genes in the medical field was excluded. Fourth, the study design included all quantitative and qualitative studies on parents of children with autism disorders.

2.2 Analysis Criteria

This study selected 24 intervention studies conducted by parents of children with autism disorders, Independent variable, dependent variable, The study design was analyzed. In addition, characteristics based on qualitative indicators of evidence-based reality were analyzed. The qualitative indicator is prior studies that evaluated the qualitative level of group design research and single-object research in order to analyze thesis based on Twenty-eight detailed indicators in eight areas[20][28-30]. If the contents of the index were not satisfied, it was calculated as zero points, if only a part was satisfied, one point, and if completely satisfied, it was calculated as two points.

[Table 1] General Feature Analysis

	Contents
Research subject	-Number of children participating -Number of participating parents
Independent variable	-Social interaction training -Support positive behavior -Complementary and alternative communication tools -Center axis reaction training -Sensory integration program -Developmental play treatment -Structured Approach
Dependent variable	-Behavior change -Social interaction -Communication ability -Daily life function -Parent-related factors -Sensory control function
Research design	-Design method: group design study, single subject study -Reliability -Validity -Arbitration fidelity

2.3 Reliability between Analysts

This study analyzed the reliability between analysts for 24 papers that analyzed qualitative indicators based on evidence-based reality.

For the analysis of intervention studies based on evidence-based practice, a researcher and one person who has completed a doctoral course in special education department randomly selects 4 papers (16.7%) to be analyzed, and is individually analyzed according to the general characteristics analysis items and the qualitative indicators of evidence-based practice After independently evaluating, consultation and training were carried out until the degree of agreement for each item reached 90%. After the agreement between the analysts reached 90%, the remaining 20 articles (approximately 83.3%) were divided into 10 pieces by two analysts. The inter-analyst confidence in this study was 96%.

2.4 Data Processing

The data processing method of this study is as follows.

First, in order to find out the general research trends of domestic research on parents of children with autism disorders, Independent Variable, Dependent Variable, The frequency and percentage for the study design were calculated.

Second, in order to find out the characteristics based on the evidence-based reality of intervention studies on parents of children with autism disorders, the qualitative index of CEC was applied and evaluated on a 3-point scale, and the frequency and percentage were calculated. When each variable was treated as overlapping, multiple responses were analyzed and marked.

3. Results

3.1 General Characteristic Analysis

For general characteristics, this study was analyzed by categorizing it into research subjects, independent variables, dependent variables, and research design.

3.1.1 Research Subject

[Table 2] Analysis of the Research Subject

Subject of study	Division	Thesis (Edition)/Number of Persons (persons)	(%)	All(%)
	1 person	9	37.5	
	2 people	2	8.33	
Number of children involved	3 people	9	37.5	
	4 people	1	4.17	24 episodes
	5 or more	3	12.5	(100%)
Whether to indicate the gender of	Notation	21	87.5	
the child	Not marked	3	12.5	
	male	34	55.74	61
Child gender	female	14	22.95	occupants
	Not marked	13	21.31	(100%)
	part	0	0	61
Number of parents involved	mother	36	59.02	occupants
	parents	25	40.98	(100%)

As shown in [Table 2], the study subjects were 9 cases (37.5%) with 1 child, 2 cases (8.33%) with 2 participants, 9 cases (37.5%) with 3 participants, and 1 case with 4 participants. (4.17%), 3 cases (12.5%) when more than 5 participants participated. When the gender of the child was indicated, 21 articles (87.5%), when not indicated, 3 articles (12.5%), and when the gender is indicated, 34 boys (55.74%) and 14 girls (22.95%). Was. Looking at the number of parents involved, there was no case that only the father participated, 36 cases (59.02%) of mothers participated, and 25 cases (40.98%) of parents participated together.

3.1.2 Independent Variable

[Table 3] Analysis of Independent Variables

Independent variable	Number of thesis (edits)	(%)	All(%)
Social interaction training	6	25.00	
Support for positive behavior	5	20.84	
Environment-oriented mediation	3	12.50	
Complementary and alternative communication tools	3	12.50	24 episodes (100%)
Central axis response training	2	8.33	(100%)
Sensory Integration Program	2	8.33	
Developmental play therapy	2	8.33	
Structured approach	1	4.17	

As shown in [Table 3], 6 pieces (25.00%) for social interaction training, 5 pieces for positive behavior support (20.84%), 3 pieces for environment-centered interventions and complementary and alternative communication tools (12.5%), and central axis response. Training, sensory integration program, and developmental play treatment were each two (8.33%), and structured approach was one (4.17%). Since the independent variable was a study conducted by parents, studies on social interaction training and positive behavior support were dominated.

3.1.3 Dependent Variable

[Table 4] Analysis of Dependent Variable

Dependent variable	Number of thesis (edits)	(%)	All(%)
Behavior change	10	29.41	
Social interaction	9	26.47	
Communication skills	6	17.65	34 types
Daily life function	4	11.76	(100%)
Parent-related factors	4	11.76	
Sensory control function	1	2.95	

As shown in [Table 4], the dependent variables of the thesis analyzed for intervention studies were 10 types of behavioral change (29.41%), 9 types of social interaction (26.47%), 6 types of communication ability (17.65%), daily life functions and parents. The related factors were 4 types (11.76%) and 1 sensory control function (2.95%). Therefore, it can be seen that more studies have been conducted on the child with autism disorder than on the parent factor as the dependent variable. In addition, as for the dependent variable, it can be seen that the study was designed mainly in accordance with behavior change, social interaction, communication ability, etc., which are themes to improve the main characteristics of children with autism disorder.

3.1.4 Research Design

[Table 5] Analysis of Research Design

Study design	Division Number of thesis (edits)		(%)	All(%)	
Design method	Group Design Research	3	12.5		
	Single subject study	21	87.5		
Reliability	Mark	22	91.67		
	Not marked	2	8.33		
Validity	Mark	12	50.0	24 episodes (100%)	
	Not marked	12	50.0	(10078)	
Arbitration fidelity	Mark	14	58.33		
	Not marked	10	41.67		

As shown in [Table 5], the study design of the thesis for the analysis of interventional studies was 3 group-designed studies (12.5%) and 21 single-subject studies (87.5%). Among the papers to be analyzed, there were 22 studies (91.67%) that indicated reliability and 2 (8.33%) studies that did not. Among the papers to be analyzed, 12 studies (50.0%) each with validity and no validity were the same. Among the papers to be analyzed, 14 studies (58.33%) indicated the fidelity of intervention, and 10 studies (41.67%) were not indicated.

3.2 Analysis of Qualitative Indicators of Evidence-based Practice

In accordance with CEC's (2014) criteria for evaluating the qualitative indicators of evidence-based practice, group design studies did not include the contents of 6.5, 6.6, 6.7, and 8.2 in the evaluation, and single-subject studies were 6.4, 6.8, 6.9, 7.6., 8.1, and 8.3 are not included in the rating. As a result of analyzing the papers to be analyzed based on evidence-based actual qualitative indicators, the average

of the environmental category was 1.04 points, the average of the research subject category was 1.69 points, the average of the mediator category was 1.36 points, and the average of the intervention fidelity category was 0.33 points. The average of the internal validity category was 0.78 points, the average of the dependent variable category was 1.27 points, and the average of the data analysis category was 1.39 points.

Eight areas of qualitative indicators of evidence-based reality in this study consist of environment, research subject, mediator, experiment, mediation fidelity, internal validity, dependent variable, and data analysis.

[Table 6] Qualitative Indicators of Evidence-based Practice

division		Qualitative indicator	Group Design Resear ch	Single subject study
1	Environment	(1) Describe the key features and key features of the context or environment. E.g.) program or class type, school type, curriculum, geographic location, community situation, society. Economic status, physical environment	0	0
		(2) Describe the demographic characteristics of the study participants (gender, age/grade, religion/race, socioeconomic level, language level).	0	0
2	Subject of study	(3) How to determine the degree and degree of disability or risk (specific learning disability, autism spectrum disorder, problem behavior) of the research participant (IDEA standards, teacher recommendation, standardized intelligence test, curriculum-centered evaluation, rating scale, etc.) Is explaining.	0	0
3	Moderator	(4) The role of research mediators (teachers, researchers, assistants, parents, volunteers, peer mediators, siblings, engineering devices/computers), and background variables (religion/race, educational background/qualification) are explained.	0	0
		(5) It describes the specific training (volume, training standards) or qualifications (professional qualifications, etc.) required to apply the intervention, indicating that the mediator has reached it.	0	0
4	Experiment	(6) Intervention procedures (mediation components, instructional behavior, major elements, manual or scripted procedures, amount of intervention) and behavior of the mediator (facilitation, verbal expression, physical behavior, access, etc.) in detail. I am explaining.	0	0
		(7) If tools (activity sheets, timers, clues, toys, etc.) are used, explain them.	0	0
	Arbitration fidelity	(8) Evaluate the fidelity of the intervention in relation to the severity of the intervention using direct, reliable means (such as observation using a checklist of the main elements of the experiment).	0	0
5		(9) Measure the integrity of the intervention for the amount of intervention (exposure) using direct and reliable means (observation or self-report on the duration, frequency, and scope of the curriculum).	0	0
		(10) Assess and report on the fidelity of the arbitration throughout the arbitration process. (a) The entire duration of the arbitration application period (start-intermediate-end of the arbitration), (b) by moderator, environment, participant, or other analysis unit	0	0
6	Dot product Validity	(11) Researchers controlled and systematically manipulated independent variables. (12) Describes the conditions of the baseline (in a single subject study) or control/experiment (in a group design study) such as curriculum, teaching, and intervention (definition, duration, time, frequency, learner: professor's ratio).	0	0
		(13) Subjects under control/experimental conditions or baseline conditions have no or extremely limited access to interventions.	0	0

		(14) Explain clearly how to assign participants to each group in one of the following ways. (a) random, (b) non-random, or comparison groups correspond similarly to the intervention group, (c) non-random, or statistical techniques are used to measure statistically significant differences (more than 5% standard deviation). Example) Differences in pre-test scores or statistical characteristics of the two groups (such as ANCOVA), (d) Non-random (regression break model) according to appropriate cutoff points	0	
		(15) The study design shows the effect of at least three experiments at three different times.		0
	Dot product Validity	(16) The baseline stage of the single-subject study design is at least three times or more.		0
6		(17) Design control to secure internal validity (use of generally accepted designs such as inverted design, mid- and multi-baseline design, etc.)		0
Ü		(18) The overall decrease in study participants should be low within the group (e.g. less than 30% over a year).	0	
		(19) The difference in the reduction of study subjects between groups was small (eg, 10% or less) or was controlled through adjustment.	0	
	Dependent variable	(20) Research results are socially important (quality of life, developmental/learning outcomes, both theoretically and empirically improved).	0	0
		(21) The measurement of the dependent variable is clearly defined and explained.	0	0
7		(22) The intervention effect (not limited to the positive effect) is reported.	0	0
		(23) Results The frequency and timing of measurement are appropriate.	0	0
		(24) Provide adequate evidence for internal reliability, inter-observer reliability, and test-retest reliability.	0	0
		(25) Providing adequate evidence (content, composition, criteria, social validity, etc.) on validity.	0	
	Data analysis	(26) Data analysis techniques are suitable for comparing the performance changes of two groups (or more) (t-test, ANOVA/MANOVA, ANCOVA/MANCOVA, etc.).	0	
8		(27) Provide a single target graph in which the results are clearly displayed.		0
		(28) Provide one or more statistics of an appropriate effect size, or provide an appropriate effect size that can be calculated.	0	

4. Discussion

The discussion based on the results of this study is as follows.

First, as a result of examining the number of parents involved, there was no study involving only fathers, and 59.0% of studies involving only mothers. In addition, reliability was indicated in 91.6% of all studies, but the case where validity was not indicated occupied half of all studies. 41.6% of the studies did not indicate the integrity of the intervention. As indicators such as validity and arbitration fidelity are important indicators that affect the reliability of independent variables and the reliability of the research results as a whole [19][21], researchers need to manage them thoroughly.

Second, regarding the independent variable, social interaction training, positive behavior support, environment-centered intervention and complementary and alternative communication tools, central axis response training, sensory integration program, developmental play therapy, and a structured approach were implemented. Among the independent variables, social interaction training (25.0%) accounted for the largest proportion, and positive behavior support was also studied (20.8%). It seems necessary to study various independent variables such as complementary and alternative communication tools, sensory integration programs, and therapeutic approaches through more in-depth parental education.

Third, it was found that the study was designed in accordance with the main characteristics of children with autism disorders, such as social interaction, behavior change, and communication ability, such as social interaction and communication ability. In order for the dependent variable to build an evidence-based reality, a clear operational definition of the dependent variable, validity and reliability of measurement should be verified[31]. Despite the fact that the dependent variable must be accurately measured, there have been many studies in which variable control was not performed accurately while living with parents.

Fourth, looking at the experimental design of the intervention studies, in the previous [28] [32] [33] that analyzes the evidence-based practice of single-objective studies in the field of special education. The experimental design for intervention for students with disabilities can be understood in a similar context to the report that there are many middle and multiple baseline designs. In the case of multi-intermittent baseline design and multi-baseline design, it is easy to prove the experimental effect, but there is a risk factor that it is difficult to secure internal validity, so it seems that it is necessary to clearly understand and apply the evidence-based reality when designing a study.

Fifth, looking at the rating table for the qualitative indicators of evidence-based reality, in the case of information on the research environment, 29.1% and 58.3% information on the selection criteria for research subjects, it seems necessary to design more clearly about the research environment or screening criteria. The items on the evaluation of the fidelity of the arbitration related to the strictness of the intervention and the measurement of the fidelity of the intervention to the amount of intervention are 91.6% and 100%, respectively. Even in controlling the risk factors of internal validity, 80.3% of the cases were not satisfied. This is a case where education or training is performed while living with parents, and it is considered that a more detailed design is necessary in a future study. As for the dependent variable, most of the studies satisfies the qualitative index in many cases, and 76.1% of the studies provide a single target graph, so it is necessary to refer to the results of future studies.

5. Conclusions

Based on the discussion of this study, conclusions are presented as follows.

First, there were a total 24 intervention studies targeting parents of children with autism disorders

Second, regarding the independent variable, social interaction training, positive behavior support, environment-centered intervention and complementary and alternative communication tools, central axis response training, sensory integration program, developmental play therapy, and a structured approach were implemented

Third, it was found that more studies were conducted on children with autism disorders than on parental factors as the dependent variable.

Fourth, when looking at the experimental design of the intervention study, the most frequent intermediate and intermittent baseline designs were followed by the middle and multiple baseline designs.

Fifth, it can be seen that the education table for the qualitative indicators of evidence-based reality satisfield the research information in most studies and was presented relatively faithfully compared to other items.

In this study, through the analysis of domestic intervention studies, we researchers analyzed whether there is an intervention with scientific evidence that meets the actual evidence-based criteria, and there seems to be no intervention that meets all the criteria yet. However, in the study, only previous studies related to parents of children with autism were analyzed, and the study period was also limited, so there are limitation in generalization. Therefore, in future studies, a study that presents the characteristics of children as an average through a group study for children with autistic disorders is also necessary.

The implications of this study, such as support for parents of children with autism, can be seen in that

this study tried to clarify evidence-based reality based on the domestic research on parents of children with autism. Evidence-based practice means having a scientific basis to prove the performance of an educational program or teaching method actually used. Therefore, in this study, we analyzed whether there are any interventions with scientific evidence that conform to the evidence-based actual standards through the analysis of domestic intervention studies. The results shown in this study have several implications as follows when conducting a study on the parents of children with autism in the future. First, selecting and using a method with proven results is an important task to increase the effectiveness of interventions for children with autism. Therefore, when conducting interventional research on children with autism, it is thought that evidence-based intervention strategies should be presented and implemented. In addition, it seems that continuous attention should be paid to the development and effectiveness of new intervention strategies according to the unique characteristics of the domestic field as in [34].

6. Acknowledgments

This study was supported(in part) by research funds from Nambu University, 2021. This work was supported by the Ministry of Education of the Republic of Korea and the National Research Foundation of Korea (NRF-2020S1A5A2A03044034).

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