

Title	Does Treatment Stigma among adolescents with autism spectrum disorder and their guardians affect the effectiveness of cognitive behavioral therapy?A secondary of a randomized controlled trial
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Citation	大阪大学, 2023, 博士論文
Version Type	VoR
URL	https://doi.org/10.18910/92004
rights	
Note	

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(博士論文表紙様式)

Does Treatment Stigma among adolescents with autism spectrum disorder and their guardians affect the effectiveness of cognitive behavioral therapy?

A secondary of a randomized controlled trial

(児童思春期の自閉スペクトラム症児および保護者の治療スティグマは認知行動療法の効果に影響があるか？ランダム化比較試験の二次解析)

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2023年2月 博士学位論文

Does Treatment Stigma among Adolescents with Autistic Spectrum Disorder and Their Guardians Affect the Effectiveness of Cognitive Behavioral Therapy? A Secondary Analysis of a Randomized Controlled Trial

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Summary

This study explored the effect of treatment stigma on the intervention effects of cognitive behavioral therapy (CBT) on adolescents with autism spectrum disorder (ASD) and their guardians. Secondary analyses were conducted using data from a randomized controlled trial, and only the intervention group (adolescents with ASD [n=23; 16 boys and 7 girls; mean age=12.8±2.2 years] and their guardians [n=23; 22 women and 1 man; mean age=44.8±6.1 years]) was used. We used the Japanese version of the Barriers to Access to Care Evaluation scale version 3 (BACEv3) to assess treatment stigma. Correlations between the BACEv3 scores at pre-intervention and the difference scores for pre-to-post-intervention in each measure were analyzed using Spearman's rank correlation coefficient. Adolescents' BACEv3 scores at pre-intervention were not correlated with difference scores in any measure. However, guardians' BACEv3 scores at pre-intervention demonstrated a significant positive correlation with adolescents' knowledge of ASD and a significant negative correlation with the communication of adaptive behaviors. Interventions through CBT are expected to be somewhat effective, regardless of adolescents' or their guardians' pre-treatment stigma. Further research is required to clarify whether treatment stigma in adolescents with ASD and their guardians affects CBT intervention effectiveness.

Key words: treatment stigma, adolescents with ASD, guardians, cognitive behavioral therapy, autism spectrum disorder

Background

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders characterized by “impaired interpersonal communication” and “limited and repetitive behavioral patterns.”⁽¹⁾ Its heterogeneity ranges across the full range of IQ and language functioning, communication, and social and behavioral deficits.⁽²⁾ Adolescents with ASD may have poor adaptive behaviors even with normal cognitive abilities.^{(3)–(7)} Therefore, although high cognitive ability cases require diagnosis and support,⁽⁸⁾ stigma can still hinder support and treatment.^{(9), (10)} In addition, the stigma held by the person concerned hinders support-seeking behavior and, therefore, does not allow them to receive adequate support.^{(11), (12)} Stigma refers to prejudice against “undesirable kinds of attributes.”⁽¹³⁾ Self-stigma refers to prejudice and discrimination where the party stigmatizes themselves, sees themselves as less worthy, and limits their own behavior.⁽¹⁴⁾ Treatment stigma refers to prejudice and discrimination against receiving treatment and support,⁽¹⁵⁾ and it is a stigma held by the person concerned. It is a factor that inhibits seeking help from treatment and support agencies.^{(16), (17)}

In contrast, regarding adolescents, Calzada et al. suggest that a diagnosis of ASD may have a negative impact on exacerbating stigma, with a

lack of interest in the diagnosis on the part of adolescents with ASD being shown to exacerbate treatment stigma.⁽¹⁸⁾ Therefore, treatment stigma may be a disincentive for support. Guardians of adolescents with ASD also experience treatment stigma. Studies on parents of children with ASD show that the more the parents internalize stigma, the more their help-seeking behavior decreases.⁽¹⁹⁾ Parents of children with ASD are more likely to experience severe psychological distress than those of children with other developmental disabilities; they are also less likely to receive adequate support.^{(20), (21)}

Through studying the relationship between autism and stigma, Japanese researchers developed and implemented an awareness program about public stigma regarding disabilities; it resulted in reduced public stigma and improved knowledge.⁽²²⁾ Online classes on ASD improved college students' knowledge of ASD and reduced the stigma against it.^{(23), (24)} However, these studies were solely about the public stigma around ASD, and no study has thus far examined treatment stigma in relation to ASD. Therefore, it is valuable to examine the impact of treatment stigma.

Cognitive behavioral therapy (CBT) has been effective for both children and adults with ASD.^{(25)–(27)} CBT reduces anxiety symptoms in young people and patients with ASD,^{(28)–(30)} decreases depression and stress symptoms,⁽³¹⁾ and is effective in treating comorbid obsessive-compulsive disorder.⁽³²⁾ The Program for Education and Enrichment of Relationship Skills (PEERS) for Young Adults improves the social skills of adolescents and young adults.^{(33)–(35)}

Psychoeducation about disability increases knowledge and positive attitudes toward disabilities.⁽³⁶⁾ These programs teach adolescents about their disability, increasing their knowledge and awareness of ASD.⁽³⁷⁾ Public stigma around ASD also undermines the mental health and quality of life of the guardians of adolescents with ASD,^{(38)–(40)} whereas a decrease in guardianship treatment

stigma contributes to improved parental mental health.^{(41), (42)} We developed Aware and Care for my Autistic Traits (ACAT)—a program that integrates CBT and psychoeducation to promote understanding of ASD for diagnosed adolescents and their guardians. We implemented it for two years, beginning in 2018.⁽⁴³⁾ The results showed that the intervention group of children with ASD had significantly improved awareness and mental health and reduced treatment stigma. Awareness of ASD significantly improved in the guardian intervention group as well, as compared to the control group.⁽⁴⁴⁾

Our study purpose was to determine whether the treatment stigma of adolescents with ASD and their guardians, who participated in the ACAT clinical trials as the intervention group, affected the effectiveness of the trial intervention. Two hypotheses were formulated in this study. First, adolescents with ASD who have higher treatment stigma have poorer outcomes from ACAT interventions than those who have lower treatment stigma. Second, when guardians' treatment stigma is high, they are less likely to have positive outcomes from ACAT interventions. High guardian treatment stigma also has a negative effect on the effectiveness of ACAT for adolescents with ASD.

Methods

Our study was a secondary analysis that used data from the ACAT clinical trial⁽⁴⁴⁾—a six-week psychosocial education program by CBT at Chiba and Fukushima University.

Participants

The intervention group constituted groups receiving both outpatient psychotherapy with a psychiatrist and ACAT in the randomization, consisting of adolescents with ASD, $n=23$ (16 boys and 7 girls; mean age=12.8 years, $SD=2.2$); and their guardians, $n=23$ (22 women and 1 man;

mean age=44.8 years, $SD=6.1$). A control group was created from groups receiving only outpatient psychotherapy with a psychiatrist and observed for six weeks, $n=22$ (17 boys and 5 girls; mean age=14.1 years, $SD=2.0$); and their guardians, $n=22$ (all women; mean age=46.6 years, $SD=4.5$). An *a priori* power calculation showed that a sample of at least 23 participants was required to determine the α and power levels using a correlation analyses ($\alpha=0.05$, power=0.75, correlations among repeated measures=0.5).

Ethics approval

This study was approved by the Chiba University Clinical Research Ethics Review Committee (CRB3180015, no. G29027). It was conducted in accordance with the Declaration of Helsinki. This clinical trial has been registered with the University Hospitals Medical Information Network (UMIN 000029851). Informed written consent was obtained from a parent or legally authorized representative.

Relevant standards

For adolescents with ASD, the inclusion criteria were as follows: (1) those diagnosed and notified by a psychiatrist with ASD as their primary diagnosis and those who met the criteria for ASD on either the Autism Diagnostic Observation Schedule (ADOS-2) or Autism Diagnostic Interview-Revised (ADI-R), (2) those with a verbal IQ of 90 or higher on the Wechsler Intelligence Test, (3) those with a score of moderate (some need) or higher on the Strengths and Difficulties Questionnaires (SDQ), and (4) those aged 10–17 years at the time of obtaining consent.

For guardians, the inclusion criteria were as follows: (1) those living with adolescents with ASD as a guardian or grandparent and acting as guardian and (2) those able to attend CBT once a week accompanied by the adolescent with ASD.

For adolescents with ASD, the exclusion criteria

were as follows: (1) those with active suicidal intent, (2) those with active repetitive antisocial behavior, and (3) those with an active severe degenerative physical disorder that could disrupt CBT.

For guardians, the exclusion criteria were as follows: (1) those who met the diagnostic criteria for psychiatric disorders measured by the Mini International Neuropsychiatric Interview; (2) those who were unable to accompany the patient to the sessions; and (3) those who were diagnosed with any of the following: organic brain disorder (including dementia), psychotic disorder, bipolar disorder, drug dependence, or other mental severe disorders complicated by psychosis, imminent suicide risk, antisocial behavior, or significant progressive physical illness.

The demographic characteristics of participants are summarized in Tables 1 and 2.

Materials

This study was exploratory and based on the ACAT intervention study; we sought to determine the association between the measures used and treatment stigma.

We used **the Autism Knowledge Quiz-Child (AKQ-C)** and **the Autism Knowledge Quiz-Guardians/Parents (AKQ-P)**,⁽³⁷⁾ a five-item structured interview that measures understanding of ASD characteristics, and 15 sections of the item knowledge quiz. Both adolescent self-administered and guardian self-administered questions were to be answered. An interviewer asked adolescents about their strengths and weaknesses related to ASD characteristics and scored for ASD-related responses (e.g., they could be scored if they answered, “I am good at rule-based behavior”). Guardians were asked about their child’s strengths and weaknesses. **The Barriers to Access to Care Evaluation scale version 3 (BACEv3) Japanese Version**⁽⁴⁵⁾ is a 30-item questionnaire that measures treatment stigma related to mental health and has a four-point

Table 1 Demographics of adolescents with ASD in COMB/TAU groups (from the original study).

Demographic variables	Total N=45	TAU group n=22	COMB group n=23	p
Sex				.5589
Male	33	17 (51.5)	16 (48.5)	
Female	12	5 (41.7)	7 (58.3)	
School attendance				.295
Every day	29	14 (48.3)	15 (51.7)	
Less than one-third of the semester	1	1 (10.0)	0 (0.0)	
No attendance	13	5 (38.5)	8 (61.5)	
Non-student	2	2 (100.0)	0 (0.0)	
Academic background (%)				.139
Primary-high school students	43 (95.6)	20 (46.5)	23 (53.3)	
Junior high school graduates	2 (4.4)	2 (100.0)	0 (0.0)	
Total years of education				.0541
Mean (<i>SD</i>)	8.0 (2.2)	8.6 (1.9)	7.3 (2.3)	
Support and consideration at school				.117
Support classes	5 (11.1)	1 (20.0)	4 (80.0)	
Special classes	2 (4.4)	0 (0.0)	2 (100.0)	
Consideration	2 (4.4)	2 (100.0)	0 (0.0)	
Non-support consideration	36 (80.0)	19 (52.8)	17 (47.2)	
Age at diagnosis (in years)				.878
Mean (<i>SD</i>)	10.3 (4.1)	10.4 (4.9)	10.2 (3.3)	
Complications				.668
Without	26 (57.8)	12 (46.2)	14 (53.8)	
With	19 (42.2)	10 (52.6)	9 (47.4)	
ADHD				.466
Without ADHD	3 (15.8)	1 (33.3)	2 (66.7)	
With ADHD	16 (84.2)	9 (56.3)	7 (43.8)	
LD				.213
Without LD	15 (78.9)	9 (60.0)	6 (40.0)	
With LD	4 (21.1)	1 (25.0)	3 (75.0)	

COMB, Intervention group, groups receiving both outpatient psychotherapy with a psychiatrist and ACAT; TAU, Control group, groups receiving only outpatient psychotherapy.

Complications are presented verbatim from the original study. ADHD: Attention-Deficit/Hyperactivity Disorder, LD: Specific Learning Disorder. Note that the mean (*SD*) is not given in the original study.

scale ranging from “*not at all*” to “*quite a bit*.” Both adolescents and guardians were asked to respond. The scale consists of two subscales: treatment stigma and non-stigma. The mean value in the previous study was 1.31.⁽⁴⁵⁾

The Depression Self-Rating Scale for Children (DSRS-C)⁽⁴⁶⁾ is an 18-item self-assessment questionnaire for depression in children. The adolescents were asked to rate their level of depression by choosing from “*always*,” “*some-times*,” and “*never*.”

The Strengths and Difficulties Questionnaire (SDQ)⁽⁴⁷⁾ is a self-administered question-

naire designed to comprehensively assess adjustment and mental health status from early childhood through adolescence. It comprises 25 items, each requiring a response of either “*yes*,” “*somewhat yes*,” or “*no*,” and responses were rated on three levels: “*low need*,” “*some need*,” and “*high need*.” Guardians were asked to complete the forms. For **the Vineland Adaptive Behavior Scales-Second Edition** (Vineland II),⁽⁴⁸⁾ the adolescents’ adaptive behavior was graded across four domains: “communication domain,” “daily skill domain,” “sociality domain,” and “motor skills.” Three of the domains were graded; the

Table 2 Demographics of guardians of COMB/TAU group (from the original study).

Demographic variables	Total N=45	TAU group n=22	COMB group n=23	p
Sex				.3226
Father	1 (2.2)	0 (0.0)	1 (100.0)	
Mother	44 (97.8)	22 (50.0)	22 (50.0)	
Total years of education				.3075
Mean (<i>SD</i>)	14.3 (1.6)	14.6 (1.4)	14.1 (1.8)	
Total years of work				.1874
Mean (<i>SD</i>)	14.4 (8.2)	12.7 (8.4)	16.0 (7.8)	
Current employment status n (%)				.0981
No (homemaker)	17 (37.0)	11 (64.7)	6 (35.3)	
Yes	28 (62.2)	11 (39.3)	17 (60.7)	
Full-time employment	13 (46.4)	5 (38.5)	8 (61.5)	
Part-time employment	15 (51.7)	6 (40.0)	9 (60.0)	
Household income n (%)				.5311
4,000,000 yen or more ^a	6 (13.4)	4 (66.7)	2 (33.3)	
5,000,000–8,000,000 yen	25 (55.6)	13 (52.0)	12 (48.0)	
9,000,000 yen or more	14 (31.0)	5 (35.7)	9 (64.3)	
Parental use of support n (%)				.4773
Non-use	37 (82.2)		18 (48.6)	
Use	8 (17.8)		5 (62.5)	
Past medical history				.7655
No	36 (80.0)		18 (50.0)	
Yes	9 (20.0)		5 (55.6)	

^a1 US dollar=115 Japanese yen.

COMB, Intervention group, groups receiving both outpatient psychotherapy with a psychiatrist and ACAT; TAU, Control group, groups receiving only outpatient psychotherapy.

“motor skills,” for which the evaluation target was up to six-years-old, was excluded. We conducted a semi-structured interview with the guardians, who were asked to respond to **the 12-item General Health Questionnaire (GHQ-12)**⁽⁴⁹⁾, a self-administered questionnaire that measures the presence of mental and physical problems in the child from the first day of the child’s life to the present. It comprises 12 items to be answered using a four-point scale: “*less than usual*,” “*no more than usual*,” “*rather more than usual*,” or “*much more than usual*.” Guardians were asked to respond to **the Parenting Resilience Elements Questionnaire (PREQ)**⁽⁵⁰⁾ for guardians

of children with developmental disabilities. This is a self-administered questionnaire that measures the strength of nurturing resilience, with 16 items to be answered using a seven-point scale ranging from “*not at all true*” to “*very true*.”

Analysis method

The hypotheses were as follows: (1) adolescents with ASD who have higher treatment stigma have poorer outcomes from ACAT interventions than those who have lower treatment stigma; and (2) when guardians’ treatment stigma is high, they are less likely to have positive out-

comes from ACAT interventions. High guardian treatment stigma also negative effects the effectiveness of ACAT for adolescents with ASD. To clarify this, we used Spearman's rank correlation coefficient to calculate the correlation coefficient between the BACEv3 scores at pre-intervention and the difference scores for pre-to-post-intervention. For the effectiveness measures used (for adolescents, AKQ-C, SDQ, DSRS, and Vineland II; for guardians, AKQ-P, GHQ-12, and PREQ were used), we calculated difference scores (pre-value-post-value) and correlated their differences. We used Spearman's correlation coefficient because it is adaptable to small samples and less affected by outliers. Analyses were performed using SPSS Version 27.0 (IBM Armonk, New York, USA). A p-value <.05 indicated significance.

Results

The result of the hypothesis (1) analysis indicated that the BACEv3 scores of adolescents with ASD in the intervention group were not correlated with the difference scores in any measure. For hypothesis (2), we found that the BACEv3 scores of the guardians in the intervention group were not correlated with the difference scores for the AKQ-P, GHQ-12, and PREQ. However, we found a positive ($r=0.681$, $p<.01$) and moderate correlation between the guardians' BACEv3 scores at pre-intervention and their difference scores for AKQ-C knowledge. There was a negative ($r=-0.534$, $p<.05$) and moderate correlation between the guardians' BACEv3 scores at pre-intervention and their difference scores got Vineland II "communication" (receptive/expressive language, reading, and writing) (Table 3). For the BACEv3, which measures treatment

Table 3 Correlation coefficients between the BACEv3 scores at pre-intervention and the difference scores in the efficacy indicators before and after ACAT intervention.

Difference scores on the questionnaires before and after the intervention		Baseline intervention group		
		Adolescents with ASD BACEv3	Guardians of adolescents with ASD BACEv3	n
Adolescents with ASD	AKQ-C strength	.094	-.036	21
	AKQ-C weak	-.251	-.103	21
	AKQ-C knowledge	-.288	.681**	18
	SDQ	-.170	-.205	21
	DSRS-C	-.333	.204	21
	Vineland II Communication	.102	-.534*	21
	Vineland II Daily living	.209	-.390	21
Vineland II Social	.204	.048	21	
Guardians of adolescents with ASD	AKQ-P strength	-.085	-.125	21
	AKQ-P weak	-.022	-.186	21
	AKQ-P knowledge	-.316	.326	19
	GHQ-12	-.412	.158	21
	PREQ	.253	-.050	21

Difference scores reflect the difference between scores pre- and post-intervention.

Significance was evaluated by Spearman's correlation coefficient.

* $p < .05$, ** $p < .01$.

AKQ-C, Autism Knowledge Quiz-Child; AKQ-P, Autism Knowledge Quiz-Guardians; SDQ, Strengths and Difficulties Questionnaire; DSRS-C, Depression Self-Rating Scale for Children; Vineland II, Vineland Adaptive Behavior Scale Second Edition; GHQ, the 12-item General Health Questionnaire; PREQ, Parenting Resilience Elements Questionnaire.

stigma, the mean pre-intervention values for adolescents with ASD and guardians in this study were 1.09 and 0.84, respectively. In Hongo et al., the mean score was 1.31.⁽⁴⁵⁾ As the participants in the previous study were adults, only parents were used as comparators in this study.

Discussion

The study examined whether the treatment stigma of adolescents with ASD and their guardians affected the effectiveness of the ACAT intervention. However, Spearman's rank correlation coefficient analysis showed that the severity of treatment stigma in adolescents with ASD was not correlated with the difference scores for any of the measures. Moreover, the guardians' severity of treatment stigma was not correlated with their difference scores. However, we found a positive and moderate correlation between the guardians' BACEv3 scores at pre-intervention and their difference scores for AKQ-C knowledge. This study suggested that even with high guardian treatment stigma, interventions improved knowledge in adolescents with ASD.

This study posited two main hypotheses:

- (1) Adolescents with ASD with higher treatment stigma have poorer outcomes from ACAT interventions than those who have lower treatment stigma.
- (2) When guardians' treatment stigma is high, they are less likely to have positive outcomes from ACAT interventions. High guardian treatment stigma also negatively impacts the effectiveness of ACAT for adolescents with ASD.

Hypothesis (1) was rejected, as no differences in outcomes between adolescents with ASD with and those without treatment stigma were observed. Therefore, we suggest that adolescents' stigma did not affect intervention effectiveness. Hypothesis (2) was also rejected as there were no observable differences in outcome between guardians of ASD individuals with and those without

treatment stigma.

Notably, the data suggested a correlation between the guardians' treatment stigma and an increase in the child's ASD knowledge. This may be because the adolescent encountered vital information related to the disease during the intervention, which the guardians, reluctant regarding the treatment, did not provide. Consequently, the adolescent was more willing to acquire knowledge to better understand the disease. Another interesting result showed a low score in communication skills in adolescents who had guardians with high stigma. As this score was evaluated from their perspective, guardians' lack of knowledge before the intervention may have interfered with communication with the child, leading to an overestimation. However, after the intervention, the guardian may have corrected their impression.

Limitations

Our data raise the issue of selection bias. The inclusion criteria for the study were individuals diagnosed with ASD and their guardians. Patients who had never received treatment for ASD were omitted. Therefore, it may be necessary to consider the treatment stigma of autistic adolescents and their guardians who have avoided treatment and to support them both in the future. The use of data from the intervention trial meant that the data sample was quite small; therefore, there is a need to test our hypotheses with a larger amount of data. The authors of a similar intervention study⁽⁵¹⁾ stated that they failed to detect small to moderate effects owing to sample size. Future studies are needed to confirm treatment stigma and ACAT intervention effects. Our participants had received treatment and support before the intervention and thus did not completely avoid it. Therefore, our conclusions cannot be generalized. In addition, the reasons people with treatment stigma received psychoeducation (intervention) may include the following.

Some participants were, for example, children/students who had experienced truancy. In some cases, they and their guardians were referred to the university for advice by their school or family physician, which led to their participation in the study; however, in other cases, their guardians found out about the study by chance through an online search, which led to their participation. The common denominator was that the need was clear, and the intervention was recommended and attended by those around them. Future studies with more rigorous inclusion assessments are necessary to clarify intervention effects when treatment stigma is high.

Conclusions

In adolescents with ASD with high treatment stigma, no clear association between high treatment stigma and intervention effects was demonstrated. Therefore, treatment stigma in adolescents with ASD could not be said to influence intervention effectiveness. However, even when guardians' treatment stigma was high, ACAT interventions for adolescents with ASD increased their knowledge, suggesting that treatment stigma also did not reduce the effectiveness of this intervention for adolescents with ASD.

Conflicts of interest

The authors declare no conflicts of interest.

Funding

This study was supported by a special research grant (no. 2017 S-1) from the Association of Japanese Clinical Psychology—a non-profit association for clinical psychology in Japan. The funders had no role in the design of the study, the collection, analysis, and interpretation of data or in the writing of the manuscript.

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