



Problem Behaviors as Perceived by Parents Before Their First Consultation at A Developmental Outpatient Clinic: A Questionnaire Research Study

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Abstract: Previous studies have suggested the importance of early detection of child developmental disorders and support for children and their parents. Child developmental and parental support are provided at both public and private facilities. Still, obtaining a physician's diagnosis at a medical institution is essential to determine whether a person has a developmental disorder. However, diagnosing a developmental disorder at the first visit to a medical institution with a child development outpatient clinic is time-consuming. Furthermore, developmental disorders are often associated with multiple comorbidities. Parents must identify children's problem behaviors before taking them to an outpatient clinic and understand how they consider such behaviors for appropriate diagnosis. Therefore, in this study, a private developmental support service company surveyed parents who had visited a child development outpatient clinic at a medical institution. Chi-square test analysis revealed that the number of parents of boys having ≥ 2 problem behaviors was significantly higher than that of parents of girls ($P < 0.01$). In addition, parents who waited for their first medical visit for >0.5 years used multiple resources rather than a single resource to gain knowledge on their child's problem behaviors ($P < 0.01$). Therefore, parents of boys who visited the developmental outpatient clinic for the first time were already aware of their children's multiple problem behaviors before the examination; when the waiting period was prolonged, the parents used multiple resources to collect information before visiting a medical institution.

Keywords: Child developmental disorders, waiting time, questionnaire survey, problem behavior, information-collecting behavior of parents

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Received On 10 July, 2023

Revised On 24 August, 2023

Accepted On 29 August, 2023

Published On 1 September, 2023

Funding This research did not receive any specific grant from any funding agencies in the public, commercial or not for profit sectors.

Citation Takaaki Kuranami, Makoto Saito, Kiminori Gemba, and Tetsuaki Oda , Problem Behaviors as Perceived by Parents Before Their First Consultation at A Developmental Outpatient Clinic: A Questionnaire Research Study.(2023).Int. J. Life Sci. Pharma Res.13(5), L408-L417 <http://dx.doi.org/10.22376/ijlpr.2023.13.5.L408-L417>



I. INTRODUCTION

Considering the importance of early detection and support for child developmental disorders, the Japanese government enforced the Developmental Disabilities Support Act in 2005. It partially revised it in 2016 to legally support children with developmental disabilities in Japan. Developmental disabilities have been clearly defined by law, consequently improving their social recognition. This has led to an increase in the number of children diagnosed with developmental disorders in Japan.¹ The prevalence of attention deficit hyperactivity disorder (ADHD) in children aged <18 years has been estimated to be 5%,² and 1–2 of 40 individuals reportedly have a predisposition to ADHD. In addition, a study on autism spectrum disorder (ASD) in 5-year-old children conducted in Japan between 2013 and 2016 reported no significant increase in the incidence rate of ASD. Still, it revealed a prevalence rate of 3.22%.³ As only physicians can establish a definitive developmental disorder diagnosis, children must visit a medical institution with an outpatient clinic for child psychiatry. The waiting period for an initial visit to a medical institution for consultation on developmental disorders or suspected developmental disabilities is >3 months, reaching up to 10 months at some institutions.⁴ Physicians who diagnose children with developmental disorders also indicate the waiting time. Dr. Kodoi, a psychiatrist, stated that the current waiting list for an appointment remains long because of the lack of specialized child psychiatric institutions, and patients may have to wait for up to 2 years to receive an initial consultation.⁵ The average time from parents noticing a delay or bias in their child's development to obtaining a definitive diagnosis is 24.5 months.⁶ A prolonged waiting period for the first visit can lead to increased patient dissatisfaction, discomfort, distrust, symptom intensification, motivation loss, and possibly giving up on visiting the physician.⁷ In some regions, a limited number of facilities assess developmental disabilities; therefore, more community healthcare institutions are needed to shorten waiting periods. Functional communication training (FCT) is a common and effective form of training that has been shown to reduce problem behaviors.⁸ According to a previous study, parents receiving telemedicine FCT from experienced behavioral consultants can reduce their children's problem behaviors.⁹ Providing such training to parents at local developmental centers during the waiting period may reduce problem behaviors in children. Regarding developmental disorders among children, care and support for the parents are also essential because they are concerned about the child and their future. In addition to public facilities, such as rehabilitation centers, private sectors provide developmental support, and the extent of support varies according to the facilities. A study on mothers of children with developmental disabilities revealed three life difficulties before obtaining a definite diagnosis, including difficulties related to the child's behavior, acceptance of the disability, and support for mothers.¹⁰ Another study highlighted that developmental disabilities in children are characterized by a prolonged period before achieving the diagnosis and that parents have conflicts and anxiety during this period about whether their children have a disability.¹¹ Hence, stress management support¹², as well as psychological and physical support for parents¹³, are necessary. A study

demonstrated the need for mothers' support to understand their children's difficulties. Mothers cannot understand their children's feelings and difficulties by asking them. They worry that their children cannot fully express their feelings; moreover, they believe they are unaware of their school life. They are also deeply concerned about the changes in their children's difficulties as they grow up and start attending school. Moreover, these mothers are unaware of effective approaches to help their children.¹⁴ The difficulties children face during early childhood may differ from those encountered when they reach school age or adolescence; therefore, it is important to provide support to parents according to the age of their children. As mentioned above, previous studies have reported the importance of support to reduce parents' stress and anxiety and the need for parental support for their children's problems depending on the duration before achieving a confirmed diagnosis. However, consideration of parents' behavior before medical intervention remains insufficient, including estimating the number of perceived problems regarding their child's behavior and determining whether their information-collecting behavior to address these problems varied with the waiting period. We believe that clarifying these behaviors would be helpful for the early detection of child developmental disorders by medical professionals. In this study, a company that supports children with developmental disabilities and their parents/guardians conducted a questionnaire survey to understand the status of the parents and children while waiting for their first visit to a developmental outpatient clinic for children. We also evaluated children's problem behaviors as perceived by their parents and assessed parents' information-collecting behavior during the waiting period.

2. MATERIALS AND METHODS

2.1 Ethical Statement

In this study, the purpose of the questionnaire was not to identify medical solutions but rather to determine the problems encountered by parents while interacting with their children. Therefore, ethical approval was not required for this study. In addition, from July 12 to September 30, 2021, the Prime Minister of Japan declared a state of emergency based on the Law Concerning Special Measures against COVID-19, imposing the regulation of staying at home or social distancing. Survey participation was free. This web-based survey ensured the anonymity of participants and confidentiality of any personal information. Responding to the questionnaire indicated that the participants agreed with the purpose of the study.

2.2. Location

This study was conducted at a private company supporting children with developmental difficulties in Japan.

2.3. Participant Demographic Details

The demographic characteristics of the participants are listed in Table I.

Table I: Demographic characteristics of the participants

No.	Sex	Age (years)	Waiting period for the first consultation
1	F	11	>0.5 year
2	F	7	>0.5 year
3	M	7	1–3 months
4	M	13	4–6 months
5	M	9	1–3 months
6	F	12	4–6 months
7	M	6	>0.5 year
8	M	6	4–6 months
9	M	9	>0.5 year
10	M	5	>0.5 year
11	M	9	>0.5 year
12	M	9	>0.5 year
13	F	7	>0.5 year
14	F	23	Within 1 month
15	M	10	>0.5 year
16	M	20	1–3 months
17	M	6	>0.5 year
18	M	7	4–6 months
19	M	20	>0.5 year
20	M	9	>0.5 year
21	M	3	>0.5 year
22	M	6	>0.5 year
23	M	10	4–6 months
24	M	8	>0.5 year
25	M	4	>0.5 year
26	M	5	4–6 months
27	M	21	>0.5 year
28	M	9	>0.5 year
29	M	13	>0.5 year
30	M	15	>0.5 year
31	F	10	>0.5 year
32	M	9	Within 1 month
33	M	13	>0.5 year
34	M	7	>0.5 year
35	M	10	>0.5 year
36	M	9	>0.5 year
37	M	7	>0.5 year
38	F	8	1–3 months
39	F	13	4–6 months
40	M	11	1–3 months
41	M	9	1–3 months
42	M	10	>0.5 year
43	M	9	>0.5 year
44	M	13	>0.5 year
45	F	8	>0.5 year
46	M	19	>0.5 year
47	M	8	>0.5 year
48	M	11	>0.5 year
49	M	5	Within 1 month
50	M	8	>0.5 year
51	M	5	>0.5 year
52	M	2	>0.5 year
53	M	8	>0.5 year
54	F	7	>0.5 year
55	M	4	1–3 months
56	M	9	Within 1 month
57	M	9	>0.5 year
58	M	7	>0.5 year
59	M	6	>0.5 year
60	M	8	>0.5 year
61	M	7	>0.5 year
62	M	7	4–6 months
63	M	12	Within 1 month

64	M	2	4–6 months
65	M	4	Within 1 month
66	M	3	4–6 months
67	F	4	4–6 months
68	M	7	1–3 months
69	M	13	>0.5 year
70	M	12	1–3 months
71	F	1	>0.5 year
72	F	10	4–6 months
73	M	6	>0.5 year
74	F	15	>0.5 year
75	M	6	>0.5 year
76	F	2	>0.5 year
77	M	2	>0.5 year
78	M	6	1–3 months
79	M	8	4–6 months
80	F	8	1–3 months
81	M	11	Within 1 month
82	M	3	Within 1 month
83	M	10	1–3 months
84	F	10	1–3 months
85	M	3	>0.5 year
86	F	4	>0.5 year
87	M	2	1–3 months
88	F	9	>0.5 year
89	M	9	Within 1 month
90	M	3	>0.5 year
91	M	16	4–6 months
92	M	2	>0.5 year
93	M	22	4–6 months
94	M	10	>0.5 year
95	F	2	4–6 months
96	F	10	>0.5 year
97	M	2	4–6 months
98	M	4	>0.5 year
99	M	3	>0.5 year
100	M	11	>0.5 year
101	M	8	1–3 months
102	F	3	4–6 months
103	M	7	>0.5 year
104	M	3	>0.5 year
105	F	13	>0.5 year
106	M	10	1–3 months
107	F	16	>0.5 year
108	M	14	>0.5 year
109	F	6	>0.5 year
110	M	8	>0.5 year
111	F	10	1–3 months
112	M	10	Within 1 month
113	F	10	4–6 months
114	M	20	>0.5 year
115	M	12	>0.5 year
116	F	7	>0.5 year
117	F	12	>0.5 year
118	M	12	>0.5 year
119	M	12	>0.5 year
120	M	10	>0.5 year
121	M	10	>0.5 year
122	M	15	>0.5 year
123	F	6	1–3 months
124	M	7	>0.5 year
125	M	6	>0.5 year
126	F	7	4–6 months
127	F	14	>0.5 year
128	F	4	>0.5 year
129	M	7	1–3 months

130	M	13	>0.5 year
131	M	14	4–6 months
132	M	13	>0.5 year
133	M	19	1–3 months
134	M	14	>0.5 year
135	M	7	>0.5 year
136	F	4	1–3 months
137	M	14	>0.5 year
138	M	7	1–3 months
139	M	6	1–3 months
140	M	11	>0.5 year
141	M	11	4–6 months
142	M	5	1–3 months
143	M	6	>0.5 year
144	M	6	>0.5 year
145	M	2	1–3 months
146	F	15	>0.5 year
147	F	10	>0.5 year
148	M	12	Within 1 month
149	M	10	>0.5 year
150	F	12	1–3 months
151	F	13	1–3 months
152	F	14	>0.5 year
153	M	9	>0.5 year
154	F	14	>0.5 year
155	M	2	>0.5 year
156	M	6	>0.5 year
157	M	3	1–3 months
158	F	2	1–3 months
159	M	10	>0.5 year
160	M	13	>0.5 year
161	M	10	4–6 months
162	F	13	4–6 months
163	M	9	>0.5 year
164	M	8	>0.5 year
165	M	14	>0.5 year
166	F	5	>0.5 year
167	M	7	>0.5 year
168	M	5	>0.5 year
169	M	2	4–6 months
170	M	9	>0.5 year
171	M	2	4–6 months
172	M	10	>0.5 year
173	F	4	>0.5 year
174	M	2	1–3 months
175	F	9	4–6 months
176	M	11	>0.5 year
177	M	10	1–3 months
178	M	13	>0.5 year
179	M	13	4–6 months
180	M	9	>0.5 year
181	F	11	>0.5 year
182	M	10	1–3 months
183	F	8	1–3 months
184	F	6	>0.5 year
185	F	6	1–3 months
186	M	2	Within 1 month
187	F	9	>0.5 year

Table I shows the demographic characteristics of the children as reported by their parents, along with their waiting period before the first consultation. The demographic characteristics of the parents were not recorded in this survey.

2.4. Data Collection

This survey was conducted for 1 month (i.e., from September 1 to 30, 2021). Questionnaires answered by parents during this period were included in the survey. From July 12 to September 30, 2021, the Prime Minister of Japan declared a state of emergency

based on the Law on Special Measures against COVID-19, imposing restrictions on staying at home and social distancing. The Japanese government requested the company where the survey was conducted to switch from face-to-face to online support services. We followed suit and created a URL to access a web-based Google form, which a company representative presented during the online support service. Before answering the survey, we clarified in an explanatory document that the survey was open-ended; no section for names, e-mail addresses, phone numbers, or personal information would be confidential. There were 188 respondents in this survey; however, 1 respondent listed 2 different ages of children and was thus excluded. Thus, 187 respondents were included in the analysis.

2.5. Inclusion Criteria

We specifically included parents who were using the developmental support services of the company during the survey period and had visited a child development outpatient clinic at a medical institution as their first visit.

2.6. Exclusion Criteria

We excluded parents who did not agree with the purpose of the study.

2.7. Questionnaire Contents

Developmental disorders include ADHD, ASD, and learning disorders. Considering the increasing comorbidity of ADHD and ASD¹⁵ and wide variation in the comorbid psychiatric disorders across the lifespan,¹⁶ this study used the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)¹⁷ criteria for ADHD. The web-based questionnaire was designed using Google Forms. The questionnaire included the following questions: 1. child's sex, 2. child's age, 3. date of the first appointment at the developmental outpatient clinic in a medical institution, 4. child's problem behaviors, 5. parents' actions in response to the problem behaviors, 6. evaluation of the actions taken by the parents, 7. reasons for the visit, 8. parents' problems in their daily lives, 9. parents' coping strategies for their problems, 10. children's access time to media (e.g., games and YouTube), and 11. whether they want an online developmental consultation with a physician.

3. STATISTICAL ANALYSIS

The collected questionnaire results were analyzed using Microsoft Excel 2016. The data were analyzed using descriptive statistics and a chi-square test for ratios. A significance level of 5% ($P > 0.05$) was considered to indicate statistical significance.

4. RESULTS

4.1 Waiting Period for First Consultation

Table 2: Descriptive characteristics of children analyzed in the questionnaire survey					
Characteristics	Item	Number	Ratio	Mean	SD
Sex of children	Male (Boy)	137	73.3%		
	Female (Girl)	50	26.7%		
Age (years)				8.74	4.37
Waiting period for the first consultation					
Within 1 month					
	Male (Boy)	11	5.9%		
	Female (Girl)	1	0.5%		
1–3 months					
	Male (Boy)	23	12.3%		
	Female (Girl)	11	5.9%		
4–6 months					
	Male (Boy)	18	9.6%		
	Female (Girl)	10	5.3%		
>0.5 year					
	Male (Boy)	85	45.5%		
	Female (Girl)	28	15.0%		

Of the 187 parents included in the analysis, 73.3% had male children, and 26.7% had female children, with a mean age of 8.74 years (standard deviation [SD] = 4.37). Table 2 illustrates the waiting periods of parents and children from the first appointment to the first visit to the medical institution. In this study, 60.5% of the parents waited for >6 months, and only 6.4% had a very short waiting period of ≤1 month.

4.2. Children's Problem Behaviors as Observed by Their Parents

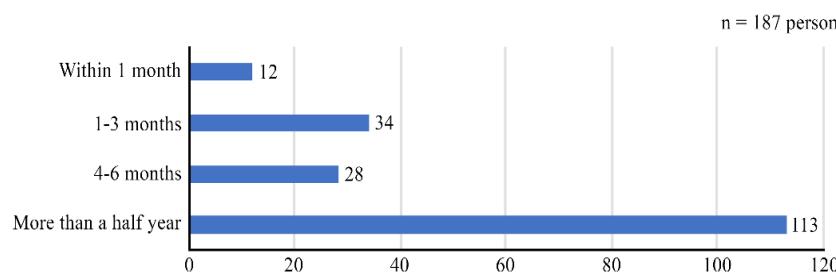


Fig 1: Children's problem behaviors as observed by their parents

Figure 1 lists the children's problem behaviors from the perspective of parents. This question item had multiple-choice responses, considering that the parents could perceive more than one problem behavior. However, parents might be concerned regarding behaviors not listed in the options; hence, a choice of "others" was provided, and the respondents could also provide a descriptive answer. If multiple problems were described, they were statistically treated as multiple problem behaviors. A total of 125 (66.8%) parents selected "others," and 103 (55.0%) claimed that their children often remained restless.

Table 3: Cross tabulation based on sex and problem behavior (chi-square test)

	One behavior	Two or more behaviors	Total number
Boy	27	110	137
Girl	20	30	50
Total number	47	140	187
		P value	0.005

A total of 47 parents responded that their children had one problem behavior, whereas 140 parents responded that their children had two or more problem behaviors (Table 3). According to the crosstabulation based on sex and problem behaviors (one or two or more) and the chi-square test, the number of parents of boys who were aware of two or more problem behaviors was significantly higher than that of girls ($P < 0.01$).

**What actions did you take when you became concerned about your child's behavior?
(Multiple answers allowed)**

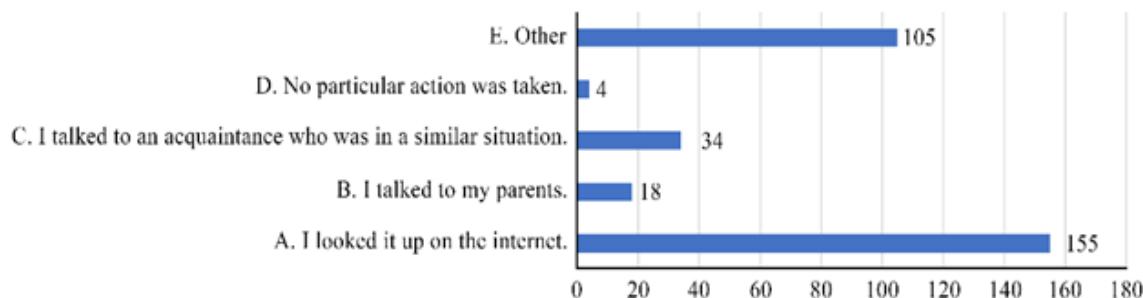


Fig 2: Parents' information-collecting behavior

Figure 2 shows the information-collecting behaviors of parents to identify their children's problem behaviors. Multiple responses were allowed as information regarding their children's problem behaviors was collected from multiple sources. Some behaviors may not be listed in the options; hence, the "others" column was provided. In addition, some parents might not have taken action; thus, an option stating "no action" was provided. We revealed that most of the parents (155 [82.8%]) researched on the Internet, and 105 (56.1%) parents chose "others." However, four parents (2%) took no action.

Table 4: Waiting period and information-collecting behavior (chi-square test)

	Waiting period of <0.5 year	Waiting period of >0.5 year	Total number
Information-collecting behavior from one resource	21	54	75
Information-collecting behavior from two or more resources	51	57	108
Total number	72	111	183
		P value	0.009

To examine whether a relationship exists between the waiting period and the number of resources from which parents collected information, we conducted a chi-square test via cross-tabulation (Table 4), where the waiting period was <6 and >6 months. The analysis excluded the four parents who answered "took no action," the results revealed that parents who had waited ≥ 6 months were significantly more likely to use two or more resources to collect information about their children's problem behaviors. This finding indicated that the longer the parents needed to wait, the more resources they used to collect information ($P < 0.01$).

5. DISCUSSION

This study analyzed the results of questionnaires completed by 187 parents waiting for their children's first consultation at a medical institution with a developmental outpatient clinic. In general, developmental disorders are more common in males than in females. For example, ASD is reportedly 4 times more common in males than females,^{18,19} and ADHD is 2–10 times more common in males than females.^{17,20,21} In this study, most children of the parents who responded to the questionnaire were boys. In our questionnaire survey, the most common response for the waiting period before the first medical examination was ≥ 6 months. Any developmental disability should be diagnosed solely by the physician, and reaching a definitive diagnosis takes longer because it involves medical interviews and various examinations, consistent with the results of studies conducted in Japan by Higashiyama and Aiura.^{6,9} Another study surveyed parents at a child and adolescent mental health services outpatient clinic and reported a low correlation coefficient for the association between waiting time and relationship with health personnel.²² Thus, shorter waiting times may improve relationships with the health personnel. Regarding children's problem behaviors from the parents' perspectives, the most common answer was "others," followed by "restlessness." Restlessness could be categorized as the hyperactive type¹⁷ of ADHD. The questionnaire items in this study were based on the DSM-5 diagnostic criteria for ADHD.¹⁷ Considering that the questionnaire did not include items about ASD characteristics, such as obsessive and addictive behaviors, these problem behaviors were incorporated into the "others" category. In the present study, the parents of boys were more aware of multiple problem behaviors than those of girls. In a study on the full variant of Fragile X syndrome, Kelly et al. used the Problem Behavior and DSM-5 Symptom Inventory Questionnaire to examine parental and teacher assessments of ADHD symptoms. Among boys, the parents' ratings revealed higher T-scores for inattentive and hyperactive types of ADHD than the teachers' ratings.²³ The present study also confirmed a trend of parents identifying multiple problem behaviors. Another study on hyperactivity objectively verified the relative restlessness of boys with ADHD.²⁴ In addition, a study investigating parents' and teachers' perceptions of the condition of children with developmental disabilities revealed that parents reported problems regarding items related to inattention. In contrast, teachers reported problems regarding hyperactivity and communication skills. This study showed that several parents perceived the child's "restlessness" as problematic.²⁵ This result may have been reported by the parents of school-aged children who spend more time in social situations; they notice these behaviors from their subjective viewpoints and third parties outside the family, such as school teachers. Further research is warranted to determine whether such behaviors are due to ADHD. When parents were

surveyed about what action they take when they become aware of their children's problem behaviors, many responded that they searched for answers on the internet, confirming the tendency of parents to seek information online. In a study by Mackintosh et al., parents of children with ASD reported that the most common source of information was parents of other children with ASD.²⁶ In the present study, parents of children with other developmental disabilities were included along with those of children with ASD; we revealed that 34 (18%) parents consulted with other parents who were in the same situation. Further research is warranted regarding the information-collecting behavior of parents of children with developmental disabilities. However, the current study revealed a prolonged waiting period before consultation. The longer the waiting period, the more time the parents will spend collecting information, possibly leading to the identification of further problem behaviors in their children. Therefore, we performed a cross-tabulation of the waiting periods (<6 and ≥ 6 months) as well as information-collecting behaviors (from one resource and two or more resources). The results were analyzed using chi-square test. The parents who waited for ≥ 6 months were significantly more likely to engage in collecting information from two or more resources. Thus, parents use the internet and seek other sources to acquire more information about their children's behaviors. However, although searching for information on the internet is easy, there is a risk that parents may obtain incorrect or biased information.²⁷ Therefore, information about developmental disorders on the internet should be accompanied by evidence and should be of high quality.²⁸

6. CONCLUSIONS

This study examined children's problem behaviors as perceived by their parents and the actions (e.g., information gathering) taken by these parents while waiting for their first consultation at a child development outpatient clinic in a medical institution. This study has certain limitations. The analysis was limited to a single company providing developmental disability support and had a small sample size (187 parents). In future studies, more participants and further developmental disabilities in children should be included. Support must be provided not only for children with developmental disabilities but also for their parents/guardians. Parents live with their children and are deeply concerned about their children's behaviors. Hence, they wish to visit medical institutions for consultation. For early detection and support, increasing the availability of medical institutions specializing in child development disorders and shortening patient waiting times are urgently required. Regarding early support, nonspecialized institutions have sufficient potential for providing treatment and education to these children and their parents/guardians.²⁹ Moreover, appropriate measures should be taken to shorten the waiting period for the initial diagnosis of developmental disabilities.

7. ACKNOWLEDGEMENTS

We have not received any funding for this research. We want to thank all the parents who participated in the study. Thanks to the company president for allowing us to perform this study.

8. AUTHORS CONTRIBUTION STATEMENT

Conceptualization, Takaaki Kuranami; Methodology, Takaaki

Kuranami, Makoto Saito; Writing-original draft preparation, Takaaki Kuranami; Writing-review and editing, all authors; Statistical calculations, Takaaki Kuranami. All authors have read and agreed to the published version of the manuscript.

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9. CONFLICT OF INTEREST

Conflict of interest declared none.

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