

Effect of Childhood Disease on Hospital Presentation: A Survey of Pediatricians

Hanako Tajima¹, Juri Ogawa¹, Izuru Nose², Ruby Pawankar³,
Miho Maeda³, Yutaka Momota² and Miki Kakinuma²

¹Department of Pediatrics, Nippon Medical School Musashikosugi Hospital, Kanagawa, Japan

²School of Veterinary Medicine, Faculty of Veterinary Science, Nippon Veterinary and Life Science University, Tokyo, Japan

³Department of Pediatrics, Nippon Medical School Hospital, Tokyo, Japan

Background: Determining when caregivers should take their children to a hospital is crucial in ensuring the health and safety of children. Because children cannot make these decisions on their own, caregivers bear the core responsibility for the wellness of their children. The aim of this study was to determine how disease, disability, and child behavior affect when and how often caregivers take their children to a hospital.

Methods: A structured anonymous online survey was circulated to pediatricians in Japan. Pediatricians were queried about the characteristics of their patients, including reactivity to pain, expression of pain, behavior at the hospital, and the timing of presentation. Patients were school-aged children and included those with autism spectrum disorder, attention-deficit hyperactivity disorder, Down syndrome, mental retardation, epilepsy, premature birth, and allergies.

Results: Sixty-eight of 80 pediatricians responded to the survey (85% response rate). The results indicated that caregivers of children with autism spectrum disorder, attention-deficit hyperactivity disorder, and mental retardation took them to the hospital later than was optimal. Conversely, children born prematurely and those with allergies were taken to hospitals even when symptoms were mild.

Conclusions: Caregivers make decisions on when to present to hospital on the basis of their child's expression of pain and behavior. Guidelines should be developed to assist caregivers in determining when to present for treatment at a hospital. (J Nippon Med Sch 2022; 89: 190–195)

Key words: autism spectrum disorder, attention-deficit hyperactivity disorder, mental retardation, parental support, hospital presentation

Introduction

Caregivers are often solely responsible for determining if a child requires a hospital consultation. If children cannot adequately express their physical condition because of a disease or disability, presentation to hospital may be delayed or, conversely, may be unnecessary. Understanding why some caregivers wait too long before presenting to hospital while others present unnecessarily would help medical personnel provide appropriate advice to caregivers. Since one mode of expressing pain is social communication, which was acquired during evolution¹, it is cru-

cial that caregivers are highly sensitive to their children's expression of pain.

Veterinary medicine is often compared to pediatric medicine since in both cases the patient/sick pet does not decide when to present for treatment at a hospital. In terms of pediatric visits by caregivers, it is not easy to identify the factors that influence the caregiver's behavior and personality or the characteristics of their children. A study of hospital presentation in relation to dog breed found that pet owners' behavior was influenced by dog behavior rather than by the personality of the owner.

Correspondence to Hanako Tajima, Department of Pediatrics, Nippon Medical School Musashikosugi Hospital, 1-396 Kosugi-cho, Nakahara-ku, Kawasaki, Kanagawa 211-8533, Japan

E-mail: s7047@nms.ac.jp

https://doi.org/10.1272/jnms.JNMS.2022_89-214

Journal Website (<https://www.nms.ac.jp/sh/jnms/>)

Table 1 Questions in Part Two

-
1. Are these children obedient in the consultation room?
 2. Do they have a high tolerance for pain?
 3. Do the caregivers of these children consult pediatricians when symptoms are too mild?
 4. Are the caregivers nervous in the consultation room?
 5. Do the caregivers ask pediatricians for help with parenting or behavior problems?
 6. Do you think the relationships of the children and the caregivers are strong?
 7. Do you think these children are self-reliant?
 8. Do the caregivers often become aggressive in the consultation room?
 9. Do these children have difficulty being quiet in the waiting room?
 10. Is the consultation time longer with these caregivers?
 11. Are you likely to have a disagreement with these caregivers in the consultation room?
-

Kakinuma et al. reported that caregivers of dog breeds that were sensitive to pain were more likely to be anxious and aggressive and therefore presented to veterinarians frequently, whereas caregivers of dog breeds insensitive to pain tended to delay visits to the veterinarian². They also reported that caregivers of dogs that caused difficulties during veterinarian visits were more likely to delay consultation. These findings suggest that caregivers make their decisions not purely on the basis of physical condition but rather on the expression of pain or the behavior of the family member².

Hypotheses as to why caregivers take children to the hospital too frequently include parental fear, unreasonable expectations, and parental psychiatric disorders such as narcissistic personality disorder^{3,4}. On the basis of our previous research, we hypothesized that caregivers become nervous and aggressive as a natural reaction to protect their children, especially when the child has a psychological disease or disability². In the present study, we analyzed the impact of a child's disease, disability, and behavior on the likelihood the caregiver would take that child to a hospital.

Materials and Methods

Survey

A structured anonymous online survey was circulated to pediatricians in Japan in 2020. The questionnaire consisted of two parts. Part one included demographic data such as age, gender, and workplace of the pediatrician. Part two included questions about patients' reactivity to pain, expression of pain, behavior at the hospital, and timing of presentation. The 11 questions were measured with a 5-point Likert scale (Table 1). Patients were school-aged children with autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), Down syndrome (DS), mental retardation (MR), epilepsy,

premature birth, or allergies. Diagnoses of ASD, ADHD, and MR were based on criteria specified in DSM-5. The pediatricians were asked to respond to the questions by comparing their patients to healthy children.

Statistical Analysis

The answers were rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), and the analyses were performed with Microsoft Excel 2016. The average rate for each disease was calculated. One-way analysis of variance (seven diseases) was conducted and was followed by multiple comparisons (Shaffer's method) to determine if the main effects were statistically significant.

Ethics

Informed consent was obtained from all pediatricians prior to the questionnaire-based survey. All procedures performed in this study were in accordance with the ethical standards of the Nippon Medical School Musashi Kosugi Hospital Research Ethics Committee (No. 582-2-47).

Results

Participants (Questions in Part One)

The questionnaire was sent to 80 pediatricians and 68 (85%) responded to the survey. The demographic characteristics of the participants are shown in Table 2. There were 45 male respondents and 23 female respondents, and 14 (20.6%) of the respondents specialized in pediatric neurology. More than 95% (65) reported working in Tokyo and its suburbs; 85.3% (58) were working in hospitals, while 14.8% were working in private clinics.

Responses to Questions (Questions in Part Two)

The average response for each question is shown in Figure 1. Results of one-way analysis of variance are shown in Table 3, and the results of multiple comparisons are described below.

Table 2 Demographic characteristics of pediatricians

Characteristics	Study sample (n=68)
Gender	
Male	45 (66.2%)
Female	23 (33.8%)
Age	
≤29	5 (7.4%)
30-39	14 (20.6%)
40-49	29 (42.6%)
50-59	9 (13.2%)
≥60	11 (16.2%)
Subspecialty	
Pediatric neurology	14 (20.6%)
Others	54 (79.4%)
Length of work	
≤5 years	6 (8.8%)
5-10 years	5 (7.4%)
11-14 years	12 (17.6%)
≥15 years	45 (66.2%)
Place of work in Japan	
Tokyo	39 (57.4%)
Kanagawa	20 (29.4%)
Chiba	6 (8.8%)
Others	3 (4.4%)
Type of medical facilities	
University hospital	38 (55.9%)
General hospital	20 (29.4%)
Private clinic	10 (14.8%)

Responses to Question 1: The average was significantly higher for DS ($p < .05$) and significantly lower for ADHD ($p < .05$), as compared with the other groups. The average for ASD was significantly lower than those for epilepsy and premature birth ($p < .05$), and the average for MR was lower than that for epilepsy ($p < .05$).

Responses to Question 2: The average for ADHD was significantly lower than the averages for the other groups ($p < .05$), and the averages for ASD and MR were lower than those for DS, epilepsy, premature birth, and allergies ($p < .05$).

Responses to Question 3: The average for ASD was lower than those for DS, MR, epilepsy, premature birth, and allergies ($p < .05$), whereas the average for MR was lower than that for premature birth ($p < .05$). The averages for allergies and epilepsy were lower than that for premature birth ($p < .05$).

Responses to Question 4: The average for DS was lower than those for MR, premature birth, and allergies ($p < .05$), and the average for epilepsy was lower than that for premature birth ($p < .05$).

Responses Question 5: The average for ASD was higher than those for DS, MR, epilepsy, premature birth, and allergies ($p < .05$), the average for ADHD was higher than those for DS, MR, epilepsy, premature birth, and allergies ($p < .05$), and the averages for allergies and epilepsy were lower than that for premature birth ($p < .05$). The average for epilepsy was lower than those for MR and premature birth ($p < .05$).

Responses to Question 6: The average for MR was higher than those for ADHD and epilepsy ($p < .05$), and the average for ASD was higher than that for ADHD ($p < .05$).

Responses to Question 7: The average for MR was lower than those for ASD, ADHD, epilepsy, and premature birth ($p < .05$), whereas the average for ADHD was lower than those for DS and allergies ($p < .05$).

Responses to Question 8: The average for DS was lower than those for the other groups, whereas the average for ADHD was higher than those for ASD, MR, epilepsy, premature birth, and allergies ($p < .05$).

Responses to Question 9: The average for ADHD was higher than those for the other groups, whereas the averages for ASD and MR were higher than those for DS, epilepsy, premature birth and allergies ($p < .05$).

Responses to Question 10: The average for ASD was higher than those for DS, epilepsy, premature birth, and allergies, whereas the averages for ADHD and MR were higher than those for DS, epilepsy, and premature birth ($p < .05$).

Responses to Question 11: The average for DS was lower than those for ADHD, MR, premature birth, and allergies, whereas the average for allergies was higher than those for ASD, ADHD, epilepsy, and premature birth ($p < .05$).

Discussion

According to the pediatricians, children with ASD, ADHD, and MR were less tolerant of pain and more sensitive but did not present to a hospital early enough (Table 1; Q2 and Q3). Previous reports on the sensory characteristics of children with ASD, ADHD, and MR mention hyperesthesia and bluntness⁵⁻⁸. In this study, pediatricians reported that children with ASD, ADHD, and MR were more likely to be hypersensitive than blunt.

According to the survey responses, children with ASD, ADHD, and MR often could not remain quiet in hospitals and sometimes refused, or acted out during, medical examinations (Table 1; Q1 and Q9). Furthermore, children with difficulties using public transportation because of developmental problems may be a burden for caregiv-

Childhood Disease and Hospital Presentation

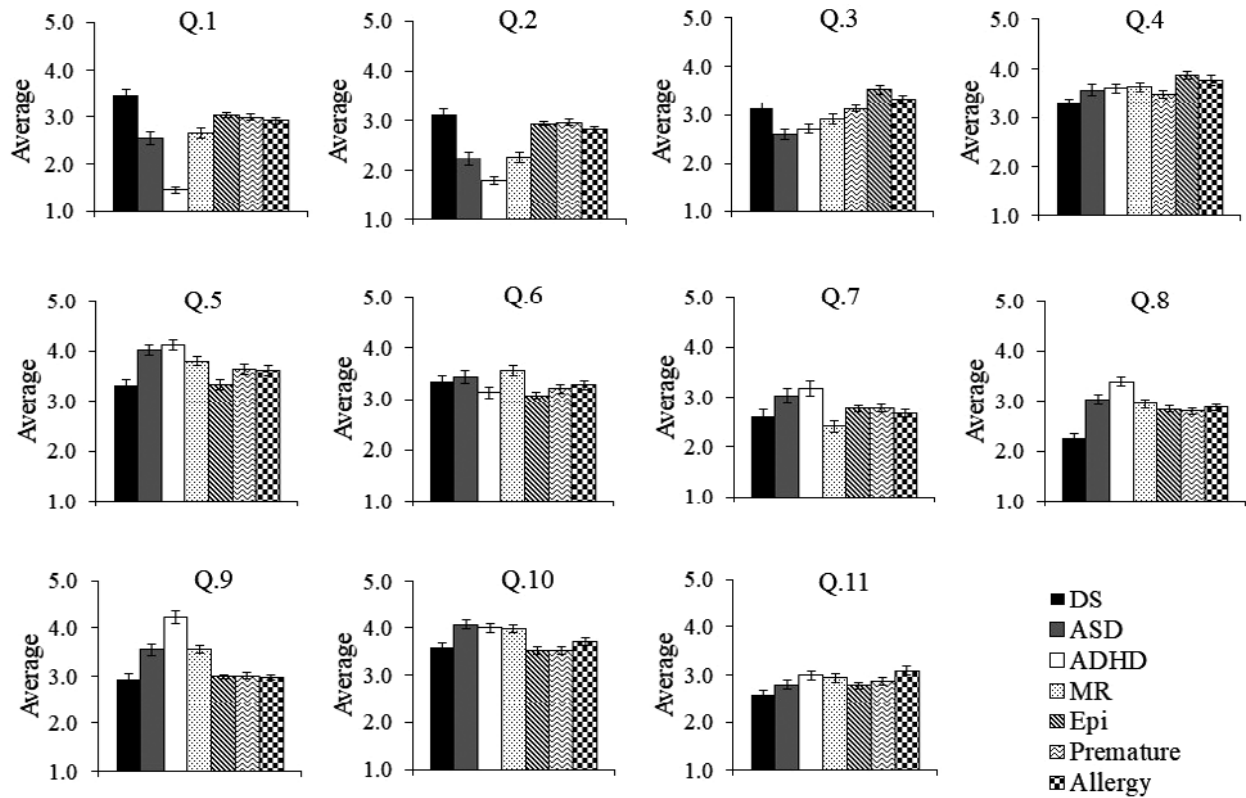


Fig. 1

The averages for the responses: Question 1 (Q1) to Question 11 (Q11). Strongly disagree = 1, disagree = 2, neither agree nor disagree = 3, agree = 4, strongly agree = 5.

DS: Down syndrome, ASD: autism spectrum disorder, ADHD: attention-deficit hyperactivity disorder, MR: mental retardation, Epi: epilepsy, Premature: premature birth

Table 3 Results of one-way analysis of variance (Part Two). Responses were rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), and the average rate of each disease was calculated.

Question Number	Main effect
1	Significant, $F(6,402) = 51.24, \eta p^2 = 0.43, p < .001$
2	Significant, $F(6,402) = 35.30, \eta p^2 = 0.35, p < .001$
3	Significant, $F(6,402) = 15.92, \eta p^2 = 0.19, p < .001$
4	Significant, $F(6,402) = 6.07, \eta p^2 = 0.08, p < .001$
5	Significant, $F(6,402) = 15.68, \eta p^2 = 0.19, p < .001$
6	Significant, $F(6,402) = 4.28, \eta p^2 = 0.06, p < .001$
7	Significant, $F(6,402) = 8.43, \eta p^2 = 0.53, p < .001$
8	Significant, $F(6,402) = 24.36, \eta p^2 = 0.27, p < .001$
9	Significant, $F(6,402) = 32.31, \eta p^2 = 0.33, p < .001$
10	Significant, $F(6,402) = 11.16, \eta p^2 = 0.14, p < .001$
11	Significant, $F(6,402) = 8.72, \eta p^2 = 0.12, p < .001$

ers traveling to hospitals by taxi. These issues may affect the likelihood that a caregiver takes their child to a hospital, which could worsen the child's condition. In addition, children with ASD or MR have difficulty in verbally expressing pain severity. Reeves et al. reported an in-

creased risk of appendicitis complications in children with ASD⁹. Adams et al. reported that children with ASD had significantly higher rates of acute otitis media, otitis media with effusion, otorrhea, and PE tube placement and were more than twice as likely to develop mastoidi-

tis and undergo mastoidectomy and tympanoplasty¹⁰. Ferrazzano et al. reported that children with ASD have a higher risk of severe caries¹¹. Children and caregivers would benefit from waiting rooms that are adequately equipped for these children. An automatic calling system would allow them to wait in their cars or other places, thereby reducing waiting time. Home health care using a home-visiting medical service or telemedicine is another option to consider. Moreover, families of children with severe physical and mental disabilities would benefit if family doctors or nurses performed home visits for regular health checks and then decided whether the child needed to present for treatment at a hospital. This service is becoming more common in some cities in Japan.

Bluntness has been reported in children with ASD or DS but was not a concern in the present study^{8,12}. Inability to sense or express pain could delay hospital presentation. Use of a pain scale for noncommunicating children, eg, the noncommunicating children's pain checklist-revised (NCCPC-R) may be helpful for assessing pain in such children¹³. Furthermore, the incidence and hospital management of such cases should be investigated.

Caregivers of children born prematurely and those with allergies took their children to a hospital even when symptoms were mild (**Table 1**; Q3), although expressions of pain and child behavior were typical (**Table 1**; Q2, Q5 and Q9). Caregivers may have been nervous (**Table 1**; Q4) because of previous difficult experiences regarding their child's health, the presence of an unfamiliar condition, and, in some cases, a life-threatening condition, eg, a child with allergy exhibiting symptoms of anaphylaxis, a prematurely born child requiring intensive care^{14,15}. Moreover, children born prematurely may have developmental issues that differ from those of other children, despite appearing healthy in infancy¹⁶. Therefore, caregiver anxiety toward premature children may be more severe. The quality of life of children and their caregivers could be improved by coaching caregivers as to when to present to a hospital, eg, by providing individualized advice by a doctor or nurse, psychological counseling, peer counseling, as represented by a patients' association, and conferences between parent, teacher, and medical staff.

A significant association between children with MR and caregivers was found (**Table 1**; Q6), while results were nonspecific for children with ADHD ("Agree", "Neither agree nor disagree", and "Disagree" answers were equally distributed). The results were similar (**Table 1**; Q7) for ASD and ADHD. This may be attributable to

the frequency of patients who were diagnosed with MR and ASD, ASD and ADHD, or MR, ASD, and ADHD simultaneously and the possibility that pediatricians who are not specialized in pediatric neurology may be unfamiliar with MR, ASD, and ADHD.

Caregivers of children with ADHD were more likely to be aggressive in the consultation room (**Table 1**; Q8), and consultation time tended to be longer (**Table 1**; Q10 and Q11). We did not ask the pediatricians for additional information, but overprotective behaviors of caregivers could result in exaggerated behaviors. Caregivers of children with medical conditions or disabilities, especially developmental disabilities, may feel anxious because of the lack of societal understanding/acceptability of their child's condition¹⁷⁻²⁰, or because the caregivers themselves may have developmental disabilities²¹. Alternatively, caregivers may simply be actively advocating for their children. Future studies should examine the reasons for aggressive parental behavior.

Although this study highlights the effects of child disease, disability, and behavior on the likelihood a caregiver will take their child to hospital, it has certain limitations. The sample size was small, and bias of the responding pediatricians, by workplace and subspecialty, is a concern. Disease and disability severity was not considered, and the reason for presentation to the pediatrician at hospital (common cold, trauma, other emergency or regular consultation) is not specified in this research. Parental mental illness and developmental traits also need to be considered. Future studies should have larger enrollments and should assess the type and severity of children's conditions at the hospital, to help in the development of guidelines for the optimal timing and necessity of hospital presentation. We are planning a survey and interviews of caregivers of patients and healthy children, to evaluate associations of sensitivity, behaviors, caregiver-child relationships, and disease severity with hospital presentation.

Conclusions

This study suggests that caregivers decide to seek treatment at a hospital after considering their child's expression of pain and behavior, as we predicted in our hypothesis. Healthcare providers respond to patients from a holistic perspective that considers their genetics, environment, and characteristics. The present findings suggest that information can be provided to explain the child's characteristics so that caregivers can make better-informed decisions regarding the necessity and timing of

hospital treatment.

Acknowledgments: We are grateful to the pediatricians for their participation. This research was funded by the Program to Support the Research Activities of Female Researchers, the Japan Science and Technology Agency, and the Ministry of Education, Culture, Sports, Science and Technology.

Conflict of Interest: The authors declare no conflict of interest.

References

- Craig KD. Social communication model of pain. *Pain*. 2015 Jul;156(7):1198–9.
- Kakinuma M, Nose I, Takarabe M, et al. Dog temperament and veterinary consultation -Poodle owners consult more than Shih Tzu owners. 52nd annual meeting of the international society for developmental psychobiology. Chicago, Oct. 17, 2019.
- Pinquart M. Do the parent-child relationship and parenting behaviors differ between families with a child with and without chronic illness? A meta-analysis. *J Pediatr Psychol*. 2013;38(7):708–21.
- Hullmann SE, Wolfe-Christensen C, Ryan JL, et al. Parental overprotection, perceived child vulnerability, and parenting stress: a cross-illness comparison. *J Clin Psychol Med Settings*. 2010;17(4):357–65.
- Gomes E, Pedroso FS, Wagner MB. Auditory hypersensitivity in the autistic spectrum disorder. *Pro Fono*. 2008;20(4):279–84.
- Lane SJ, Reynolds S. Sensory over-responsivity as an added dimension in ADHD. *Front Integr Neurosci*. 2019; 13:40.
- Marco EJ, Hinkley LB, Hill SS, Nagarajan SS. Sensory processing in autism: a review of neurophysiologic findings. *Pediatr Res*. 2011;69(5 Pt 2):48R–54R.
- Posar A, Visconti P. Sensory abnormalities in children with autism spectrum disorder. *J Pediatr (Rio J)*. 2018;94(4):342–50.
- Reeves PT, Susi A, Hisle-Gorman E, Gorman GH, Nylund C. Brief report: association of complicated appendicitis in children with autism spectrum disorders. *J Autism Dev Disord*. 2020 Dec;50(12):4535–40.
- Adams DJ, Susi A, Erdie-Lalena CR, et al. Otitis media and related complications among children with autism spectrum disorders. *J Autism Dev Disord*. 2016;46(5): 1636–42.
- Ferrazzano GF, Salerno C, Bravaccio C, et al. Autism spectrum disorders and oral health status: review of the literature. *Eur J Paediatr Dent*. 2020;21(1):9–12.
- Bruni M, Cameron D, Dua S, Noy S. Reported sensory processing of children with Down syndrome. *Phys Occup Ther Pediatr*. 2010;30(4):280–93.
- Breau LM, McGrath PJ, Camfield CS, Finley GA. Psychometric properties of the non-communicating children's pain checklist-revised. *Pain*. 2002;99(1-2):349–57.
- Ward CE, Greenhawt MJ. Treatment of allergic reactions and quality of life among caregivers of food-allergic children. *Ann Allergy Asthma Immunol*. 2015;114(4):312–8 e2.
- Bener A. Psychological distress among postpartum mothers of preterm infants and associated factors: a neglected public health problem. *Braz J Psychiatry*. 2013;35(3):231–6.
- Leon Hernandez A. The impact of prematurity on social and emotional development. *Clin Perinatol*. 2018;45(3): 547–55.
- van Steijn DJ, Oerlemans AM, van Aken MA, Buitelaar JK, Rommelse NN. The reciprocal relationship of ASD, ADHD, depressive symptoms and stress in parents of children with ASD and/or ADHD. *J Autism Dev Disord*. 2014;44(5):1064–76.
- Berenguer C, Rosello B, Miranda A. Mothers' stress and behavioral and emotional problems in children with ADHD. Mediation of coping strategies. *Scand J Psychol*. 2021 Apr;62(2):141–9.
- Miranda A, Mira A, Berenguer C, Rosello B, Baixauli I. Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Front Psychol*. 2019;10:464.
- Kuo HC, Chang LS, Tsai ZY, Wang LJ. Allergic diseases do not impair the cognitive development of children but do damage the mental health of their caregivers. *Sci Rep*. 2020;10(1):13854.
- Psychogiou L, Daley DM, Thompson MJ, Sonuga-Barke EJ. Do maternal attention-deficit/hyperactivity disorder symptoms exacerbate or ameliorate the negative effect of child attention-deficit/hyperactivity disorder symptoms on parenting? *Dev Psychopathol*. 2008;20(1):121–37.

(Received, April 7, 2021)

(Accepted, June 9, 2021)

(J-STAGE Advance Publication, September 14, 2021)

Journal of Nippon Medical School has adopted the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<https://creativecommons.org/licenses/by-nc-nd/4.0/>) for this article. The Medical Association of Nippon Medical School remains the copyright holder of all articles. Anyone may download, reuse, copy, reprint, or distribute articles for non-profit purposes under this license, on condition that the authors of the articles are properly credited.