The Impact of Childhood Disease on Hospital Visiting: A Survey of Pediatricians

Running title: Childhood Disease on Hospital Visiting

Hanako Tajima 1, Juri Ogawa 1, Izuru Nose 2, Ruby Pawankar 3, Miho Maeda 3, Morihisa Takarabe 4, Yutaka Momota 2, and Miki Kakinuma 2

1 Department of Pediatrics, Nippon Medical School Musashi-Kosugi Hospital, 1-396, Kosugi-cho, Nakahara-ku, Kawasaki City, Kanagawa, 211-8533, JAPAN.
2 School of Veterinary Medicine, Nippon Veterinary and Life Science University, 1-7-1, Kyonan-cho, Musashino City, Tokyo, 180-8602, JAPAN.
3 Department of Pediatrics, Nippon Medical School Hospital, 1-1-5, Sendagi, Bunkyo-ku, Tokyo, 113-8603, JAPAN.
4 Department of Child Education, Minami Kyusyu University, 3764-1, Tateno-cho, Miyakonojo City, Miyazaki, 885-0035, JAPAN.

Correspondence: Hanako Tajima,
Department of Pediatrics, Nippon Medical School Musashi-Kosugi Hospital, 1-396, Kosugi-cho, Nakahara-ku, Kawasaki City, Kanagawa, 211-8533, JAPAN.
Tel. +81-44-733-5181; Fax. +81-44-711-8826; E-mail. s7047@nms.ac.jp
Abstract

**Background:** The precise timing as to when caregivers should take their children to the hospital is crucial to ensure the health and safety of children. As 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, disabilities and child behavior can influence when and how often caregivers take their children to the hospital.

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

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

**Conclusions:** Caregivers make decisions on when to visit the hospital based on the child’s expression of pain and their behavior. The creation of guidelines to give appropriate guidance to caregivers as to when to visit the hospital is essential.
Keywords: autism spectrum disorder; attention-deficit hyperactivity disorder; mental retardation; parental support; hospital visit
Introduction

Caregivers are often the sole decision makers when determining if a child needs to have a consultation at a hospital. If children cannot express their physical condition appropriately due to the disease itself or the disability, the visit to the hospital may be delayed or conversely, may be unnecessary. Understanding why some caregivers wait too long before consulting the hospital or make unnecessary visits would guide medical personnel to provide the appropriate advice to caregivers. Since one of the modes of expression of pain is social communication, which is acquired in the process of evolution \(^1\), it is crucial that caregivers should be 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 visit the hospital. In terms of the pediatric visits by the caregivers, it is not easy to determine what the parameters that influence the caregiver’s behavior, the caregiver’s personality or the children’s characteristics. A study conducted on hospital visitation based on the dog breeds demonstrated that the pet owners’ behavior is influenced by dog behavior rather than the personality of the owner. Kakinuma et al. reported that the caregivers of the dog breeds sensitive to pain were more likely to be anxious and aggressive, therefore, visited veterinarians frequently, whereas the caregivers of the dog breeds insensitive to pain tended to delay their visits to the veterinarian \(^2\). They also demonstrated that the caregivers of the dogs causing trouble over visiting veterinarians were more prone to a delayed consultation. The study suggested that caregivers might make their decisions not purely on the basis of the physical condition but rather on the expression of the pain or behavior of the family member \(^2\).
The reasons for caregivers taking children to the hospital too frequently have been hypothesized by many and include parental fear, unreasonable expectations and parents suffering from psychiatric disorders like narcissistic personality disorder \(^3,4\). Based on 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 disability \(^2\). In the present study, we analyzed the impact of disease, the disability and behavior of the child on the caregiver’s likelihood to take their child to the 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 the patients’ reactivity to pain, expression of pain, behavior at the hospital, and the timing of visit. There were 11 questions and were measured using 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 and allergies. The diagnosis of ASD, ADHD and MR were based on DSM-5. The pediatricians were asked to respond to the questions in comparison to normal 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 of each disease was calculated. A one-way analysis of variance (seven diseases) was conducted and 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 the 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 (Part one questions)

The questionnaire was sent to 80 pediatricians and 68 (85%) responded to the survey. The demographic characteristics of participants are as 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 and 85.3% (58) were working in hospitals, while 14.8% were working in private clinics.

Response for each question (Part two questions)

The average response for each question is as 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.

Results to Question 1: The response of children with DS was significantly higher than the other groups (p < .05), whereas ADHD was significantly lower than the other groups (p < .05), ASD was lower than epilepsy and premature birth (p < .05), and MR was lower than epilepsy (p < .05).

Results to Question 2: The response of children with ADHD was significantly lower than the other groups (p < .05), and ASD and MR were lower than DS, epilepsy, premature birth and allergies (p < .05).

Results to Question 3: The response of children with ASD was lower than DS, MR, epilepsy, premature birth and allergies (p < .05), whereas MR was lower than premature birth (p < .05), and allergies, and epilepsy was lower than premature birth (p < .05).
Results to Question 4: The response of children with DS was lower than MR, premature birth and allergies (p < .05), and epilepsy was lower than premature birth (p < .05).

Results to Question 5: The response of children with ASD was higher than DS, MR, epilepsy, premature birth and allergies (p < .05), ADHD was higher than DS, MR, epilepsy, premature birth and allergies (p < .05), and allergies and epilepsy were lower than premature birth (p < .05), whereas that of epilepsy was lower than MR and premature birth (p < .05).

Results to Question 6: The response of children with MR was higher than ADHD and epilepsy (p < .05), and ASD was higher than ADHD (p < .05).

Results to Question 7: The response of children with MR was lower than ASD, ADHD and epilepsy and premature birth (p < .05), whereas that of ADHD was lower than DS and allergies (p < .05).

Results to Question 8: The response of children with DS was significantly lower than the other groups, whereas ADHD was higher than ASD, MR, epilepsy, premature birth and allergies (p < .05).

Results to Question 9: The response of children with ADHD was significantly higher than the other groups, whereas ASD and MR were higher than DS, epilepsy, premature birth and allergies (p < .05).

Results to Question 10: The response of children with ASD was higher than DS, epilepsy, premature birth and allergies, whereas ADHD and MR were higher than DS, epilepsy and premature birth (p < .05).
Results to Question 11: The response of children with DS was lower than ADHD, MR, premature birth and allergies, whereas allergies was higher than ASD, ADHD, epilepsy and premature birth (p < .05).
Discussion

Children with ASD, ADHD and MR were less tolerant to pain and more sensitive while they did not visit the hospital early enough according to the pediatricians (Table 1; Q2 and Q3). Previous reports on the sensory characteristics of children with ASD, ADHD and MR have indicated their hyperesthesia or bluntness. In this study, pediatricians answered that children with ASD, ADHD and MR are hypersensitive rather than being blunt.

According to the answers to the survey, children with ASD, ADHD and MR often could not be quiet in hospitals and they sometimes refuse or rampage during medical examination (Table 1; Q1 and Q9). Furthermore, if the children have difficulty in using public transportation because of developmental problems, it would be a burden for caregivers to visit a hospital by taxi. These issues may impact the likelihood of a caregiver in taking their child to the hospital. Given the difficulties that can arise as a result, this would make the children’s issues more severe. Also, children with ASD or MR have difficulty in verbally expressing their degree of pain. Reeves et al. reported about the increased risk of complicated appendicitis in children with ASD. Adams et al. reported that children with ASD had a significantly increased rate of acute otitis media, otitis media with effusion, otorrhea, and PE tube placement and were more than twice as likely to develop mastoiditis, and undergo mastoidectomy and tympanoplasty. Ferrazzano et al. reported that children with ASD are at a higher risk of severe caries. Children and caregivers would benefit from waiting rooms that are adequately equipped for these children with an automatic calling system allowing them to wait in their cars or other places thereby reducing waiting time, or home health care using home-visiting medical service or telemedicine. Moreover, especially for children with
severe physical and mental disabilities, it would be desirable to have family doctors or nurses do home visits for regular health checks and subsequently decide whether they need to visit the hospital or not under any circumstances. This service is becoming more widely used in some cities in Japan.

Previous studies reported the bluntness in children with ASD or DS, which was not applicable to this study 8,12. Such a lack of their ability to sense or express pain would result in a delay in visiting hospitals. Using the pain scale for children that are not communicative, for example, non-communicating children's pain checklist-revised (NCCPC-R) may be helpful for measuring the pain in these children 13. Furthermore, it would be necessary to investigate further as to how often these cases exist and what is the desirable way for hospitals to effectively handle these cases are.

Conversely, caregivers of children born prematurely or of those with allergies took their children to the hospital even when the symptoms were mild (Table 1; Q3), although the expressions of pain and child behavior were typical (Table 1; Q2, Q5 and Q9). The reason may be that the caregivers are nervous (Table 1; Q4) because of previous difficult experiences with their child’s health, unfamiliar condition and in certain cases the life-threatening condition, for example, child with allergies presenting with symptoms of anaphylaxis, child of premature birth needing intensive care 14,15. Moreover, children born prematurely may have developmental issues different from that of other children, despite appearing healthy in their infancy 16. Therefore, the anxiety of caregivers of premature children may be relatively severe. Coaching the caregivers as to when to visit the hospital, for example, advice by doctor or nurse based on the characteristics of the child, psychological counseling, peer counseling represented by
patients' association, parent-teacher-medical staff conference, may improve the quality of life for both the children and the caregivers.

A significant relationship between children with MR and caregivers was found (Table 1; Q6), while non-specific results were found for children with ADHD (“Agree”, “Neither agree nor disagree” and “Disagree” were equally answered.). Similar results were also observed in (Table 1; Q7) with ASD and ADHD. This may be due 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 to MR, ASD and ADHD.

Caregivers of ADHD children were more likely to be aggressive in the consultation room (Table 1; Q8) and the consultation time tended to be longer (Table 1; Q10 and Q11). We did not ask the pediatricians for more details, but these caregivers may be overprotective due to their fears resulting in exaggerated behaviors. Caregivers of children with diseases or disabilities, especially developmental disabilities may feel stressed due to a lack of societal understanding/acceptability of their child’s condition \(^{17-20}\), or because the caregivers themselves may have several developmental disabilities \(^{21}\). Perhaps it may also be that these caregivers are advocating for their children. Additional research is needed to investigate the reasons behind such aggressive parental behavior.

While this study highlights the impact of disease, the disability and behavior of the child on the caregiver’s likelihood to take their child to the hospital, this study has certain limitations. A general problem with this survey is the small sample size and a bias of the responding pediatricians, by workplace and subspecialty. The severity of the underlying disease or disability is not considered and the types of the issues (common
cold, trauma, other emergency or regular consultation) when they see the pediatricians are not specified in this research. Parental mental illness and developmental traits also need to be considered. Further research with larger sample size and assessing the types and the severity of the children’s issues at the hospital is needed to determine and develop guidelines on the precise timing and necessity of the hospital visit. We are planning survey and interviews of caregivers of patients as well as caregivers of normal healthy children to evaluate the sensitivity, behaviors, caregivers-child relationships and the severity of the diseases on hospital visiting.

**Conclusions**

This study suggests that caregivers make decisions on when to visit the hospital based on the child's expression of pain and their behavior, just as predicted in our hypothesis. Healthcare providers respond to patients with a holistic view, considering their genetics, environment, and characteristics. From these findings, it would be possible to provide information explaining the child's characteristics so that caregivers can make more informed decisions regarding when to visit the hospital.
Acknowledgments

We are grateful to the pediatricians for their participation.

This research was funded by the Program to supporting research activities of female researchers, Japan Science and Technology Agency, Ministry of Education, Culture, Sports, Science and Technology.

Conflicts of Interest

The authors declare no conflict of interest.
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Figure legend

Fig. 1

The average of 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’s syndrome, ASD: Autism spectrum disorder, ADHD: Attention-deficit hyperactivity disorder, MR: Mental retardation, Epi: Epilepsy, Premature: premature birth, Allergy: Allergic diseases.
Table 1. Part two questions.

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 the self-reliant children?
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?
**Table 2. Demographic characteristics of the 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**

| Type                  |       |       |
|-----------------------|-------|-------|
| University hospital   | 38 (55.9%) |       |
| General hospital      | 20 (29.4%) |       |
| Private clinic        | 10 (14.8%) |       |
**Table 3.** Results of one-way analysis of variance (Part two). The answers 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 | The main effect                               |
|-----------------|----------------------------------------------|
| 1               | Significant, F(6,402) = 51.24, η2 = 0.43, p < .001 |
| 2               | Significant, F(6,402) = 35.30, η2 = 0.35, p < .001 |
| 3               | Significant, F(6,402) = 15.92, η2 = 0.19, p < .001 |
| 4               | Significant, F(6,402) = 6.07, η2 = 0.08, p < .001 |
| 5               | Significant, F(6,402) = 15.68, η2 = 0.19, p < .001 |
| 6               | Significant, F(6,402) = 4.28, η2 = 0.06, p < .001 |
| 7               | Significant, F(6,402) = 8.43, η2 = 0.53, p < .001 |
| 8               | Significant, F(6,402) = 24.36, η2 = 0.27, p < .001 |
| 9               | Significant, F(6,402) = 32.31, η2 = 0.33, p < .001 |
| 10              | Significant, F(6,402) = 11.16, η2 = 0.14, p < .001 |
| 11              | Significant, F(6,402) = 8.72, η2 = 0.12, p < .001 |
