The Impact of Childhood Disease on Hospital Visitation Timing; Down Syndrome and Other Chronic Diseases – A survey of pediatricians in JAPAN

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Introduction

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.

We hypothesized that the behavior (represented by hospital visitation timing) or emotion (become nervous or aggressive) of the caregivers are the natural reaction to protect their children, especially when the child has a disease or disability.

In this study, the impact of disease, disability and child behavior on caregiver's likelihood to take their child to the hospital was examined.

Methods

A structured anonymous online survey was sent to pediatricians in Japan in January 2020.

Questionnaire:

- Demographic data of the respondents
- 11 questions about the patients' reactivity in comparison to typically developing, healthy children (shown in the "Responses for Q1~Q11").

  The answers were rated on a 5-point Likert scale ranging from 1(strongly disagree) to 5 (strongly agree).

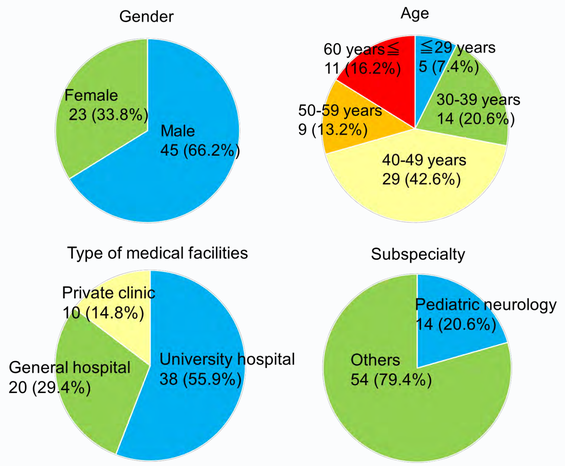
Patients:

School age children with

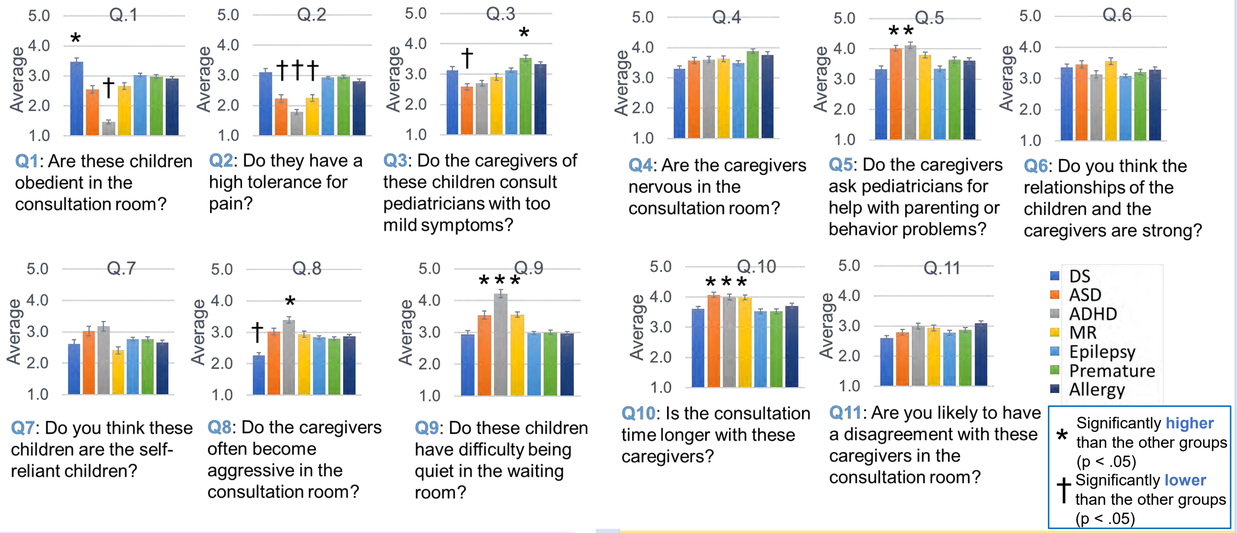
- Down syndrome (DS)
- Autism spectrum disorder (ASD)
- Attention-deficit hyperactivity disorder (ADHD)
- Mental retardation (MR)
- Epilepsy
- Premature birth
- Allergies

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.

Demographic data of the pediatricians (n=68)



Responses for Q1~ Q11



The hospital visitation timing of children with Down syndrome seemed to be appropriate (Q3), and caregivers were less nervous about the hospital visit (Q4). And they did not have serious behavior issues (Q1,5,8, and 9).

Both children and caregivers of Down syndrome did not have serious problem in hospital visit but feel comfortable in general in Japan.

Children with ASD, ADHD and MR were less patient to pain (Q2), but they did not visit the hospital early enough (Q3).

It may be because children with ASD, ADHD and MR are often difficult to be quiet in hospitals (Q1 and Q9) and these children often have difficulty in using public transportation.

Children and caregivers would benefit from waiting rooms that are adequately prepared for these children, an automatic calling system which lets them to wait in the cars or other places, home health care or telemedicine.

Caregivers of the children born prematurely or with allergies took them to the hospital with too mild symptoms (Q3), although the expression of pain and child behavior seemed to be typical (Q2, 5 and 9).

The reason may be that their caregivers are nervous (Q4) because of past experiences with unexpected changes of their child such as anaphylactic shock, and so on.

Coaching for these caregivers on when to visit the hospital may improve the quality of life for both the children and the caregivers.

Summary

Caregivers made decisions on when to visit the hospital based on the child's expression of pain and their behavior, just as predicted in our hypothesis.

The hospital visitation timing of children with Down syndrome was appropriate and the caregivers did not have serious emotional issues in Japan, however, it is important to remember that certain characteristics of children lead to delay in the hospital visit or emotional issues of the caregivers.

The creation of guidelines to assist the caregivers of the children with disease or disability to make the determination of when to visit the hospital are necessary.

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