

ORIGINAL MANUSCRIPT

Effects of maintaining web-based diaries by caregivers on adherence to care regimens in preschoolers with asthma

Shinobu Hashi RN, MSN^{1,2}  | Keiko Tsukasaki RN, PHN, DSN³ | Toshimi Nakamura MD⁴ |
Kaoru Kyota RN, PHN, PhD³ | Tomoya Itatani RN, PHN, PhD³

¹Division of Health Sciences, Graduate School of Medical Sciences, Kanazawa University, Kanazawa, Japan

²School of Nursing, Kanazawa Medical University, Kanazawa, Japan

³Faculty of Health Sciences, Institute of Medical, Pharmaceutical and Health Sciences, Kanazawa University, Kanazawa, Japan

⁴Department of Pediatrics, Kanazawa Medical University, Kanazawa, Japan

Correspondence

Shinobu Hashi, School of Nursing, Pediatric Nursing, Kanazawa Medical University, Daigaku 1, Uchinada, Kahoku-gun, Ishikawa 920-0276, Japan.
Email: hashi-s@kanazawa-med.ac.jp

Funding information

JSPS KAKENHI, Grant/Award Number: JP16K15943. 2016

Abstract

Background: The objective of this pilot study was to assess the effects of maintaining web-based diaries by the caregivers of preschoolers with asthma on the adherence to asthma care regimens, the recognition of asthma symptoms, and their perceived levels of parenting stress, quality of life, and family functioning.

Design and Methods: The caregivers of preschoolers with asthma completed a 4-week web-based diary and received weekly emails that depicted their children's asthma symptoms. We compared asthma symptoms from before and after the intervention. We analyzed demographic data, such as the caregivers' age and education, and assessment scores from the Japanese Pediatric Asthma Control program (JPAC), Adherence with Asthma Management for Caregivers of Preschoolers (AAMCP), General Functioning subscale of the Family Assessment Device (GF-FAD), Parenting Stress Index Short Form (PSI-SF), and Quality of Life assessment scale for Caregivers of Asthmatic Children 24 (QOLCA-24).

Results: A total of 45 participants were included in the analyses. The mean scores depicting asthma control were significantly improved postintervention (pre: 12.29 ± 2.65 ; post: 13.02 ± 2.01 ; $t = -2.15$, $p = .037$). Mean AAMCP scores postintervention (52.13 ± 6.25) were significantly greater than before (49.78 ± 7.20 ; $t = -3.07$; $p = .004$).

Practice Implications: Adherence to asthma care and the recognition of asthma symptoms improved following the use of a web-based diary, making it a potential cost-effective intervention for asthma patients and their families.

KEYWORDS

asthma, caregivers, patient web portal, preschool, therapeutic adherence

1 | WHAT IS CURRENTLY KNOWN?

Many children in Japan require continuous asthma management. Parenting is a key determinant of adherence to asthma care protocols in young children. Yet, caregivers of children with

chronic illnesses often experience psychological vulnerabilities that negatively impact adherence to treatment protocols. Internationally, asthma management using web-based systems has gained popularity as a way to potentially decrease the negative impacts on psychology and physiology. Studies investigating

caregivers use of web-based systems for asthma management in young children in Japan are sparse.

2 | WHAT DOES THIS STUDY ADD?

This study revealed that caregivers who tracked their children's asthma status daily with a web-based diary and who were provided with empathetic clinical communications saw improved adherence to asthma management protocols and improvements in their children's asthma symptomatology. Based on these results, we think that this intervention may be useful to improve caregiver adherence and the lives of young patients with asthma or potentially those with other chronic diseases.

3 | INTRODUCTION

Asthma is the most common noncommunicable disease in children requiring hospitalization or emergency care. The mortality rates and number of hospital admissions due to asthma have decreased since the development of antiallergy medications and inhaled corticosteroid (ICS; Szeffler, 2011). Studies conducted on allergies in childhood by the American Thoracic Society-Division of Lung Diseases (ATS-DLD) and the International Study of Asthma have surveyed the prevalence of childhood asthma in Japan and reported rates of 3.2–6.5% (Arakawa et al., 2017). A recent study further indicated that the prevalence of asthma has started to decline (Arakawa et al., 2017). However, a survey by the Japanese Pediatric Asthma Control program (JPAC) found that the rates of poor asthma control ranged from 32.1% to 47.0%, indicating that many patients are unable to manage their symptoms effectively. Furthermore, reports indicate that 35.3–38.6% of asthma patients still experience moderate to most severe persistent symptoms of asthma. Challenges regarding the continuous management of asthma patients persist (Hashi, 2018; Yoshida, Ido, Sato, Shimazu, & Habukawa, 2012). According to the 2017 Japanese Guidelines for Childhood Asthma Treatment (JPGL), the aims of daily control include complete control of asthma symptoms, preserving normal lung functions, and achieving an improved quality of life (QOL; Arakawa et al., 2017). Outpatient asthma management is therefore critically important. Caregivers of pediatric patients must assume responsibility for regular clinic visits and medication administration at home. These responsibilities are often taxing and stressful.

The World Health Organization (WHO) defines adherence as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (World Health Organization [WHO], 2003). WHO has further indicated that patients should understand their own disease status and participate in clinical decision-making, which should be supported by medical professionals. WHO has proposed a five-factor model for adherence. This model consists of social and economic, healthcare team and

health system, condition-related, therapy- (or treatment-) related, and patient-related factors (WHO, 2003). However, Schwartz and Axelrad (2015) pointed out that this model was developed to characterize the adherence in adults and that it omits a critical dimension of pediatric adherence—parenting. Morawska, Calam, and Fraser (2015) further indicated the value of caregiver support for caregivers of children with chronic illnesses. The major forms of support are as follows: (a) Preparing caregivers to maintain adherence to their child's medical treatment, (b) providing information on the relationship between their child's disease, behavior, and emotional adaptation, and (c) giving support with preventing and managing their child's anxiety and behavioral problems. Furthermore, encounters with empathic healthcare professionals not only increase patient satisfaction, but also improve healthcare outcomes (Brand, Klok, & Kaptein, 2013).

Originally, adherence was an ambiguous aspect of chronic disease control. One American study of inner-city children reported exceptionally high rates (>80%) of self-reported caregiver adherence (Otsuki et al., 2009). Another study reported ICS adherence in an intervention group that was 25.4% higher than that of the controls (Bender et al., 2015). Self-report questionnaires have a number of strengths, as they are inexpensive, comprehensive, and available for multiple informants; however, they tend to overestimate adherence, assess global perceptions rather than the frequency of behaviors, and can be difficult to administer to younger children (Quittner et al., 2008). These findings suggest that overestimation may be a pervasive problem, which may result from biased questionnaires or other factors. In a recent study (Monti & Nealis, 2017), strong correlations were found between indicators of nonadherence and the number of emergency visits and hospitalizations. Therefore, assessing adherence requires a diversified approach.

Psychological factors related to caregiving are critically important for the chronic management of illness in children (Hullmann et al., 2010). Many studies have reported that caregivers of children with chronic illness experience psychological vulnerabilities across multiple domains (Bellin et al., 2015; Hashi, 2018; Yamaguchi et al., 2018). Parenting stress was also revealed to be higher in caregivers of children with asthma than among those of children with other chronic diseases including cancer, type 1 diabetes, and cystic fibrosis (Hullmann et al., 2010). These caregivers experienced a diminished QOL, which was perceived to be associated with higher life stress and asthma caregiving stress, as well as with poorer asthma control (Bellin et al., 2015). Additionally, based on the results of the Family Assessment Device (FAD), the family functioning of mothers of young children with asthma was found to have a ratio over the cut-off score of 41.2%, indicating that they felt the family relationship was unhealthy. With respect to the subcategories of FAD, diminished role and affective involvement in a family's functioning is further associated with increased parenting stress (Hashi, 2018). Thus, the long-term management of chronic illnesses is often a psychological burden for caregivers and negatively impacts their care-taking.

The development of digital devices for healthcare purposes in recent years has been remarkable, and has the potential to facilitate

the management of chronic illnesses by improving adherence (Quittner et al., 2008). Thus, this easy-to-use and convenient technology is expected to improve health outcomes. Randomized clinical trials have further reported modest improvements in asthma control and quality of life, as well as greater treatment adherence, significantly fewer courses of oral steroids, and fewer hospital admissions with electronic monitoring that features daily reminder alarms and text messages (Britto, Rohan, Dodds, & Byczkowski, 2017; Morton et al., 2017).

In Japan, the Ministry of Health, Labor and Welfare (2015) declared its support for the widespread use of a portable information infrastructure by the year 2035, which includes long-term care information. Moreover, health care databases should be developed and utilized to support telemedicine applications, such as remote diagnosis, treatment, and telesurgery. Many international studies have focused on adherence to medications using web system and digital devices (Britto et al., 2017; Morton et al., 2017). However, studies investigating adherence to asthma management for young children with asthma by caregivers are sparse in Japan. Furthermore, few studies have addressed the problems with developing continuous partnerships between health care professionals and patients with asthma and their caregivers (Brand et al., 2013; Morawska et al., 2015; Schwartz & Axelrad, 2015). Thus, the aim of the pilot study was to test whether the use of web-based diaries improved caregivers' recognition of asthma conditions in children. As part of the study, the participants were provided weekly feedback regarding their children's asthma symptoms, and we investigated participants' perceived levels of parenting stress, QOL, and family functioning before and after the use of the web-based asthma diary. We subsequently reviewed whether the intervention improved participants' adherence to pediatric asthma management.

4 | METHODS

We utilized an interventional, before-and-after study design without a control group. The control group was omitted because of the use of a new support method, no-treatment being a burden on the research participants, and a limit to data collection in an outpatient allergy clinic in rural Japan. We calculated the appropriate sample size before collecting any data. An a priori power analysis using G* power was performed using the paired, two-tailed *t* test, an effect size of 0.5 for variables (asthma condition, adherence, family functioning, PSI-SF, and QOL-CA), an alpha value of 0.05, and a power of 0.8. This yielded a sample size of 34. Data collection was conducted between October 2017 and March 2018.

4.1 | Participants

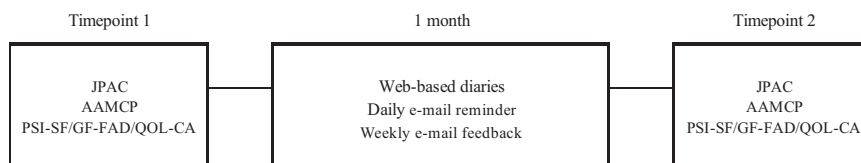
A collaborating pediatric physician at an outpatient pediatric allergy clinic selected eligible caregivers of young children with asthma between one and 6 years of age. All the caregivers grew up in Japan and could read and write in Japanese. Only those caregivers of young children who had been diagnosed with asthma or asthmatic bronchitis that persisted for more than 6 months and required hospitalization and medication were included. In cases of caregivers of multiple children with asthma, a collaborating pediatric physician consulted with the caregiver and selected only one child with asthma (1–6 years of age) for inclusion.

Caregivers were excluded if they cared for children with asthma who had other episodic diseases, such as congenital diseases, or a severe psychological disorder. In addition, caregivers who themselves had a severe psychological illness, such as schizophrenia or depression, used psychotropic medication, experienced difficulties with daily functioning or answering questionnaires, or were deemed psychologically vulnerable or unstable to effectively complete the study were excluded. Finally, a judgment regarding whether or not a particular participant should be included in the present study was made in consultation with a collaborating pediatric physician, who considered all relevant medical history information.

4.2 | Examination and intervention

The procedures used for both pilot testing and full testing are described below. To initially confirm the effectiveness of a diary-based intervention, a pilot test including six participants was performed in accordance with the procedures described above. Participants received an explanation about the examinations and interventions involved in this study upon their recruitment from an outpatient pediatric allergy clinic at a university hospital. Participants were communicated with via e-mail and SMS upon their recruitment. Study outcomes were divided into two timepoints—Timepoint 1, at study outset, and Timepoint 2, at study completion (Figure 1). Participants accessed an internet survey delivered via SurveyMonkey® with their own mobile device (a smartphone) and answered Timepoint 1 questions. After answering all Timepoint 1 questions, participants proceeded to manage the asthma of their young children as usual and entered daily entries into the asthma diary for 1 month. During the study, participants received daily reminder e-mails at 8:30 a.m. Participants were permitted to omit 1 or 2 daily entries throughout the course of the study, but were instructed to write in the diary daily and avoid any lapses. If they unintentionally forgot to write an asthma diary entry, they were instructed to not provide

FIGURE 1 Study design



entries for the forgotten days. Data for any omitted days were considered missing.

Asthma diary entries included the presence or absence of asthma attacks, the type of asthma attacks, the presence or absence of wheezing, the presence or absence of respiratory distress (chest tightness), the presence or absence of any exercise-triggered attacks, activities of daily living, the quality of nighttime sleep, coughing, rhinorrhea presence or absence of sneezing, presence or absence of a stuffy nose, number of times a day the medication was administered (orally or by inhalation) to children (every time, half, or none), temporary use of medication, and any other concerns, which were freely described. Researchers replied weekly to participant feedback by summarizing feedback contents. In this summary, participants' comments were rephrased (repeated and confirmed).

Given that this study was conducted between autumn and winter, seasonally-related health changes, such as the prevalence of influenza, that were related to changes in weather patterns (e.g., snow, atmospheric pressure, etc.) were also described. Researcher feedback never contained educational or instructive comments. Instead, the researcher provided supportive comments on an asthma symptom summary to further encourage caregivers. After 1 month, participants completed the Timepoint 2 questionnaire.

4.3 | Measures (timepoints 1 and 2)

4.3.1 | Demographic data: 23 items (timepoint 1)

Demographic characteristics of both caregivers (age, smoking status, educational background, and employment status) and children with asthma (age, sex, number of siblings, age of asthma diagnosis, history of hospital admissions, allergies other than asthma, family structure, and family income) were obtained.

4.3.2 | Japanese Pediatric Asthma Control Program (JPAC)

Asthma condition was assessed using the JPAC. The Japanese Society of Pediatric Allergy and Clinical Immunology developed JPAC (2011). The JPAC evaluates the level of asthma control (indicated by a score between 1 and 15, with 15 being perfect), asthma severity (five levels: intermittent to most severe persistent), and the degree of clinical control (poor, good, and perfect) (Nishimuta, Kondo, Hamasaki, Morikawa & Nishima, 2011).

4.3.3 | Adherence with Asthma Management for Caregivers of Preschoolers (AAMCP)

Adherence was assessed using the AAMCP. Kyngas (1999) initially developed the Chronic Disease Compliance Instrument, which was modified by Yamada and Ishiguro (2009) for use in Japanese adolescents with asthma. This Japanese version of the Asthma Compliance Index (JACI) was found to be reliable and its validity has been verified (Yamada & Ishiguro, 2009). The JACI has two domains: compliance and factors related to compliance. The compliance

domain has four subscales with a total of 13 items, which comprise 7 items for "self-care behavior," 2 items for "responsibility," 1 item for "intention," and 3 items for "collaboration." Before its development, there was no Japanese scale for measuring asthma treatment adherence for caregivers of young children with asthma.

It is important to note that adherence differs from compliance. Adherence is not a one-sided process, in which a patient strictly follows the recommendations of a medical provider, but it rather relies on the patient's (or caregiver) understanding of the medical staff's indications and instructions. Hashi, Maru, Okawa, Yamada, and Murakami (2012) modified the "compliance" domain of the JACI for targeting caregivers of preschool-aged children. We revised this domain of scale, with permission, for use in measuring levels of adherence in caregivers of young children with asthma. The Cronbach's α (a measure of variability, with a value closer to 1 representing less variability within the group) for this measure was 0.80 in the present study.

4.3.4 | Parenting Stress Index Short Form (PSI-SF)

Parenting stress was assessed using the Japanese version of the PSI-SF (Kanematsu et al., 2013). The original version of the Parenting Stress Index (PSI) was developed by Abidin (Abidin, 2012). This version was then modified by Kanematsu et al. (2013) for a Japanese population and found to have good reliability and validity. The PSI-SF consists of 19 items, including 9 on stress related to the child's characteristics and 10 related to the parents. Parenting stress totals are also calculated. A high PSI score indicates high parenting stress. In a report on stress among caregivers of healthy children aged 1 and half years of age, child and parenting stress were scored at 20.2 ± 4.5 and 22.2 ± 5.6 , respectively, whereas the total parenting stress was scored at 42.4 ± 8.6 (Kanematsu et al., 2013). The Cronbach's α for each of these domains were 0.80, 0.74, and 0.82, respectively. In the present study, we detected Cronbach's α 's of 0.84, 0.83, and 0.88, for each of these three domains, respectively.

4.3.5 | General Functioning Subscale of the Family Assessment Device (GF-FAD)

General family functioning was assessed with the FAD. The FAD consists of 60 items which are categorized into subscales (Epstein, Baldwin, & Bishop, 1983; Ryan, Epstein, Keither, Miller, & Bishop, 2005). We used 12 of these 60 items relevant to evaluate the GF of the enrolled families. The reliability of using a subset of these 60 items to evaluate particular dimensions in studies has been confirmed and used before (Byles, Byrne, Boyle, & Offord, 1988). We obtained permission for scale use from its creator. Family members over the age of 12 years completed a four-point Likert-type questionnaire by rating "how well" statements in the assessment that described their family. Family mental health was considered low if scores were equivalent to or higher than the distinct cut-off value, which was originally 2.0 (Epstein et al., 1983). The internal consistency of the Japanese version of the FAD is nearly equivalent

to the original version (Saeki, Asukai, Miyake, Miguchi, & Yamawaki, 1997; Saeki et al., 1999). The internal GF score consistency in the Japanese version of the FAD was 0.87 (Cronbach's α ; Saeki et al., 1997), whereas it was 0.77 in the present study.

4.3.6 | Quality of Life Assessment Score for Caregivers of Asthmatic Children-24 (QOL-CA)

QOL scores were assessed using the QOLCA-24. The QOLCA-24 was developed for assessing the QOL of caregivers of young children with asthma (Watanabe, Katsunuma, Kondo, Asakawa, & Ohya, 2008). The full possible score for this measure is 96 points, where higher scores indicate an impaired QOL. This scale was originally shown to have a Cronbach's α of 0.94 (Watanabe et al., 2008), which was 0.86 in the present study.

4.4 | Definition of terms

The definition of adherence used in the present study was that first defined by the WHO. The definition of adherence used here was modified slightly to include asthma management, specifically. In this study, we considered "parenting" factors that are important in the adherence management of childhood asthma. Adherence was measured by AAMCP by means of "self-care behavior," "responsibility," "intention," and "collaboration." AAMCP was developed taking into consideration the preschoolers' character and parenting. Adherence was not limited to medication adherence in the present study.

4.5 | Data analysis

We performed both descriptive and inferential analyses in the present study. Inferential analyses involved analyzing the relationships between variables using χ^2 tests and Pearson's correlation coefficients. We conducted paired *t* tests for participants with the asthmatic condition to compare adherence, parenting stress, QOL, and family functioning between Timepoints 1 and 2. Statistical analyses were performed using SPSS 22 J for Mac (IBM, Armonk, NY). $p < .05$ were considered to indicate statistical significance.

5 | RESULTS

Data collection processes are depicted in Figure 2. We recruited 58 participants from the outpatient pediatric allergy clinic at a university hospital. Five (8.6%) refused to participate and 53 (91.4%) consented. Six of these 53 (11.3%) dropped out. Although the six patients who dropped out had no problems during recruitment and did not differ from other participants, they did not provide a response to the diary and the questionnaires at Timepoint 2. Two participants, one with network problems and the other not receiving the reminder messages had missing data at Time 2 and were excluded from the study. Given this, a total of 45 participants (84.9%) were retained for

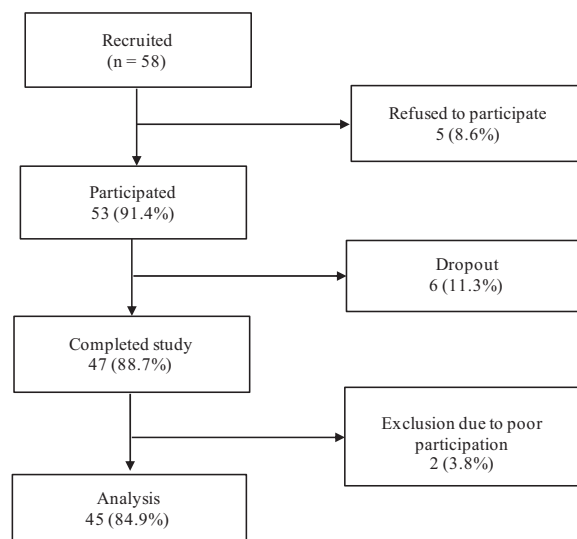


FIGURE 2 Data selection flowchart

analyses. The average rate of daily asthma diary entry completion among the participants was 93.5%.

Participant characteristics are shown in Table 1. A total of 42 participants (93.3%) worked, while 2 (4.4%) were smokers. Some children with asthma included in the present study also had other allergies including 28 (62.2%) with food allergies, 5 (11.1%) with atopic dermatitis, 4 (8.9%) with allergic rhinitis, and 2 (4.4%) with other allergies. Among the young children with asthma, 31 (68.9%) experienced prior hospitalization(s). Their family structures included a nuclear family in 31 cases (68.9%) and an extended family in 14 (31.1%).

5.1 | Medication administration

Twenty-four of the 45 participants (53.3%) gave medicine to their children as prescribed, every time, each day, while 21 participants (46.7%) could not give the medication as prescribed to their children every time (only half was given, or could not give the medication at all).

5.2 | Asthma condition

The patients' asthma severity are shown in Table 1. Asthma control analysis are shown in Table 2. It was also significantly improved following the intervention (pre: 12.29 ± 2.65 ; post: 13.02 ± 2.01 ; $t = -2.15$, $p = .037$, 95% confidence interval [CI] $[-1.42, -0.05]$).

5.3 | Adherence

Participant adherence is shown in Table 2. The average AAMCP score was 49.78 ± 7.20 before the diary intervention. Following the intervention, it increased to 52.13 ± 6.25 . A paired *t* test revealed a significant difference in adherence between the pre- and postintervention timepoints ($t = -3.07$, $p = .004$, 95% CI $[-3.90, -0.81]$).

TABLE 1 Participant demographics ($n = 45$)

Characteristics	n (%)	AVG $\pm$ SD
Caregivers		
Father	3 (6.7)	
Mother	42 (93.3)	
Age (years)		
20–29	4 (8.9)	
30–39	28 (62.2)	
40–49	13 (28.9)	
Educational background		
High school	12 (26.7)	
Diploma school	12 (26.7)	
Associate's degree	11 (24.4)	
Bachelor's/Master's/PhD degree	10 (22.2)	
Employment status		
Homemaker	3 (6.7)	
Part-time job	24 (53.3)	
Full-time job	13 (28.9)	
Other	5 (11.1)	
Children		
Age		3.47 $\pm$ 1.42
Sex		
Boy	29 (64.4)	
Girl	16 (35.6)	
Number of siblings		
0	6 (13.3)	
1	27 (60.0)	
≥ 2	12 (26.7)	
Age at time of asthma diagnosis		1.67 $\pm$ 0.93
Asthma severity		
Intermittent	13 (28.9)	
Mild persistent	13 (28.9)	
Moderate persistent	4 (8.9)	
Severe persistent	13 (28.9)	
Most severe persistent	2 (4.4)	
Family		
Family yearly income (yen)		
1–3 million	3 (6.7)	
3–5 million	17 (37.8)	
5–7 million	15 (33.3)	
7–10 million	8 (17.8)	
Over 10 million	2 (4.4)	

5.4 | Parenting stress

Measurements of parenting stress are shown in Table 2. PSI-SF total scores were 40.73 ± 9.02 before the intervention and 40.62 ± 8.31 afterward. There were no significant differences in any of these

TABLE 2 Paired t test of asthma control, AAMCP, PSI-SF, QOL-CA, and GF-FAD ($n = 45$)

	Time 1 Mean $\pm$ SD	Time 2 Mean $\pm$ SD	t	p
Asthma control	12.29 $\pm$ 2.65	13.02 $\pm$ 2.01	-2.15	.037*
AAMCP	49.78 $\pm$ 7.20	52.13 $\pm$ 6.25	-3.07	.004**
PSI-SF child domain	21.04 $\pm$ 6.05	20.80 $\pm$ 5.65	0.39	.697
PSI-SF parent domain	19.69 $\pm$ 4.61	19.82 $\pm$ 4.55	-0.26	.795
PSI-SF total	40.73 $\pm$ 9.02	40.62 $\pm$ 8.31	0.11	.910
GF-FAD	2.01 $\pm$ 0.32	2.07 $\pm$ 0.35	-1.44	.158
QOL-CA	36.76 $\pm$ 8.01	37.04 $\pm$ 8.44	-0.43	.669

Note: Paired t test.

Abbreviations: AAMCP, Adherence with Asthma Management for Caregivers of Preschoolers; PSI-SF, Parenting Stress Index Short Form; GF-FAD, General Functioning Subscale of the Family Assessment Device; QOL-CA, Quality of Life assessment scale for Caregivers of Asthmatic Children-24.

* $p < .05$.

** $p < .01$.

domains, via t test, between the pre- and postintervention timepoints.

5.5 | GF of family functioning

The GF of Family Functioning is shown in Table 2. The average GF of family functioning exceeded the cutoff value in both the before- and after-intervention data. The mean before the intervention was 2.01 ± 0.32 . The mean after the intervention was 2.07 ± 0.35 . There was no difference according to the results of a paired t test in the GF of family functioning scores between pre- and postintervention timepoints.

5.6 | Quality of life

QOL data are shown on Table 2. The average QOLCA-24 score before the intervention was 36.76 ± 8.01 . After the intervention, it was 37.04 ± 8.44 . There was no statistically significant difference in this value by t test.

5.7 | Participants' impressions of the intervention

Participants were asked for their impressions of the intervention following the conclusion of the study. Some notable responses included the following: "I found out what I should observe by looking at the items in the diary," "I was able to look back on the situation (weekly results were sent)," "It's easier than a paper asthma diary," and "Daily e-mails (reminder mail) were good." Some notable negative comments include: "I'm bothered to enter password every time," and "I'm bothered to enter the date." The six participants that dropped out did not provide any feedback. In addition, the excluded two participants complained about not receiving reminder e-mails

over the duration of the study. We could not judge if network trouble existed or not.

6 | DISCUSSION

The participants' asthma control showed improvement between the two-time points, Timepoint 1 and Timepoint 2. Adherence to asthma management procedures improved with the use of a web-based diary in the present study. This may have been attributed to the fact that the children included in the study received allergy outpatient management at a university hospital due to the severity of their asthma. Family functioning, as recognized by caregivers, was also poor; however, the parenting stress and QOL scores were not poor during either timepoint. Thus, while the intervention improved some domains, it did not universally improve them all.

6.1 | Adherence improvements

Improvements in AAMCP scores indicated increased adherence to asthma management strategies. We added parenting factors to the five factors already outlined by the WHO (2003) and hypothesized that improvements in these parenting factors (caregiver stress, QOL, and family functioning) would also benefit asthma management in the present study. The asthma diary entry rate was exceptionally high (93.5% on average) in the present study. We also found that daily medication administration rates were relatively high relative to those of other reports (Bender et al., 2015; Otsuki et al., 2009), with 25 caregivers (55.6%) reporting total medication compliance and 20 (44.4%) describing being unable to achieve full compliance with medication regimens. It is important to note here; however, that a social desirability bias may have driven some participants to answer more favorably when asked about medication compliance or to complete diary entries. Given this bias, it is possible that we have greatly underestimated the actual proportions of noncompliant children in our sample. In addition to receiving continuous email reminders, participants received supportive comments and weekly asthma symptom summaries. We did not provide any criticism or guidance, however. These measures, when employed collectively, seem to have led to improvements in adherence in a population of pediatric asthma patients and their caregivers.

Comments provided by participants on their impressions of the asthma diary and related feedback further support this conclusion that daily reinforcement via a diary improved adherence. Participants frequently commented on how the diary helped them identify symptoms. However, some areas that were mentioned need improvement, including entering of dates and the password.

Asthma diaries and weekly feedback improved participants' adherence to asthma medication regimes and recognition of important symptoms. Thus, it led to improvements in asthma management adherence in this study population.

6.2 | Improvements in asthma condition with diary use

Asthma conditions were improved by the diary intervention used in the present study, as it has been reported in the past (Britto et al., 2017; Morton et al., 2017). Our results indicate a reciprocal relationship between improved support for asthma management using a web-based caregiver platform and improved disease control. Namely, this intervention effectively improved adherence to asthma management and improved asthma symptoms in children.

However, there are some limitations in the interpretation of the effects reported here regarding the use of a web-based asthma diary to improve asthma symptoms. Factors beyond a high rate of diary entry use may underlie these symptom improvements. For instance, young children may have been reminded more consistently by their caregivers to take their medications during the study period than they would have been otherwise. The diary work may also have led caregivers to notice their child's symptoms earlier and address them more appropriately. Collectively, the results of the present study demonstrate that behavioral intervention, without criticism, effectively modify health-related practices. Furthermore, not all caregivers can participate in this type of intervention due to literacy or technological limitations, and cases of asthma can vary in severity.

6.3 | Poor family functioning

A critical limitation of the present study, which might have driven the lack of change in family functioning with our intervention, was related to the study participants. Participants in the present study were caregivers of children being treated for asthma at an outpatient pediatric allergic clinic at a university hospital. As such, these children's asthma may have been more severe than that of children who were treated at local clinics. As the burden of caring for a young child with asthma is significant, and even more so when the asthma is severe, family functioning may have been poorer in our sample than in other less critical populations. In fact, out of the six participants who did not finish the study, two participants had network errors. In this regard, having access to a network and keeping up with the diary can be a burden. Therefore, the intervention used in this study could potentially negatively impact family functioning.

While it offers some important findings to the field, the present study also has several critical limitations worthy of discussion. First, most caregiver participants were in their thirties and all participants had access to digital devices, such as a smartphone. This may have led to a selection bias. Second, given that the intervention period was only 1 month, the present study was not long-term. As asthma is associated with seasonal changes, a more long-term intervention might capture seasonal changes in asthma symptomatology covaried with the use of a web-based intervention. Third, we collected all the data for the present study at a single facility. Thus, this may have been influenced by the Hawthorne Effect, which is a type of reactivity in which individuals modify an aspect of their behavior in response to their awareness of being observed. Fourth, we did not

include a control group. It was possible to analyze the significance and the effect using *t* test, but the participants were caregivers of young children with asthma; additionally, there was a limitation in collecting data from the allergy outpatient clinic at the university hospital located in the rural area of Japan. Data collection from other facilities is needed.

We found a significant improvement in asthma control before and after the study that could be attributed to our intervention, but could also be due to the natural fluctuations of pediatric asthma. In addition, since our study did not have a control group, it was not possible to properly assess for the effect of no intervention. Based on the results, with some improvements, our intervention has the potential to improve caregiver adherence and the lives of young patients with asthma, or possibly other chronic diseases. Future controlled studies should use a more multifaceted, multivariable approach to understand the improvements in caregiver and patient outcomes with the use of a web-based diary intervention.

ACKNOWLEDGMENTS

We wish to express our gratitude to all participating families and institutions for their cooperation with this study. This study was supported by a Grant-in-Aid for Challenging Exploratory Research by JSPS KAKENHI (Grant Number JP16K15943, 2016).

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

S. H. and K. T. designed the study. S. H. and T. N. collected the data. S. H. performed statistical analyses. K. T., K. K., and T. I. made statistical suggestions and confirmed the analyses. S. H. and K. T. wrote the manuscript. K. T. supervised the study. All the authors read and approved the final manuscript.

ETHICS STATEMENT

The present study was approved by the institutional review board of the first author's institution (Approval No. 785-1) and by the university hospital where all the research was conducted (Approval No. I219). After the participants were recruited, they were informed of the purpose of the study and all related methods and ethical considerations. Additionally, participants were told that future medical treatments would not be affected by their participation or refusal to participate. Participants were informed that their participation was voluntary and that they could refuse to participate or withdraw from the study at any time. All participants provided informed written consent before the study commencing. Due to the extended duration of this study, researchers paid particular attention to the

participants' psychological fitness. Those who were deemed to be psychologically vulnerable or unstable (as determined by the researcher and a collaborating pediatrician) were excluded. Additionally, due to some security risk inherent to the internet-based nature of the diary intervention, participants were told to exclude all personal information from diary entries, including names and birthdates. Online diary access was granted via an allocated ID and password.

ORCID

Shinobu Hashi  <http://orcid.org/0000-0003-2800-0750>

REFERENCES

- Abidin, R. R. (2012). *Parenting stress index* (4th ed.). Lutz, FL: PAR.
- Arakawa, H., Hamasaki, Y., Kohno, Y., Ebisawa, M., Kondo, N., Nishima, S., ... Morikawa, A. (2017). Japanese guidelines for childhood asthma. *Allergy International*, 66(2), 190–204. <https://doi.org/10.1016/j.alit.2016.11.003>
- Bellin, M. H., Osteen, P., Kub, J., Bollinger, M. E., Tsoukleris, M., Chaikind, L., & Butz, A. M. (2015). Stress and quality of life in urban caregivers of children with poorly controlled asthma: A longitudinal analysis. *Journal of Pediatric Health Care*, 29(6), 536–546. <https://doi.org/10.1016/j.pedhc.2015.04.018>
- Bender, B. G., Cvietusa, P. J., Goodrich, G. K., Lowe, R., Nuanes, H. A., Rand, C., ... Magid, D. J. (2015). Pragmatic trial of health care technologies to improve adherence to pediatric asthma treatment: A randomized clinical trial. *JAMA Pediatrics*, 169(4), 317–323. <https://doi.org/10.1001/jamapediatrics.2014.3280>
- Brand, P. L. P., Klok, T., & Kaptein, A. A. (2013). Using communication skills to improve adherence in children with chronic disease: The adherence equation. *Paediatric Respiratory Reviews*, 14(4), 219–223. <https://doi.org/10.1016/j.prrv.2013.01.003>
- Britto, M. T., Rohan, J. M., Dodds, C. M., & Byczkowski, T. L. (2017). A randomized trial of user-controlled text messaging to improve asthma outcomes: A pilot study. *Clinical Pediatrics*, 56(14), 1336–1344. <https://doi.org/10.1177/000922816684857>
- Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario child health study: Reliability and validity of the general functioning subscale of the McMaster family assessment device. *Family Process*, 27(1), 97–104.
- Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital Family Therapy*, 9, 171–180. <https://doi.org/10.1111/j.1752-0606.1983.tb01497.x>
- Hashi, S. (2018). Zensoku no youji wo sodateru hahao ga ninshikisuru ikujisutoresu to kazokukinou no kannren [Relationship between parenting stress and family functioning recognized by mothers of young children with asthma]. *Japanese Pediatric Allergy Clinical Immunology*, 32, 241–248. <https://doi.org/10.3388/jspaci.32.241>
- Hashi, S., Maru, M., Okawa, H., Yamada, T., & Murakami, I. (2012). Developing asthma compliance index for mothers of preschoolers with asthma: Testing content validity. *The Proceedings of the 9th International Conference of the Global Network of WHO Collaborating Centres for Nursing and Midwifery*. (p. 84). Kobe, Japan.
- Hullmann, S. E., Wolfe-Christensen, C., Ryan, J. L., Fedele, D. A., Rambo, P. L., Chaney, J. M., & Mullins, L. L. (2010). Parental overprotection, perceived child vulnerability, and parenting stress: A cross-illness comparison. *Journal of Clinical Psychology in Medical Settings*, 17, 357–365. <https://doi.org/10.1007/s10880-010-9213-4>

- Japanese Society of Pediatric Allergy and Clinical Immunology (2011). Japanese Pediatric Asthma Control Program (JPAC) usage manual. Japan: Japanese Society of Pediatric Allergy and Clinical Immunology. Retrieved from <http://www.jspaci.jp/modules/membership/index.php?page=article&storyid=55>
- Japanese the Ministry of Health, Labour and Welfare. (2015). The Japan Vision: Health Care 2035 Executive Summary. Japan: Japanese Health Care and Welfare Ministry. Retrieved from https://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/shakaihoshou/hokeniryoku2035/assets/file/healthcare2035_proposal_150703_summary_en.pdf
- Kanematsu, Y., Araki, A., Narama, M., Shirahata, N., Maru, M., & Arayashiki (2013). *PSI Ikuji stress index tebiki kaiteibann [Parenting stress index manual revised version]*. Tokyo, Japan: Koyomonndaikennkyukai.
- Kyngas, H. A. (1999). Compliance of adolescents with asthma. *Nursing and Health Sciences*, 1, 195–202.
- Monti, M. D., & Nealis, R. M. (2017). Indicators of non-adherence to asthma treatment in pediatric primary care. *Journal of Pediatric Nursing*, 36, 7–12. <https://doi.org/10.1016/j.pedn.2017.04.011>
- Morawska, A., Calam, R., & Fraser, J. (2015). Parenting interventions for childhood chronic illness: A review and recommendations for intervention design and delivery. *Journal of Child Health Care*, 19, 5–17. <https://doi.org/10.1177/1367493513496664>
- Morton, R. W., Elphick, H. E., Rigby, A. S., Daw, W. J., King, D. A., Smith, L. J., & Everard, M. L. (2017). STAAR: A randomized controlled trial of electronic adherence monitoring with reminder alarms and feedback to improve clinical outcomes for children with asthma. *Thorax*, 72(4), 347–354. <https://doi.org/10.1136/thoraxjnl-2015-208171>
- Nishimuta, T., Kondo, N., Hamasaki, Y., Morikawa, A., & Nishima, S. (2011). Japanese guideline for childhood asthma. *Allergology International*, 60(2), 147–169. <https://doi.org/10.2332/allergolint.11-RAI-0328>
- Otsuki, M., Eakin, M. N., Rand, C. S., Butz, A. M., Hsu, V. D., Zuckerman, I. H., ... Riekert, K. A. (2009). Adherence feedback to improve asthma outcomes among inner-city children: A randomized trial. *Pediatrics*, 124, 1513–1521. <https://doi.org/10.1542/peds.2008-2961>
- Quittner, A. L., Avani, C., Modi, A. C., Lemanek, K. L., Ievers-Landis, C. E., Michael, A., & Rapoff, M. A. (2008). Evidence-based assessment of adherence to medical treatments in pediatric psychology. *Journal of Pediatric Psychology*, 33(9), 916–936. <https://doi.org/10.1093/jpepsy/jsm064>
- Ryan, E. C., Epstein, B. N., Keither, I. G., Miller, I. W., & Bishop, D. S. (2005). *Evaluating and treating families: The McMaster approach* (1st ed.). New York, NY: Routledge.
- Saeki, T., Asukai, N., Miyake, Y., Miguchi, M., & Yamawaki, S. (1997). Family Assessment Device (FAD) nihonngobann no shinnraisei to datousei [Reliability and validity of the Japanese version of the Family Assessment Device (FAD)]. *Archives of Psychiatric Diagnostics and Clinical Evaluation*, 8(2), 181–192.
- Saeki, T., Yokoyama, T., Saeki, M., Asukai, N., Miyake, Y., & Yamawaki, S. (1999). Family Assessment Device (FAD) nihonngobann niokeru kaitohannou [Response bias on the Japanese version of the family assessment device (FAD): Low correlation with social desirability and score disagreement between family members]. *Archives of Psychiatric Diagnostics and Clinical Evaluation*, 10(1), 75–82.
- Schwartz, D. D., & Axelrad, M. E. (2015). *Healthcare partnerships for pediatric adherence: Promoting collaborative management for pediatric chronic illness* (1st ed.). New York, Dordrecht, London: Springer Cham Heidelberg.
- Szeffler, S. J. (2011). Advancing asthma care: The glass is only half full! *Journal of Allergy Clinical Immunology*, 128, 485–494. <https://doi.org/10.1016/j.jaci.2011.07.010>
- Watanabe, H., Katsunuma, T., Kondo, N., Asakawa, A., & Ohya, Y. (2008). Shounikikannshizennsokuyouikusya QOL (QOLCA-24) no kaiatsu [Development of quality of life assessment scale for caregivers of asthmatic children (QOLCA-24)] *Allergy*, 57(12), 1302–1316.
- World Health Organization (2003). *Adherence to long-term therapies evidence for action*. Geneva: World Health Organization. Retrieved from http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1
- Yamada, T., & Ishiguro, A. (2009). Assessment of reliability and validity of a Japanese version of the asthma compliance instrument. *Medicine and Biology*, 153(5), 143–151.
- Yamaguchi, C., Ebara, T., Hosokawa, R., Futamura, M., Ohya, Y., & Asano, M. (2018). Factors determining parenting stress in mothers of children with atopic dermatitis. *Allergology International*, 68, S1323–S8930. <https://doi.org/10.1016/j.alit.2018.08.006>
- Yoshida, N., Ido, S., Sato, Y., Shimazu, S., & Habukawa, C. (2012). Wakayamakenn ni okeru JPAC wo mochiita shounikikannshizennso-kujittaichousa-2003 nenn nojittaichousakekka to hikakushite. [A Survey of Pediatric Asthma patients using the Japanese Pediatric Asthma Control Program (JPAC) in Wakayama prefecture—Comparing with the survey in 2003]. *Shounikarinnsyo*, 65, 467–474.

How to cite this article: Hashi S, Tsukasaki K, Nakamura T, Kyota K, Itatani T. Effects of maintaining web-based diaries by caregivers on adherence to care regimens in preschoolers with asthma. *J Spec Pediatr Nurs*. 2019;e12263. <https://doi.org/10.1111/jspn.12263>