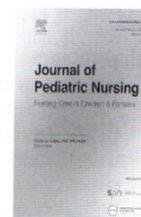




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Parental readiness for the transition to adulthood of children with a chronic disease



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ABSTRACT

Purpose: To investigate parental readiness for their child's transition to adulthood among pediatric patients with chronic disease in Japan.

Design and methods: In this cross-sectional study, parents of children with chronic diseases attending a pediatric outpatient hospital completed an anonymous self-administered questionnaire to investigate demographics and parental readiness for children's transition to adulthood. Logistic regression analysis was conducted to determine whether parents' readiness differed according to their children's disease types.

Results: A total of 179 parents responded to the survey. Of these, 60% confirmed awareness and knowledge of their children's disease and treatment with their children. They also thought and accepted that there would be a time when their children would move from pediatrics to an adult department. More than half of parents had discussions with their children about the children's interests and would discuss with each other if their children's choice differed from the parents' opinion. <20% of parents had gathered information about the transition and made sure their children saw the outpatient clinic alone or encouraged them to write a record of their visits. The readiness of parents of children with diabetes and of children with cardiovascular disease was higher than those of children with cancer and blood diseases on several items.

Conclusions: Parental readiness to support their children's transitions did not progress well, suggesting the need for relevant interventions.

Practice implications: Children and parents should be supported in acquiring information about the transition to adulthood and in implementing child-oriented outpatient visits.

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Introduction

With the development of medical care, many pediatric patients with chronic diseases are now able to enter adulthood, and a smooth transition to adult care from pediatric care is essential (Acharya et al., 2017; American Academy of Pediatrics, 2018; National Center for Health Statistics, 2021). However, many pediatric patients in Japan continue seeing pediatricians into adulthood, with only a few transitioning to adult health services (Ishizaki et al., 2016). One reason is the lack of an adult healthcare system that accepts pediatric patients with chronic conditions. Nevertheless, even with such a system in place, the transition to an adult healthcare system is often difficult (Fegran et al., 2014;

Stinson et al., 2014) because children and their parents want to continue using the pediatric healthcare system to which they are accustomed (Bemrich-Stolz et al., 2015). If children and parents who are not ready or willing to transition to adult health services make the transfer, they may not be able to adapt to and continue attending the adult healthcare system, and in some cases, their physical conditions may worsen.

Therefore, pediatric patients in early adolescence are recommended to have transitional support (Aldiss et al., 2015; Kao et al., 2021; Stinson et al., 2014) to transition to adulthood successfully. Transitional support enables pediatric patients to develop skills and autonomy to manage their illness proactively and communicate with healthcare providers before transitioning to adult care (Asp et al., 2015; Ishizaki, 2011). Increasing readiness for transition among pediatric patients is essential in providing optimal care for children as they continue to grow and

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develop, whether they transition into the adult sector or not (Schmidt et al., 2020; Stehouwer et al., 2017).

Although age and growth facilitate children's readiness to transition (Zhang et al., 2014), children with chronic illnesses have less broad social experience and autonomy than healthy children and receive more overprotective care from their parents (Higashino et al., 2006; Maurice-Stam et al., 2019). In particular, parental involvement may make achieving children's transition readiness more difficult. Some parents do not recognize their children's autonomy in self-care (e.g., taking medications and applying bandages) and instead care for them (Doyle & Werner-Lin, 2015). Previous studies have reported that in addition to care coordination and early planning by healthcare providers for children's transition to adulthood, appropriate parental support for children with chronic illnesses can lead to increased autonomy regarding children's illnesses and preparation for a successful transition to adulthood (Colver et al., 2018; Holmbeck et al., 2002; Pai & Schwartz, 2011; Schmidt et al., 2020). Parents' ability to provide such appropriate support to their children is known as parental readiness for the child's transition, and it is essential to ensure that children are supported in this transition (Gray et al., 2015; Varty et al., 2020). However, few studies in Japan have focused on parental readiness for children's transition to adulthood.

Hence, the present study aimed to investigate parental readiness for their child's transition to adulthood among pediatric patients in Japan.

Design and methods

Design

We conducted a cross-sectional survey using self-administered questionnaires.

Participants

We recruited parents of children with chronic diseases from two hospitals. We enrolled parents whose children 1) were adolescents, that is, 10 to 19 years of age, 2) had one of the following chronic pediatric diseases: diabetes, cardiovascular disease, allergies, or blood cancer, and 3) visited a pediatric outpatient clinic of a university hospital or a children's hospital in Japan. We excluded parents who have difficulty reading and writing Japanese or are unable to complete the questionnaire on their own and whose children have terminal illnesses or developmental delays. Transitional support is needed from adolescence and is generally recommended to begin around 13 years of age (Aldiss et al., 2015; Kao et al., 2021; Stinson et al., 2014). In addition, some recent reports support for independence should be provided much earlier. Some Japanese children's hospitals have begun to provide transitional support for children 10 years and older as part of their pre-transition preparation. Hence, we set the age for this study at 10 years and older. In addition, children's readiness differed depending on the type of children's disease (Campbell et al., 2016; Watson et al., 2011), suggesting that the type of illness a child has is also related to parental readiness. Hence, to examine the differences by disease, we selected four diseases requiring transitional support and with a high number of patients in the hospitals.

Data collection

Data were collected from September 2020 to September 2021 using an anonymous self-administered questionnaire. We distributed a questionnaire to eligible parents and asked them to answer the questionnaire while waiting for their outpatient examination. After completing the questionnaire, participants were asked to place it in a collection box installed in the outpatient department. If they could not answer the questionnaire at the hospital, they were asked to complete it at home and post it back to us within two weeks. The questionnaire

included items on background characteristics and parental readiness for their child's transition to adulthood.

Background characteristics

We collected data regarding participants' sex and their children's age, sex, and type and duration of disease. Considering that parental health literacy could be related to readiness for children's adult transition (Lazaroff et al., 2019; Nutbeam, 1999), we collected data on parents' health literacy by using the 14-item Health Literacy Scale (HLS-14) (Suka et al., 2013). The scale is reliable and has been validated for Japanese adults. The HL14 contains three subscales: functional (5 items), communicative (5 items), and critical (4 items) health literacy. Functional HL includes items about the basic skill to read instructions or leaflets from hospitals or pharmacies. Communicative HL includes items about the skill to obtain information about the disease and treatment and ability to use the obtained information in everyday situations. Critical HL includes items regarding the skill to think critically about disease and treatment information. Each item is answered on a scale from 1 to 5, with higher scores indicating higher health literacy (Suka et al., 2013).

Parental readiness for their child's transition to adulthood

We used 16 items that covered five concepts in the present study: 1) understanding medical or health information needs and health education (4 items), 2) fostering self-care abilities and autonomous medical treatment behavior (4 items), 3) improving children's motivation and abilities (2 items), 4) communication with medical professionals and decision-making ability (5 items), and 5) recognition of the transition of children from minors to adults (1 item). The items were based on the Child-to-Adult Transitions of Care Checklist in the *Transitions of Care Guidebook for Adolescent Nurses* (Ishizaki & Maru, 2012) and were reviewed by a pediatric outpatient nurse, a pediatric nursing researcher, and a pediatric specialist physician to ensure content validity. This confirmed that the items necessary to ascertain the child's readiness for transition were included and adequately represented. Each item comprised a dichotomous scale that indicated whether respondents implemented what the item said.

Before the survey, we asked four mothers with children aged 10 to 17 years to complete a questionnaire to check whether there were any questions they did not understand or that were difficult to answer.

Ethical considerations

This study was approved by the ethics review committee of each hospital that collaborated with this study. We gave participants a written explanation of the study. The "I agree" check on the questionnaire was considered as consent to participate.

Analysis

The data were analyzed using IBM SPSS Statistics version 27.0. We used Fisher's exact test to compare parental readiness among the different diagnoses of children's chronic illnesses. We used logistic regression models to adjust for the effect of potential confounders. Each item of parental readiness with a statistically significant result in Fisher's exact test was used as a response variable. The disease of the child was used as an explanatory variable, with three dummy variables with cancer and blood illness as a reference. The total score obtained on the HLS-14 and the age of the child were used as potential confounders. The statistically significant level was set to 0.05%.

Results

We enrolled 200 parents, and 179 completed the survey. The background characteristics of the participants are shown in Table 1. Of the patients, 14.5% ($n = 26$) had diabetes, 46.4% ($n = 83$) had cancer/

develop, whether they transition into the adult sector or not (Schmidt et al., 2020; Stehouwer et al., 2017).

Although age and growth facilitate children's readiness to transition (Zhang et al., 2014), children with chronic illnesses have less broad social experience and autonomy than healthy children and receive more overprotective care from their parents (Higashino et al., 2006; Maurice-Stam et al., 2019). In particular, parental involvement may make achieving children's transition readiness more difficult. Some parents do not recognize their children's autonomy in self-care (e.g., taking medications and applying bandages) and instead care for them (Doyle & Werner-Lin, 2015). Previous studies have reported that in addition to care coordination and early planning by healthcare providers for children's transition to adulthood, appropriate parental support for children with chronic illnesses can lead to increased autonomy regarding children's illnesses and preparation for a successful transition to adulthood (Colver et al., 2018; Holmbeck et al., 2002; Pai & Schwartz, 2011; Schmidt et al., 2020). Parents' ability to provide such appropriate support to their children is known as parental readiness for the child's transition, and it is essential to ensure that children are supported in this transition (Gray et al., 2015; Varty et al., 2020). However, few studies in Japan have focused on parental readiness for children's transition to adulthood.

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Table 3
Results of multiple logistic regression of the readiness.

	Q2		Q3		Q5		Q7		Q10	
	n = 179		n = 179		n = 179		n = 179		n = 179	
	OR	95%CI								
Disease of the Child										
Diabetes	13.16*	[4.48, 38.68]	6.67*	[1.41, 97.21]	8.83*	[3.09, 25.24]	5.09	[0.69, 37.66]	16.4	[4.47, 60.20]
Cardiovascular	0.78	[0.28, 2.16]	3.70*	[1.13, 12.04]	3.37*	[1.50, 7.57]	4.42*	[1.04, 18.83]	4.34*	[1.22, 15.51]
Allergies	2.59	[0.86, 7.80]	0.69	[0.74, 6.40]	1.20	[0.39, 3.62]	0.00	[0.00, —]	5.61	[0.53, 13.00]
Cancer and Blood	Ref	/								
Health Literacy	0.99	[0.93, 1.05]	0.94	[0.86, 1.02]	0.95	[0.90, 1.01]	1.04	[0.94, 1.14]	1	[0.94, 1.18]
Age of the Child	1.16*	[1.01, 1.33]	1.04	[0.87, 1.23]	1.28*	[0.90, 1.00]	1.47*	[1.14, 1.90]	0.99*	[0.83, 1.17]
Hosmer Lemeshow's test	0.887		0.828		0.391		0.740		0.944	
Nagelkerke's R square	0.232		0.149		0.271		0.291		0.215	

* $p < 0.05$; Ref = Reference.

over medication management and care," Q7, "I make sure my child is seen alone, and the results are reported," Q10, "I introduce my child to peer support groups and family groups regarding diseases and confirm my child's desires to participate."

In the multiple logistic regression model, the type of disease a child had, had a statistically significant effect on five items (Table 3). Parents of children with diabetes were more likely to agree with the three items: Q2, which had an odds ratio (OR) of 3.63 (95% CI 4.48–38.68), Q3 with an OR of 6.67 (95% CI 1.41–97.21), and Q5 with an OR of 8.83 (95% CI 3.09–25.24). Parents of children with cardiovascular diseases were significantly more likely to agree to the four items: Q3, which had an OR of 3.70 (95% CI 1.13–12.04), Q5 with an OR of 3.37 (95% CI 1.50–7.57), Q7 with an OR of 4.42 (95% CI 1.04–18.83), and Q10 with an OR of 4.34 (95% CI 1.22–15.51). Parental health literacy and children's age had no statistically significant effects on parental preparedness.

Discussion

We surveyed parental readiness for their child's transition to adulthood among parents of pediatric patients in Japan. Many parents confirmed their children's understanding of the illness, had discussions with their children about their intention in daily life and accepted that their children would move into adult care. However, parental readiness for their children's transition was generally low. In particular, many parents could not gather information about transition (Q3, Q4) and were not sufficiently involved in fostering their children's self-care abilities and autonomous medical treatment behavior (Q7, Q8). We also found differences in readiness by type of illness in five items. The following discussion about support measures for parental readiness includes differences in parental readiness by disease type.

Support for understanding medical or health information needs and health education

The agreement rates for Q3 and Q4 were low (Table 2), indicating that parents may not have gathered sufficient information about their children's adulthood. Considering that where children receive medical care should not be decided by medical professionals but by children and their parents, it is important that both children and parents be involved. The acceptance of children's transition by both children and parents leads to a smooth transition to adulthood (De Hosson et al., 2021); therefore, it is desirable for children and parents to acquire sufficient information and make shared decisions on children's transition to adulthood with medical staff (Barry & Edgman-Levitan, 2012; Elwyn et al., 2012; Steffensen, 2019). In addition, as chronically ill children and their parents tend to rely on the pediatric care they have received for many years (Cole et al., 2015), if they do not have sufficient information, decision-making regarding the transition to adulthood may be more medically centered. As a foundation for children's transition to

adulthood, healthcare providers should help children and their parents or guardians obtain step-by-step information on children's transition to adulthood.

In addition to decision-making issues, the medical subsidy system in Japan changes significantly between childhood and adulthood (Ochiai et al., 2017; Yamamura, 2017). Therefore, even if children are not transferred to an adult care department, for children to deal with their illnesses autonomously, it is essential to support and help them gather the necessary information after they transition to adulthood.

Support for fostering self-care ability and autonomous medical treatment behavior

Items with low agreement rate, ranging from single digits to 20%, were related to autonomous outpatient consultation behavior, such as items Q6, Q7, and Q8.

One possible reason for the low rate of endorsement is that parents of chronically ill children are often overprotective of their children (Berkelbach van der Sprenkel et al., 2021; Higashino et al., 2006; Maurice-Stam et al., 2019; Sattoe & Staa, 2021) and are likely to feel great anxiety about not being able to monitor their child's hospital visits. But allowing a child to visit a medical facility alone provides an opportunity for the child to talk to a medical professional about issues that they may not be able to talk about in front of their parents. It is also an opportunity for the child to make the transition to adulthood themselves (Gray et al., 2015). Therefore, support must be provided so that children can go to their outpatient consultations alone.

The second reason is that these items may require more involvement from healthcare providers, such as setting up a support system to allow the child to visit a medical facility alone. Few medical professionals provide transitional support, suggesting the need to educate these professionals to support children and parents appropriately.

Differences in readiness by type of disease

Similar to previous studies on children's readiness (Campbell et al., 2016; Watson et al., 2011), we found differences by disease type in several items. The readiness of parents of children with diabetes and cardiovascular disease was higher than those of parents of children with cancer and blood diseases on several items. One reason may be the disease status. For example, type I diabetes requires lifelong medication, and parents are likely to be more interested in subsidizing medical expenses when their children become adults (Q3) (Sheehan et al., 2015). Furthermore, as the daily recording of blood glucose levels is essential, parents likely support their children in recording their conditions (Q4). As for cardiovascular diseases, many children have congenital heart disease and have experienced frequent doctor visits and hospitalization from a young age (Heery et al., 2015). We can infer that they are more involved with medical personnel and are

more likely to visit the doctor alone (Q7) and receive medication (Q8) about visiting behavior.

Conversely, children with cancer, blood diseases, and allergic diseases require daily medication and behavioral restrictions less frequently. As the need for medication management is an extraordinary situation, parents may often manage it for their children. During the follow-up period, outpatient visits are less frequent, and there are fewer opportunities to engage with healthcare providers, which may lead parents to become overprotective (Doyle & Werner-Lin, 2015; Maurice-Stam et al., 2019). However, even when routine management is not necessary, it is essential to be able to cope when needed, and autonomy should be encouraged (Syed et al., 2016). There is a readiness that is difficult for parents to feel the need and obtain depending on the type of illness, but all are necessary to provide comprehensive care for children (Bashore & Hobbie, 2021). Our findings suggest that support methods tailored to the characteristics of the disease are necessary to improve readiness, in addition to common support for chronically disease children (Bomba et al., 2017). Although previous studies on children's transitions have focused on diabetes and cardiovascular disease (Ochiai et al., 2017; Pai & Schwartz, 2011; Schmidt et al., 2020), the opportunities for children with all chronic diseases and their parents should be expanded to receive transitional support.

Practice implications

Parents need support to proactively acquire information about their children's transition to adulthood and work together with medical professionals to examine how they relate to their children so that their children can proactively engage in outpatient behavior. For example, introducing peer parents who have completed the transition to adulthood (Gray et al., 2015) or information on how treatment will continue in adulthood (De Hosson et al., 2021) may help children and parents who have not transitioned to adult care have a concrete image of the transition and gather adequate information.

Moreover, in order to support children to visit outpatient clinics on their own, healthcare providers need to have discussions with parents about the benefits of seeing their child alone, while also understanding the parents' concerns.

Finally, healthcare providers should also be aware that parents' needs vary depending on their children's illnesses. Healthcare providers should support parents to promote their children's readiness for the transition to adulthood, leading to children's increased autonomy and a smooth transition to adulthood.

Limitations and strengths

As only two facilities were included in this study, the number of participating facilities needs to be expanded in order to understand the situation in Japan. In addition, as a cross-sectional study was conducted in this study, it is necessary to continue the longitudinal study to understand the processes related to readiness. Furthermore, the reliability of the questionnaire used in this study has not been confirmed; hence, future studies should confirm the reliability of the questionnaire.

However, this is one of the few studies to examine parental readiness for their children's transition to adulthood in Japan. It is significant in that we could clarify how well parents are helping their children at this time and what support they need from healthcare providers to help their children. Future studies should investigate the extent to which parental readiness affects children's readiness to transition into adulthood when the children have a chronic disease.

Conclusion

This study investigated the readiness of parents of chronically ill children for their children's transition to adulthood and how parental readiness differs among diseases in Japan. The results showed that

nearly 60% of parents knew the necessity of transferring their children to an adult department. Nonetheless, the agreement rate of parental support for children tended to be low.

In addition, depending on readiness, it was suggested that parents of children with diabetes and cardiovascular disease could get more than parents of children with cancer, blood, or allergic disease. Healthcare providers should support children and parents in acquiring information about the transition to adulthood and implementing child-oriented outpatient visits. In particular, transition support is needed for parents of children who have chronic conditions other than diabetes or cardiovascular disease.

Author statement

The authors acknowledge that they have all made substantive contributions to the information or materials submitted for publication, that they have all read and approved the final manuscript, that there are no direct or indirect commercial financial incentives associated with the publication of the article, and that the manuscript or any part of it is not under consideration by another journal and has not been previously published.

CRediT authorship contribution statement

Noriko Ozawa: Data curation, Formal analysis, Visualization, Writing – original draft. **Noriko Hiraga:** Data curation, Formal analysis, Supervision. **Taiga Shibayama:** Formal analysis, Visualization, Supervision. **Hiriko Fukusima:** Data curation, Supervision. **Ryoko Suzuki:** Data curation, Supervision. **Kayuri Furuya:** Formal analysis, Supervision.

Declaration of Competing Interest

The authors have no conflicts of interest to declare.

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