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**Survey of Transitional Care between Pediatrics and Obstetrics/Gynecology in Japan**

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Short running title: Current status of transitional care in Japan

**Keywords:** transitional care, pediatric cancer, cancer survivor, obstetrics/gynecology

## ABSTRACT

**Purpose:** This study aimed to conduct a survey of obstetricians/gynecologists on the actual situation regarding transitional care for pediatric cancer patients (PCPs)**[Please note that the use of the term “cancer patient” is typically reserved for patients currently undergoing treatment. Otherwise, “person/people/patient with cancer” is preferred. Please consider revising this as “patients with pediatric cancer (PPC)” throughout the text.]** in Japan.

**Methods:** A questionnaire survey on transitional medicine was conducted in the form of an online questionnaire at 579 major training facilities nationwide that were registered with the Japanese Society of Obstetrics and Gynecology.

**Results:** While 40% of the facilities had received referrals for PCPs, only 13% provided transitional care specifically for PCPs. The most common problems with referrals were related to an “insufficient explanation” in many cases. In addition, at facilities with no experience in treating PCPs, many respondents commented that they did not know how to follow up on the progress of the disease. Regarding the necessity of obstetrics/gynecology visits for PCPs, more than half of the respondents at facilities with experience treating PCPs answered that such visits were “necessary”; only 1% answered that they were “unnecessary.” On the other hand, 37% of the facilities that had no experience treating PCPs answered that it was “necessary,” whereas 4% answered that it was “unnecessary.”

**Conclusion:** Our survey on the actual situation of transitional care between pediatrics and obstetrics/gynecology in Japan identified issues to be addressed for the dissemination of transitional care. The results suggested that in the future, health-care professionals need to be educated through knowledge and patient education that leads to patients’ awareness of their own self-management.**[232/250 words]**

## Introduction

Advances in cancer treatment have led to an increase in the number of cancer survivors, and improving quality of life after overcoming cancer has become an issue. According to the 2022 Cancer Statistics published by the National Cancer Center,<sup>1</sup>**[Please note that all references must be set in superscript Arabic numerals after punctuation. Reference numbers should not be set in parentheses or brackets. To cite several references at once, use commas to separate non-sequential citations and en dashes to separate sequential citations; do not include spaces (e.g.,<sup>3,7,12–15</sup>). Please apply this format throughout the text.]** the 10-year relative survival rate for childhood cancer in Japan is approximately 70%–80%, whereas in other countries, it is reported that approximately 90% of pediatric cancer patients (PCPs)**[Please see the comment about this term in the abstract.]** reach adulthood (2). One major difference between PCPs and patients with adult-onset cancer is that there are stages of both physical and mental growth from childhood to adulthood. PCPs should transition departments as they grow physically, and the transition from pediatrics to adult departments can benefit PCPs (3,4).

In Europe and the United States, web-based patient support systems and passports are being utilized as tools to educate PCPs about their treatment history and the need for long-term follow-up (5,6). These tools include information on the individual patient's treatment history and when the patient should return to the hospital for prevention and diagnosis of late complications by organ, which is effective for educating patients and facilitating information sharing among health-care providers. Systems for transitional care are also being established in other countries.

On the other hand, it is important for obstetricians and gynecologists to be involved in the treatment of PCPs because of the risk of various late complications of childhood cancer, including the effects on reproductive functions (7). However, transitional care between pediatric and obstetrician/gynecologist physicians and health-care providers is not widely enforced in Japan, leading to a deficit in this area.

Therefore, in the present study, we decided to conduct a survey on transitional care for PCPs in Japan targeting obstetricians and gynecologists.

## Methods

### *Survey subjects*

We surveyed 579 major training facilities in Japan registered with the Japanese Society of Obstetrics and Gynecology and asked representatives of obstetrics and gynecology departments at those facilities to respond. The response period was from January 2021 to March 2022. The major medical training facilities included 113 university hospitals and 466 city hospitals.

### *Questionnaire survey*

A questionnaire on transitional care in the form of an online survey was developed and answered by the delegates. The facilities were classified according to whether they had any experience treating PCPs, and were asked to answer each question and tabulate the results (Table 1A). Facilities that responded that they had experience treating PCPs were asked to complete a questionnaire consisting of 11 questions (Table 1B). The contents were “Reasons why the PCP was referred,” “Trouble with the referral of the PCP,” “Specific episodes of trouble,” “Recommendations in treating the PCP,” and “Necessity for the PCP to attend obstetrics and gynecology.” Facilities that responded that they had no experience treating PCPs were asked to complete a questionnaire consisting of nine questions (Table 1C), the contents of which were “Anticipated difficulties when a PCP is referred,” “Things I would recommend when treating a PCP,” and “Necessity for the PCP to attend obstetrics and gynecology.”

The following scores were used to represent graphically the current status of transitional care in each prefecture: 0 for no transitional care, 5 for having an outpatient clinic specializing in transitional care, 3 for not having an outpatient clinic specializing in transitional care, and 1 for having plans to open an outpatient clinic specializing in transitional care (Figure 2[Please note that figures must be cited in sequential order. Please renumber the figures or add a callout to Figure 1 before this callout to Figure 2.]).

### *Ethical considerations*

In this study, consent was indicated in the questionnaire and free answers were given. This study was approved by the Institutional Review Board at St. Marianna University School of Medicine (approval No. 5387).

## **Results**

### *Current status of transitional care between pediatrics and obstetrics/gynecology*

The total response rate was 58.5% (339/579), and only one of the responding facilities did not agree to complete the questionnaire. The respondent facilities consisted of 99 university hospitals and 240 city hospitals.

First, when asked if they provide transitional care specifically for PCPs between pediatrics and obstetrics/gynecology, only 13% (44/338) responded that they do (Figure 1), while 40% (136/338) of the facilities had received referrals for PCPs (Figure 1). In addition, the national distribution of facilities providing transitional care was concentrated in the Tokyo and Osaka metropolitan areas (Figure 2).

### *Reasons for referral from pediatrics to obstetrics/gynecology*

The most common reasons for referral were “irregular menstruation or irregular genital bleeding” and “suspected ovarian dysfunction after puberty,” followed by “request for surgical intervention” and “request for fertility preservation therapy before cancer treatment.” Other reasons included “information about fertility before treatment,” “desire to have a baby, desire to confirm ovarian function and semen findings,” “perinatal management,” “dysmenorrhea,” and “transition to adulthood with ovarian dysfunction” (Figure 3).

#### *Problems obstetricians and gynecologists face when referring PCPs*

The response to the question of whether there were any current or anticipated problems with the referral was “none in particular,” but among the facilities that had experienced problems, many responded that they did not know how to follow up on the progress of the referral. Other breakdowns included the “patient’s lack of knowledge (not explained) that they have gonadal dysfunction,” “unannounced disease name to the patient,” “desire to have a baby in patients with ovarian dysfunction,” “lack of time to start treatment for the underlying disease,” and “difficulties in the timing of starting hormone replacement and difficulties in examining children” (Figure 3).

The specific episodes of actual difficulties at the facilities could be categorized into (I) explanation, (II) system, (III) knowledge, (IV) fertility preservation and ovarian dysfunction-related, (V) perinatal-related, (VI) primary disease-related, and (VII) unfamiliarity with pediatric care (Table 2).

The most common response to the question of whether there were any problems anticipated upon referral of a PCP at a facility with no experience treating PCPs was “I don’t know how to follow up” (Figure 3). The “other” category included “cannot follow up because the facility does not treat gynecological diseases.”

#### *Details of treatment of PCPs in obstetrics/gynecology*

Concerning the question about women’s health care, although about 80% of the facilities that had treated PCPs or survivors recommended human papillomavirus (HPV) vaccine and cervical cancer screening, including for healthy children, only about 10% did so actively[\[Please check that this conveys your intended meaning.\]](#) (Figure 4). While about half of the centers actively recommended hormone measurements, only 24% actively recommended anti-Müllerian hormone (AMH) measurements to confirm ovarian reserve, and only 14% actively recommended antral follicle counts to evaluate ovarian reserve. Bone densitometry was actively recommended by about 40% of the facilities.

The respondents also indicated that they provided information on ovarian dysfunction, infertility treatment, perinatal prognosis, and hospital visits in advance, in addition to measuring basal body temperature, checking menstrual cycles, checking for glucose intolerance and lipid abnormalities, etc., evaluating cardiac function, and recommending

hormone replacement therapy for premature ovarian failure[Please check that this conveys your intended meaning.].

On the other hand, the responses from facilities that had not treated PCPs were similar to those from facilities that had treated such patients. In terms of differences, more facilities reported recommending HPV vaccine and cervical cancer screening when “recommend the same as for healthy children” was included (Figure 5).

#### *Necessity of obstetrics/gynecology visits in PCPs*

Figure 6 shows the results of responses regarding the need for PCPs to visit an obstetrician/gynecologist. More than half of the facilities with experience treating PCPs responded that it was “necessary”; only 1% responded that it was “unnecessary.”

The most common reason given for the “necessary” response (n = 68) was “Evaluation is necessary because long-term effects on reproductive function are not known based on the individual’s perception of menstrual status alone, and intervention may be necessary to avoid osteoporosis and cardiovascular events,” with 33 responses. The following responses were also given: “The activity will contribute to the improvement of survivorship for PCPs who need long-term follow-up,” “It has a therapeutic and preventive effect because gynecological diseases increase with life stage,” “Because of the possibility of premature ovarian failure,” and “Some patients may not be old enough at the time of treatment to understand the explanation, or may not have time to think about it, so another opportunity to explain is necessary.”

The most common reason given for the “yes and no” response (n = 47) was “It is acceptable to see a doctor after symptoms such as menstrual abnormalities appear,” with 11 responses. The following responses were also given: “It is necessary in cases of suspected ovarian dysfunction, but not necessarily in cases of normal ovarian function,” “Because regular follow-up, such as ovarian function, can be handled by pediatrics,” “Gynecological care does not need to be actively encouraged because of patient embarrassment,” “The hospital visits may be a hindrance to work and personal life for PCPs or may lead to flashbacks to the past,” and “It depends on the patient’s wishes.”

No response was received regarding the reason for the “unnecessary” response.

On the other hand, only 37% of the facilities that had no experience treating PCPs responded “necessary.” In addition, 4% responded “unnecessary,” a higher percentage than the facility responses with experience treating PCPs.

The reasons given for the “necessary” response (n = 51) were similar to those given by facilities with experience in treating PCPs: 21 responses were seen for “Ovarian function needs to be assessed.” The following responses were also given: “Necessary from sexual and reproductive health and rights perspective” and “To reduce the burden of pediatrics.”

The most common reason given for “yes and no” (n = 70) was “Depends on the patient’s

condition,” with 15 responses. The 10 facilities that responded that “It is acceptable to see a doctor after symptoms such as menstrual abnormalities appear” were comparable to those with experience in pediatric care. The following responses were also given: “Only patients who need to go to the hospital after screening should go to the hospital,” “Unmarried, ovarian reserve confirmation may be information that is better not to know,” “It depends on the patient’s wishes,” “The follow-up can be done by internal medicine, not obstetrics and gynecology,” “I don’t think there is any reason to go to obstetrics/gynecology specifically because you are a PCP,” and “Little understanding of special care needs and their usefulness.”

The reasons for the “unnecessary” response (n = 2) were “I don’t believe that just being a PCP requires a visit to obstetrics/gynecology” and “If there are no symptoms, it is as good as a healthy person.”

## **Discussion**

In recent years, the incidence of cancer in children and adolescents has been gradually increasing, and as of 2020, approximately 300,000 cancers worldwide had been diagnosed in those under the age of 19 years[\[Please check that this conveys your intended meaning.\]](#) (8). At the same time, treatment for childhood and adolescent cancers has evolved, and patients who once had to abandon treatment are now treatable (7). After being diagnosed with cancer at a young age, cancer survivors face long-term survivorship. During this follow-up, the risk of cancer recurrence decreases while the risk of treatment-related health problems increases. In other words, PCPs may experience a variety of irreversible effects from cancer treatments administered during childhood and adolescence. Therefore, although PCPs have a high survival rate, they often require a long follow-up period while taking on various health risks (9).

Common late effects include infertility, endocrine abnormalities, cardiovascular disease, bone disease, respiratory dysfunction, and secondary cancers. Tonorezos et al. (9) summarized specific diseases and recommendations. In this context, obstetricians and gynecologists should follow up on infertility and other aspects of women’s health care. The results of this study indicated that “irregular menstruation or atypical genital bleeding” and “ovarian dysfunction” were the most common reasons for referral from pediatrics to obstetrics/gynecology. While there are a number of matters to be followed in the field of obstetrics/gynecology, many cases are actually referred after the appearance of genital-related symptoms, suggesting the possibility that the need for obstetric care is not yet recognized among pediatricians.

On the other hand, when obstetricians and gynecologists treated PCPs, HPV vaccine and cervical cancer screening were relatively recommended, but only about 60% of the facilities answered that they recommended bone densitometry. As many pediatric cancers are relatively radiosensitive and radiotherapy is often the treatment of choice (10), bone densitometry

should be a matter of recommendation by most obstetricians. As multiple respondents noted a “Lack of knowledge about pediatric cancer treatment,” it is assumed that this factor is due to the lack of knowledge about the details of pediatric cancer treatment among obstetricians and gynecologists.

More facilities responded that they had not decided on the confirmation of ovarian reserve capacity compared with the other questions, but they might do so if they judged it to be clinically necessary.

Regarding the necessity of visiting an obstetrician/gynecologist, about 40% of the facilities with experience in referring PCPs, and more than half of the facilities with no experience in referring PCPs, did not necessarily believe that a visit to an obstetrician/gynecologist was necessary. The reasons for this were a perception that “they should see a doctor only after symptoms appear,” and reluctant responses such as “just follow up with someone other than the obstetrician/gynecologist.” In addition, many respondents stated that they did not know how to follow up on the progress of their patients, which is thought to be one of the reasons why transitional care is not widely used. This lack of knowledge and awareness among obstetricians and gynecologists needs to be improved and is considered one of the challenges associated with the dissemination of transitional medicine. To overcome this challenge, one solution may be to develop guidelines and other materials to follow the progress of PCPs, as mentioned in the responses to the results of this study.

As survivors of child and adolescent cancer age, they transition from pediatric to adult health care. A successful transition to adult health care benefits patients because new health problems may be identified during the transition, and this may improve patient outcomes (3,4). However, the results of this study revealed that only 13% of the facilities actually provided transitional care, indicating that regional differences exist in Japan, where transitional care is not widespread (Figure 2). This was to be expected, as the current state of transitional medicine in Japan is more backward than in other countries. The primary reason for this is the lack of a system in place.

Key points for optimal transitional care include a clear plan and process, the use of patient navigators, the adoption of a phased and flexible approach, clear and effective communication, the promotion of educational opportunities for self-management, access to online resources such as tailor-made roadmaps and treatment overviews, and joint pediatric and adult care clinics (9). It will be difficult to incorporate these key points immediately, as it will take a certain amount of time to establish a nationwide transitional care system. On the other hand, one thing that can be improved relatively early on is seamless communication between the pediatric and adult departments. In addition to ensuring the transfer of patient information from the pediatrician to the adult care physician, it is believed that the pediatrician’s reiteration of the patient’s medical condition and other information during the transition can facilitate a smooth transition to the adult care department (11). However, the



results of this study showed that there were some cases in which pediatricians' lack of an explanation to patients led to problems when they visited obstetricians and gynecologists. In addition, episodes exist in which obstetricians and gynecologists have struggled with how to explain issues to patients, and "explaining to patients" is an important factor for smooth and successful transitional care. To overcome this problem and assist with "explanations," it may be helpful for pediatric and adult departments to create leaflets and other materials that can be used when explaining the disease to PCPs.

In addition to health-care provider education, patient education is also necessary to promote transitional medicine. For patient education, a web-based Survivorship Passport (SurPass) that summarizes the clinical histories of patients who have overcome childhood and adolescent cancer in Europe is available (5). SurPass provides a summary of each PCP's clinical history, detailed information about the cancer and the treatment received, and individualized follow-up and screening recommendations. In the United States, attempts are being made to distribute credit card-sized passports as a tool to educate PCPs about their treatment history and the need for long-term follow-up (6).

The results of this study indicate that the fact patients are concentrated in facilities that treat acute patients should be avoided as much as possible, and it may be necessary to triage patients before considering hospital visits. For example, treated patients with a high risk of late effects should be transferred to a specialized facility, such as a university hospital, whereas low-risk patients should be transferred to a general practitioner. Risk-specific approaches have been proposed to match the risk of long-term health outcomes with the most appropriate health-care setting for care delivery (12,13), and supportive self-management systems such as Oncokompass may be useful in this regard (14). However, there are no such materials available in Japan, and the development of such materials for the spread of transitional medicine is an issue to be addressed in the future.

A limitation of this study is that not all facilities in Japan responded to the questionnaire, so caution must be exercised in interpreting the results. Furthermore, as this study was conducted as a questionnaire survey in Japan, caution is needed when applying the results to global populations.

## **Conclusions**

In this study, we surveyed the actual situation of transitional care between pediatrics and obstetrics/gynecology in Japan and extracted issues for the dissemination of transitional care. The results suggested that health-care professionals need to be educated further, such as by providing knowledge to health-care workers, and that patient education that leads to patients' own awareness of self-management needs to be provided.

## **Acknowledgments**

N/A

### **Authors' Contributions**

**Kentaro Nakamura:** Data curation, Investigation, Methodology, Resources, Validation, Visualization, Writing – original draft. **Yukayo Terashita:** Investigation, Methodology, Writing – review & editing. **Atsushi Manabe:** Supervision, Writing – review & editing. **Nao Suzuki:** Conceptualization, Funding acquisition, Project administration, Supervision, Writing – review & editing.

### **Author Disclosure statement**

N/A[Do you mean “No competing financial interests exist.”?]

### **Funding Information**

This work was supported by MHLW Research for Promotion of Cancer Control Program Grant No. JPMH20EA1004.

**References**[Please note that the format of the references deviates substantially from that required by the journal. The first 5 references have been reformatted in the required style. Please reformat the remaining references based on the following examples or adjust your reference manager software accordingly. **Journal article with 1–3 authors:** “Wang Q, Nambiar K, Wilson JM. Isolating natural adeno-associated viruses from primate tissues with a high-fidelity polymerase. *Hum Gene Ther* 2021;32(23–24):1439–1449; doi: 10.1089/hum.2021.055 [insert article-specific DOI if available].” **Journal article with more than 3 authors:** “Pfister EL, DiNardo N, Mondo E, et al. Artificial miRNAs reduce human mutant Huntington throughout the striatum in a transgenic sheep model of Huntington’s disease. *Hum Gene Ther* 2018;29(6):663–673; doi: 10.1089/hum.2017.199 [insert article-specific DOI if available].”]

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## Figure legends

**FIG. 1.** Current treatment of pediatric cancer patients[\[Please see the comment about this term in the abstract.\]](#). A: Facilities dealing with transitional care. B: Experience in treating pediatric cancer patients in obstetrics/gynecology.

**FIG. 2.** Current status of transitional care facilities in Japan. The number of facilities in Japan that treat pediatric cancer patients in obstetrics and gynecology departments is shown. The following scores were used to represent graphically the current status of transitional care in each prefecture: 0 for no transitional care, 5 for having an outpatient clinic specializing in transitional care, 3 for not having an outpatient clinic specializing in transitional care, and 1 for having plans to open an outpatient clinic specializing in transitional care.

**FIG. 3.** Results of a survey on the content of referrals for pediatric cancer patients. A: Results of a questionnaire on reasons for the referral of pediatric cancer patients at facilities with experience treating pediatric cancer patients. B: Results of a survey of problems with referrals at facilities with experience treating pediatric cancer patients. C: Results of a survey of anticipated problems with referrals at facilities with no experience treating pediatric cancer patients.

**FIG. 4.** Results of a questionnaire about the treatment of pediatric cancer patients in obstetrics/gynecology (from facilities with experience in treating pediatric cancer patients). A: About HPV vaccine, B: About cervical cancer screening, C: About hormone measurements, D: About confirmation of ovarian reserve (AMH), E: About confirmation of ovarian reserve (AFC), F: About bone densitometry. HPV: human papillomavirus, AMH: anti-Müllerian hormone, AFC: antral follicle count.

**FIG. 5.** Results of a questionnaire about the treatment of pediatric cancer patients in obstetrics/gynecology (from facilities with no experience in treating pediatric cancer patients). A: About HPV vaccine, B: About cervical cancer screening, C: About hormone measurements, D: About confirmation of ovarian reserve (AMH), E: About confirmation of ovarian reserve (AFC), F: About bone densitometry. HPV: human papillomavirus, AMH: anti-Müllerian hormone, AFC: antral follicle count.

**FIG. 6.** Results of a survey on the need for obstetric and gynecological care for pediatric cancer patients. A: Results of a survey by facilities with experience treating pediatric cancer patients. B: Results of a survey by facilities with no experience treating pediatric cancer patients.