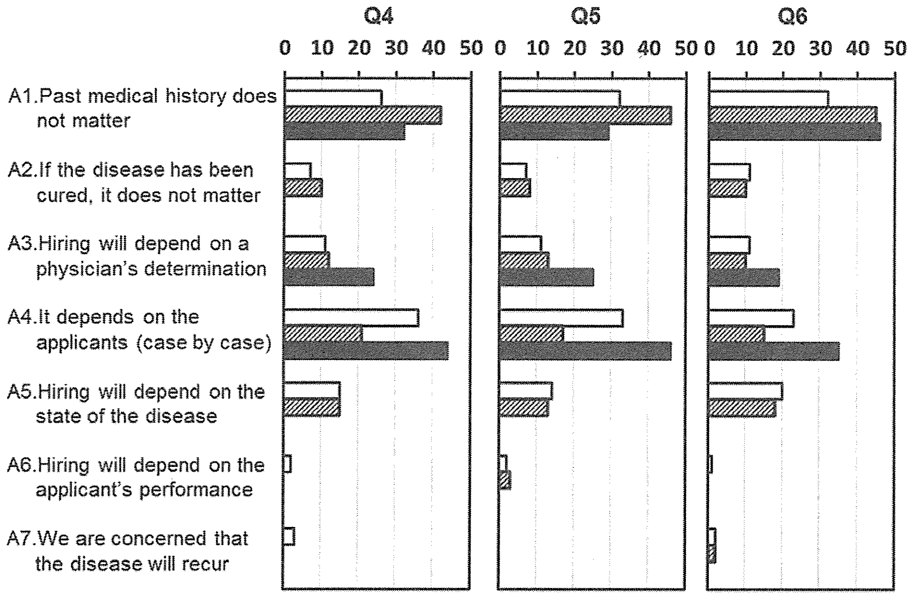

Fig. 1 Comparison of detailed answers to question (Q) 4–Q6 among three groups. Q4. How do you deal with childhood cancer in the applicant's medical history? Q5. How do you deal with some childhood disease other than cancer in the applicant's medical history? Q6. How do you deal with workers who turn out to be childhood cancer survivors after hiring? Answer (A) 1: past medical history does not matter (hiring is based on job performance). A2. If the disease has been cured, it does not matter. A3. Hiring will depend on a physician's determination. A4. It depends on the applicants (case by case). A5. Hiring will depend on the state of the disease. A6. Hiring will depend on the applicant's performance during the trial period. A7. We are concerned that the disease will recur. □, listed companies; ▨, unlisted companies; ■, public offices (general desk workers).

number of companies and even public offices. Opportunities to provide specific vocational assistance to high-risk CCS should be advocated and advanced.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1 Questionnaire.

Appendix S2 Background information of the companies and public offices.

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Factors Affecting Health Care Utilization for Children in Japan

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Factors Affecting Health Care Utilization for Children in Japan

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KEY WORDS
ecology, medical care, physician visit, primary care, health diary

ABBREVIATION
OR—odds ratio

Dr Ishida participated in the conception and design of the study, analysis and interpretation of data, statistical analysis, and drafting the article; Drs Ohde and Takahashi participated in the conception and design of the study, acquisition of data, analysis and interpretation of data; Dr Deshpande participated in the interpretation of data and drafting the article; Drs Shimbo and Hinohara participated in the interpretation of data and critical revision of the article; Dr Fukui participated in the conception and design of the study, analysis and interpretation of data, and critical revision of the article. Final approval was made by all coauthors.

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WHAT'S KNOWN ON THIS SUBJECT: In the United States, the ecology of children's medical care is similar to that of adults. Health care utilization for children varies significantly by age, race, ethnicity, income, and health insurance status.

WHAT THIS STUDY ADDS: Compared with data from the United States, children in Japan more frequently visit both community physicians and hospital-based outpatient clinics. Pediatric health care utilization is influenced significantly by age but not affected by income or residence location in Japan.

abstract

BACKGROUND AND OBJECTIVE: Studies on the ecology of medical care for children have been reported only from the United States. Our objective was to describe proportions of children receiving care in 6 types of health care utilization seeking behaviors in Japan on a monthly basis and to identify care characteristics.

METHODS: A population-weighted random sample from a nationally representative panel of households was used to estimate the number of health-related symptoms, over-the-counter medicine doses, and health care utilizations per 1000 Japanese children per month. Variations in terms of age, gender, socioeconomic status, and residence location were also examined.

RESULTS: Based on 1286 households (3477 persons including 1024 children) surveyed, on average per 1000 children, 872 had at least 1 symptom, 335 visited a physician's office, 82 a hospital-based outpatient clinic, 21 a hospital emergency department, and 2 a university-based outpatient clinic. Two were hospitalized, and 4 received professional health care in their home. Children had 2 times more physician visits and 3 times more emergency visits than adults in Japan, and Japanese children had 2.5 times more physician visits and 11 times more hospital-based outpatient clinic visits than US children. Pediatric health care utilization is influenced significantly by age but not affected by income or residence location in Japan.

CONCLUSIONS: Compared with the data from the United States, more children in Japan visit community physicians and hospital-based outpatient clinics. Results of this study would be useful for further delineation of health care utilization of children in the context of a health care system unique to Japan. *Pediatrics* 2012;129:e113–e119

White et al[1] reported the first study on the ecology of medical care based on the population of the United States and the United Kingdom ~50 years ago. They showed that the main bulk of health service utilization occurred at physician visits (250 out of 1000 per month) with hospitalization comprising only 9 incidences out of 1000. Fukui et al[2] previously revealed that, compared with data in the United States, people in Japan visited community physicians and hospital-based outpatient clinics more frequently. This ecology model has been replicated over several decades,[3–6] including from our group,[2,7,8] with findings that were consistent with those of White et al.[1] This model has subsequently been widely used by both policy makers and educators.[9,10]

Unlike the medical system in the United States, Japan has a universal health care system, which allows virtually free health care access to everyone including children. Per recent Organization for Economic Co-operation and Development data,[11] Japan spent considerably less money, compared with the United States, on health care in terms of total health spending per capita (US$ 2729 vs 7538 in 2008) and percent of gross domestic product (8.1% vs 16.0% in 2008). Thus, it is speculated that health care–seeking behavior and health service utilization in Japan may be substantially different from that in the United States. However, no well-designed studies on patients' health care–seeking behavior for health-related symptoms have been conducted, although there are reports of limited sample size.[7,12]

To date, studies on the ecology of medical care for children have been reported only from the United States.[13,14] No similar investigation has been made for the Japanese population. The medical ecology of Japanese children's health care may be different from not only that of Japanese adults but also that of children in the United States. Our objective for this study was to assess health care–seeking behavior of children in Japan by using a nationally representative panel of households.

METHODS

Study Design

A prospective cohort design was employed.

Sample

A nationally representative panel belonging to Japan Statistics and Research Co Ltd that comprised 210 000 households was used (Fig 1). Taking into consideration the size of the cities, towns, and villages, a population weighted random sample of 5387 households was chosen and each household was sent an offer letter with a return envelope. Of the total, 1857 agreed to participate. The sample size was readjusted demographically to 1464 households to make it nationally representative.

Data Collection

Questionnaires and diaries were used for data collection. The questionnaires were scripted to note children's baseline characteristics including family information. The diary was designed to keep a record of any health-related events, symptoms, health care–seeking behavior, and actual use of health services, along with other variables of interest. Parents or other eligible persons were asked to fill out the questionnaires and diaries for children younger than 13 years and those who could not write on their own. The advantage of health diaries includes the ability to keep a record of events continuously and consistently while minimizing recall bias.

Definitions of Variables

1. Age: 4 age groups were identified: <2 years, 2 to 5 years, 6 to 12 years, and 13 to 17 years.
2. Gender
3. Education: 3 categories were defined by the highest degree attained by the head of the household in which a child resided: high school or lower, college/vocational school, and university/graduate school.
4. Economic status: family annual income was divided into 3 categories: <5 million Japanese yen, 5 million to 7 million Japanese yen, and >7 million Japanese yen.
5. Residence location: a large city was defined as a city with a population >1 million, a medium-sized city was identified as 100 000 to 1 million, and a small city/town as <100 000 inhabitants. Residents living outside a city or town were defined as rural.
6. Number of children: the number of children in a family was divided into 3 groups: 1 child, 2 children, and ≥3 children.
7. Single-parent households were defined as family units in which a child's mother or father served as the sole caretaker; responses were classified as "yes" or "no."

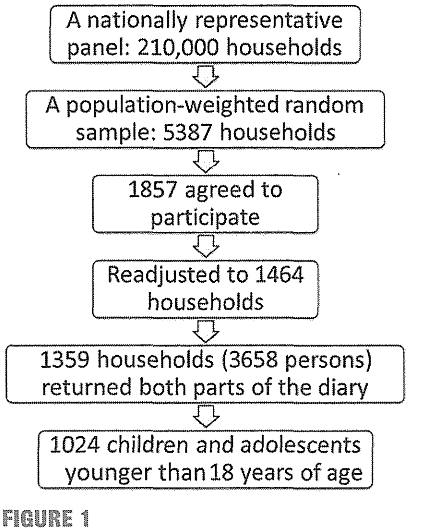

FIGURE 1
Sampling process of this study. Of 1857 households agreeing to participate, the sample size was readjusted to 1464 households to make it nationally representative. Among 3658 persons in 1359 households who returned the diary, we analyzed those of 1024 children and adolescents aged 0 and 17 years.

8. Family living together with grandparents; responses were classified as "yes" or "no".

Ethical Considerations

After obtaining informed consent by post, health diaries (divided into 2 parts, each of 2 weeks duration), questionnaires for recording baseline data, and gift vouchers of 3000 Japanese yen (~30 US$) per person were sent to each member of the 1464 enrolled households in September 2003. The diaries were recorded from October 1, 2003, to October 31, 2003.

A manual accompanied the health diaries to facilitate recording the required information. The diary was in the form of a softbound letter-sized book. Participants were asked to return the first part of the diary after 15 days of entries, whereas the second part was returned after completion of the study period. A weekly phone call to each enrolled family was made as a reminder. Ethical approval was obtained from the research ethics committee of Kyoto University Graduate School of Medicine, Japan.

Statistical Analysis

Descriptive analyses, along with confidence intervals, were performed to estimate the number of different health care–seeking behaviors per 1000 persons per month. We performed χ^2 tests or a Fisher's exact test (for any cells with expected counts <5) within categorical predictors. Dichotomous analyses indicated strong associations between each predictor variable and participation by children in 1 or more health care settings. Too few children used home care services and university hospitals to produce reliable estimates. Therefore, 4 separate logistic regression analyses were performed to derive adjusted odds ratios (ORs) of the independent association of each predictor variable. All data were analyzed by SPSS statistical software, version 19.0 (IBM Japan Ltd, Tokyo, Japan).

RESULTS

Of 1000 children aged 0 to 17 years, on average each month, 872 had at least 1 symptom, 167 visited a physician in the community clinic office setting, 82 visited a hospital-based outpatient clinic, 20 received care in an emergency department, 4 received professional health services in their home, and 2 spent time as an inpatient in a hospital (Fig 2).

Table 1 shows the estimated proportion of children reporting clinical symptoms during a typical month. Most symptoms were significantly dependent on the age of the child. Frequency of symptoms associated with upper respiratory infections (sneezing, cough, fever) or gastrointestinal symptoms (diarrhea and vomiting) was closely correlated with younger age. In contrast, frequency of symptoms associated with pain (sore throat, abdominal pain, headache, leg or toe pain, knee pain, and lumbago) was closely correlated with older age. Children in the older age group (13–17 years) showed similar patterns compared with the adult group; 8 out of the 10 most frequent symptoms were shared between the 2 groups, with the exception of stiff neck and knee pain, which were more common in adults.

Table 2 compares the ecology of medical care for Japanese children in this study with that of adults in Japan[2] and children in the United States.[13] Nearly the same proportion of Japanese children and adults reported at least 1 symptom (OR = 1.14).[2] The ORs of Japanese children visiting a physician's clinic or outpatient hospital clinic were 2.51 and 11.1, respectively, compared with children in the United States.[13] The ORs associated with Japanese children taking over-the-counter medicine, visiting a physician's community clinic, outpatient hospital clinic, or being admitted to hospital were 0.76, 2.15, 3.04, and 0.25, respectively, compared with Japanese adults.[2]

Table 3 demonstrates the estimate for number of children receiving care in different health care settings, stratified by the child/family sociodemographic characteristics. Univariate analysis using χ^2 test or Fisher's exact test revealed that children's age, annual income of the family, education level of

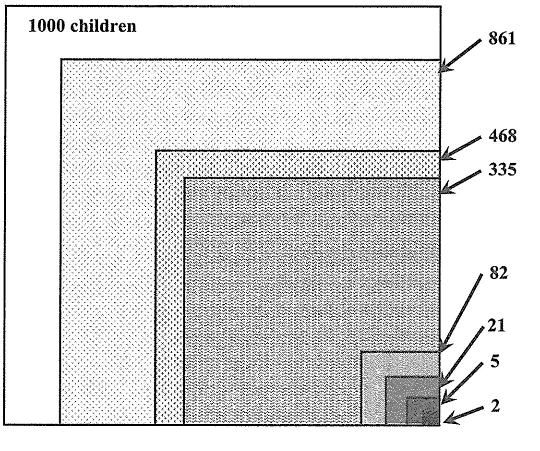

FIGURE 2
Participation in medical care in a typical month for 1000 children and adolescents aged 0 and 17 years. Boxes visually represent proportional participation categorized by type of medical care; smaller boxes do not indicate inclusive subgroups of larger boxes; 861 participants report some clinical symptoms, 468 take some medicine, 335 visit physician's office, 82 visit a hospital outpatient clinic, 21 visit an emergency clinic, 5 visit a university hospital outpatient clinic, and 2 are hospitalized.

TABLE 1 Estimated Proportion of Children Experiencing Clinical Symptoms During a Typical Month, *n* (%)

Symptoms	<2 y (*n* = 89)	2–5 y (*n* = 263)	6–12 y (*n* = 468)	13–17 y (*n* = 204)	χ^2,*P*	Total (*n* = 1024)	Reference (Japanese adults, *n* = 2453)[a]
Sneezing	67 (75.3)	168 (63.9)	184 (39.3)	58 (28.4)	<.0001	477 (48.6)	394 (16.1)
Cough	47 (52.8)	161 (61.2)	150 (32.1)	22 (10.8)	<.0001	380 (37.1)	338 (13.8)
Sore throat	7 (7.9)	33 (12.5)	99 (21.2)	59 (28.9)	<.0001	198 (19.3)	441 (18.0)
Fever	33 (37.1)	71 (27.0)	62 (13.2)	24 (11.8)	<.0001	190 (18.6)	166 (6.8)
Abdominal pain	1 (1.1)	30 (11.4)	73 (15.6)	43 (21.1)	<.0001	147 (14.4)	267 (10.9)
Headache	1 (1.1)	9 (3.4)	67 (14.3)	50 (24.5)	<.0001	127 (12.4)	719 (29.3)
Abrasion	7 (7.9)	30 (11.4)	54 (11.5)	5 (2.5)	.001	96 (9.4)	36 (1.5)
Leg or toe pain	1 (1.1)	6 (2.3)	53 (11.3)	25 (12.3)	<.0001	85 (8.3)	191 (7.8)
Common cold	6 (6.7)	20 (7.6)	29 (6.2)	15 (7.4)	.889	70 (6.8)	202 (8.2)
Muscle pain	0	1 (0.4)	25 (5.3)	38 (8.2)	<.0001	64 (6.3)	171 (7.0)
Bruising	9 (10.1)	11 (4.2)	37 (7.9)	6 (2.9)	.016	63 (6.2)	36 (1.5)
Itching	2 (2.2)	24 (9.1)	26 (5.6)	6 (2.9)	.014	58 (5.7)	75 (3.1)
Diarrhea	12 (13.5)	22 (8.4)	18 (3.8)	5 (2.5)	<.0001	57 (5.6)	121 (4.9)
General fatigue	1 (1.1)	6 (2.3)	25 (5.3)	14 (6.9)	.032	46 (4.5)	443 (18.1)
Dermatitis	9 (10.1)	12 (4.6)	17 (3.6)	6 (2.9)	.032	44 (4.3)	40 (1.6)
Nausea	1 (1.1)	9 (3.4)	24 (5.1)	9 (4.4)	.319	43 (4.2)	112 (4.6)
Knee pain	0	4 (1.5)	24 (5.1)	12 (5.9)	.009	40 (3.9)	206 (8.4)
Tooth pain	0	5 (1.9)	21 (4.5)	5 (2.5)	.056	31 (3.0)	112 (4.6)
Vomiting	7 (7.9)	12 (4.6)	11 (2.4)	1 (0.5)	.002	31 (3.0)	14 (0.6)
Hand or finger pain	1 (1.1)	7 (2.7)	19 (4.1)	3 (1.5)	.194	30 (2.9)	86 (3.5)
Dry skin	2 (2.2)	5 (1.9)	15 (3.2)	7 (3.4)	.696	29 (2.8)	28 (1.1)
Lumbago	0	1 (0.4)	13 (2.8)	14 (6.9)	<.0001	28 (2.7)	650 (26.5)

[a] Other common symptoms in adults, *n* (%): stiff neck, 555 (22.6); stomachache, 188 (7.7); shoulder pain, 149 (6.1); and menstrual pain, 130 (6.1).

the head of household, number of children in the family, and single parenthood were significant factors in the health care–seeking behavior of children.

Table 4 shows the results of multivariate analyses. Receipt of care in physicians' community clinic was the most sensitive to various sociodemographic characteristics in the model (age, education level, number of children, and single parenthood), with the exception of annual income and residence location. Community clinic visits were significantly more likely for younger children compared with children ≥13 years of age (OR = 7.32, $P < .001$ for children aged <2 years; OR = 5.66, $P < .001$ for children aged 2–4 years; OR = 2.41, $P = .001$ for children aged 6–12 years). Conversely, physicians' clinic visits were significantly less likely for children in families where the head of the household had a university or graduate school level of education (OR = 0.55, $P = .008$), 3 or more children in the family (OR = 0.55, $P = .024$), or single parenthood (OR = 0.49, $P = .032$; Table 4, including 95% confidence intervals of ORs).

As for over-the-counter medicines, use of these medications increased with older age. Of note, children living with grandparents took less over-the-counter medicines in the multivariate model (Table 4).

Children's age was also the strongest predictor for seeking care in an emergency department (OR = 6.82) and a hospital-based outpatient clinic (OR = 3.31). Families with higher annual income tended to visit community clinics (OR = 1.19) over hospital outpatient clinics (OR = 0.43). Gender and residence location were not independently associated with variation in proportions of children receiving care in any of the health care settings investigated.

DISCUSSION

This study is the first application of the classic ecology of medical care model to Japanese children. We demonstrate that the same proportion of Japanese children as adults reported at least 1 symptom during the study period[2] and that a substantial proportion of children have an encounter with the health care system in a typical month. Although overall patterns appear generally

TABLE 2 Ecology of Medical Care for Japanese Children Versus Adults in Japan and children in the United States

	This Study (Children <18 y)	OR of Children in Japan Versus the United States	OR of Japanese Children Versus Adults	Children in the United States (Dovey et al[13])	Adults in Japan (Fukui et al[2])	Adults in the United States (Dovey et al[13])
Having at least 1 symptom	872 (850–892)	NA	1.14 (0.88–1.47)	NA	857 (842–871)	NA
Taking an over-the-counter medicine	468 (442–494)	NA	0.76 (0.64–0.91)	NA	536 (510–562)	NA
Visiting a physician's clinic	335 (306–365)	2.51 (2.03–3.11)	2.15 (1.75–2.64)	167 (161–174)	190 (174–206)	235 (229–241)
Visiting an emergency department	20.5 (12.7–31.2)	1.63 (0.81–3.27)	3.04 (1.29–7.19)	12.8 (11.7–13.9)	6.5 (3.4–11.3)	13.0 (12.2–13.8)
Visiting an outpatient clinic in community hospital	82 (66–101)	11.1 (5.33–23.0)	0.86 (0.63–1.17)	8.2 (7.0–9.4)	94 (81–108)	25.8 (24.0–27.6)
Visiting an outpatient clinic in a university hospital	4.9 (1.6–11.4)	NA	0.71 (0.23–2.26)	NA	6.5 (3.4–11.3)	NA
Requiring hospitalization[a]	2.0 (0.2–7.0)	0.50 (0.09–2.73)	0.25 (0.05–1.17)	3.5 (2.7–4.3)	7.6 (4.4–12.7)	13.3 (9.6–11.0)
Requiring home health care	3.9 (1.1–10.0)	2.00 (0.37–11.0)	1.34 (0.30–5.98)	2.2 (1.4–3.0)	3.3 (1.4–6.4)	17.7 (15.6–19.8)

Values are given as number per 1000 (95% confidence interval) unless otherwise stated. NA, not available.
[a] Excluding hospital stays for birth.

TABLE 3 Estimates for Number of Children Per 1000 Participating in Health Care in a Typical Month by Sociodemographic Characteristics and Settings (%)

Demographic Characteristic	Taking an Over-The-Counter Medicine	Visiting a Physician's Clinic	Visiting an Emergency Department	Visiting an Outpatient Clinic in a Community Hospital	Visiting an Outpatient Clinic in a University Hospital	Requiring Hospitalization[a]
Age, y	*P* < .0001	*P* < .0001	*P* < .0001	*P* < .0001	*P* = .537	–
<2 (*n* = 89)	21 (24.7)	52 (59.6)	8 (9.0)	16 (18.0)	1 (1.1)	0
2–5 (*n* = 263)	107 (41.8)	115 (44.9)	8 (3.0)	31 (12.2)	1 (0.4)	0
6–12 (*n* = 468)	229 (50.0)	134 (29.3)	3 (0.6)	25 (5.6)	3 (0.6)	1 (0.2)
13–17 (*n* = 204)	110 (55.4)	34 (17.2)	2 (1.0)	10 (4.9)	0	1 (0.5)
Gender	*P* = .992	*P* = .554	*P* = .068	*P* = .565	*P* = .999	*P* = .999
Boy (*n* = 530)	242 (46.8)	178 (34.3)	15 (2.8)	45 (8.7)	3 (0.6)	1 (0.2)
Girl (*n* = 494)	226 (46.8)	157 (32.6)	6 (1.2)	37 (7.7)	2 (0.4)	1 (0.2)
Annual income, JPY	*P* = .597	*P* = .371	*P* = .011	*P* = .020	*P* = .458	–
<5 million (*n* = 342)	164 (46.2)	125 (35.4)	5 (1.5)	37 (10.5)	1 (0.3)	0
5–7milion (*n* = 309)	161 (50.2)	104 (32.4)	13 (4.2)	30 (9.4)	3 (1.0)	2 (0.6)
≧7 million (*n* = 314)	158 (48.4)	98 (30.3)	3 (1.0)	16 (4.8)	1 (0.3)	0
Education of head of household	*P* = .040	*P* = .031	*P* = 0170	*P* = .853	*P* = .801	*P* = .999
High school or lower (*n* = 391)	197 (40.7)	177 (36.6)	10 (2.0)	37 (7.7)	1 (0.3)	1 (0.3)
College/vocational school (*n* = 188)	114 (48.9)	74 (31.9)	1 (0.5)	17 (7.4)	1 (0.5)	0
University/graduate school (*n* = 228)	141 (50.0)	74 (26.3)	7 (2.6)	25 (8.8)	1 (0.4)	1 (0.4)
Residence location	*P* = .416	*P* = .720	*P* = .464	*P* = .665	–	–
Large city (*n* = 94)	42 (45.7)	33 (36.2)	4 (4.3)	6 (6.4)	1 (1.1)	0
Middle city (*n* = 225)	105 (48.0)	72 (32.9)	4 (1.8)	16 (7.1)	0	0
Small town (*n* = 450)	194 (44.2)	152 (34.7)	8 (1.8)	41 (9.3)	2 (0.4)	0
Rural area (*n* = 255)	126 (50.6)	77 (31.0)	5 (2.0)	20 (7.8)	2 (0.8)	2 (0.8)
Number of children	*P* = .147	*P* = .002	*P* = .248	*P* = .087	*P* = .845	*P* = .213
1 (*n* = 165)	70 (41.2)	67 (39.4)	14 (8.5)	3 (1.8)	0	1 (0.6)
2 (*n* = 522)	266 (49.4)	188 (34.9)	51 (9.4)	16 (3.1)	3 (0.6)	0
≧3 (*n* = 283)	145 (49.8)	72 (24.7)	18 (6.0)	2 (0.7)	2 (0.7)	1 (0.4)
Single parent	*P* = .002	*P* = .914	*P* = .096	*P* = .841	*P* = .999	*P* = .999
Yes (*n* = 127)	42 (33.9)	41 (33.1)	0	11 (8.7)	0	0
No (*n* = 897)	426 (48.6)	294 (33.6)	21 (2.3)	71 (8.1)	5 (0.6)	2 (0.2)
Living with grandparents	*P* = .821	*P* = .795	*P* = .152	*P* = .134	*P* = .590	*P* = .999
Yes (*n* = 182)	92 (48.9)	60 (31.9)	1 (0.5)	10 (5.5)	0	0
No (*n* = 788)	390 (48.0)	267 (32.9)	21 (2.5)	72 (8.9)	5 (0.6)	2 (0.3)

JPY, Japanese yen.

[a] Excluding hospital stays for birth.

similar for children and adults,[2] the proportions of each group differed significantly. Despite the same frequency of clinical symptoms,[2] twice as many children visited a community clinic and 3 times as many children visited emergency rooms, whereas the number requiring hospitalization was 4 times that of adults in Japan.[2] Compared with results from the United States,[13] 2.5 times more Japanese children visited a community physician's office or emergency clinic, and 11 times more Japanese children visited hospital-based outpatient clinics.

As expected, age strongly affected the ecology of medical care for children. Among all children, those <2 years of age were less likely to take over-the-counter medicine and most likely to receive care at least once in a typical month regardless of clinical setting. Children 2 to 5 years of age were more likely than those 13 to 17 years of age to receive care regardless of setting. In contrast, a smaller proportion of children aged 6 to 12 years, compared with those aged 13 to 17 years, received care in emergency departments, whereas the oldest age group comprised the least visits to both outpatient hospital-based and community clinics. These results are consistent with the previous report from the United States.[13]

Recently, pediatric professional organizations in the United States and elsewhere have recommended that over-the-counter medications, including cough and cold remedies, should not be given to infants.[15–18] Our data suggest that Japanese parents restrict use of over-the-counter medications for younger children, especially those younger than 2 years of age. Of note, living with grandparents was associated with significantly reduced over-the-counter medicine use. Several possible interpretations for this association may be considered; grandparents may have a lower threshold taking an ill grandchild to a clinic, or grandparents may be especially adverse to over-the-counter medicine use for children.

Multivariate regression analysis in our study confirmed that children's health care–seeking behavior is affected more substantially by age than by any other socioeconomic characteristics included in our study, a finding also consistent with previous reports from

TABLE 4 Adjusted ORs (95% Confidence Interval) for Children's Health Care Participation by Sociodemographic Characteristics and Setting

Demographic Characteristic	Taking an Over-the-Counter Medicine	Visiting a Physician's Clinic	Visiting an Emergency Department	Visiting an Outpatient Clinic in Any Hospital
Age, y				
<2	0.18 (0.09–0.36)	7.32 (3.64–14.7)	6.82 (1.22–38.1)	3.31 (1.30–8.46)
2–5	0.42 (0.26–0.69)	5.66 (3.21–9.97)	2.52 (0.47–13.4)	1.56 (0.67–3.66)
6–12	0.72 (0.46–1.11)	2.41 (1.41–4.11)	0.23 (0.02–2.58)	0.82 (0.35–1.93)
13–17	Reference	Reference	Reference	Reference
Gender				
Boy	0.82 (0.60–1.13)	0.90 (0.64–1.26)	0.62 (0.20–1.90)	1.04 (0.60–1.79)
Girl	Reference	Reference	Reference	Reference
Annual income of family, JPY				
<5 million	Reference	Reference	Reference	Reference
5–7milion	0.97 (0.65–1.46)	1.05 (0.69–1.61)	2.40 (0.66–8.74)	0.86 (0.45–1.65)
≧7 million	0.81 (0.53–1.25)	1.19 (0.76–1.87)	1.22 (0.24–6.09)	0.43 (0.19–0.96)
Education of head of household				
High school or lower	Reference	Reference	Reference	Reference
College/vocational School	1.40 (0.91–2.13)	0.75 (0.49–1.17)	0.19 (0.02–1.56)	1.11 (0.53–2.32)
University/graduate school	1.17 (0.77–1.77)	0.55 (0.35–0.86)	0.81 (0.25–2.67)	1.80 (0.88–3.68)
Residence location				
Large city	0.72 (0.40–1.28)	0.78 (0.42–1.43)	1.03 (0.21–5.04)	0.64 (0.22–1.88)
Middle city	0.75 (0.47–1.20)	0.85 (0.51–1.40)	0.28 (0.03–2.55)	0.88 (0.39–2.00)
Small town	0.76 (0.51–1.13)	0.89 (0.58–1.36)	0.61 (0.17–2.21)	1.05 (0.54–2.03)
Rural area	Reference	Reference	Reference	Reference
Number of children				
1	Reference	Reference	Reference	Reference
2	1.26 (0.83–1.91)	0.66 (0.42–1.01)	1.95 (0.50–7.68)	1.03 (0.52–2.03)
≧3	1.42 (0.88–2.30)	0.55 (0.35–0.86)	1.06 (0.16–7.19)	0.68 (0.28–1.60)
Single parent				
Yes	0.85 (0.48–1.53)	0.49 (0.25–0.94)	—	1.78 (0.69–4.59)
No	Reference	Reference	Reference	Reference
Living with grandparents				
Yes	0.63 (0.40–0.98)	1.06 (0.66–1.72)	0.57 (0.07–4.98)	1.31 (0.59–2.92)
No	Reference	Reference	Reference	Reference

JPY, Japanese yen.

the United States.[13,14] Of particular interest is the physicians' office setting where, adjusting for other variables, fewer children received care if they had 2 or more siblings, a single parent, or were living with a head of household with a higher level of educational attainment. No association of medical access with either annual family income or residence location was demonstrated, a fact to which the robust Japanese universal health care system might plausibly contribute.[19–21] It is interesting to consider that the United States might also anticipate a trend toward the findings in this study if recent health reforms, in addition to promotion of the medical home concept, provide wider insurance coverage to help ensure that all children have equitable access to appropriate health care resources.[13,22,23]

Although Dovey et al[13] were unable to reproduce estimates of clinical symptoms reported in the original study by White et al,[1] our study produced comparable estimated proportions of reported clinical symptoms for children. Population-based literature on children experiencing clinical symptoms is sparse and outdated. Our nationally representative study provides these estimates for children in Japan according to age group. This study revealed that frequency of symptoms associated with upper respiratory infections or gastrointestinal symptoms was closely correlated with younger age and that frequency of pain symptoms was closely correlated with older age.

This study has important strengths. First, this analysis was based on a nationally representative sample that was large enough to produce reasonably precise estimates of the true proportions of children receiving care. This is particularly helpful to generalize our findings to the Japanese pediatric population at large. Second, data were collected from the surveyed sample by using a medical diary, which minimized recall bias. Shaul et al[24] reported that providing both an adult and child survey to an adult could result in lower response rates. However, the response rate in our study (92.8%) was satisfactory. D'Souza-Vazirani et al[25] showed that mothers are a good source of information regarding children's acute health care use. Third, the summary findings are based on a single cohort.

There are, however, some limitations to our study. First, data were collected during a single month (October). Seasonal variations of disease incidence and prevalence, especially in children, could result in estimates different from the current data. October is soon after school begins in the United States and is a time of relatively high numbers of upper respiratory infections and minor illnesses that may result in a significant increase of health care utilization. In contrast, in Japan, the school year begins in April. As such, October represents a typically uneventful and calm month for children in terms of health status. Second, we did not evaluate the appropriateness of particular health care–seeking behaviors because disease outcome data related to individual children's symptoms were not collected.

CONCLUSIONS

Compared with the data from the United States, more children in Japan visit both community physicians' clinics and hospital-based outpatient clinics. The health care–seeking behavior of children was influenced significantly by children's age but not affected by income or location of residence in Japan. Results of this study will be useful for further delineation of health care–seeking behavior of children in the context of a health care system unique to Japan.

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Factors Affecting Health Care Utilization for Children in Japan

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Original Article

Physician Preferences and Knowledge Regarding the Care of Childhood Cancer Survivors in Japan: A Mailed Survey of the Japanese Society of Pediatric Oncology

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Objective: Japanese physicians' attitudes regarding the health-care needs of young adult childhood cancer survivors (CCSs) are not well described. Thus, we examined the self-reported preferences and knowledge of pediatric oncologists and surgeons.

Methods: A mailed survey was sent to 858 physician members of the Japanese Society of Pediatric Oncology. We compared the responses of pediatric oncologists and pediatric surgeons.

Results: The pediatric oncologists' response rate was 56% (300 out of 533) and that of pediatric surgeons 32% (105 out of 325). The median age of respondents was 46 and 48 years, respectively; 79 and 84% were men. When comfort levels in caring for CCSs were described (i.e. 1 = very uncomfortable; 7 = very comfortable), the mean levels were 4.4 and 3.8 with CCSs $\leq$ 21 years, 3.6 and 3.6 with 21 years $<$ CCSs $\leq$ 30 years, and 2.8 and 3.3 with CCSs $>$ 30 years, respectively. In clinical vignette questions, 62% of the pediatric oncologists and 43% of the surgeons answered three or more questions appropriately. Pediatric surgeons reported significantly lower familiarity with long-term follow-up guidelines than pediatric oncologists. Most pediatric oncologists and many surgeons conducted truth-telling of cancer diagnosis to adult CCSs now. They thought that the most important issues are an original long-term follow-up guideline suitable for the Japanese situation and collaborations with adult-based general physicians.

Conclusions: Many Japanese pediatric oncologists are uncomfortable with caring for survivors as they age and have suboptimal knowledge regarding late effects. The change in truth-telling situation and preference for collaboration with adult-based physicians was demonstrated also in Japan.

Key words: pediatric cancer – long-term survivors – transition to adult care – pediatric oncologist – pediatric surgeon

INTRODUCTION

As a result of treatment advances, almost 80% of children diagnosed with cancer become long-term survivors (1). In Japan, there are over 50 000 childhood cancer survivors (CCSs), or approximately 1 in 700 adults between the ages of 20 and 39 years has cancer experience (2). Many of these survivors face significant life-long health risks (3) and early mortality (4). Treatment-related late effects are often clinically insidious for years or decades after the completion of cancer treatment (5,6). Promotion of healthy lifestyle behaviors and provision of regular risk-based medical care and surveillance may modify the evolution of these late effects. However, many CCSs engage in risky health behaviors and do not receive adequate risk-based medical care (7).

In 2007, the members of the International Berlin-Frankfurt-Munster (I-BFM) Early and Late Toxicity Educational Committee (ELTEC) published the Erice statement to summarize what the group considers essential for the care of survivors (8). Included in the Erice statement was the following point: 'when the survivor enters adulthood, he/she should be referred to an appropriate health care provider who coordinates long-term care' (8). Despite these recommendations, many reports suggest that effective transitions from the pediatric to the adult-focused health-care system are difficult (9–11).

One well-described barrier to risk-based long-term health-care is that CCSs themselves are not well informed regarding their previous therapies or their potential risks for late effects (12,13). In the past study, CCSs in Japan did not always know the precise diagnosis of cancer itself (14). We recently reported that the previous treatment hospitals (where CCSs were treated for their cancer) were the most commonly visited medical facilities for the CCS group (74% for females and 64% for males) and more than half of CCSs preferred to continue visiting the previous treatment hospitals with full satisfaction in Japan (15). Recently, Henderson et al. (16) published a comprehensive report on physicians' attitudes and knowledge regarding the health-care needs of CCSs in the USA. On the other hand, there is no information in Japan regarding whether the pediatric oncologists in the previous treatment hospitals are comfortable with these adult-aged CCSs and have knowledge of the published guidelines or recommendations for late-effect surveillance (17,18). In addition, many CCSs have received long-term follow-up not only with pediatric oncologists but also with pediatric surgeons in Japan. To further understand physician attitudes and knowledge regarding the care of CCSs as they transition into adulthood in Japan, we conducted a comparative survey of pediatric oncologists and pediatric surgeons who belonged to the Japanese Society of Pediatric Oncology (JSPO).

PATIENTS AND METHODS

Participants

The approval of both St Luke's International Hospital review board and the director board in JSPO was obtained before initiation of this study. Candidate participants were selected from the 2010 JSPO Membership Directory. From the available directory, 1381 potential survey members with sufficient addresses for survey mailings were identified. Of those, we identified 1022 members specialized in pediatric hematology/oncology or pediatric surgical oncology.

Survey Mailings

A self-addressed survey was mailed to the 1022 eligible members. Through the initial mailing, 16 physicians were eliminated because of incorrect mailing addresses or because physicians were no longer clinically active, yielding a final sample of 1006 survey members. A second mailing was sent to all potential participants 4 weeks after the initial mailing.

Survey Method

The survey instrument was developed originally. Survey content and format was based on a previous study (16) regarding physician preferences and knowledge. The survey included 14 questions and used both quantitative (i.e. closed-ended questions) and qualitative (i.e. open-ended questions that asked for short responses) items (Supplementary data 1). The survey sought demographic information about participant's age, sex, practice environment, years since completion of formal training, estimated number of patients with cancer and cancer survivors seen per week in clinical practice, and information regarding prior learning with regard to childhood cancer survivorship. The definition of CCS was a patient who was at least 5 years from the completion of cancer therapy and was malignancy free.

Quantitative survey items queried participants regarding whether their practices were affiliated with a long-term follow-up program for cancer survivors and if it was routine practice to eventually refer their long-term survivors to other physicians. By using a seven-point Likert scale, physicians were asked about their comfort with caring for survivors at varying ages and were asked about their familiarity with the available monitoring guidelines for adolescent and young adult cancer survivors. Quantitative questions queried self-reported attitudes toward caring for long-term CCSs, referral pattern practices for their CCSs and their opinion of the best trajectory of care for CCSs.

The survey included a vignette of a 25-year-old woman treated at age 1 year for acute lymphoblastic leukemia whose treatment included prophylactic cranial radiation (24 Gy) and anthracycline and cyclophosphamide chemotherapy in Supplementary data 2. Three follow-up questions sought physicians' self-reports of the knowledge of health risks caused by pediatric cancers and the physicians' understanding of appropriate surveillance for these health risks on the basis of Japanese leukemia/lymphoma study group (JPLSG)'s recommendation (19).

Finally, participants were asked to give a free description whether they had anything else to add about their

Table 1. Demographic and practice characteristics of eligible study respondents

Characteristic	Pediatric oncologists ($n = 300$)		Pediatric surgeons ($n = 105$)		χ^2 (P value)
	No.	Per cent	No.	Per cent	
Age, years					
39 years of age or younger	87	30	22	21	0.180
40–47 years of age	79	27	24	23	
48–53 years of age	69	24	29	28	
54 years of age or older	58	20	28	27	
Gender					
Male	233	79	87	84	0.279
Female	63	21	17	16	
Years in practice					
14 years or shorter	82	28	26	26	0.316
15–21 years	74	25	22	22	
21–27 years	80	28	25	25	
28 years or longer	55	19	28	28	
Childhood cancer patients in outpatient clinic per week					*t*-test
Mean ± SD (median, range)	8.3 ± 11.8 (5.0, 0–100)		1.5 ± 2.4 (0.5, 0–10)		<0.001
Position					
Professor/Head	76	26	27	26	0.441
Associate Prof./Lecturer/Chief	103	35	42	41	
Assistant Prof./Fellow	87	30	25	24	
Resident/Doctor course	10	3	1	1	
Other (Clinics etc.)	16	6	8	8	
Living place (Post stamp)					
Hokkaido	15	5	4	4	0.001
Touhoku	21	7	4	4	
Kantou-Koushinetsu	78	26	34	32	
Toukai-Hokuriku	31[a]	10	3	3	
Kinki	51[a]	17	8	8	
Chu-Shikoku	20	7	11	10	
Kyusu-Okinawa	16	5	17[a]	16	
Unknown	68	23	24	23	
Practice environment					
Children's Hospital	24	8	12	11	0.152
University Hospital	154	52	52	50	
General Hospital	93	31	38	36	
Cancer Center	12[a]	4	0	0	
Private practice/others	15	5	3	3	
LT-FU Clinic at Hospital					
Yes	63	21	14	13	0.008
No	230	77	83	79	
Not sure	7	2	8[a]	8	

Continued

Table 1. *Continued*

Characteristic	Pediatric oncologists (n = 300)		Pediatric surgeons (n = 105)		χ^2 (P value)
	No.	Per cent	No.	Per cent	
Received Education or Learned about Late effects					
Yes	168[a]	56	21	20	<0.001
No	106	36	80[a]	77	
Not sure	24	8	3	3	
Educational experiences in the evaluation and management of childhood cancer survivors					
Government-sponsored meeting	70	23	1	1	<0.001
Symposium/Workshop	113	38	15	14	<0.001
Special Lecture	64	21	3	3	<0.001
Journal article(s)	104	35	12	11	<0.001
Book(s)	82	27	6	6	<0.001
Other	3	1	0	0	0.571

[a]Adjusted standardized residual >+1.96.

experiences with CCSs or the survey itself. After conducting a pilot testing with five pediatric oncologists, revisions were made. The survey questions were mailed with a cover letter to explain the purpose of the study and how to return the survey and introduce the original article (16). The survey was designed to be sealed within an envelope and mailed back to the study investigator (Y.I.) anonymously.

Statistical Analyses

All survey data were coded and entered into a database by using standard SPSS statistical software, ver. 19.0 (IBM Japan Co. Ltd, Tokyo, Japan). Descriptive statistics reported included the following: proportions, means and standard deviations, or medians and ranges. For between-group comparisons of continuous or ordinal variables, t-tests or non-parametric Wilcoxon's rank-sum tests were used as appropriate. For comparisons of categorical variables, χ^2 tests were used. As for cross-table comparisons, we used adjusted standardized residuals to evaluate the difference between the observed and expected values; the columns which give more than 1.96 of the adjusted standardized residual were considered as significant.

RESULTS

The two survey mailings were completed between October 2010 and January 2011. Four hundred fifty surveys returned; we excluded 45 sheets from non-pediatricians or non-pediatric surgeons. The total final survey response rate was 47% (405 out of 858): pediatric oncologists 56% (300 out of 533) and pediatric surgeons 32% (105 out of 325).

Demographic Data

Respondent demographic characteristics are listed in Table 1. The median age of respondents was 46 years (range: 29–78) for pediatric oncologists and 48.5 years of age (range: 29–71) for pediatric surgeons. Respondents had been in clinical practice a median of 20 years for pediatric oncologists and 22.5 years for pediatric surgeons. They saw a median of 5.0 and 0.5 CCS patients per week, respectively. A total of 19% of respondents reported that their hospital had a long-term follow-up clinic for CCSs. Pediatric surgeons had significant fewer learning experiences for care about CCSs in any type than pediatric oncologists did. The most popular educational or learning experience consisted of symposiums or workshops at the annual meeting and journal article for pediatric oncologists.

Physician Preferences in Care of CCSs and Optimal (Ideal) Care of Long-term CCSs

Physicians were asked to choose one of four responses that best summarized their current attitudes toward caring for long-term CCSs. As depicted in Table 2, 38% of the pediatric oncologists and 32% of the pediatric surgeons preferred following long-term CCSs as long as possible. There was no statistically significant difference between pediatric oncologists and pediatric surgeons.

As the optimal care of long-term CCSs, 51% of the pediatric oncologists and 42% of the pediatric surgeons answered that a CCS stays in their care until age 21 and then is referred. More pediatric surgeons answered that a CCS stays in their care anywhere between 2 and 5 years after the completion of therapy and then is referred regardless of his/her age.

Table 2. Responses to survey question

Response (select only one)	Pediatric oncologists (%)	Pediatric surgeons (%)	χ^2 (*P* value)
About current attitude toward care for long-term survivors of childhood cancer			
(a) I prefer to be their doctor as long as possible	115 (38)	34 (32)	0.211
(b) Although I enjoy some of the social aspects of their clinic visits, I prefer these patients be seen by a physician other than myself	23 (8)	14 (13)	
(c) I prefer to refer them and/or discharge them from my clinic at the first opportunity	19 (6)	7 (7)	
(d) I am willing to see them and continue to care for them in the absence of a more suitable clinician	129 (43)	50 (48)	
(e) Other	14[a] (5)	0	
About the trajectory which best summarizes your opinion of the OPTIMAL care of long-term cancer survivors			
(a) The patient stays in my care forever (throughout childhood and adulthood)	60 (21)	23 (23)	0.089
(b) The patient stays in my care anywhere between 2 and 5 years after the completion of therapy and then is referred regardless of his/her age	67 (23)	34[a] (34)	
(c) The patient stays in my care until age 21 and then is referred	148 (51)	42 (42)	
(d) Other	15 (5)	2 (2)	

[a]Adjusted standardized residual $> +1.96$.

Referral Preferences

Respondents were asked to report if it was their practice to eventually refer their long-term cancer survivors to other physicians and 31% of respondents answered yes. One-third (34%) of these respondents reported referring long-term survivors to a long-term follow-up program, 23% reported referring them to a primary care physician, 29% responded that they referred them to adult oncologists and 13% reported referring them to some other physician or health-care provider.

Comfort Levels of Caring for CCSs

Three survey items queried participants' comfort levels with caring for pediatric cancer survivors within three different age groups (Fig. 1). Respondents were asked to report their comfort levels on a seven-point Likert scale. A score of 1 was associated with very uncomfortable; a score of 7 was associated with being very comfortable. Both pediatric oncologists and pediatric surgeons reported being most comfortable with caring for survivors who were 21 years of age or younger (mean $\pm$ SD, 4.4 ± 1.3 and 3.8 ± 1.4 level, respectively), being less comfortable with survivors older than 21 years and <30 years (3.6 ± 1.4 and 3.6 ± 1.4 level, respectively) and being most uncomfortable caring for survivors 30 years or older (2.8 ± 1.5 and 3.3 ± 1.6 level, respectively). While pediatric oncologists became less comfortable with survivors as they aged out of the pediatric age range, pediatric surgeons' comfort levels remained relatively consistent throughout all age groups.

Knowledge of Recommendations for Late Effects

Participants' knowledge of the current JPLSG recommendations for surveillance of late effects was examined through a vignette that described a 25-year-old woman treated at age 1 year for ALL with 24 Gy cranial radiation and anthracyclines (cumulative dose: 180 mg/m^2). Respondents were asked about the follow-up frequency and method, hepatitis C infection and late effects of cranial radiation (Supplementary data 2). On the basis of the JPLSG recommendations, 78% of the pediatric oncologists and 70% of the pediatric surgeons appropriately recommended the follow-up frequency and method (not significant); however, 53% of the pediatric oncologists and 38% of the pediatric surgeons appropriately recommended hepatitis C infection treatment; this difference was significant. Lastly, 92/49% of the pediatric oncologists and 77/36% of the pediatric surgeons appropriately answered the questions related with the late effects of cranial radiation (statistically significant, respectively). Overall, only 47% of the respondents (62% of the pediatric oncologists and 43% of the pediatric surgeons) answered three or more questions appropriately.

Familiarity with Long-term Follow-up Guidelines

Participants were queried about their familiarity with the available monitoring guidelines for adolescent and young adult cancer survivors by using a seven-point Likert scale. The definition of familiarity was left to the discretion of the individual respondent. A score of 1 meant a respondent was very unfamiliar, a score of 4 meant they were somewhat familiar and a score of 7 reflected that a respondent was very

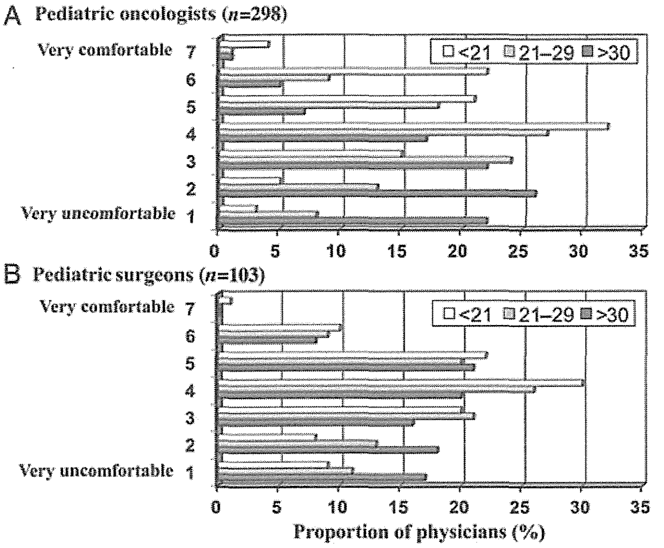

Figure 1. How comfortable are you in managing and caring for adolescent and young adult survivors of childhood cancer depending age? Respondents were asked to report their comfort levels on a seven-point Likert scale. A score of 1 was associated with very uncomfortable; a score of 7 was associated with being very comfortable. (A) Pediatric oncologists and (B) pediatric surgeons.

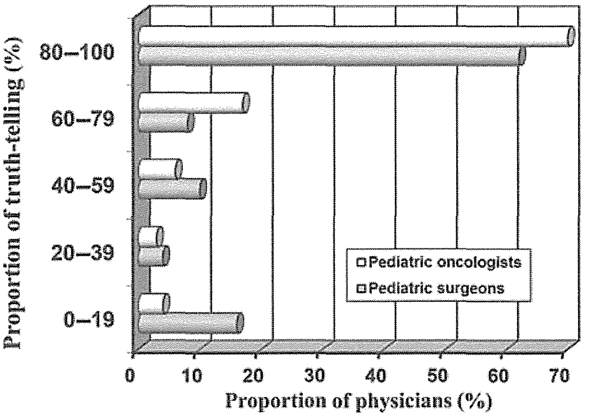

Figure 2. The proportion of truth-telling of cancer diagnosis in adult survivors with childhood cancer. The percentage of adult survivors with childhood cancer giving truth-telling of cancer diagnosis was categorized into five groups: 0–19, 20–39, 40–59, 60–79 or 80–100%.

familiar. Overall, surveyed pediatric oncologists were significantly more familiar with the available guidelines than pediatric surgeons; the mean score (±SD) was 2.8 (±1.4) for pediatric oncologists and 1.5 (±1.4) for pediatric surgeons ($P < 0.001$).

The Proportion of Truth-telling of Cancer Diagnosis in Adult CCSs

Seventy percent of the pediatric oncologists and 62% of the pediatric surgeons in this study reported that the proportion of truth-telling of cancer was 80–100% (Fig. 2). There was a statistical significant difference in distribution between pediatric oncologists and pediatric surgeons ($P < 0.001$).

Level of Interest in Collaborations with Adult-based Clinicians to Care for CCS

Participants were queried about their interest in collaborations with adult-based clinicians to care for CCSs by using a seven-point Likert scale. Overall, both pediatric oncologists and pediatric surgeons were much interested in collaborations with adult physicians, as the mean score (±SD) was 3.1 (±1.6) for pediatric oncologists and 3.0 (±1.5) for pediatric surgeons.

Important Issues for a Long-term Follow-up of Adult CCSs

The most important issues for long-term follow-up for adult CCSs cited by both pediatric oncologists and pediatric surgeons were an original long-term follow-up guideline suitable for the Japanese situation and a passport (individualized clinical records) to share information (Table 3). There was no significant difference in distribution between pediatric oncologists and pediatric surgeons with regard to the most important issues. However, as for important issues for collaboration with adult-based general physicians, both pediatric oncologists and surgeons think that it is of prime importance to have enough knowledge about late effects. More pediatric oncologists than pediatric surgeons demanded sympathy with CCSs and/or their parents, and the ability to introduce organ-specific specialists.

DISCUSSION

We found that pediatric oncologists in Japan were increasingly uncomfortable with caring for adult survivors as they age, and the preference and knowledge with regard to long-term follow-up care of young-adult CCSs were different between pediatric oncologists and surgeons in Japan. To our knowledge, our survey is the first large study in Japan that examines physician attitudes toward and knowledge of risk-based healthcare, including surveillance of late effects of CCSs.

The results of our study are consistent with Henderson et al.'s study of US pediatric oncologists (16). First, as the age of CCSs increases, pediatric oncologist-reported comfort levels in caring for them decrease. However, in contrast to the Henderson study, more physicians report that they prefer to observe their CCSs for as long as possible when compared with US physicians (16). Japanese physicians have had profound attachment with their patients, which is observed in doctor–patient relationships in chronically or severely ill children as reported also in western countries (20–22). In this study, many Japanese physicians had felt uncomfortable to follow adult CCSs by themselves. Systematic efforts should be made after cancer treatment not only to empower the CCSs/families by making available age-appropriate

Table 3. Important issue when you conduct a long-term follow-up for adult childhood cancer survivors and collaboration with adult-based general physicians

Issues	Pediatric oncologists (%)	Pediatric surgeons (%)	*P* value
Long-term follow-up of adult CCSs (select only one)			
(a) An original long-term follow-up guideline suitable to Japan situation	110 (39)	50 (50)	0.494
(b) A passport (individualized clinical records) to share with information	100 (38)	30 (30)	
(c) Provide information to adult-based physician	24 (9)	7 (7)	
(d) Education and empowerment for CCSs	41 (15)	13 (13)	
(e) Other	1 (0.4)	0	
Collaboration with adult-based general physicians (select all that apply)?			
(a) Enough knowledge about late effects of CCSs	270 (90)	82 (98)	0.495
(b) Sympathy with CCSs and/or their parents	238 (79)	73 (70)	0.040
(c) Ability to introduce organ-specific specialists if needed	184 (61)	46 (44)	0.002
(d) Equipment of enough machines for further examination	35 (12)	15 (14)	0.483
(e) Experience as a pediatrician	18 (6)	12 (11)	0.068
(f) Other	3 (0.1)	0	—

information but also to provide adult-based physicians the necessary information (8). These efforts will be especially important in dealing with the sustainable transition from the pediatric to the adult-focused health-care system. A specific program will be needed to facilitate these transitions (10,23,24).

Secondly, the survey results suggest that many pediatric oncologists in Japan are not familiar with available long-term follow-up guidelines compared with US pediatric oncologists (16), mainly because there is no available long-term follow-up guideline for CCSs in Japanese today. Recently, we formulated the Japanese translated version of COG long-term follow-up guidelines in JPLSG homepage (http://www.jplsg.jp/) (19). Only 62% of the pediatric oncologists and 43% of the pediatric surgeons answered three or more of our four vignette-based questions regarding late effects on the basis of available JPLSG recommendations (19).

To achieve effective follow-up for CCSs, truth-telling is an indispensable process for CCSs (12,13). In 2007, Parsons et al. (14) reported that US physicians had a consistent pattern of telling children (65% always told the child; <1% rarely or never told), while Japanese physicians had greater variability in their patterns of telling (with only 9.5% always telling and 34.5% rarely or never telling). During these 10 years, the situation around truth-telling to children with cancer has been dramatically changed in Japan. Our study demonstrated that most pediatric oncologists conduct truth-telling of cancer diagnosis at least to adult CCSs now, and there are no barriers to facilitating effective follow-up.

The most important issues for long-term follow-up for adult CCSs cited by both pediatric oncologists and pediatric surgeons in this survey were an original long-term follow-up guideline suitable for the Japanese situation and a follow-up passport to share information. The long-term follow-up committee of JPLSG has been developing new original guidelines and a long-term follow-up diary now.

It is very interesting that most pediatric oncologists and pediatric surgeons demand not only enough knowledge about late effects of CCSs but also 'sympathy' with CCSs and/or their parents from adult-based general physicians for the purpose of collaboration. There were a lot of opinions to list 'sympathetic ability' as an indispensable nature to succeed transition though semi-structured interviews of the pediatricians in long-term follow-up (25). To our knowledge, many CCSs who were once introduced to an adult department returned to the pediatric department again because of the reasons: 'an adult-based physician is cold' or 'he/she doesn't listen to my story enough', and many CCSs had a sense of hesitation in consulting the adult-based physician.

This study has important strengths. First, this study is based on a national study including not only pediatric oncologists but also pediatric surgeons involved in pediatric oncology practice in JSPO. We can compare between pediatric oncologists and pediatric surgeons with regard to their preference and knowledge about adult CCSs. Secondly, this study revealed for the first time the change in the truth-telling situation in Japan and the preference for collaboration with adult-based physicians to care for adult CCSs.

There are, however, some limitations to our study. First, the response rates were not satisfactory especially for pediatric surgeons. These results may be subject to a response bias (i.e. those with a stronger interest in the topic may have been more likely to have responded to our survey). Conversely, there was no statistically significant difference in the gender or geographic location of responders compared with non-responders, age and time in practice of non-responders by the available JSPO member's information. Secondly, the results were entirely based on pediatric oncologists' self-report of comfort levels with caring for and transitioning care for CCSs. Thus, these results cannot necessarily be relied on to represent what occurs in actual pediatric oncologist clinical practice. In addition, these results cannot be relied on to represent the experiences of other physicians who may be involved in caring for long-term CCSs (e.g. primary care physicians). Given the limitations, it is important that additional studies be undertaken to explore physician attitudes and knowledge outside the cancer center-based pediatric oncology specialty to include physicians in adult oncology as well as in primary care, including pediatrics, internal medicine and family medicine. Lastly, it must be highlighted that the current JPLSG recommendations, on which our clinical vignette questions were created, are based on limited data and, in many cases, expert opinion.

In conclusion, our study suggests that pediatric oncologists are increasingly uncomfortable with caring for survivors as they age and have suboptimal knowledge regarding the current recommendations for late effects. Preference and knowledge with regard to long-term follow-up care of young-adult CCSs are different between pediatric oncologists and pediatric surgeons in Japan. Findings from this study should provide a foundation for additional research and possible targeted interventions that hope to improve physician knowledge.

Authors' contributions

Conception and design: Y.I., M.T. and M.Ma.; financial support: Y.I., M.Mo. and A.M.; administrative support: Y.I.; provision of study materials or patients: Y.I. and A.M.; collection and assembly of data: Y.I.; data analysis and interpretation: Y.I., M.T., M.Ma., T.O.H. and C.K.D.; manuscript writing: Y.I., M.T., T.O.H. and A.M.; final approval of manuscript: Y.I., M.T., M.Ma., M.Mo., T.O.H., C.K.D. and A.M.

Supplementary data

Supplementary data are available at http://www.jjco.oxfordjournals.org.

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Conflict of interest statement

None declared.

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ORIGINAL ARTICLE

Implications of surgical intervention in the treatment of neuroblastomas: 20-year experience of a single institution

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Abstract

Purpose The implications of surgical intervention for neuroblastomas were assessed in one institution.

Methods We analyzed the clinical characteristics and extension of resection in 123 pediatric patients with neuroblastoma diagnosed between 1985 and 2004.

Results The 5-year survival rate of the 82 patients under 12 months of age, 59 of whom were treated with complete resection of the primary tumor, was 97%. The 5-year survival rate of the 41 patients over 12 months of age did not differ significantly according to whether complete ($n = 19$) or incomplete resection ($n = 22$) was performed (46 vs. 38%, respectively). No local recurrence was observed in ten patients over 12 months of age with stage 4 disease who underwent complete resection of the primary tumor; however, four of these ten patients died of metastatic recurrence.

Conclusion Considering that the majority of infantile neuroblastomas in this study had favorable biology, complete resection might be unnecessary for patients under 12 years of age. For advanced neuroblastomas in patients over 12 months of age, the main treatment for metastasis is systemic chemotherapy, although extirpation of the primary tumor without extensive surgery might prevent local recurrence when combined with radiation therapy.

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Keywords Neuroblastoma · Surgical intervention · Biology

Introduction

Neuroblastoma is the most common solid tumor in children, and its development is still uncharacterized [1]. The prognosis varies greatly, based on the clinical prognostic and biological prognostic factors [2]; thus, it is important to select the optimal therapy according to the properties of these tumors [3]. There are three types of surgical intervention for neuroblastoma: initial tumor extirpation, biopsy of the tumor at initial diagnosis; and radical surgery as a second-look operation after biopsy and induction chemotherapy. The role of surgical resection in the treatment of neuroblastomas is still controversial [4]. We conducted the present study to evaluate the implications of surgical intervention for neuroblastomas in patients under 12 months of age versus those over 12 months of age, based on an analysis of patients treated at one institution.

Patients and methods

A total of 123 patients had neuroblastoma diagnosed and treated at the Department of Pediatric Surgery, Kyushu University, between 1985 and 2004. This study was performed according to the Ethical Guidelines for Clinical Research published by the Ministry of Health, Labor, and Welfare of Japan on July 30, 2003. Consent for tumor preservation and biological analysis was obtained from the parents of each pediatric patient before surgery. Of the 123 patients, 82 were less than 12 months of age and 41 were 12 months of age or older. Of the 82 neuroblastomas in