

## A national profile of the impact of parental cancer on their children in Japan



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### ABSTRACT

**Objective:** Dependent children under the age of 18 are particularly vulnerable to the stress of parental death from cancer or of having a parent diagnosed and treated for the disease. More and more Japanese couples are postponing parenthood, which increases their chances of developing cancer while they still have a dependent child. However, the problem has not received enough attention from healthcare professionals and policy-makers because the extent and breadth of the problem has never been examined in the Japanese population. Therefore, we aimed to estimate the nationwide incidence of cancer patients who have children under the age of 18 years, as well as the incidence of children who have a parent diagnosed with cancer in Japan.

**Study design:** We calculated the proportion of patients who have children stratified by age, gender and cancer type using electronic medical records of cancer patients (20–59 years old) admitted to the National Cancer Center Hospital (NCCH) for the first time between January 2009 and December 2013. We projected these estimates onto the Japanese population using 2010 population-based cancer registry data, and repeated the projection using 2011 hospital-based cancer registry data so that estimates of patients receiving care at Designated Cancer Care (DCC) hospitals could be obtained.

**Results:** We found that an estimated 56,143 cancer patients who have 87,017 dependent children are diagnosed with cancer every year in Japan. The proportion of children in Japan who had a parent newly diagnosed with cancer in 2010 was approximately 0.38%. We estimated that in 2011 there were on average about 82 cancer patients with minor children and 128 minor children who have at least one parent diagnosed with cancer in every DCC hospital in Japan.

**Conclusion:** Parental cancer is common. We have identified that many adults diagnosed with cancer have the double burden of coping with the diagnosis and treatment as well as supporting their children through this experience. Additional data on socioeconomic characteristics and needs assessment of these patients are required to understand how best to help children and families cope with cancer.

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## 1. Background

A cancer diagnosis often has a significant negative impact on the lives of patients and their families [1]. It influences the psychosocial and emotional wellbeing of minor children. [2] However, cancer among parents who have dependent children is becoming an increasing problem in many developed countries as more people postpone parenthood [3]. The lifetime risk of cancer

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in Japan is stunningly high compared to that in other countries – 56% for males and 43% for females [4] (US: 43% and 38% [5], UK: 44% and 40% [6], respectively) – which means that a greater number of individuals will become parents at an age where cancer risks are high and their children are still young and dependent. Even if these patients constitute a small group of cancer patients, it is nonetheless a growing problem that deserves special attention because of its severe and long-lasting impact on both the child and the patient.

In spite of this clear need for more attention, no study has ever captured the severity of the issue in Japan. In Norway, approximately 4% of children aged 0–25 years have or have had parents diagnosed with cancer, which corresponds to a population prevalence of 1.4% [7]. At least 18% of cancer patients in the United States have minor children. [8] The purpose of this study was to obtain national estimates for the number and proportion of cancer patients who have dependent minor children, as well as the national estimates for the number of children with a cancer parent in Japan.

## 2. Methods

### 2.1. Data sources

Using the NCCH's electronic medical records (EMRs), we identified patients between the ages of 20 and 59 who were admitted to the National Cancer Center Hospital (NCCH) for the first time between January 2009 and December 2013. We extracted their age at their first hospital admission, gender, and the number, age, and gender of their children, and excluded patients who could not be identified within the hospital-based cancer registry (HBCR) database which contained their International Classification of Diseases Oncology, 3rd edition (ICD-O-3) topography and morphology codes.

We used the 2010 population-based cancer registry (PBCR) and the 2011 HBCR data to make inferences for the burden of cancer among patients with children for the total Japanese population and also for patients who received care at a designated cancer care

(DCC) hospital in Japan. The PBCR collects cancer surveillance data from 35 prefectures (out of a total of 47) that have a case reporting system for newly diagnosed and treated cancer patients from hospitals and clinics within their prefecture. Because case reporting is not mandatory, PBCR data do not capture all cancer incidence in Japan [9]. The HBCR, on the other hand, is a compulsory cancer incidence reporting system for DCC hospitals in Japan. In 2011, there were 395 hospitals that were designated as DCC by the Ministry of Health, Labor, and Welfare, to play a major role in the prevention, diagnosis, and treatment of cancer for most cancer patients. Although there are non-designated hospitals that also care for cancer patients, they are not required to submit their surveillance data to the HBCR.

### 2.2. Analyses

We calculated the number and proportion of cancer patients with dependent children under the age of 18, stratified by the patient's gender, age group (ages 20–29, 30–39, 40–49 and 50–59) and cancer types from data obtained from NCCH's EMRs. We also counted the total number of children among all cancer parents according to the child's age group (ages 0–6, 7–12, 13–15, and 16–18) and gender. Data were analyzed using Stata 13.1 (Stata Corporation, College Station, TX, USA).

We made inferences for the number of cancer patients who have dependent children in Japan, as well as the number of children with a parent diagnosed with cancer in a year, by multiplying them by the incidence of cancer for patients in the same strata of gender, age group, and cancer type as the PBCR. We also estimated the number of cancer parents and the number of children who have a parent with cancer who received care at DCC hospitals in Japan.

## 3. Results

Among 12,399 men and 10,786 women who were admitted to the NCCH for the first time between January 2009 and December

**Table 1**

The distribution of cancer patients who are parents between the ages of 20 and 59 at the time of first admission to the National Cancer Center Hospital between 2009 and 2013.

Age of patients	Male		Female		Total	
	N of patients (% of patients with minors)	Average N of children	N of patients (% of patients with minors)	Average N of children	N of patients (% of patients with minors)	Average N of children
20–29	142 3.5%	1.2	136 11.8%	1.6	278 7.6%	1.5
30–39	389 31.1%	1.7	555 34.2%	1.7	944 32.9%	1.7
40–49	726 46.4%	1.7	1310 41.3%	1.6	2036 43.1%	1.7
50–59	1705 16.8%	1.4	1727 8.9%	1.3	3432 12.8%	1.3
Total	2962 25.3%	1.6	3728 24.1%	1.6	6690 24.7%	1.6

Common cancer types	Male				Total N of patients with minors	Female					
	N of patients with minors					Common cancer types	N of patients with minors			Total N of patients with minors	
	Patients' age						Patients' age				
	20–29	30–39	40–49	50–59		20–29	30–39	40–49	50–59		
Gastric	0	15	48	54	117 (15.6%)	Breast	2	61	241	57	361 (40.1%)
Lung	0	13	41	45	99 (13.2%)	Uterus	0	18	61	15	94 (10.4%)
Colorectal	0	7	44	37	88 (11.7%)	Gastric	2	12	44	9	67 (7.4%)
Sarcoma	0	23	31	13	67 (8.9%)	Sarcoma	6	23	31	5	65 (7.2%)
Lymphoma	1	18	27	16	62 (8.3%)	Colorectal	2	11	31	14	58 (6.4%)

2013, we identified 8412 patients between the ages of 20 and 59. We excluded 1295 patients whose data could not be linked to HBCR data, and further excluded 427 patients with in-situ carcinoma because these patients were not registered within the PBCR. This left 2962 males (44.3%) and 3731 females (55.7%) in the analyses.

We identified 2593 minor children among 1650 cancer patients in our study. Roughly a quarter of both male (25.3%) and female (24.1%) patients had at least one minor child (Table 1). The average age of fathers who had cancer was 3 years older than mothers with cancer (mean: 46.6 versus 43.7 years, SD: 7.0 versus 6.1 years,  $P < 0.05$ ). The average number of minor children for a cancer patient in our study was highest among patients in their 30s and 40s. The most common cancer types for fathers with children were gastric (15.6%), lung (13.2%), and colorectal (11.7%) cancers, and for the mothers breast (40.1%), uterus (10.4%), gastric (7.4%) cancers (Table 1). The average age of the children was 11.2 years (SD: 5.2). The proportion of children whose parent had cancer tended to increase as the child's age increased (Fig. 1).

Using incidence rates of cancer patients from the PBCR and HBCR within the same strata of age, gender, and cancer type, we estimated that 56,143 patients with 87,017 children were diagnosed with cancer in Japan in 2010, and among these 32,679 cancer patients with 50,752 minor children received care at DCC hospitals (Table 2).

#### 4. Discussion

Our study showed that an estimated 56,143 cancer patients who had 87,017 dependent children were diagnosed with cancer in Japan in a year. Given that the total population of minors in Japan was 22,780,000 in 2010 [10], the proportion of children with a parent diagnosed with cancer was approximately 0.38%. The most common age group for cancer patients with children was 40–49 years old, and the most common cancer type was breast cancer. The number of children with parental cancer increased as the child's age increased.

**Table 2**

National estimates of the incidence of cancer patients with children and children with cancer parents projected from population-based and hospital-based cancer registry (PBCR and HBCR) data (per 1 year).

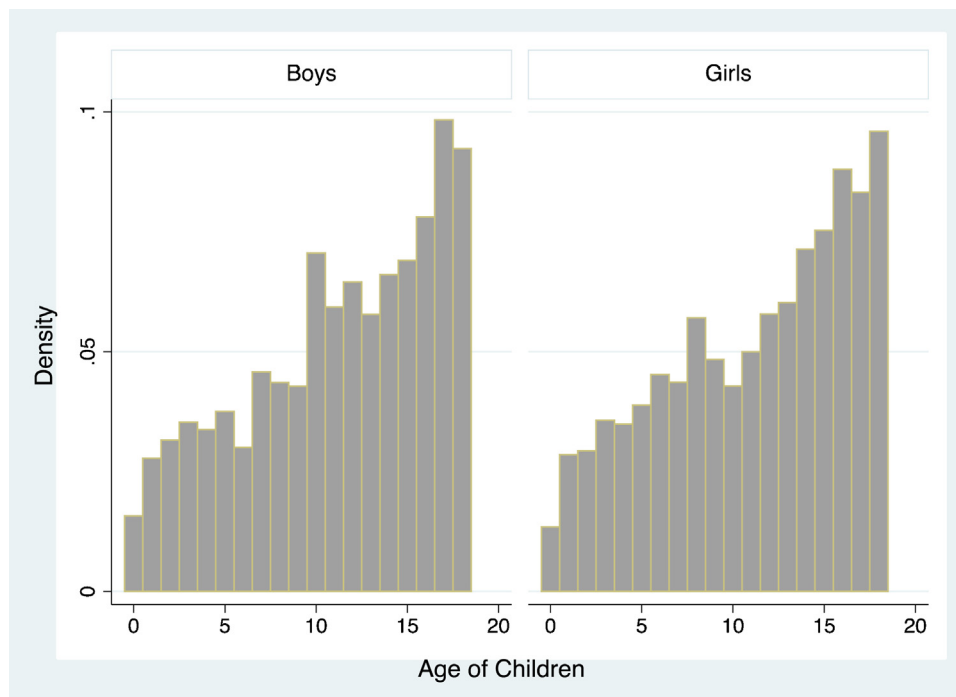
Age of patients	Male		Female		Total	
	PBCR	HBCR	PBCR	HBCR	PBCR	HBCR
20–29	66	78	310	291	377	369
30–39	1922	1417	5702	5196	7623	6613
40–49	9460	5210	18885	11121	28345	16331
50–59	13478	5910	6320	3456	19797	9366
Total	24926	12615	31217	20064	56143	32679

Age of children	Boys		Girls		Total	
	PBCR	HBCR	PBCR	HBCR	PBCR	HBCR
0–6	13591	7927	13625	7947	27216	15874
7–12	14598	8515	12685	7399	27283	15913
13–15	8625	5030	8759	5108	17383	10139
16–18	7886	4600	7249	4228	15135	8827
Total	44700	26071	42317	24681	87017	50752

PBCR, population-based cancer registry; HBCR, hospital-based cancer registry.

Prior study has shown that patients with invasive cancer who have dependent children tend to be more anxious, more likely to prefer aggressive treatment over palliative care, and more likely to have worse quality of life in their last weeks of life compared to patients without dependent children [11]. Adolescent teens who have a parent with cancer experience higher levels of emotional stress compared to their younger school-aged counterparts [12,13]. Gender, birth order and number of siblings, and single parenthood also may predict the risk of emotional problems in the child or adolescent [14]. Future research should investigate the background and specific needs of cancer patients and their children, so that healthcare providers and policy-makers can develop necessary support services for future patients and their children. Other countries have developed various programs and interventions to support children who have a parent with cancer. Support ranges from family sessions to parallel group sessions for children and



**Fig. 1.** The distribution of the ages of dependent children with a parent diagnosed with cancer in the National Cancer Center Hospital between 2009 and 2013.

parents [15]. These programs suggest the need to explore the types of psychosocial support that might be provided in Japan.

There are several limitations to this study. First, we used figures obtained at the NCCH to make national inferences using PBCR cancer incidence data from patients in the same strata of age, gender, and cancer type. Therefore, if the number of the children within the same stratum in our study is different from that of the entire cancer patient population in Japan, our estimates may be biased. Another limitation arises from the use of PBCR data, which does not have a mandatory reporting system and does not capture all incidences of cancer in Japan. This may have resulted in an underestimation of our findings. Lastly, we did not include data from cancer patients who were very young or very old. However, we obtained similar results to those of a study in Norway that used cancer registry and national birth cohort data of cancer patients between 17 and 70 years of age. They report that annual incidence of parental cancer for children under 18 years of age was 0.3%. Future studies should include data from various hospitals so that a more representative estimate is obtained.

## 5. Conclusion

To our knowledge, this is the first study to estimate the nationwide incidence of cancer among patients who have minor children in Japan. Our finding showed that a substantial number of children are likely to be experiencing the hardships of having their parents diagnosed with cancer. Greater attention should be paid to these children by both service-providers and policy-makers. The cancer parent also faces the added burden of child-rearing while undergoing cancer treatment. More research on the demographic and socioeconomic characteristics of these patients will be helpful in understanding the needs of the patients and in planning effective support programs for both cancer patients and their children.

## Authors' contribution

I declare that all authors participated sufficiently in this research. All authors participated in drafting the article or revising it critically for important content, and gave final approval of the version to be submitted and any revised version.

Specific contributions were made by:

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