



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%)

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