Trend in the Number of Registrations for Neuroblastoma in Japan

To the Editor:

In 1984, a nationwide mass screening (MS) program of 6-month-old infants for neuroblastoma (NB) was launched throughout Japan (1). However, some studies demonstrated that while NB screening was useful, it also resulted in ‘over-diagnosis’. In the Quebec cohort study, the standardized mortality ratio when compared with that in a control area was 1.4 [95% confidence interval (CI): 0.85–2.3] and the standardized incidence ratio was 2.2 (95% CI: 1.8–2.6) (2). In addition, according to a German study, the mortality ratio was 1.4 per 100 000 births in a screened area and 1.2 per 100 000 births in a control area; furthermore, the incidence rate of NB was 14.2 per 100 000 births in the screened area and 7.3 per 100 000 births in the control area (3). These data indicate that screening for NB in children less than 1 year old increased the incidence rate of NB, but did not lead to any significant reduction in the mortality from NB.

Follow-up without treatment is also an important medical therapeutic selection, and children with NB detected by screening are more often watched than treated (4). Although children who present after the age of 1 year with advanced disease have a poor prognosis (5), this does not justify the continuation of nationwide MS for NB.

Reports of spontaneous regression of NBs and complications following surgical treatment after MS also accelerated withdrawal of the MS program in Japan in 2004. Although one large cohort study from Japan reported that the mortality from NB was lower in children who were screened at 6 months old than that in a matched pre-screening cohort (6), it has been argued that the study was limited by its retrospective design and the lack of concurrent population-based controls (7).

There is a financial support system available in Japan for registered cases of children with chronic pediatric diseases, which are often refractory to treatment. NB is one of the diseases included in this registry system, and registrations are still ongoing (8), even though MS of 6-month-old infants for NB was discontinued in Japan in 2004 (9). The author used these data to describe the trend in the number of registrations.

As epidemiologic information, I present here the yearly trend in the number of new and continuous registrations of patients with NB who were included in the official database of the government (Fig. 1). The number of new registrations decreased by about half when compared with the number in 2004 (n = 255). The number of continuous registrations also decreased steadily and were half in number when compared with the number in 2004 (n = 2274).

Barrette et al. (10) reported, based on the North American project report, that the incidence of NB from a screened region dropped dramatically once the screening project was discontinued when compared with the results from the screened population of Quebec. I confirmed the same trend as the reports from the North American trial by using data from the patient registry system in Japan.

There is a possibility that some patients are not registered, although provision of financial support would accelerate registration of the patients. There is the issue of how good the national registry program for chronic pediatric diseases actually is. There is no legal obligation, and financial incentives for registering patients cannot guarantee that the number of registrations is a valid indicator. As a study to validate the NB registration data, the yearly number of NB registration by the Japanese Society of Pediatric Surgeon (11) is also presented in Fig. 1. Cancer registration by the Japanese Society of Pediatric Surgeons is considered to be research activity, and the regulation of personal information protection law, which was set in 2005, is strictly applied to it. Time-consuming process for obtaining informed consent from all the patients is required to make cancer registration, and the decrease in percentage of registration in 2005 and thereafter is suspected. The number of registration in 2004 was almost half compared with the number of registration in 2003.

The drop in the incidence rate of NB was clearly evident after the discontinuation of the MS program in Japan. In addition to the decrease in the number of newly registered cases after the discontinuation of MS, the number of continuous registrations also decreased. I speculate that the parents of patients in the continuous registration group stopped registration based on information about discontinuation of the MS for NB with suggestion by a medical specialist. The percentage of registered NB patients receiving medical treatment would also affect the trend of registration. Katanoda et al. (12) reported the secular trends in NB mortality before and after the discontinuation of the national MS program in Japan and concluded that no significant increase in the NB mortality rate was observed after the discontinuation of the MS program in Japan. Although determination...
of the life prognosis of NB is most important, the national registry program for chronic pediatric diseases is also a source of information about the clinical epidemiology of NB during the era of MS and after discontinuation of the MS program.

Conflict of interest statement
None declared.

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