



# Factors associated with employment status among mothers of survivors of childhood cancer: a cross-sectional study

Hiromi Okada<sup>1,2</sup> · Wataru Irie<sup>1</sup> · Akiko Sugahara<sup>1</sup> · Yuko Nagoya<sup>1,3</sup> · Masayo Saito<sup>1,4</sup> · Yoji Sasahara<sup>5</sup> · Yasuko Yoshimoto<sup>6</sup> · Fuminori Iwasaki<sup>7</sup> · Masami Inoue<sup>8</sup> · Maho Sato<sup>8</sup> · Miwa Ozawa<sup>9</sup> · Shigenori Kusuki<sup>10</sup> · Junji Kamizono<sup>11</sup> · Yasushi Ishida<sup>12</sup> · Ryoko Suzuki<sup>13</sup> · Ryoko Nakajima-Yamaguchi<sup>14</sup> · Hitoshi Shiwaku<sup>1</sup>

Received: 22 October 2022 / Accepted: 31 January 2023 / Published online: 14 February 2023  
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2023

## Abstract

**Purpose** To identify the factors associated with employment status among mothers of childhood cancer survivors (CCSs).

**Methods** We conducted a questionnaire survey on mothers of survivors of childhood cancer to clarify practical factors such as care demands, psychological factors such as motivation to work, and support. After calculating descriptive statistics for all variables, binary logistic regression analysis was performed.

**Results** Of 171 mothers, 129 (75.4%) were employed. The most common form of employment was non-regular ( $n = 83$ ; 48.5%), including part-time, dispatched, and fixed-term workers. At the time of the survey, compared with nonworking mothers, working mothers tended to be more motivated to work and have lower scores for “Long-term Uncertainty” on the Parent Experience of Child Illness Scale. The results of the binary logistic regression analysis indicated that employment was related to higher motivation to work, the continuation of employment during treatment, more outpatient visits, and a higher amount of support.

**Conclusion** As employment of CCSs’ mothers is associated with psychological factors such as motivation to work and long-term uncertainty, psychological support for CCSs’ mothers might promote employment. In addition, because the continuation of employment during treatment affects the employment of mothers after the end of cancer treatment, a leave system that covers the treatment period for childhood cancer needs to be established.

**Keywords** Childhood cancer survivors · Cross-sectional study · Employment status · Mothers

✉ Hiromi Okada  
h-okada@thcu.ac.jp

<sup>1</sup> Department of Child Health Nursing, Tohoku University Graduate School of Medicine, Sendai, Miyagi, Japan

<sup>2</sup> Faculty of Healthcare, Tokyo Healthcare University, 4-1-17 Higashi-Gotanda, Shinagawa-ku, Tokyo 141-8648, Japan

<sup>3</sup> Department of Nursing, Miyagi University, Sendai, Miyagi, Japan

<sup>4</sup> Department of Nursing, School of Health Science, Akita University Graduate School of Medicine and Faculty of Medicine, Akita, Akita, Japan

<sup>5</sup> Department of Pediatrics, Tohoku University Graduate School of Medicine, Sendai, Miyagi, Japan

<sup>6</sup> Sapporo Hokuyu Hospital, Sapporo, Hokkaido, Japan

<sup>7</sup> Division of Hematology and Oncology, Kanagawa Children’s Medical Center, Yokohama, Kanagawa, Japan

<sup>8</sup> Department of Hematology/Oncology, Osaka Women’s and Children’s Hospital, Izumi, Osaka, Japan

<sup>9</sup> Department of Pediatrics, St. Luke’s International Hospital, Chuo-Ku, Tokyo, Japan

<sup>10</sup> Child Chemo Clinic, Kobe, Hyogo, Japan

<sup>11</sup> Children’s Medical Center, Kitakyushu City Yahata Hospital, Kitakyushu, Fukuoka, Japan

<sup>12</sup> Pediatric Medical Center, Ehime Prefectural Central Hospital, Matsuyama, Ehime, Japan

<sup>13</sup> Department of Child Health, Faculty of Medicine, University of Tsukuba, Tsukuba, Ibaraki, Japan

<sup>14</sup> Child Health and Cancer Research Center, Ibaraki Children’s Hospital, Mito, Ibaraki, Japan

## Introduction

The standard of psychosocial care for childhood cancer includes assessments and interventions into the financial burden of families, which should be taken during the cancer treatment trajectory from the time of diagnosis throughout survivorship [1]. As the parental socioeconomic position might be associated with the health and survival rate of childhood cancer survivors (CCSs), support is needed to ease the financial burden on families during survivorship [2–4].

The disruption of parental employment is one of the main factors in a conceptual model that depicts the complex network contributing to financial toxicity (i.e., a financial burden related to a cancer diagnosis that has deleterious effects on familial quality-of-life outcomes) [5]. Changes in employment, including leaving a job, changes in work hours, or extended leave, occur from immediately to up to 1 year after a diagnosis [6, 7]. In particular, mothers discontinue work at a higher rate than do fathers because of their increased care burden for children with cancer during treatment [7–12]. Although the long-term impact on parental employment depends on the local labor market, labor policies, and social welfare systems, maternal unemployment rates remain high after treatment in some high-income countries [6, 9]. In Japan, if a child becomes ill, the Act on Childcare Leave/Caregiver Leave allows caregivers to take leave referred to as time-off for sick/injured childcare; however, only up to 5 days a year per child (younger than primary school age) are permitted. In addition, working individuals with a family member who requires constant care for 2 weeks or more because of an injury, illness, or physical/mental disability can use caregiver leave; however, this is set to a total of 93 days per family member. A reduction in income because of long-term interruptions in work increases the risk that the entire family of a CCS could fall into a vulnerable financial situation [8, 11]. Qualitative surveys of parents of CCSs have reported barriers that hinder a return to work, such as the child's health-care needs, anxiety about the child's health, feelings of guilt about returning to work, work inflexibility, a toxic work environment, and inadequate social and health-care services [13, 14].

Some mothers have reported anxiety and uncertainty about recurrence and late effects after treatment [15, 16]. The prevalence of anxiety, depression, and posttraumatic stress disorder in mothers of CCSs is higher than that of parents in general, and psychological problems at the clinical level can continue for years after the end of treatment [15, 17]. In addition, mothers often accompany their children on follow-up outpatient visits and provide care such as physical condition management [8]. They also deal with calls from the school in the event of a sudden deterioration of their CCS's physical condition [13, 14]. Because the risk of late effects increases with the duration

of treatment [18, 19], mothers continue to be involved in the medical care of their children regardless of how many years have passed [20, 21]. Previous studies [13, 14, 22] have indicated that psychological factors such as anxiety about recurrence or practical factors such as care demands for CCSs affect the employment of CCSs' mothers. Given this background, the present study aimed to identify the factors associated with maternal employment status, explore the employment status of mothers of CCSs in relation to support and both practical and psychological factors, and to clarify whether working mothers differ from nonworking mothers.

## Methods

### Study design and participants

We conducted a cross-sectional exploratory study on mothers of children who had been diagnosed with cancer before the age of 15 years, had been hospitalized for chemotherapy, and had completed cancer treatment. No criteria were set for the age of the mother, the age of the CCS (at the time of diagnosis and at present), or the number of years since completion. The exclusion criteria were mothers of CCSs who had experienced a recurrence and mothers who could not read or write Japanese and had difficulty understanding the purpose of this study. More than 40 mothers were included in both working and nonworking groups.

### Procedure

We recruited the participants from six hospitals (including two designated pediatric cancer hospitals) and one child clinic that provide intensive childhood cancer care from March to September 2021. However, due to the low participation of nonworking mothers, we conducted additional data collection from another four hospitals from September 2021 to May 2022. There are approximately 2000 new pediatric cancer patients per year in Japan, and the number of new patients in 2020 at the above 11 facilities was about 340. To grasp the current maternal work situation in Japan, we collected data from the following six areas: Hokkaido, Tohoku, Kanto, Kinki, Shikoku, and Kyushu. Pediatric oncologists and certified nurse specialists in child health nursing explained the details of the study to the participants who accompanied their children to a follow-up visit. Subjects were invited to participate in a survey on their own thoughts regarding working. The questionnaires were distributed to mothers who agreed to join or considered joining the research. The completed questionnaires were returned by mail. Participants were informed, both orally and in written form, of the purpose of this study, the guaranteed protection

of privacy, and the right to refuse to participate. Consent to participate in the research was obtained by checking the consent column of the questionnaire.

### Measures (available in the Supporting Information)

We developed a questionnaire based on previous studies [11, 14, 22, 23], and experts in pediatric oncology examined its validity. For the care demands question items, we listed care that was predicted to affect mothers' employment referring to research on the employment of mothers of children with disabilities [24]. Two mothers participated in the pretest.

#### Demographic data

The following demographic data were collected: age, education, marital status, postal code, household income, child's diagnosis, age of the child with cancer (both at the time of the diagnosis and at the time of the survey), months since the end of treatment, and late effects. Postal codes were used to classify residential areas into urban and rural areas.

#### Maternal employment status

The employment status of the mother at the time of the diagnosis, during treatment, and at the time of the survey was recorded using the following four possible answers: "regular employment," such as workers employed by a company for an indefinite period, "non-regular employment," such as part-time, dispatched, and fixed-term workers, "self-employment," and "homemaker." Additionally, we asked about changes in employment during treatment and whether the participants had any professional qualifications/licenses issued by a national or private organization (e.g., nurse, driver's license).

#### Practical factors

The following practical factors were recorded: frequency of outpatient visits, care demand, transfers to schools, nurseries, and kindergartens, and staying with the child at schools, nurseries, and kindergartens. The frequency of outpatient visits was grouped after confirming the frequency of each item, including the content of free descriptions. If one or more care items were marked "yes," care demand was coded as "yes."

#### Psychological factors

**Motivation to work** The following four options were provided regarding motivation to work at the time of the survey:

"I want to work/I want to continue to work (4)," "I'd prefer to work if I can/I'd prefer to continue to work if I can (3)," "I'd prefer not to work if I can avoid it/I'd prefer not to continue to work if I can avoid it (2)," and "I do not want to work/I do not want to continue to work (1)." To examine the reasons why the mothers wanted or did not want to work, questionnaire items were included with possible answers on a five-point scale ranging from "very applicable (5)" to "not applicable at all (1)."

**Parent Experience of Child Illness Scale (PECI)** The PEGI scale developed by Bonner and colleagues [25] is a 25-item self-report scale designed to assess parents' adjustment to their child's chronic illness. A Japanese version was subsequently developed by Nakajima-Yamaguchi and colleagues [26]. The PEGI has four subscales: "Guilt and Worry" (11 items,  $\alpha = 0.895$ ), "Unresolved Sorrow and Anger" (eight items,  $\alpha = 0.828$ ), "Long-term Uncertainty" (five items,  $\alpha = 0.827$ ), and "Emotional Resources" (five items,  $\alpha = 0.726$ ), and some items load onto multiple subscales. All items are rated on a five-point Likert scale from "never (0)" to "always (1)." Subscale scores are calculated by computing the mean.

#### Support

Questionnaire items for examining who provided support to mothers ("husband," "childhood cancer survivor," "sibling of childhood cancer survivor," "parent/relative," "friend," "neighbor," "doctor," "nurse," "boss/colleague," and "other") were included, with possible answers on a six-point scale, from "very helpful (5)" to "there is no such person (0)." Answers of "very helpful" or "helpful" to the above items were coded "1," and the sum was defined as the amount of support. We also asked about the financial support received for the CCS.

#### Analysis

Descriptive statistics were conducted for each item using SPSS (version 28.0; IBM SPSS Statistics, Tokyo, Japan). To clarify the differences between working and nonworking mothers, employment status at the time of the survey was divided into two groups: the "working mother (1)" group, which included regular employment, non-regular employment, and self-employment, and the "nonworking mother (0)" group. Then, the Mann-Whitney test,  $\chi^2$  test, and Fisher's exact test were performed, and the question items were compared. Binary logistic regression was used to estimate the factors for the employment status of mothers of CCSs based on the variables that were found to be significant in the bivariate analysis. The variables to be input into the model were selected from those found to be significant ( $p < 0.1$ ) in the Mann-Whitney,  $\chi^2$ , and Fisher's exact tests and those previously suggested to be related to the employment of mothers of CCSs

[13, 14, 22]. We confirmed that the covariate variables had a correlation coefficient and a coefficient of association  $\leq 0.2$ . To avoid biases and ensure the accuracy of the results, the numbers of mothers in the working and nonworking groups were set to the number of explanatory variables  $\times 10$  or over [27]. We input four variables from the mothers' demographic data, practical factors, psychological factors, and support into the model because of the sample size. Independent variables were selected by forward selection (likelihood ratio) and backward elimination (likelihood ratio). Then, variables from four factors (demographic data, practical factors, psychological factors, and support) were entered into a binary logistic regression analysis to identify the most suitable model. A two-sided  $p$  value  $< 0.05$  was considered to indicate statistical significance.

Missing values accounted for less than 3% of total items and appeared random. Because no measure had a specific rule for handling missing data in the PEGI scoring instructions, the mean value of the subscale of the respondent with missing data was replaced in "Guilt and Worry," "Long-term Uncertainty," and "Emotional Resources."

## Results

Of the 387 questionnaires distributed, 178 (45.9%) were returned. After excluding seven questionnaires that had incomplete data, 171 (44.2%) were finally analyzed (Fig. 1).

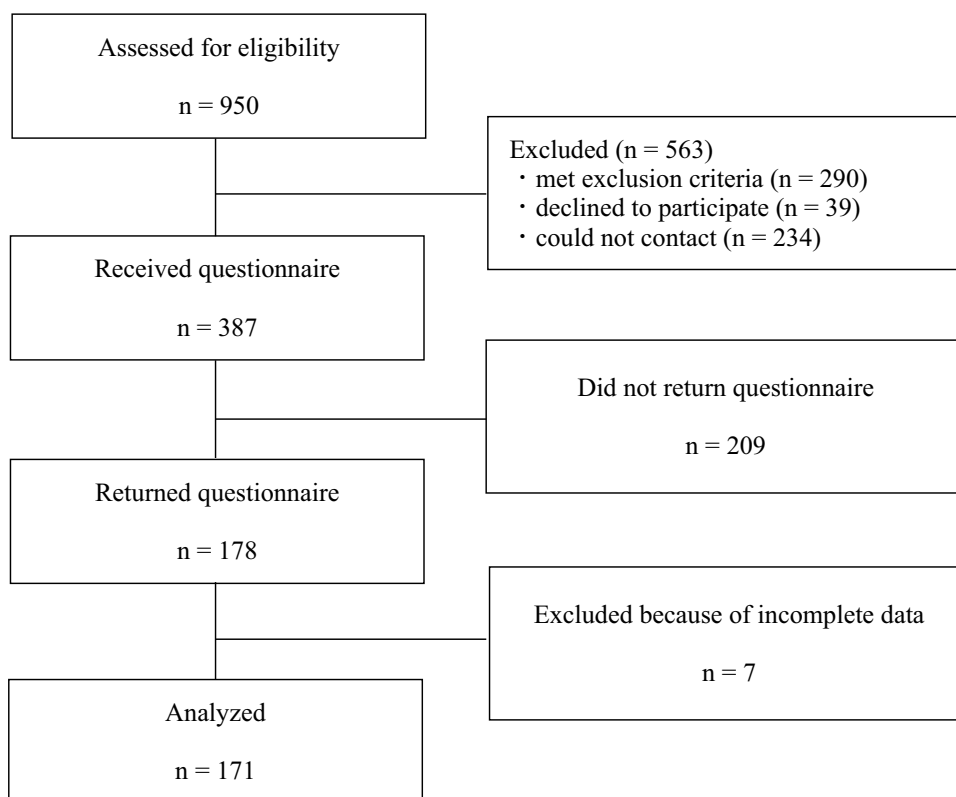
## Demographic characteristics (Table 1)

The median age (interquartile range) of the mothers in this study was 44 (41–49) years, and the median age of CCSs was 12 (8–17) years. The median elapsed period from treatment was 5 (2–10) years. The most common diagnosis was leukemia ( $n = 94$ ; 55.0%), followed by neuroblastoma ( $n = 19$ ; 11.1%), lymphoma ( $n = 14$ ; 8.2%), and brain tumor ( $n = 10$ ; 5.8%). Compared with nonworking mothers, working mothers had a significantly longer time since the end of treatment ( $p < 0.001$ ), fewer hematological tumors ( $p = 0.028$ ), and younger CCSs at the time of diagnosis ( $p = 0.047$ ).

## Employment status of mothers of CCSs

At the time of the survey, 129 mothers (75.4%) were working: 83 (48.5%) were non-regular employees, 37 (21.6%) were regular employees, and nine (5.3%) were self-employed. Of the 102 mothers (59.6%) who were working at the time of diagnosis, 20 regular employees (40.0%) and eight non-regular employees (18.6%) took a long leave of absence, and 18 regular employees (36.0%) and 25 non-regular employees (58.1%) quit their job. Working mothers worked significantly more often at the time of diagnosis ( $p = 0.002$ ) and during treatment ( $p = 0.003$ ) than did nonworking mothers.

**Fig. 1** Flowchart of study participation



**Table 1** Characteristics of the working and nonworking mothers in this study

Items	Total <i>n</i> = 171 <i>n</i> (%) or <i>M</i> [IQR]	Working mothers <i>n</i> = 129 (75.4%) <i>n</i> (%) or <i>M</i> [IQR]	Nonworking mothers <i>n</i> = 42 (24.6%) <i>n</i> (%) or <i>M</i> [IQR]	<i>P</i> value
<b>Mothers</b>				
Age, years	44 [41–49]	44 [41–49]	43 [40–49]	0.531
<b>Education</b>				
Completed university or graduate school	53 (31.0)	44 (34.3)	9 (22.5)	0.411
Completed college	32 (18.6)	22 (17.2)	10 (25.0)	
Completed vocational or technical training	42 (24.6)	33 (25.8)	9 (20.0)	
Completed high school	42 (24.6)	27 (21.1)	14 (32.5)	
Completed junior high school	2 (1.2)	2 (1.6)	0 (0.0)	
<b>Marital status</b>				
Married	151 (88.3)	112 (86.8)	39 (92.9)	0.410
Estranged/widowed/non-wedlock	20 (11.7)	17 (13.2)	3 (7.1)	
<b>Place of residence</b>				
Urban	70 (40.9)	50 (38.8)	20 (47.6)	0.369
Rural	100 (58.5)	78 (60.4)	22 (52.4)	
Missing	1 (0.6)	1 (0.8)	0 (0.0)	
<b>Household income (yen)</b>				
> 13,000,000	8 (4.7)	8 (6.2)	0 (0.0)	0.242
10,000,000–13,000,000	10 (5.8)	9 (7.0)	1 (2.4)	
7,000,000–10,000,000	48 (28.1)	34 (26.4)	14 (33.3)	
5,000,000–7,000,000	51 (29.8)	38 (29.5)	13 (31.0)	
3,000,000–5,000,000	31 (18.1)	20 (15.5)	11 (26.2)	
< 3,000,000	20 (11.7)	17 (13.2)	3 (7.1)	
Missing	3 (1.8)	3 (2.2)	0 (0.0)	
<b>Employment status at the time of diagnosis</b>				
Regular employment	50 (29.2)	44 (34.1)	6 (14.3)	0.002
Non-regular employment	43 (25.1)	34 (26.4)	9 (21.4)	
Self-employment	9 (5.3)	9 (7.0)	0 (0.0)	
Homemaker	69 (40.4)	42 (32.6)	27 (64.3)	
<b>Employment status during treatment</b>				

**Table 1** (continued)

Items	Total <i>n</i> = 171 <i>n</i> (%) or <i>M</i> [IQR]	Working mothers <i>n</i> = 129 (75.4%) <i>n</i> (%) or <i>M</i> [IQR]	Nonworking mothers <i>n</i> = 42 (24.6%) <i>n</i> (%) or <i>M</i> [IQR]	<i>P</i> value
Regular employment	30 (17.5)	26 (20.2)	4 (9.5)	0.003
Non-regular employment	22 (12.9)	21 (16.3)	1 (2.4)	
Self-employment	7 (4.1)	7 (5.4)	0 (0.0)	
Homemaker	112 (65.5)	75 (58.1)	37 (88.1)	
Qualifications/licenses				
Have	97 (56.7)	74 (57.4)	23 (54.8)	0.855
Not have	69 (40.4)	51 (39.5)	18 (42.8)	
Missing	5 (2.9)	4 (3.1)	1 (2.4)	
Childhood cancer survivors				
Age at diagnosis, years	4 [1–8]	3 [1–8]	5 [3–9]	0.047
Age at survey, years	12 [8–17]	12 [9–17]	11 [7–16]	0.113
Time since end of treatment, months	60 [24–114]	72 [32–120]	31 [12–62]	<0.001
Diagnosis				
Hematological tumor	110 (64.3)	77 (59.7)	33 (78.6)	0.028
Solid tumor	61 (35.7)	52 (40.3)	9 (21.4)	
Late effects				
Yes	65 (38.0)	53 (41.1)	12 (28.6)	0.200
No	106 (62.0)	76 (59.8)	30 (71.4)	
Care demands				
Yes	33 (19.3)	21 (16.3)	12 (28.6)	0.113
No	138 (80.7)	108 (83.7)	30 (71.4)	

*n* number, *M* median, *IQR* interquartile range

Qualitative variables:  $\chi^2$  test or Fisher's exact test; quantitative variables: Mann–Whitney *U* test

## Practical factors (Table 2)

The frequency of outpatient visits with CCSs was “once/4 months or more” in 83 mothers (48.6%), and 144 (84.2%) “always” accompanied their CCS to outpatient visits. Forty-two mothers (24.5%) picked up/dropped off their CCS at a nursery school, kindergarten, or school, and seven mothers (4.1%) stayed at school or kindergarten for care. Working mothers had a significantly longer interval between outpatient visits than did nonworking mothers ( $p=0.011$ ).

## Psychological factors (Table 2)

Regarding motivation to work at the time of the survey, 152 mothers (88.9%) reported motivation levels such as “I want to work/I want to continue to work” and “I’d prefer to work if I can/I’d prefer to continue to work if I can.” Among the nonworking mothers at the time of the survey, 26 (61.9%) reported having motivation to work. The most common reasons for mothers not wanting to work were “care for families other than childhood cancer survivor” ( $n=12$ ; 63.2%) and “care for a childhood cancer survivor” ( $n=10$ ; 52.6%). Regarding the PEGI, the highest score ( $M=1.59$ ) was for “Guilt and Worry”. No correlation was found between PEGI scores and time since the end of treatment. Compared with nonworking mothers, working mothers were significantly more motivated to work ( $p<0.001$ ) and had a lower PEGI score for “Long-term Uncertainty” ( $p=0.034$ ).

## Support (Table 2)

Regarding those who provided “very helpful” and “helpful” support to mothers, 147 (86.0%) were doctors and 144 (84.2%) were CCSs. In total, 124 (72.5%) CCSs were receiving financial support related to childhood cancer, and 107 (62.6%) were receiving subsidies for medical expenses for chronic specified diseases of children. Working mothers were receiving more support from others ( $p=0.004$ ) than were nonworking mothers, but less financial support ( $p=0.029$ ).

## Factors related to the employment status of mothers with a CCS (Table 3)

According to the multivariate model, statistically significant factors associated with employment among working mothers were motivation to work ( $p<0.001$ , odds ratio [OR] = 10.023, 95% confidence interval [CI]: 4.167–

24.105), working during treatment ( $p=0.007$ , OR = 5.475, 95% CI: 1.606–20.553), frequency of outpatient visits ( $p=0.002$ , OR = 2.774, 95% CI: 1.472–5.227), and amount of support ( $p=0.002$ , OR = 1.605, 95% CI: 1.195–2.155).

## Discussion

The results showed that about half of the CCSs’ mothers worked in non-regular employment, including part-time, dispatched, and fixed-term workers. The employment status of CCSs’ mothers was related to higher motivation to work, the continuation of employment during treatment, more hospital visits, and a higher amount of support.

In this study, which was conducted during the coronavirus disease 2019 (COVID-19) pandemic, the employment rate of mothers of CCSs was 75.4%. A previous study reported that some family members of children with cancer had been dismissed or were unemployed because of the COVID-19 pandemic [28]. However, the employment rate of mothers in the present study might not have been significantly affected by COVID-19 compared with that of mothers in general (72.4%) before the pandemic [29].

The results of the univariate analysis indicated a significant difference in long-term uncertainty between working and nonworking mothers. As the mean score of nonworking mothers was higher than that of working mothers, long-term uncertainty might be a barrier to employment for mothers. Childhood brain tumor survivors and their caregivers reported that parents expressed uncertainty about the health of CCSs and difficulties in planning future activities [30]. The present results did not indicate an association between long-term uncertainty and time since the end of treatment, thereby suggesting that long-term uncertainty might not decrease over time. Regardless of the time that has passed since the end of treatment, it may be difficult for mothers to decide whether to start work if they have no prospects regarding the health of their CCS.

The results of the multivariate analysis indicated that motivation to work was associated with employment among mothers of CCSs. A previous study reported that motivation to work was associated with changes in mothers’ employment such as quitting a job after a diagnosis of cancer in their child [23]. The present findings suggest that motivation to work might also affect maternal employment after the end of treatment. The frequency of hospital visits was also found to be related to employment among mothers after treatment, and mothers with low motivation to work reported the need to provide physical and psychological care to their CCS as the reason for this. After treatment is completed, mothers are typically the main caregiver responsible for the physical,



**Table 2** Practical and psychological factors and support for mothers of childhood cancer survivors

Items	Total <i>n</i> = 171 <i>n</i> (%) or <i>M</i> <sup>±</sup> [IQR] <i>M</i> <sup>±</sup> ±SD	Working mothers <i>n</i> = 129 (75.4%) <i>n</i> (%) or <i>M</i> <sup>±</sup> [IQR] <i>M</i> <sup>±</sup> ±SD	Nonworking mothers <i>n</i> = 42 (24.6%) <i>n</i> (%) or <i>M</i> <sup>±</sup> [IQR] <i>M</i> <sup>±</sup> ±SD	<i>P</i> value
<b>Practical factors</b>				
Frequency of outpatient visits				
More than once a month	38 (22.2)	22 (17.1)	16 (38.1)	0.011
Once/2–3 months	50 (29.2)	38 (29.5)	12 (28.6)	
Once/4 months or more	83 (48.6)	69 (53.4)	14 (33.3)	
Accompany outpatient visit				
Always	144 (84.2)	107 (82.9)	37 (88.0)	0.599
Generally	12 (7.0)	11 (8.5)	1 (2.4)	
Sometimes	9 (5.3)	7 (5.5)	2 (4.8)	
Never	6 (3.5)	4 (3.1)	2 (4.8)	
Pick up/drop off at school, nursery, or kindergarten				
No	126 (73.7)	101 (78.3)	25 (59.5)	
Yes	42 (24.5)	27 (20.9)	15 (35.7)	0.058
Missing	3 (1.8)	1 (0.8)	2 (4.8)	
Stay with the child at school, nursery, or kindergarten				
No	161 (94.2)	125 (96.9)	36 (85.7)	
Yes	7 (4.1)	3 (2.3)	4 (9.5)	0.056
Missing	3 (1.8)	1 (0.8)	2 (4.8)	
<b>Psychological factors</b>				
Motivation to work				
I want to work/I want to continue to work	92 (53.8)	88 (68.2)	4 (9.5)	<0.001
I'd prefer to work if I can/I'd prefer to continue to work if I can	60 (35.1)	38 (29.5)	22 (52.4)	
I'd prefer not to work if I can avoid it/I'd prefer not to continue to work if I can avoid it	17 (9.9)	3 (2.3)	14 (33.3)	
I do not want to work/I do not want to continue to work	2 (1.2)	0 (0.0)	2 (4.8)	
Reason why you want to work ( <i>n</i> = 152)				
Desire for an affluent life (e.g., finance for education, living expenses after retirement)	137 (90.1)	116 (92.1)	21 (80.8)	0.139
Social connections and making friends	95 (62.5)	88 (69.8)	7 (26.9)	<0.001
For a living	90 (59.2)	79 (62.7)	11 (42.3)	0.078



Table 2 (continued)

Items	Total n = 171 n (%) or M <sup>±</sup> [IQR] M <sup>±</sup> ± SD	Working mothers n = 129 (75.4%) n (%) or M <sup>±</sup> [IQR] M <sup>±</sup> ± SD	Nonworking mothers n = 42 (24.6%) n (%) or M <sup>±</sup> [IQR] M <sup>±</sup> ± SD	P value
Self-actualization	85 (55.9)	75 (59.5)	10 (38.5)	0.054
Child requires less care	67 (44.1)	57 (45.2)	10 (38.5)	0.665
Working is natural for me	64 (42.1)	56 (44.4)	8 (30.8)	0.276
Have spare time	41 (27.0)	36 (28.6)	5 (19.2)	0.351
Family business	5 (3.3)	5 (4.0)	0 (0.0)	0.589
Reason why you do not want to work (n = 19)				
To care for those other than a childhood cancer survivor	12 (63.2)	1 (33.3)	11 (68.8)	0.523
To care for a childhood cancer survivor	10 (52.6)	1 (33.3)	9 (56.3)	0.582
Worried about the physical/mental condition of a childhood cancer survivor	8 (42.1)	0 (0.0)	8 (50.0)	0.228
To respond to sudden calls from kindergartens and schools related to the physical deconditioning of children	8 (42.1)	0 (0.0)	8 (50.0)	0.228
To reduce the risk of COVID-19 infection	8 (42.1)	0 (0.0)	8 (50.0)	0.228
My family can get by even if I do not work	5 (26.3)	1 (33.3)	4 (25.0)	1.000
If there is a recurrence, I would suddenly have to quit, which would cause trouble in my workplace	4 (21.1)	0 (0.0)	4 (25.0)	1.000
My own health reasons	2 (10.5)	0 (0.0)	2 (12.5)	1.000
I searched for but could not find a job	1 (5.3)	0 (0.0)	1 (6.3)	1.000
Parent Experience of Child Illness Scale				
Guilt and Worry	1.59 ± 0.76	1.54 ± 0.74	1.72 ± 0.82	0.229
Unresolved Sorrow and Anger	1.06 ± 0.65	1.02 ± 0.63	1.18 ± 0.69	0.125
Long-term Uncertainty	1.22 ± 0.81	1.14 ± 0.77	1.48 ± 0.89	0.034
Emotional Resources	2.33 ± 0.73	2.33 ± 0.73	2.34 ± 0.74	0.732
Support				
Doctor	147 (86.0)	114 (88.4)	33 (78.6)	0.128
Childhood cancer survivor	144 (84.2)	112 (86.8)	32 (76.2)	0.141
Husband	126 (73.7)	96 (74.4)	30 (71.4)	0.840
Parent/relative	125 (73.5)	95 (74.2)	30 (71.4)	0.840
Nurse	124 (72.9)	94 (73.4)	30 (71.4)	0.842

Table 2 (continued)

Items	Total <i>n</i> = 171 <i>n</i> (%) or <i>M</i> <sup>†</sup> [IQR] <i>M</i> <sup>‡</sup> ± <i>SD</i>	Working mothers <i>n</i> = 129 (75.4%) <i>n</i> (%) or <i>M</i> <sup>†</sup> [IQR] <i>M</i> <sup>‡</sup> ± <i>SD</i>	Nonworking mothers <i>n</i> = 42 (24.6%) <i>n</i> (%) or <i>M</i> <sup>†</sup> [IQR] <i>M</i> <sup>‡</sup> ± <i>SD</i>	<i>P</i> value
Expected childhood cancer survivor	112 (65.5)	90 (69.8)	22 (52.4)	0.043
Friend	90 (52.6)	72 (55.8)	18 (42.9)	0.158
Boss/colleague	72 (42.4)	69 (53.9)	3 (7.1)	<0.001
Neighbor	37 (21.8)	30 (23.4)	7 (16.7)	0.398
Other	8 (4.8)	7 (5.5)	1 (2.5)	0.682
Amount of support	6 [5–7]	6 [5–7]	6 [3–6]	0.004
Financial support				
Yes	124 (72.5)	88 (68.2)	36 (85.7)	0.029
No	47 (27.5)	41 (31.8)	6 (14.3)	

*n* number, *M*<sup>†</sup> median, *IQR* interquartile range, *M*<sup>‡</sup> mean, *SD* standard deviation

Qualitative variables:  $\chi^2$  test or Fisher's exact test; quantitative variables: Mann–Whitney *U* test

psychological, and social care of their CCS [13, 14]; therefore, high care needs would affect their motivation to work. Moreover, a German study reported that mothers had a high level of fear of progression (known as fear of cancer recurrence or fear of relapse) after their child's cancer treatment was completed [16]. A Swedish study reported that mothers' anxiety about the physical health of their CCS reduced their ability to work [13]. If a mother is highly anxious about the physical and mental health of her CCS, including recurrence, then their motivation to work is considered to be low. Meanwhile, similar to previous studies [22], more than 60% of the nonworking mothers in the present study showed motivation to work. In a survey of Japanese working parents with children aged 0–6 years [31], 75.3% of mothers reported difficulty in balancing work and childcare, with the biggest reason being that they had to work with time in mind. Little flexibility in working hours might make them hesitate to work.

The employment status of mothers of CCSs was found to be related to their employment status during treatment. Among the mothers who were working in regular employment at the time of diagnosis, 40.0% were on leave, and 18.0% had changed their working hours and/or style. Among mothers working at the time of diagnosis, maintaining their work position could have led to employment after treatment. A Danish cohort study reported that improving the national welfare system for parents with severely ill children improves employment rates and income levels among mothers [32]. For example, in the case of leukemia, the treatment period is usually 1–2 years [33], so the current leave system in Japan does not cover the treatment period. Therefore, the mother might have to quit after a diagnosis. In addition, to utilize these systems, conditions such as minimum employment periods and a required number of working days per week must be met, so mothers who are working in non-regular employment might not be covered by the system. A Swedish study emphasized the flexibility of a social welfare system as one of the factors that drive parents' return to work after cancer treatment for children [13]. The balance between the mother and worker roles desired by each mother would be different. Therefore, for mothers to adjust their balance according to various changes, a flexible leave system that covers not only the hospitalization period, but also the entire treatment period for childhood cancer, and that can be expanded to cover all eligible recipients, is needed.

## Limitations

Because this study was a self-report questionnaire survey and recruited mothers who accompanied their children to follow-up visits, it cannot be said that it reflects the employment rate of all mothers with CCSs in Japan. Mothers who

**Table 3** Binary logistic regression analysis regarding employment among mothers with childhood cancer survivors

	Partial regression coefficient	<i>p</i> value	Odds ratio	95% confidence interval	
Motivation to work <sup>a</sup>	2.305	< 0.001	10.023	4.167	to 24.105
Working during treatment <sup>b</sup>	1.748	0.007	5.475	1.606	to 20.553
Frequency of outpatient visits <sup>c</sup>	1.020	0.002	2.774	1.472	to 5.227
Amount of support <sup>d</sup>	0.473	0.002	1.605	1.195	to 2.155

Model  $\chi^2$  test:  $p < 0.001$ , percentage of correct classifications: 84.8%, Hosmer–Lemeshow test:  $p = 0.538$

<sup>a</sup>“I do not want to work/I do not want to continue to work (1),” “I’d prefer not to work if I can avoid it/I’d prefer not continue to work if I can avoid it (2),” “I’d prefer to work if I can/I’d prefer to continue to work if I can (3),” and “I want to work/I want to continue to work (4).”

<sup>b</sup>Not working (0), working (1)

<sup>c</sup>More than once a month (1), once/2–3 months (2), once/4 months or more (3)

<sup>d</sup>Number

were working or interested in working might have participated. In Japan, it is not possible to analyze nationwide data such as diseases, treatment status, employment status, and economic status by linking. Therefore, our ability to clarify the employment rate of mothers in this study was limited.

Mothers have diverse reasons for seeking employment. Although various factors affect maternal employment, the number of nonworking mothers in this study was small, and the number of variables that could be input into the logistic regression analysis was limited. In future research, a larger sample, especially in regard to nonworking mothers, is needed.

### Clinical implications

Because the medical needs of CCSs and maternal anxiety about the physical and mental health of a CCS reduce mothers’ motivation to work, further assessments of maternal anxiety and CCS care are needed. The decreasing frequency of hospital visits might be one of the major factors that provide employment support to mothers. Because maintaining a job during treatment affects maternal employment after the end of treatment, policymakers should consider establishing a leave system that covers the entire treatment period for childhood cancer.

### Conclusions

The results of this study suggest that motivation to work, employment during treatment, frequency of hospital visits, and amount of support are related to maternal employment. As maternal employment is associated with psychological factors such as motivation to work and long-term uncertainty, increased psychological support for mothers might promote maternal employment. Because an interruption of employment during treatment affects maternal employment

after the end of treatment, a leave system that covers the entire treatment period for childhood cancer needs to be established.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s00520-023-07623-8>.

**Acknowledgements** The authors thank the following for assistance with the data collection: Dr. Hidetaka Niizuma, Dr. Masahiro Irie, Dr. Takeshi Rikiishi (Department of Pediatrics, Tohoku University Hospital), Ms. Hiromi Watanabe, Ms. Hiroe Hayasaka, Ms. Yui Horiuchi (Miyagi Children’s Hospital), Ms. Manami Makino (Sapporo Hokuyu Hospital), Dr. Satoshi Hamanoue (Division of Hematology and Oncology, Kanagawa Children’s Medical Center), and Dr. Yuni Yamaki (Department of Pediatrics, University of Tsukuba Hospital). We also thank Dr. Nami Honda (Graduate School of Education, University of Tohoku) for providing mental support to the participants and Dr. Michihiro Yano (Department of Pediatrics, Akita University Hospital) for support in recruiting the participants.

**Author contribution** Hiromi Okada, Wataru Irie, Akiko Sugahara, Yuko Nagoya, Ryoko Nakajima-Yamaguchi, and Hitoshi Shiwaku conceived, designed, and developed the methods for the study. Masayo Saito, Yoji Sasahara, Yasuko Yoshimoto, Fuminori Iwasaki, Masami Inoue, Maho Sato, Miwa Ozawa, Shigenori Kusuki, Junji Kamizono, Yasushi Ishida, and Ryoko Suzuki coordinated the running of the study. Hiromi Okada, Wataru Irie, Akiko Sugahara, Yuko Nagoya, and Hitoshi Shiwaku contributed to the data analysis and drafted the manuscript. All authors contributed to the interpretation of the data analysis and critically revised the manuscript.

**Funding** This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. Editorial assistance in English was financed by Tokyo Healthcare University.

**Data availability** The data that support the findings of this study are available from the corresponding author upon reasonable request.

### Declarations

**Ethics approval** This study was approved by the Ethics Committee of Tohoku University Graduate School of Medicine (No. 2020–1–946), the Institutional Research Board of Sapporo Hokuyu Hospital (No. 210303.04), the Ethics Committee of Miyagi Children’s Hospital (Miya Ko Rinri No. 519), the Institutional Review Board of the Graduate School of Medicine, Akita University (No. 2699), the

Ethics Committee of the University of Tsukuba Hospital (R03-269), the Institutional Research Board of St. Luke's International Hospital (No. 21-R001), the Ethics Committee of Kanagawa Children's Medical Center (No. 2102-1), the Ethics Committee of Osaka Women's and Children's Hospital (1415), the Institutional Research Board of Ehime Prefectural Central Hospital (Ken. 03-60), and the Institutional Research Board of Kitakyushu City Hospital Organization (No. 202106012).

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent for publication** Not applicable.

**Competing interests** The authors declare no competing interests.

## References

- Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ (2015) Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer* 62:S419–S424. <https://doi.org/10.1002/pbc.25675>
- Erdmann F, Feychting M, Mogensen H, Schmiegelow K, Zeeb H (2019) Social inequalities along the childhood cancer continuum: an overview of evidence and a conceptual framework to identify underlying mechanisms and pathways. *Front Public Health* 7:84. <https://doi.org/10.3389/fpubh.2019.00084>
- Mogensen H, Modig K, Tettamani G et al (2018) Survival after childhood cancer—social inequalities in high-income countries. *Front Oncol* 8:485. <https://doi.org/10.3389/fonc.2018.00485>
- Kim Y (2022) Factors associated with post-traumatic growth in Korean survivors of childhood cancer. *Oncol Nurs Forum* 49:71–80
- Santacroce SJ, Kneipp SM (2019) A conceptual model of financial toxicity of pediatric oncology. *J Pediatr Oncol Nurs* 36:6–16. <https://doi.org/10.1177/1043454218810137>
- Norberg AL, Montgomery SM, Bottai M, Heyman M, Hoven EI (2017) Short-term and long-term effects of childhood cancer on income from employment and employment status: a national cohort study in Sweden. *Cancer* 123:1238–1248. <https://doi.org/10.1002/cncr.30436>
- Tsimicalis A, Stevens B, Ungar WJ et al (2012) A prospective study to determine the costs incurred by families of children newly diagnosed with cancer in Ontario. *Psychooncology* 21:1113–1123. <https://doi.org/10.1002/pon.2009>
- Kelada L, Wakefield CE, Vetsch J et al (2020) Financial toxicity of childhood cancer and changes to parents' employment after treatment completion. *Pediatr Blood Cancer* 67:e28345. <https://doi.org/10.1002/pbc.28345>
- Mader L, Rueegg CS, Vetsch J et al (2016) Employment situation of parents of long-term childhood cancer survivors. *PLoS One* 11:e0151966. <https://doi.org/10.1371/journal.pone.0151966>
- Hiyoshi A, Montgomery S, Bottai M, Hoven EI (2018) Trajectories of income and social benefits for mothers and fathers of children with cancer: a national cohort study in Sweden. *Cancer* 124:1492–1500. <https://doi.org/10.1002/cncr.31123>
- Roser K, Erdmann F, Michel G, Winther JF, Mader L (2019) The impact of childhood cancer on parents' socio-economic situation – a systematic review. *Psychooncology* 28:1207–1226. <https://doi.org/10.1002/pon.5088>
- Öhman M, Woodford J, von Essen L (2020) Socioeconomic consequences of parenting a child with cancer for fathers and mothers in Sweden: a population-based difference-in-difference study. *Int J Cancer* 148:2535–2541. <https://doi.org/10.1002/ijc.33444>
- Hjelmstedt S, Forinder U, Montgomery S, Norberg AL, Hoven E (2021) Facilitators and barriers to return to work and financial needs in parents of children with cancer. *Pediatr Blood Cancer* 68:e29245. <https://doi.org/10.1002/pbc.29245>
- Wakefield CE, McLoone JK, Evans NT, Ellis SJ, Cohn RJ (2014) It's more than dollars and cents: the impact of childhood cancer on parents' occupational and financial health. *J Psychosoc Oncol* 32:602–621. <https://doi.org/10.1080/07347332.2014.936653>
- Ljungman L, Cernvall M, Grönqvist H et al (2014) Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PLoS One* 9:e103340. <https://doi.org/10.1371/journal.pone.0103340>
- Peikert ML, Inhestern L, Krauth KA et al (2020) Fear of progression in parents of childhood cancer survivors: a dyadic data analysis. *Psychooncology* 29:1678–1685. <https://doi.org/10.1002/pon.5508>
- van Warmerdam J, Zabih V, Kurdyak P et al (2019) Prevalence of anxiety, depression, and posttraumatic stress disorder in parents of children with cancer: a meta-analysis. *Pediatr Blood Cancer* 66:e27677. <https://doi.org/10.1002/pbc.27677>
- Suh E, Stratton KL, Leisenring WM et al (2020) Late mortality and chronic health conditions in long-term survivors of early adolescent and young adult cancers: a retrospective cohort analysis from the Childhood Cancer Survivor Study. *Lancet Oncol* 21:421–435. [https://doi.org/10.1016/S1470-2045\(19\)30800-9](https://doi.org/10.1016/S1470-2045(19)30800-9)
- Ozono S, Ishida Y, Honda M et al (2014) General health status and late effects among adolescent and young adult survivors of childhood cancer in Japan. *Jpn J Clin Oncol* 44:932–940. <https://doi.org/10.1093/jjco/hyu102>
- Christen S, Mader L, Baenziger J et al (2019) "I wish someone had once asked me how I'm doing": disadvantages and support needs faced by parents of long-term childhood cancer survivors. *Pediatr Blood Cancer* 66:e27767. <https://doi.org/10.1002/pbc.27767>
- Lewandowska A (2021) Influence of a child's cancer on the functioning of their family. *Children (Basel)* 8:592. <https://doi.org/10.3390/children8070592>
- Okada H, Maru M, Maeda R et al (2022) The maternal employment status after the completion of their child's cancer treatment: a cross-sectional exploratory study. *Nurs Open*. <https://doi.org/10.1002/nop2.1428>
- Okada H, Maru M, Maeda R et al (2015) Impact of childhood cancer on maternal employment in Japan. *Cancer Nurs* 38:23–30
- Matsuzawa A, Ejiri K (2019) The relationship between employment attitudes, workforce participation and health-related quality of life in mothers caring for children with disabilities in Japan [in Japanese]. *The Journal of Child Health* 78:445–452
- Bonner MJ, Hardy KK, Guill AB et al (2006) Development and validation of the parent experience of child illness. *J Pediatr Psychol* 31:310–321. <https://doi.org/10.1093/jpepsy/jsj034>
- Nakajima-Yamaguchi R, Morita N, Nakao T et al (2016) Parental post-traumatic stress symptoms as predictors of psychosocial problems in children treated for cancer. *Int J Environ Res Public Health* 13:812. <https://doi.org/10.3390/ijerph13080812>
- Peduzzi P, Concato J, Kemper E, Holford TR, Feinstein AR (1996) A simulation study of the number of events per variable in logistic regression analysis. *J Clin Epidemiol* 49:1373–1379. [https://doi.org/10.1016/S0895-4356\(96\)00236-3](https://doi.org/10.1016/S0895-4356(96)00236-3)
- Wimberly CE, Towry L, Caudill C, Johnston EE, Walsh KM (2021) Impacts of COVID-19 on caregivers of childhood cancer survivors. *Pediatr Blood Cancer* 68:e28943. <https://doi.org/10.1002/pbc.28943>
- Ministry of Health, Labour and Welfare (2019) Summary Report of Comprehensive Survey of Living Conditions 2019. pp 7–9. [https://www.mhlw.go.jp/english/database/db-hss/dl/report\\_gai-kyo\\_2019.pdf](https://www.mhlw.go.jp/english/database/db-hss/dl/report_gai-kyo_2019.pdf). Accessed 11 Jul 2022
- Nicklin E, Velikova G, Hulme C et al (2019) Long-term issues and supportive care needs of adolescent and young adult childhood brain tumour survivors and their caregivers: a systematic review. *Psychooncology* 28:477–487. <https://doi.org/10.1002/pon.4989>

31. Meiji Yasuda Life Insurance Company (2022) Kosodate ni kannsuru annkēto chōsa [Child-rearing survey]. p 10. [https://www.meiji-yasuda.co.jp/profile/news/release/2022/pdf/20220928\\_01.pdf](https://www.meiji-yasuda.co.jp/profile/news/release/2022/pdf/20220928_01.pdf). Accessed 19 Dec 2022
32. Mader L, Hargreave M, Bidstrup PE et al (2020) The impact of childhood cancer on parental working status and income in Denmark: patterns over time and determinants of adverse changes. *Int J Cancer* 147:1006–1017. <https://doi.org/10.1002/ijc.32867>
33. Kato M, Manabe A (2018) Treatment and biology of pediatric acute lymphoblastic leukemia. *Pediatr Int* 60:4–12. <https://doi.org/10.1111/ped.13457>

**Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.