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RESEARCH ARTICLE

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The maternal employment status after the completion of their child's cancer treatment: A cross-sectional exploratory study

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Abstract

Aim: To clarify the details of mothers' employment status after the completion of their child's cancer treatment.

Design: A cross-sectional exploratory study.

Methods: Data are collected from 62 mothers of childhood cancer survivors using self-report questionnaires. Fisher's exact test was used to determine the statistical significance of factors between the mothers who worked and those who did not work after their child's cancer treatment had been completed.

Results: Thirty-two mothers worked after the completion of their child's cancer treatment. There were significant differences in age, education level, employment status at the diagnosis and time elapsed since the diagnosis between the working mothers and non-working mothers. Twenty-two non-working mothers reported that they had some motivation to work, but the most common reason for not working was "To nurse or care for the child with cancer". Some mothers also stated that they did not work due to anxiety about cancer recurrence.

KEYWORDS
childhood cancer survivors, employment status, maternal employment, work motivation

1 | INTRODUCTION

Changes in parental employment are a clear consequence of the diagnosis of childhood cancer that affects the whole family. Previous studies have reported that during the treatment of childhood cancer, the parents of the patients reduced their working hours, while some even left their work (Norberg et al., 2017; Kelada et al., 2020). It has been reported that childhood cancer impacts the socioeconomic status of the parents, and that parental discontinuance of work often occurs within the year immediately after the diagnosis; the main characteristics associated with employment disruption were a diagnosis of haematological cancer, younger age of the child at the time of the diagnosis, a lower education level in the mother and having more children (Roser et al., 2019). In particular, mothers had a higher rate of discontinuing work or retiring from the workforce than did fathers due to the expectation that

they are responsible for attending to their child with cancer (Bona et al., 2014;Kelada et al., 2020; Norberg et al., 2017). Following the diagnosis of childhood cancer, mothers felt most stressed with the physical condition and prognosis of their child with cancer, and 68.8% of mothers exhibited a decline in motivation to work. There was an association between willingness to work and a change in employment, and 37.5% of mothers chose to take a leave of absence from work, while 31.3% of mothers opted to retire from the workforce (Okada et al., 2015). Interruptions to a mother's employment not only affect the mother's social life but can also cause financial harm to the family.

2 | BACKGROUND

Maternal work interruptions continue after treatment impacts the mother's career development and affects her participation in society and life satisfaction (Wakefield et al., 2014). Many maternal work interruptions occur within the year immediately after diagnosis (Hoven et al., 2013), and studies in Switzerland (Mader et al., 2016) and Sweden (Norberg et al., 2017) reported that maternal unemployment rates remain high for a prolonged period after the diagnosis. In addition, the decline in income due to the discontinuation of work persisted for up to 6 years after the diagnosis and contributed to the economic difficulties faced by families experiencing long-term childhood cancer (Hiyoshi et al., 2018; Norberg et al., 2017).

As in many developed countries, the 5-year survival rate for childhood cancer in Japan has surpassed 70% due to improved treatments. It is estimated that there are more than 50,000 adults who have experienced cancer as a child. However, the experience of dealing with cancer and its treatment continues to affect the psychosocial well-being of the patient's family even after the cessation of treatment (Hoven et al., 2017; Ljungman et al., 2014, 2015; Roser et al., 2019). Although the employment and economic situation of mothers following their child's treatment has been studied in the last 10 years, these studies were mainly undertaken in North America, Europe and Australia (Roser et al., 2019). Moreover, many of these reports analysed demographic data with a focus on the economic impact. Few studies have revealed the mother's perceptions on and intentions about working or their employment experience after the completion of their child's cancer treatment.

We used a part of the data from a previous study on the impact of childhood cancer on maternal employment in Japan (Okada et al., 2015). We explored the characteristics of maternal work changes after their child was diagnosed with cancer. We also asked about the employment situation of the mothers after the completion of the cancer treatment. There have been few studies on the employment status of mothers after the end of their child's cancer treatment. Thus, we compiled data on their employment status after the end of treatment, which have not been previously analysed. The aim of this study was to clarify the details of maternal employment after their child's cancer treatment had been completed.

3 | DEFINITION OF TERMS

Childhood cancer survivors were defined as children who were diagnosed with cancer before the age of 15 years and had completed cancer treatment at the time of this survey.

Employment status was defined as the presence or absence of employment and transition in working status.

4 | METHOD

4.1 | Study design and participants

A cross-sectional exploratory study was conducted. The participants were the mothers of children who were diagnosed with cancer before the age of 15 years, had been hospitalized for chemotherapy and had completed cancer treatment. The inclusion criteria were: mothers of childhood cancer survivors; age of 20–69 years; and ability to understand Japanese, i.e. they could read the questionnaire and answer in Japanese.

4.2 | Procedures

The participants were selected from a university hospital and a children's hospital located in the Tokyo metropolitan area in Japan. Paediatric oncologists explained the details of the study and distributed questionnaires to the participants when they accompanied their child to a follow-up visit between March and November 2012. The completed questionnaires were returned by mail.

4.3 | Measurements (available in the Supporting Information)

We reviewed previous studies and developed a draft questionnaire. After the face and content validity was examined by a group of professionals consisting of three nurses, one physician and one occupational health physician, the questionnaire was pre-tested with three mothers.

4.3.1 | Demographic data

The following were recorded: age, education level, diagnosis and age of the child with cancer (both at the time of the diagnosis and at the time of the survey).

4.3.2 | Employment

The employment status of the mother at the time of the diagnosis, during treatment and at the time of the survey was recorded. Four

possible answers were given: "regular employment", "non-regular employment", "self-employment" and "homemaker". Additionally, multiple answers were collected from among eight options about factors that impacted their current employment status; they included "I feel that it is difficult to be re-employed", "I am influenced by promotions and salary increases", "I am influenced by wages and bonuses", "I cannot work at a job I want to do", "I started to work more efficiently", "I started to prioritize time with my family", "I started trying to keep tasks running smoothly with colleagues who have children" and "Other".

4.3.3 | Questions for mothers who worked after treatment (employment group)

Eight options were give about their reasons for working: "To achieve self-fulfillment", "To connect with society and make friends", "To maintain my livelihood", "To have enriching hobbies", "Working is natural for me", "Because quitting my job would cause trouble for my colleagues", "Because my situation does not allow me to quit" and "Other". Meanwhile, six options were given about the timing when mothers considered continuing or returning to work: "During treatment", "When the child's outpatient treatment has been completed", "When the child's outpatient visits are less often than once every 3 months", "When the child with cancer is able to attend school as usual", "When the child's medication is finished" and "Other". Subsequently, seven options were given about when they started to work: "During treatment", "After the discharge decision, but before discharge", "Within 1 month after discharge", "Within 6 months after discharge", "Within 1 year after discharge", "Within 3 years after discharge" and "More than 3 years after discharge". Lastly, seven options were given about their sentiments on working after treatment: "Treatment has settled down", "The child with cancer is fine", "I have returned to everyday life", "I realized a connection with society", "I can feel the joy of working more than ever", "I don't have any particular thoughts on it" and "Other".

4.3.4 | Questions for mothers who did not work after treatment (unemployment group)

Four options were given about work motivation: "I want to work", "I'd prefer to work if I can", "I'd prefer not work if I can avoid it" and "I do not want to work". To examine the reasons for not working, questionnaire items were included with possible answers on five-point scale ranging from "very applicable" to "not applicable at all". These items were: "To nurse or care for the child with cancer", "To nurse or care for family members other than the child with cancer", "My family does not show support for me working", "I searched for, but could not find a job", "I do not want to work", "Long-term leave from work is not allowed", "My family can get by even if I do not work", "My own health reasons" and "Other". The details of "Other" could be given in a space for an open-ended description.

4.4 | Analysis

Using SPSS® 21.0 for Windows®, a descriptive statistical analysis was conducted for each survey item. Continuous variables were categorized from the clinical findings after confirmation of the data distribution. Descriptive statistics were used to describe the frequency (%) of categorical variables and to categorize continuous variables. Fisher's exact test was carried out to determine the statistical significance of differences in the factors between the employment group and non-employment group. p values <.05 were considered to indicate statistical significance.

4.5 | Ethics

The study was reviewed and approved by the Institutional Review Boards of the university school of medicine and children's medical centre. The participants were informed of the purpose of the study, the method and their freedom of choice for participation. Their consent was deemed to have been obtained if they returned the questionnaire. The results were statistically processed, the participants were not identified, and the results were presented at academic conferences and in papers.

5 | RESULTS

Of the 96 distributed questionnaires, 62 (64.6%) were returned.

5.1 | Demographic data

The demographic data are shown in Table 1.

5.1.1 | The mothers of children with cancer

Thirty-four participants (54.8%) were over the age of 40 years. Seventeen participants (27.4%) had a university degree or higher. Thirty-two mothers (51.6%) were working at the time of their child's cancer diagnosis. About the working mothers' annual incomes, 17 participants were earning less than 1.2 million yen, four participants were earning 1.2–3 million yen, six participants were earning 3–5 million yen, four participants were earning 5–8 million yen and one participant did not disclose her annual income. Mothers who were more than 40 years of age ($p < .05$), had a university degree ($p < .05$) or worked at the time of the diagnosis ($p < .05$) showed a greater tendency to work after the completion of their child''s treatment.

TABLE 1 The demographic characteristics of the mothers $n = 62$

Characteristics/groups	Working mothers $n = 32$		Non-working mothers $n = 30$		
	n	%	*n*	%	*p*
Age (years)					
20 to 39	9	28.1	18	60.0	.010
≥40	23	71.9	11	36.7	
Unknown	0	0.0	1	3.3	
Education					
Below a bachelor's degree	18	56.3	26	86.7	.015
Bachelor's degree or higher	13	40.6	4	13.3	
Unknown	1	3.1	0	0.0	
Employment status at diagnosis					
Employed	24	75.0	8	26.7	.000
Not employed	8	25.0	22	73.3	
Survivor's age (years)					
<7	10	31.3	14	46.7	.298
≥7	22	68.7	16	53.3	
Time since diagnosis (years)					
<3	4	12.5	11	36.7	.038
≥3	28	87.5	19	63.3	
Cancer type					
Haematological tumour	17	53.1	19	63.3	.607
Solid tumour	15	46.9	11	36.7	

TABLE 2 The patterns of maternal employment $n = 62$

At the time of diagnosis		During treatment		At the time of the survey	*n*	%
Homemaker	→	Homemaker	→	Homemaker	22	35.5
Regular employment	→	Regular employment	→	Regular employment	9	14.5
Homemaker	→	Homemaker	→	Non-regular employment	7	11.3
Non-regular employment	→	Homemaker	→	Non-regular employment	6	9.7
Non-regular employment	→	Non-regular employment	→	Non-regular employment	4	6.5
Non-regular employment	→	Homemaker	→	Homemaker	4	6.5
Self-employed	→	Self-employed	→	Self-employed	3	4.8
Regular employment	→	Regular employment	→	Homemaker	2	3.2
Self-employed	→	Homemaker	→	Homemaker	2	3.2
Homemaker	→	Homemaker	→	Regular employment	1	1.6
Regular employment	→	Homemaker	→	Self-employed	1	1.6
Regular employment	→	Homemaker	→	Non-regular employment	1	1.6

5.1.2 | The children with cancer

Thirty-eight children (61.3%) were 7 years of age or older, which are the ages at which children attend school. The number of years from the time of the diagnosis to the time of the survey was 3 years or more in 47 children (75.8%), and the mothers of these children showed a greater tendency to work after the completion of their child's treatment ($p < .05$).

5.2 | The employment status of mothers after the completion of treatment

Table 2 shows the changes in maternal employment status at the time of the diagnosis, during treatment and after the completion of the treatment. There were 32 mothers (51.6%) who worked and 30 mothers (48.4%) who did not work after the treatment was completed.

About whether the child's cancer diagnosis affected their current employment status, 16 working mothers (50.0%) and 9 non-working mothers (30.0%) responded "Yes". A common factor indicated by 12 (37.5%) of the working mothers and 7 (23.3%) of the non-working mothers was "I started to prioritize time with my family", and among the non-working mothers, 7 (23.3%) also responded "I feel that it will be difficult to be re-employed". The following responses were obtained for the open-ended descriptions under the "Other" option: "I changed my working hours to times that would allow me to accompany my child to clinic visits", "My work changed to medical care" and "I feel hesitant to start to work".

5.3 | The mothers who were working after the completion of treatment

The reasons for working among the mothers who were working after the completion of the treatment were: "To maintain my livelihood" (23 participants [71.9%]); "To achieve self-fulfillment" (4 participants [12.5%]); "To connect with society and make friends" (3 participants [9.4%]); "To have enriching hobbies" (1 participant [3.1%]); and "Working is natural for me" (1 participant [3.1%]).

"During treatment" was the most common timing when mothers considered starting to work, while two mothers who chose "Other" reported "When 2 years had passed after the end of treatment and the tumor markers had stabilized" and "When I got divorced after discharge". Seven of the 10 mothers who took a leave of absence began working within 6 months from their child's discharge. Eleven unemployed mothers who were not working or left work at the time of the diagnosis started to work more than a year after their child's discharge (Table 3).

After their child's discharge from the hospital, eight mothers (25.0%) answered "I have returned to everyday life" about their employment, five mothers (15.6%) answered "The child with cancer is fine", four mothers (12.5%) answered "Treatment has settled down" and four mothers (12.5%) answered "I realized a connection with society".

5.4 | The mothers who were not working after the completion of treatment

As shown in Table 4, the most common reason for not working was "To nurse or care for the child with cancer", which was answered by 14 mothers (46.7%). When the 30 non-working mothers were asked about their motivation to work, 22 (73.3%) of them showed a willingness to work by answering "I want to work" or "I'd prefer to work if I can". Clarifications for their answers were obtained by asking the mothers to elaborate freely: 16 mothers (72.7%) cited economic reasons; six cited personal reasons, such as "I want to feel a sense of fun and fulfillment when I work", "I want to have a connection with society" and "For self-fulfilment"; and four cited reasons that were related to their child, such as "My child's independence decreased since I stayed with the child at the hospital 24 h every day, so I think my child needs to spend time independently".

For an answer of "Other", details for the response were obtained through an open-ended description; they included: "I want to be with my child", "I cannot work since there could be a recurrence of

TABLE 3 The timing of considering to work and starting to work among the working mothers $n = 32$

	Employment status of mothers during treatment						Total	
	Working $n = 9$		On extended leave $n = 10$		Not working $n = 13$			
Items	*n*	%	*n*	%	*n*	%	*n*	%
The timing of considering to work								
During treatment	8	25.0	5	15.6	0	0.0	13	40.6
When the child is able to go to school as usual	0	0.0	3	9.4	7	21.9	10	31.3
When the child's outpatient visits are less often than once every 3 months	0	0.0	0	0.0	3	9.4	3	9.4
When the child's outpatient treatment has been completed	0	0.0	0	0.0	1	3.1	1	3.1
Other	1	3.1	2	6.3	2	6.3	5	15.6
The timing of starting to work								
During treatment	9	28.1	0	0.0	0	0.0	9	28.1
After the discharge decision, but before discharge	0	0.0	2	6.3	0	0.0	2	6.3
Within 1 month after discharge	0	0.0	3	9.4	0	0.0	3	9.4
Within 6 months after discharge	0	0.0	3	9.4	1	3.1	4	12.5
Within 1 year after discharge	0	0.0	0	0.0	1	3.1	1	3.1
Within 3 years after discharge	0	0.0	2	6.3	8	25.0	10	31.2
More than 3 years after discharge	0	0.0	0	0.0	3	9.4	3	9.4

cancer" and "If my child's cancer recurs, I will have to quit abruptly. I think it would cause trouble for the workplace".

6 | DISCUSSION

6.1 | Post-treatment maternal employment

Half of the mothers worked post-treatment, which was equivalent to the total number of mothers who worked at the time of the diagnosis. As seen in a previous study (Hoven et al., 2013), mothers aim to return to becoming active members of society after the completion of their child's cancer treatment. Working at the time of the diagnosis may affect the ease with which the mothers can return to work after their child's discharge. In particular, 70% of mothers who took a leave of absence from work shortly after the diagnosis returned to work within 6 months of their child's discharge. Generally, these mothers began working earlier than those who did not work or had retired from the workforce at the time of the diagnosis. Thus, it appears that mothers who stop working due to their child's cancer are more likely to return to work after treatment if they take a leave of absence.

In a study on the career development of women (Wu, 2016), 45.5% of mothers continued to work after marriage or childbirth for reasons that included economic independence and social participation. In this study, a relation was seen between working at the time of the diagnosis and returning to work after the completion of their child's cancer treatment. Mothers who worked at the time of the diagnosis and decided to take a leave of absence were considered to be more motivated to return to work post-treatment. Even though the treatment could last several months, some workplaces allowed long-term leave for mothers so that they could accompany their child during treatment. Mothers were likely to find it easier to return to work in workplaces that showed understanding and trusted the mother to decide when to return to work, taking into account her child's physical condition and the frequency of outpatient consultations. Early after the diagnosis, mothers tend to become stressed and stop working (Okada et al., 2015). For cases in which the mother is working at the time of the diagnosis, nurses should give psychological care, check the mother's willingness to work and explore with the mother the possibility of her taking a leave of absence from work rather than retiring from the workforce.

6.2 | Post-treatment psychological support for mothers

After their child's discharge from the hospital, approximately 50% of mothers considered beginning or returning to work depending on their child's treatment and outpatient conditions. Moreover, working mothers realized that their everyday life and the child's physical condition had recovered. According to previous studies (Boman et al., 2013; Vander Haegen & Etienne, 2018; Wikman et al., 2018), mothers experience anxiety and uncertainty after discharge, such as worrying about the recurrence of cancer, the onset of late effects and symptoms of posttraumatic stress. However, because of the reduced frequency of outpatient visits and the return of their child to school, some mothers return to work despite having psychological problems. Norberg et al. (2012) reported that social networks in the workplace contributed positively to the mental health of parents whose child had cancer. The results of this study may indicate that through communication with work colleagues, mothers feel that they are returning to their everyday lives and that their child is recovering.

In this study, we also observed that some mothers decided not to work due to concerns about the possibility of recurrence of their child's cancer. Wakefield et al. (2014) reported that the mothers of children with cancer had difficulty returning to work due to psychological and mental fatigue, and that they felt guilty about returning to work. Our findings indicated that mothers are more likely to hesitate to work if they feel a high level of anxiety about cancer recurrence in their child. Thus, nurses should check the mother's level of anxiety about the prognosis and health status of their child even after the cancer treatment is over. If the mother's level of anxiety is high, nurses should reassure them by reviewing with them the child's post-discharge course, growth and development, because such confirmation can help alleviate the concerns of the mothers about their child's health.

6.3 | Motivated mothers who did not work after treatment

Generally, the employment rate of mothers in Japan tends to increase as the age of their children increases, i.e. when they enter elementary school (Ministry of Health, Labour and Welfare, 2019, 2020). However, in this study, there was no association between the age of the child with cancer and maternal employment. This suggested that the mothers' post-treatment employment status was affected by the cancer in her child. About 70% of the non-working mothers showed some motivation to work, but they reported that they did not work, because they were giving care for their child with cancer.

It is thought that children with cancer have decreased physical strength immediately after discharge due to prolonged hospitalization and treatment. Thus, these children often spend time at home until they regain their physical strength. Additionally, children with leukaemia are immunocompromised at the end of therapy, and the immune dysfunction can persist for 6 months after the end of treatment (Perkins et al., 2017). Thus, to prevent infections, cancer survivors of preschool age usually stay at home and do not attend preschools and kindergartens. To avoid infections, some child cancer survivors are driven to and from school by their parents. According to a previous study (Wakefield et al., 2014), parents must be able to respond to a sudden deterioration in the condition of their child with cancer. The study also reported that the child's medical care demands were a factor that affected the parents' ability to return

TABLE 4 The reasons of mothers for not working $n = 30$

Items	Very applicable		Applicable		Neutral		Not applicable		Not applicable at all	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
To nurse or care for the child with cancer	9	30.0	5	16.7	4	13.3	4	13.3	8	26.7
My family can get by even if I do not work	4	13.3	7	23.3	11	36.7	2	6.7	6	20.0
My own health reasons	2	6.7	4	13.3	3	10.0	2	6.7	18	60.0
I do not want to work	2	6.7	4	13.3	4	13.3	4	13.3	16	53.3
To nurse or care for family members other than the child with cancer	1	3.3	5	16.7	5	16.7	3	10.0	16	53.3
My family does not show support for me working	2	6.7	2	6.7	6	20.0	2	6.7	18	60.0
I searched, but could not find a job	2	6.7	2	6.7	3	10.0	5	16.7	18	60.0
Long-term leave from work is not allowed	1	3.3	2	6.7	3	10.0	2	6.7	22	73.3
Other	3	10.0	1	3.3	0	0.0	0	0.0	26	86.7

to work. Additionally, child cancer survivors have a high risk of experiencing severe late effects of treatment (Ozono et al., 2014; Suh et al., 2020), including physical problems and psychological problems, such as anxiety and depression (Friend et al., 2018; Prasad et al., 2015), and social problems, such as difficulty in continuing with one's studies due to a learning disability, e.g. cognitive and intelligence impairments (Mavrea et al., 2021; Saatci et al., 2020). Mothers may find it challenging to make time for work as they have a central role in caring for their child's physical and/or psychosocial health after the child has survived cancer. The assumption of responsibility for the care of childhood cancer survivors by mothers as the primary caregiver may be due to the traditional gender roles in which fathers earn an income while mothers take care of children, and these traditional gender roles may be a major factor in why mothers' employment is more often disrupted than fathers' employment (Norberg et al., 2017). Mothers who take on the role of childcare during the cancer treatment tend to continue that role even after the treatment is over.

The results of this study suggested that economic independence is not the only reason for mothers to work; other reasons include social participation and life fulfilment. However, the mothers' options for working while caring for their child with cancer may be limited. Thus, nurses should confirm what mothers think about maternal employment and give support for discussing maternal working and division of roles of cere child with fathers after their child's cancer treatment is complete. Moreover, nurses should check how much burden mothers are carrying when caring for their child after the end of cancer treatment and give support to the mothers to help them lead fulfilling lives and make their own choices as members of society.

6.4 | Limitations

This study focused on only two facilities in the Tokyo metropolitan area, and the sample size was small. Thus, the generalizability of the results is limited, and there is a possible regional bias in the mothers' employment status. Mothers may have different opportunities and motivations about work depending on the region.

Additionally, the participants' characteristics were biased. The number of mothers with a child who had a cancer other than leukaemia was small, making it difficult to categorize the results by specific cancer types. A previous study listed specific diseases as factors related to parental employment (Roser et al., 2019). There is a possible cancer-type bias among medical institutions. Thus, it is hoped that future research will include many more medical institutions and patients from whom data can be collected.

7 | CONCLUSION

When contemplating their employment, approximately 50% of the working mothers considered their child's post-discharge treatment and outpatient status. On the other hand, some mothers did not work due to the possibility of cancer recurrence or to give post-treatment care for their child. Nonetheless, about 70% of non-working mothers expressed a willingness to work. Therefore, nurses should reassure mothers by reviewing with them the health status, growth and development of their child post-discharge to alleviate their concerns about their child's health as a way of offering support to enable the mothers to work.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the first author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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