

表3 Late effects に対してこれまでに考えられた日本語訳

- 晩期障害
- 晩期合併症
- 後期合併症
- 遅発性合併症
- 続発性合併症
- 晩発障害
- 晩発的影響
- 治療後合併症
- 長期的合併症
- 治療後遺症
- 治療後経験する影響
- 治療後の影響

成書を翻訳する<sup>7)</sup>にあたりこの点に関して何度も議論を重ねた。委員会でも表3に掲げたように色々な意見が出たが、大きく用語を変更すると過去の文献でのキーワード検索にも影響が出るのではとの考えもあり、暫定的に保守的な案として「晩期合併症」と呼ぶことにした。その後「晩期障害」という言葉の使用は少なくなったが、長期フォローアップが広く推奨されるようになり<sup>8)</sup>、この概念が広く流布していくにつれ、もう少し受け入れやすくするように用語を再考する必要があるが出てきた。

そこで本論策で提唱したいのが「長期的影響」という言葉である。この言葉には、小児がん罹患した結果、治療によらない疾患自体によっておきる影響も含むこと、治療に伴い短期的に起きる一過性のものではないこと、小児がんという経験は合併症や後遺症のようにマイナスのものばかりではなく、最近明らかにされつつあるような疾患罹患後・治療後の心理的・人間的な成長や家族の結びつきの強化のようなポジティブな要素も含めて表現したいという意図が込められている。

また小児がん長期生存者 (long-term survivors) に対しては、本邦では当事者たちの希望により現在のところ「小児がん経験者」と呼んでいるが、成人がんの治療成績が向上するにつれて、「サバイバー」という用語が治療を乗り越えてきた克服者としてのイメージとして定着し始めているように思える。小児がん当事者の中にも、かつては否定的であった「サバイバー」という言葉の使用に肯定的な方もでてきており、今後この点についても再検討が必要になってくるかもしれない。

最後に今後の小児がん経験者の長期フォローアップを考えていく上のキーワードとして「transition (移行)」を挙げておきたい<sup>9)</sup>。Erice 宣言の6)でも述べられているように、「移行」は医療形態の変化であり、小児がん経験者の長期フォローアップ上は大きく2つの段

階が考えられる。まず第1段階は数年以上の完全寛解状態の継続が確認され、再発の危険性が極めて低くなり、外来での主眼が再発から late effects のチェックを含めた健康管理や復学など社会的適応の支援に変化していく時であり、第2段階は当初家族に伴われ外来受診していた形態から、小児がん経験者自らが単独で外来受診する成人型診療の段階である。後者の段階では、大学などへの進学・就職などで親元を離れて一人暮らしを始める時期でもあり、この後に就労、結婚、出産など小児がん経験者にとって、未経験の大きなライフイベントが数多くある。成人後の移行については、本邦においてまさに本格的な議論が始まったばかりであり、成人後も小児科医主体で看護師やコメディカルの助けを借りながら包括的なフォロー体制を可能とする方向を目指していくべきなのか、何らかの形で特定の成人診療科と併診して協力体制をとることが可能なのか<sup>10)</sup>、産婦人科や泌尿器科などどう連携していくのかなど問題は山積している。今後小児がん経験者や家族・支援者の皆さんと討議を重ねながら、本邦に適した成人医療への移行を模索していきたいと考えている。

#### おわりに

2007年に発表された Erice 宣言に基づき、小児がん治療終了後の長期ケアと治療について考察を加えた。この宣言によると、診断や治療のまとめを提供し、必要時に適切な専門家に紹介するのは治療を担当した小児がんチームの責務であり、十分な情報交換の元に成人期のフォローに移行していけるようなシステム作りが望まれる。また「cure」、「late effects」、「survivors」などの用語に関しても、小児がん経験者が将来偏見なしに社会で活躍できる理解を得られるような日本語が使用され、社会的認知が進むことを祈っている。

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日本小児科学会の定める利益相反に関する開示事項はありません。

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## Social outcomes and quality of life of childhood cancer survivors in Japan: a cross-sectional study on marriage, education, employment and health-related QOL (SF-36)

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**Abstract** Social outcomes and quality of life (QOL) of childhood cancer survivors (CCSs) remain unknown in Japan. We investigated these outcomes in young adult CCSs compared to those of their siblings in Japan, and analyzed the association between social outcome and SF-36 health survey subscale scores. Between 2007 and 2009, we performed a cross-sectional survey using self-rating questionnaires. We estimated social outcomes and health-related QOL by performing the SF-36 in each group: CCSs with or without stem cell transplantation (SCT)/radiotherapy (RT) and their siblings. Adjusted odds ratios for outcomes of interest were estimated using logistic regression analysis. Questionnaires from 185 CCSs and 72 CCS's siblings were analyzed. There were no differences in

educational attainment or annual income. The SF-36 subscale scores of CCSs with SCT and RT were significantly lower than those of siblings in physical functioning (PF) ( $p < 0.001$  and  $0.003$ , respectively) and general health (GH) (both  $p = 0.001$ ). Lower PF scores correlated with recurrence ( $p = 0.041$ ) and late effects ( $p = 0.010$ ), and poor GH scores with late effects ( $p = 0.006$ ). The CCSs had made efforts to attain educational/vocational goals; however, a significant proportion of CCSs who had experienced late effects remain at increased risk of experiencing diminished QOL.

**Keywords** Childhood cancer survivors · Marriage · Education · Employment · Health-related QOL · SF-36

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## 1 Introduction

As a result of advances in treatment, 70–80% of children diagnosed with cancer become long-term survivors. In Japan, the estimated number of pediatric cancer survivors is upward of 50,000, or approximately one in 700 adults between the ages of 20 and 39 years. Although an increased number of children with cancer have been cured, many survivors experience various health problems or late effects as a result of their treatments [1, 2]. In addition to various physical problems in childhood cancer survivors (CCSs) [3], social outcomes vis-à-vis marriage, education and employment are apparently affected by these late effects, either directly or indirectly. An increasing number of studies have focused on the social outcomes of CCSs [4–12].

A Swedish population-based study [4] revealed that central nervous system (CNS) tumor survivors had poorer social outcomes compared to the general population, whereas outcomes for non-CNS cancer survivors were similar to those of the general population. On the other hand, the results of the Childhood Cancer Survivor Study (CCSS) suggest that CCSs generally have high school graduation rates similar to those in the general population, but they are slightly less likely to attend college; they are also more likely to be unemployed and not married as young adults [5]. Johannsdottir et al. [6] also outline important differences in social outcomes (i.e., employment and parenthood) between CCS and controls early in adult life.

The health-related quality of life (QOL) of CCSs has been studied extensively using the 36-item Short Form Health Survey (SF-36). Reulen et al. [13] demonstrated the validity and reliability of the SF-36 when used with CCSs, but they point out that ceiling effects should be recognized for researchers in using the SF-36 with CCSs. Maunsell et al. [14] show that QOL differences between CCSs and controls are small, and for the most part are probably not clinically important. In their study, survivors' scores on most subscales of the SF-36 were similar to those of controls, despite experiencing some difficulties in their daily activities [15].

Many reports including meta-analyses or systematic reviews of social outcomes [16] and QOL [17, 18] among CCSs have been published; however, the association between social outcomes and SF-36 scores remains to be elucidated [12, 19]. We have already reported that both stem cell transplantation (SCT) and radiotherapy (RT) are closely associated with the late effects of CCSs [20, 21] and that no significant differences are found between CCSs and siblings in terms of depression and anxiety, but CCSs have significantly more posttraumatic stress symptoms and greater posttraumatic growth [22]. In this article, we

investigated the social outcomes and QOL of young adult CCSs with or without SCT/RT compared to those of their siblings in the same population, and analyzed the association between social outcomes and SF-36 subscale scores.

## 2 Patients and methods

### 2.1 Study design and participants

We performed a cross-sectional survey involving self-rating questionnaires vis-à-vis the social outcomes and QOL of CCSs, compared to those of the siblings [20, 23]. The study was conducted between 1 August 2007, and 31 March 2009. The subjects were divided into three groups: the CCS with or without SCT/RT, and siblings. The last group was considered as a control that matched with the CCSs with regard to genetic capabilities and environmental similarity. The CCS and their siblings were recruited from the participating hospitals listed in the supplemental appendix 1.

The eligibility criteria for CCSs and their siblings were as follows: (1) the subjects were 16 years old or older at the time of the survey, (2) CCSs had been diagnosed with cancer at 18 years of age or younger, (3) CCSs had been in continuous remission for more than 5 years since cancer diagnosis without any additional need for anticancer therapy, (4) they had been informed about their diagnoses, and (5) informed consent was provided by both CCSs/siblings and their guardians. If CCSs had two or more siblings, we selected the subject with the nearest age to the CCSs among the siblings. The exclusion criteria were as follows: (1) the attending physicians believed that the survey would cause an undesirable effect on CCSs, (2) the subjects had some underlying disease besides cancer that affected their social outcome or QOL, or (3) the subjects were unable to answer the questionnaires by themselves.

### 2.2 Methods

After obtaining appropriate informed consent, the CCSs were provided with an anonymous questionnaire by the attending pediatricians and asked to return it within post-one month. The patients' clinical records were reviewed to analyze cancer-related variables, including the diagnosis, birth year and month, age at diagnosis, age at therapy completion, time since diagnosis, treatment variables and the late effects of CCSs observed at the time of the survey. We used an encrypted numbering system for dispatching data to the principal investigator, to maintain the confidentiality of patient information. Late effects were defined as adverse events that were grade 2 (i.e., symptomatic or needing some intervention) or higher, according to the

Common Terminology Criteria for Adverse Events, v. 3 (CTCAEv3), which was originally developed by the National Cancer Institute (Japanese CTCAE v. 3.0 by JCOG and JSCO, <http://www.jcog.jp/>).

### 2.3 Measurement of variables

The questionnaire consisted of 220 items, with three items involving free writing. We evaluated seven background items (Q1), two truth-telling-related items (Q2), seven lifestyle-associated items (Q3), nine items related to medical visits to the hospital (Q4), four general health-related items (Q5), six past operation and drug usage history items (Q6), seven daily habit items (Q7), nine pregnancy and delivery history items (Q8), 72 subjective physical dysfunctions items (Q9), 36 SF-36-related items (Q10), 64 psychosocial problems-related items (Q11) and three free-writing items (Q12).

In this article, we focus on Q3 and Q10. Q3 contained seven items relating to lifestyle, marital status, educational achievements, current employment, work status, working ability (frequency of absence) and annual income in the last year. Q10, comprising 36 SF-36 items, was often used to measure health-related QOL outcomes [24]. The SF-36 is a generic self-report measure that evaluates eight subscales that represent different aspects of well-being, with respect to eight physical and mental health dimensions in Table 1: physical functioning (PF), bodily pain (BP), role limitations caused by physical health problems (RP), role limitations caused by personal or emotional health problems (RE), general mental health (MH), social functioning (SF), vitality (VT) and general health perception (GH). It also involves two summary scales: the mental component score (MCS) and the physical component score (PCS). Multi-item subscales are scored on a 0–100 percentage scale, with higher scores representing higher levels of functioning and health. Data were presented as *T* scores, with a mean score of 50 and a standard deviation (SD) of 10. *T* scores were dichotomized, in which a *T* score below the population score (i.e., the respective nation's norm, while matching for both age and gender in 2007 [25]) indicated a respondent as having reported poor health-related QOL (HR-QOL). Interpretation guidelines link SF-36 subscales and summary scores to the probability of outcomes, allowing scores to be used as predictors of morbidity (physical and mental) and health-care utilization. SF-36 and summary scores have been extensively tested for reliability and validity [26]. The Cronbach's alpha coefficient of SF-36 was found to be 0.79 (CCSs only) and 0.71 (CCSs and siblings) in this study.

In terms of marital status, subjects were categorized as married, never married and others (i.e., divorced or remarried), while educational achievement was classified

as follows: lower than high school, high school graduate, college or vocational school graduate, and university or graduate school graduate. Further, employment status was classified as follows: company desk workers ("white collar"); part-time workers; those with medical jobs; industrial workers ("blue collar"); homemakers; those who were unemployed, including those on job training; and others. In terms of annual income, each subject was classified into one of five categories: less than 1 million Japanese yen (JPY), 1–2 million JPY, 2–3 million JPY, 3–5 million JPY and 5 million JPY or more.

### 2.4 Ethical issues

The study was performed in accordance with the Declaration of Helsinki and was approved by the ethics committee of the principal investigator's institution (Y. Ishida, Ehime University Graduate School of Medicine and St. Luke's International Hospital). The study was also approved by the local ethics committees of all the participating hospitals, prior to initiation.

### 2.5 Statistical analysis

We estimated the prevalence of outcomes among CCSs with or without SCT/RT and the siblings group. Three primary outcomes were assessed: (1) social outcomes and (2) general QOL according to SF-36 scores between each pair groups (i.e., CCSs and siblings, CCSs with SCT and CCSs without SCT, CCSs with RT and CCSs without RT), and (3) the association between social outcomes and SF-36 scores (for the CCS group only). We performed  $\chi^2$  tests or a Fisher exact test (for any cells with expected counts <5) within categorical predictors, and the *t* test or Kruskal–Wallis methods for continuous variables. As for cross-table comparisons, we used adjusted standardized residuals to evaluate the difference between the observed and expected values; the columns which gave more than 1.96 of adjusted standardized residual were considered as significant [27]. The adjusted odds ratios (ORs) for adverse outcomes were estimated by employing logistic regression analysis. As adjusted variables, we selected independent, significant risk factors such as SCT, solid tumors, recurrence and duration after therapy completion, as shown in our previous article. To avoid multi-collinearity, we assessed associations between predictors in a pairwise fashion. Data were analyzed through the use of SPSS software, v. 18.0 (SPSS IBM Japan Inc., Tokyo, Japan).

We planned a study of independent CCSs and siblings, with five CCSs per sibling. The results of a previous study [3] indicate that the probability of chronic health conditions among siblings is 0.35. If the true probability of chronic health conditions among CCSs is 0.60, we would need to

**Table 1** Information of the SF-36 subscales and summary scores [25]

Name of subscale	No. of items	Summary of contents
<b>Physical component score (PCS)</b>		
Physical functioning (PF)	10	Extent to which health limits physical activities such as self-care, walking, climbing stairs, bending, lifting, and moderate and vigorous exercises
Role limitations caused by physical health problems (RP)	4	Extent to which physical health interferes with work of other daily activities, including accomplishing less than that required, limitations in the kind of activities or difficulty in performing activities
Bodily pain (BP)	2	Intensity or pain and effect of pain on normal work, both inside and outside the home
General health perception (GH)	5	Personal evaluation of health, including current health, health outlook and resistance to illness
<b>Mental component score (MCS)</b>		
Vitality (VT)	4	Feeling energetic and full of pep versus feeling tired and worn out
Social functioning (SF)	2	Extent to which physical health or emotional problems interfere with normal social activities
Role limitations caused by personal or emotional health problems (RE)	3	Extent to which emotional problems interfere with work or other daily activities, including decreased time spent on activities, accomplishing less and not working as carefully as usual
General mental health (MH)	5	General mental health, including depression, anxiety, behavioral–emotional control, general positive affect

study 180 case patients and 36 control patients to be able to reject the null hypothesis that the outcome rates for CCSs and siblings are equal with a power of 0.8 ( $\beta = 0.2$ ) and a type I error probability ( $\alpha$ ) of 0.05. We therefore used an uncorrected  $\chi^2$  statistic to evaluate this null hypothesis. In addition, the number needed to analyze nine determinants via multivariate logistic regression methods—to determine the risk factors for late effects—was estimated as 180 for CCSs.

### 3 Results

The demographic data of the participants are shown in Table 2. Among the CCSs, 189 returned the questionnaires (response rate 72%). Of these, four subjects were excluded because two of the four had an underlying disease besides cancer that affected their QOL, one questionnaire had been completed by the patient's mother and one CCS was 20 years old at diagnosis. We also excluded two questionnaires from siblings, because they were 14 and 15 years of age at the time of survey. The mean age at diagnosis was 8.3 years (SD 4.8) for female CCSs and 8.5 years (SD 5.0) for male CCSs. The proportion of those aged 16–19 years was a little smaller in the siblings group than in the CCSs group. With regard to the primary cancers involved, acute lymphoblastic leukemia comprised 43.9% of the CCSs, followed by acute myeloid leukemia/

myelodysplastic syndrome (13.3%) and lymphoma (12.3%). A total of 128 cases of primary cancers were hematological, followed by brain tumors (10 cases), bone/soft tissue sarcoma (18 cases) and other solid tumors (29 cases). As for treatment of the primary cancer, 98% of the CCSs received chemotherapy, 61%, RT, 38% surgery; and 25% hematopoietic SCT. Among the CCSs, one or more late effects were found in 56%, two or more late effects in 17% and three or more in 6%.

The current social outcomes between each pair groups are shown in Table 3. The proportion of subjects living with a partner was higher and that living with parents was lower significantly in the sibling group, because the marriage rate within the female sibling group was high (36%). The marriage rate was especially high in the younger than 24 years of age group for siblings; however, the marriage rate was quite similar in the 25 years or more age group. There were also no large differences in educational attainment; the CCSs revealed a higher proportion of high school level and the CCS with SCT showed a higher proportion of university/graduate school level. The unemployment rate tended to be a little high in the CCSs, especially CCSs with SCT or RT compared to the siblings. The proportion of company desk workers (“white collar”) was significantly higher in the sibling group compared to the CCSs. Of particular importance was the high proportion of CCSs holding medical jobs: 15% for females and 7% for males. Finally, there were no large differences in working

**Table 2** The demographical data of participants

	Total CCS ( <i>n</i> = 184)	Siblings ( <i>n</i> = 72)	<i>t</i> test or $\chi^2$ ( <i>p</i> value) CCS versus siblings	CCS with SCT ( <i>n</i> = 46)	CCS without SCT ( <i>n</i> = 138)	<i>t</i> test or $\chi^2$ ( <i>p</i> value) SCT versus no SCT	CCS with RT ( <i>n</i> = 113)	CCS without RT ( <i>n</i> = 72)	<i>t</i> test or $\chi^2$ ( <i>p</i> value) RT versus no RT
Gender (female)	108 (58%)	42 (58%)	0.995	27 (59%)	81 (58%)	0.960	68 (60%)	40 (56%)	0.534
Age at diagnosis (median)	8.3 ± 4.8 (8)			10.1 ± 4.4 (10)	7.7 ± 4.8 (7)	0.003	8.6 ± 4.8 (8)	7.9 ± 4.9 (7)	0.350
0–5 years of age	60 (32%)	–		10 (22%)	50 (36%) <sup>a</sup>	0.036	37 (33%)	23 (32%)	0.256
6–10 years of age	50 (27%)	–		10 (22%)	40 (29%)		26 (23%)	24 (33%)	
≥11 years of age	75 (41%)	–		26 (57%) <sup>a</sup>	49 (35%)		50 (44%)	25 (35%)	
Age at survey (median)	23.1 ± 4.9 (22)	24.9 ± 5.1 (24)	0.001	22.9 ± 4.8 (22)	23.2 ± 5.0 (22)	0.659	24.1 ± 5.0 (23.5)	21.6 ± 4.5 (21)	0.001
16–19 years of age	47 (25%) <sup>a</sup>	7 (10%)	0.040	11 (24%)	36 (26%)	0.566	21 (19%)	26 (36%) <sup>a</sup>	0.026
20–24 years of age	75 (40%)	19 (41%)		19 (41%)	56 (40%)		46 (41%)	29 (40%)	
25–29 years of age	38 (21%)	12 (26%)		12 (26%)	26 (19%)		27 (24%)	11 (15%)	
≥30 years of age	25 (14%)	4 (9%)		4 (9%)	21 (15%)		19 (17%)	6 (8%)	
Duration after therapy cessation									
0–4 years	5 (3%)	–		3 (7%)	2 (1%)	0.003	4 (4%)	1 (1%)	0.255
5–9 years	50 (27%)	–		19 (41%) <sup>a</sup>	31 (22%)		28 (25%)	22 (31%)	
10–14 years	57 (31%)	–		15 (33%)	42 (30%)		31 (27%)	26 (36%)	
≥15 years	73 (40%)	–		9 (20%)	64 (46%) <sup>a</sup>		50 (44%)	23 (32%)	
Primary cancer									
Solid tumors	57 (31%)	–		46 (33%)	11 (24%)	0.242	80 (71%)	48 (67%)	0.553
Hematological	128 (69%)	–		93 (67%)	35 (76%)		33 (29%)	24 (33%)	
Treatment									
Operation	70 (38%)	–		14 (30%)	56 (40%)	0.232	40 (35%)	30 (42%)	0.391
Anthracyclines	152 (82%)	–		41 (89%)	111 (80%)	0.154	93 (82%)	59 (82%)	0.951
Alkylating agents	155 (84%)	–		45 (98%)	110 (79%)	0.003	101 (89%)	54 (75%)	0.010
Etoposide	76 (41%)	–		32 (70%)	44 (32%)	<0.001	50 (44%)	26 (36%)	0.273
Radiation	113 (61%)	–		39 (85%)	74 (53%)	<0.001	100%	0%	–
SCT	46 (25%)	–		100%	0%	–	39 (35%)	7 (10%)	<0.001
Recurrence	33 (18%)	–		18 (39%)	15 (11%)	<0.001	28 (25%)	5 (7%)	0.002
Late effects	103 (56%)	–		36 (78%)	67 (48%)	<0.001	77 (68%)	26 (36%)	<0.001
Only 1 late effects	61 (33%)	–		13 (28%)	48 (35%)	0.416	40 (35%)	21 (29%)	0.379
2 or more late effects	42 (23%)	–		23 (50%)	19 (14%)	<0.001	37 (33%)	5 (7%)	<0.001

Age was expressed as mean value ± standard deviation (median value)

CCS childhood cancer survivors, SCT stem cell transplantation, RT radiation

<sup>a</sup> Adjusted standardized residual ≥+1.96

**Table 3** Current social outcome status between each pair groups (i.e., CCS and siblings, CCS with SCT and without SCT, CCS with RT<sup>4</sup> and without RT<sup>4</sup>)

	Total CCS (n = 184)	Siblings (n = 72)	$\chi^2$ (p value) CCS versus siblings	CCS with SCT (n = 46)	CCS without SCT (n = 138)	$\chi^2$ (p value) SCT versus no SCT	CCS with RT <sup>4</sup> (n = 112)	CCS without RT <sup>4</sup> (n = 72)	$\chi^2$ (p value) RT versus no RT
<b>Living style</b>									
Living alone	37 (20%)	18 (25%)	0.031	7 (15%)	30 (22%)	0.819	22 (20%)	15 (21%)	0.456
Living with parents	116 (63%) <sup>a</sup>	32 (44%)		31 (67%)	85 (62%)		70 (63%)	46 (64%)	
Living with partner	23 (13%)	18 (25%) <sup>a</sup>		6 (13%)	17 (12%)		13 (12%)	10 (14%)	
Others	8 (4%)	4 (6%)		2 (4%)	6 (4%)		7 (6%)	1 (1%)	
<b>Marital status</b>									
Never married	158 (86%) <sup>a</sup>	54 (75%)	0.090	40 (87%)	118 (86%)	0.844	98 (87%)	60 (86%)	0.444
Married	24 (13%)	17 (24%) <sup>a</sup>		6 (13%)	18 (13%)		15 (13%)	9 (13%)	
Divorced or re-married	1 (0.5%)	1 (1%)		0	1 (1%)		0	1 (1%)	
<b>Marriage rate</b>									
≤24 years of age	2 (2%)	4 (10%)	0.014	0	2 (4%)	0.413	0	2 (4%)	0.112
25–29 years of age	8 (23%)	7 (33%)	0.328	2 (17%)	6 (26%)	0.612	3 (12%)	5 (56%)	0.011
≥30 years of age	14 (56%)	6 (55%)	0.732	4 (100%)	10 (48%)	0.053	12 (63%)	2 (33%)	0.199
<b>Educational achievement</b>									
Lower than high school	7 (4%)	2 (3%)	0.169	0	7 (5%)	0.126	3 (3%)	4 (6%)	0.033
High school	61 (33%) <sup>a</sup>	14 (19%)		14 (30%)	47 (34%)		31 (27%)	30 (42%) <sup>a</sup>	
College/vocational School	51 (28%)	24 (39%)		10 (22%)	41 (30%)		39 (35%) <sup>a</sup>	12 (17%)	
University/graduate school	66 (36%)	32 (45%)		22 (48%) <sup>a</sup>	44 (32%)		40 (35%)	26 (36%)	
<b>Current job</b>									
Student	72 (39%)	24 (33%)	0.011	22 (48%)	50 (36%)	0.694	35 (31%)	37 (51%) <sup>a</sup>	0.099
Company (white collar)	27 (15%)	18 (25%) <sup>a</sup>		5 (11%)	22 (16%)		17 (15%)	10 (14%)	
Part-time job	14 (8%)	8 (11%)		3 (6%)	11 (8%)		12 (11%) <sup>a</sup>	2 (3%)	
Medical job	20 (11%) <sup>a</sup>	0		5 (11%)	15 (11%)		13 (12%)	7 (10%)	
Industry (blue collar)	14 (8%)	3 (4%)		3 (6%)	11 (8%)		11 (10%)	3 (4%)	
Homemaker	15 (8%)	9 (13%)		3 (6%)	12 (9%)		9 (8%)	6 (8%)	
Unemployed	7 (4%)	0		3 (6%)	4 (3%)		6 (5%)	1 (1%)	
Others	16 (9%)	10 (14%)		2 (4%)	14 (10%)		10 (9%)	6 (8%)	
<b>Working ability</b>									
No. of days/month	156 (89%)	62 (94%)	0.446	37 (86%)	19 (90%)	0.822	97 (89%)	59 (88%)	0.964
1–2 days/month	13 (7%)	3 (5%)		4 (9%)	9 (7%)		8 (7%)	5 (8%)	
More than 1–2 days/week	7 (4%)	1 (1%)		2 (5%)	5 (4%)		4 (4%)	3 (5%)	



Table 3 continued

	Total CCS ( <i>n</i> = 184)	Siblings ( <i>n</i> = 72)	$\chi^2$ ( <i>p</i> value) CCS versus siblings	CCS with SCT ( <i>n</i> = 46)	CCS without SCT ( <i>n</i> = 138)	$\chi^2$ ( <i>p</i> value) SCT versus no SCT	CCS with RT <sup>a</sup> ( <i>n</i> = 112)	CCS without RT <sup>a</sup> ( <i>n</i> = 72)	$\chi^2$ ( <i>p</i> value) RT versus no RT
Annual income in the last year (JPY)									
<1 million	111 (61%)	40 (58%)	0.586	32 (71%)	79 (58%)	0.276	61 (55%)	50 (70%) <sup>a</sup>	0.098
1–2 million	33 (18%)	9 (13%)		5 (11%)	28 (20%)		27 (24%) <sup>a</sup>	6 (9%)	
2–3 million	21 (12%)	11 (16%)		3 (7%)	18 (13%)		13 (12%)	8 (11%)	
3–5 million	15 (8%)	7 (10%)		5 (11%)	10 (7%)		9 (8%)	6 (9%)	
≥5 million	2 (1%)	2 (3%)		0	2 (2%)		1 (1%)	1 (1%)	

CCS childhood cancer survivors, JPY Japanese yen, SCT stem cell transplantation, RT radiation

<sup>a</sup> Adjusted standardized residual >+1.96

ability or annual income among each group; the CCSs with RT achieved a little lower annual income compared to the CCSs without RT because of a high proportion of students.

The current social outcome status of the CCSs with SCT or RT according to the number of late effects is shown in Table 4. No difference was found with respect to living style, marriage rate and annual income between CCSs lacking any late effects and CCS with only one late effect; however, CCSs with two or more late effects showed extremely low marriage rates (0 and 3%, respectively). A high unemployment rate (from 9 to 5%) was found in CCSs with any late effects in SCT and RT groups.

Figure 1 shows a box plot analysis of the SF-36 subscales and the summary scores among the CCSs with or without SCT and the siblings group. Ceiling effects were found to be high in the PF, RP, BP, SF and RE subscales, for both the CCSs and siblings (supplemental appendix 2). The distributions of each subscale score were much skewed and non-parametric methods using Kruskal–Wallis showed that there was a statistically significant difference in the PF ( $p < 0.001$ ) and GH subscales ( $p = 0.001$ ) between the CCSs with SCT and siblings. A statistically significant difference was also found in the J-PCS and PF subscales between the CCSs with SCT and without SCT, and in the GH subscales between the CCS without SCT and siblings. Figure 2 shows a box plot analysis of the SF-36 subscales and the summary scores among the CCSs with or without RT and the siblings group. A statistically significant difference in the PF ( $p = 0.003$ ) and GH subscales ( $p = 0.001$ ) between the CCSs with SCT and siblings was found. On comparison of the CCSs with the age-matched general population, a statistically significant difference was found in the J-MCS, PF, BP and RE subscales between the CCSs and the nation's standard reference values [25] (supplemental appendix 2).

We created dichotomous variables from each subscale score, to determine whether each subject showed lower SF-36 subscale scores compared to Japan's national norm standards in 2007 [25]. We explored risk factors associated with the lower PF and GH subscale scores of the CCSs, using logistic regression analysis (Table 5). Lower PF scores were associated with recurrence [OR 2.80; 95% confidence interval (CI) 1.04–8.33;  $p = 0.041$ ] and late effects (OR 3.33; 95% CI 1.33–8.33;  $p = 0.010$ ); also, lower GH scores were associated with late effects (OR 2.81; 95% CI 1.35–5.85;  $p = 0.006$ ).

#### 4 Discussion

We found that the long-term social outcome of the CCS group was almost similar to that of siblings in Japan. In line with the Erice statement [28], the majority of survivors

**Table 4** Current social outcome status of cancer survivors with or without late effects in the SCT or RT groups

Gender	SCT group (n = 46)				RT group (n = 77)			
Late effects	Absent (n = 10)	Only 1 (n = 13)	2 or more (n = 23)	$\chi^2$ (p value)	Absent (n = 36)	Only 1 (n = 39)	2 or more (n = 36)	$\chi^2$ (p value)
Living style								
Living alone	0	2 (15%)	5 (22%)	0.126	7 (19%)	8 (21%)	7 (19%)	0.089
Living with parents	6 (60%)	8 (62%)	17 (74%)		18 (50%)	23 (59%)	28 (78%) <sup>a</sup>	
Living with partner	3 (30%)	3 (23%)	0		7 (19%)	6 (15%)	0	
Others	1 (10%)	0	1 (4%)		4 (11%)	2 (5%)	1 (3%)	
Marital status								
Never married	7 (70%)	10 (77%)	23 (100%) <sup>a</sup>	0.028	29 (81%)	33 (82%)	35 (97%) <sup>a</sup>	0.074
Married	3 (30%)	3 (23%)	0		7 (19%)	7 (18%)	1 (3%)	
Educational achievement								
Lower than high school	0	0	0	0.489	1 (3%)	1 (3%)	1 (3%)	0.342
High school	3 (30%)	3 (23%)	8 (35%)		5 (14%) <sup>a</sup>	14 (35%)	12 (33%)	
College/vocational school	1 (10%)	5 (39%)	4 (17%)		17 (47%)	13 (33%)	9 (25%)	
University/graduate school	6 (60%)	6 (39%)	11 (48%)		13 (36%)	12 (30%)	14 (39%)	
Current job								
Student	5 (50%)	3 (23%) <sup>a</sup>	14 (61%)	0.161	10 (28%)	8 (20%)	17 (47%) <sup>a</sup>	0.286
Company (white collar)	2 (20%)	1 (8%)	2 (9%)		6 (17%)	7 (18%)	4 (11%)	
Part-time job	0	2 (15%)	1 (4%)		2 (6%)	8 (20%) <sup>a</sup>	2 (6%)	
Medical job	1 (10%)	1 (8%)	3 (13%)		3 (8%)	5 (12%)	5 (14%)	
Industry (blue collar)	0	3 (23%)	0		4 (11%)	5 (12%)	2 (6%)	
Homemaker	1 (10%)	2 (15%)	0		4 (11%)	3 (7%)	2 (6%)	
Unemployed	0	1 (8%)	2 (9%)		1 (3%)	2 (5%)	2 (6%)	
Others	1 (10%)	0	1 (4%)		6 (17%)	2 (5%)	2 (6%)	
Working ability								
No. of days/month	8 (89%)	7 (64%) <sup>a</sup>	22 (96%)	0.082	33 (97%)	32 (84%)	31 (86%)	0.275
1–2 days/month	1 (11%)	2 (18%)	1 (4%)		1 (3%)	3 (8%)	4 (11%)	
More than 1–2 days/week	0	2 (18%) <sup>a</sup>	0		0	3 (8%)	1 (3%)	
Annual income in the last year (JPY <sup>a</sup> )								
<1 million	6 (60%)	10 (77%)	16 (73%)	0.247	17 (47%)	22 (56%)	21 (60%)	0.534
1–2 million	1 (10%)	2 (15%)	2 (9%)		11 (31%)	11 (28%)	5 (14%)	
2–3 million	0	0	3 (14%)		4 (11%)	3 (8%)	6 (17%)	
≥3 million	3 (30%) <sup>a</sup>	1 (8%)	1 (5%)		4 (11%)	3 (8%)	3 (9%)	

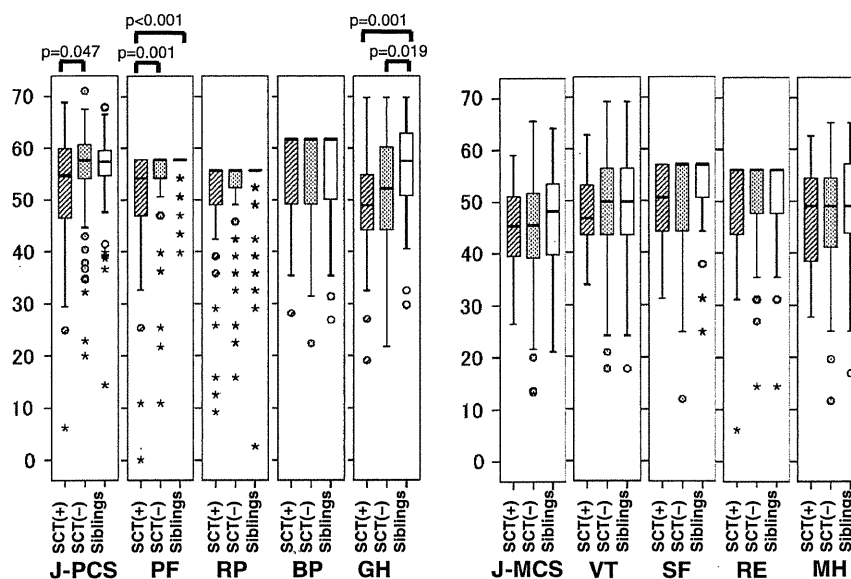
JPY Japanese yen, SCT stem cell transplantation, RT radiation

<sup>a</sup> Adjusted standardized residual >+1.96

become relatively well adjusted in adulthood; indeed, there is a proportion exhibiting extraordinary resilience. However, compared to siblings, a significant proportion of CCSs are at an increased risk of developing conditions that require medical, psychological or social care because SCT and RT are closely associated with various late effects reported previously [20, 21]. Our study showed that the marriage rate of the CCSs in 24 years of age or younger patients was a little lower than that of their siblings, and that little difference existed in educational achievement between the CCSs and their siblings [9, 15]. A limitation of

our study was that the mean and median ages of the participants were only 23–24 years; this is too young an age to evaluate the total marriage rate, as the average marriage age has been increasing recently (i.e., in 2008, the Japanese national mean age of marriage was 30.2 years for males and 28.5 years for females). By using an analysis of stratification by age, the marriage rate became almost the same in the 25 years or more age group for both females and males.

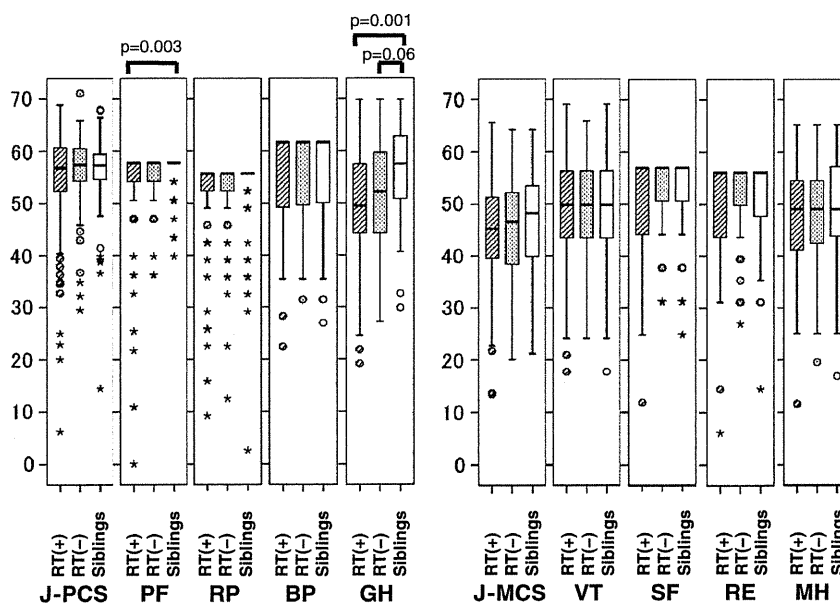
On the other hand, there were small differences in employment status and annual income among each group



**Fig. 1** Box and whisker plot of SF-36 subscale scores according to stem cell transplantation. The *bottom* and *top* of the *box* are the 25th and 75th percentile, respectively, and the thick band near the middle of the *box* is the 50th percentile (the median). The *ends of the whiskers* represent the lowest datum still within 1.5 interquartile range (IQR) of the lower quartile, and the highest datum still within 1.5 IQR of the upper quartile. The *open circles* are outliers between 1.5 and 3 IQR from the end of a *box*, and the *asterisks* are extreme values

beyond 3 IQR from the end of a *box*. Kruskal–Wallis test reveal that SF-36 subscale scores of childhood cancer survivors (CCSs) with stem cell transplantation (SCT; *hatched bars*) are significantly lower than those of siblings (*open bars*) in PF and GH subscales, respectively. The J-PCS and PF scores in CCSs with SCT are also significantly lower than those in CCS without SCT (*dotted bars*). The GH scores of CCSs without SCT are significantly lower than those of siblings. All *p* values are adjusted by pairwise multiple comparison

**Fig. 2** Box and whisker plot of SF-36 subscale scores according to radiotherapy (RT). Kruskal–Wallis test reveals that SF-36 subscale scores of childhood cancer survivors (CCSs) with radiotherapy (RT; *hatched bars*) are significantly lower than those of siblings (*open bars*) in PF and GH subscales, respectively. The GH scores of CCSs without RT are significantly lower than those of siblings. All *p* values are adjusted by pairwise multiple comparison



in our study despite that both SCT and RT had increased late effects for CCSs [20, 21]. The most important issue was that the proportion of CCSs with two or more late effects who were getting married was quite low. This finding accords with those of previous reports [5, 7]. In our study, the proportion of unemployment tended to be a little high (4%) in the CCSs, especially CCSs with SCT or RT compared to the siblings. A higher unemployment rate

(from 9 to 5%) was found in the CCSs with any late effects. The small but significant portion of CCSs experiencing employment difficulties are of great concern [16]; in fact, meta-analysis [16] showed that CCSs were nearly twice as likely to be unemployed than healthy controls (OR 1.85; 95% CI 1.27–2.69) and that survivors in the USA had an overall threefold risk of becoming unemployed, whereas no such risk was found for European survivors. This is very

**Table 5** Risk factors associated with lower subscale scores of SF-36 in cancer survivors

Factors	PF scores		$\chi^2$ ( <i>p</i> value)	Logistic regression analysis <sup>a</sup>	
	Lower <sup>a</sup> ( <i>n</i> = 51)	Higher ( <i>n</i> = 132)		Adjusted odds ratio (95% CI)	<i>p</i> value
Gender (female)	24	83	0.052	0.59 (0.28–1.27)	0.177
Age at Dx (years)					
0–5	13	45	<b>0.044</b>	0.40 (0.15–1.09)	0.074
6–10	10	41		0.41 (0.16–1.08)	0.070
≥11	28	46		Ref	
Tx off (years)					
≥15	16	56	0.170	0.88 (0.35–2.22)	0.787
≤14	35	76		Ref	
Solid tumors	23	33	<b>0.008</b>	1.85 (0.53–6.46)	0.334
Hematological	28	99		Ref	
Radiation	34	78	0.346	0.72 (0.30–1.73)	0.464
Stem cell transplantation	21	25	<b>0.002</b>	1.96 (0.78–4.88)	0.150
Operation	28	40	<b>0.001</b>	1.49 (0.45–4.95)	0.513
Recurrence	17	16	<b>0.001</b>	<b>2.80 (1.04–8.33)</b>	<b>0.041</b>
Late effects	41	61	<b>&lt;0.0001</b>	<b>3.33 (1.33–8.33)</b>	<b>0.010</b>
Factors	GH scores		$\chi^2$ ( <i>p</i> value)	Logistic regression analysis <sup>a</sup>	
	Lower <sup>a</sup> ( <i>n</i> = 107)	Higher ( <i>n</i> = 76)		Adjusted odds ratio (95% CI)	<i>p</i> value
Gender (female)	64	43	0.662	1.48 (0.77–2.87)	0.240
Age at Dx (years)					
0–5	37	21	0.148	1.31 (0.55–3.16)	0.543
6–10	24	27		0.56 (0.26–1.24)	0.155
≥11	46	28		Ref	
Tx off (years)					
≥15	40	32	0.519	0.64 (0.29–1.38)	0.255
≤14	67	44		Ref	
Solid tumors	33	23	0.933	0.65 (0.21–1.96)	0.439
Hematological	74	53		Ref	
Radiation	71	41	0.09	1.10 (0.54–2.23)	0.792
Stem cell transplantation	32	14	0.078	1.11 (0.48–2.60)	0.809
Operation	41	27	0.700	1.26 (0.43–3.63)	0.675
Recurrence	25	8	<b>0.026</b>	1.64 (0.60–4.52)	0.335
Late effects	71	31	<b>0.001</b>	<b>2.81 (1.35–5.85)</b>	<b>0.006</b>

<sup>a</sup> After data were presented as *T* scores with a mean score of 50 and a standard deviation (SD) of 10, *T* scores were dichotomized, in which a *T* score below the population score (respective nation's norm matching both age and gender in 2007) classified a respondent as having reported poor HRQOL

important, because the national health-care and social support systems must address these groups of CCSs in Japan. The Children's Cancer Association of Japan (<http://www.ccaj-found.or.jp/english/>) is now providing assistance and job training to CCSs, and an effective job-training system for CCSs will continue to be warranted in the future.

In our study, the validity and reliability of applying the SF-36 to CCSs in Japan were supported by Cronbach's alpha coefficient. Reulen et al. [13] demonstrated that the

occurrence of ceiling effects should be recognized. In our study, a ceiling effect was observed in PF, BP and SF in more than half of the CCSs; it was found to be highest in the RP (66.1%) and RE (61.7%) subscales. These results were quite similar to those pertaining to British CCSS and siblings. The Kruskal–Wallis test showed a statistical significant difference between CCSs with SCT/RT and siblings in the RP and GH subscales. In the CCSS study, the CCSs score was worse than that of siblings with respect to the overall physical ( $p < 0.001$ ), but not the emotional

aspects of HR-QOL. Nonetheless, effect sizes were small, other than in VT [29]. In a Canadian study, three clinical characteristics—having had CNS or bone cancer, more than one treatment series, and two organs dysfunction—were independently associated with poorer QOL in the physical dimensions [14]. Only survivors with two organs with dysfunction reported poorer QOL in both the physical and psychosocial domains. In our study, multivariate analysis-revealed late effects were common risk factors for lower PF and GH subscale scores, neither SCT nor RT were risk factors for lower PF and GH subscale scores after adjusting.

The limitations of our study are as follows: (1) a limited number of subjects were analyzed, (2) patients with solid tumors were underrepresented, compared to those with hematological cancers, (3) a selection bias may have been presented, because patients were not recruited through random sampling and (4) some patients' siblings were inappropriate as controls because they experienced significant psychosocial distress during the patients' cancer experience. Nonetheless, our report fills a gap in the published literature—and usefully so, given the numerous articles in Japan that survey social outcomes and QOL of young adult CCSs.

## 5 Conclusions

Our study revealed that the long-term social outcome of the CCS group was almost similar to that of the control (i.e., their siblings), but a significant proportion of CCSs were at an increased risk of developing poor social outcomes and QOL, thus requiring psychological or social care if they had some late effects.

**Acknowledgments** The institutions that provided patient data and recruited CCSs to the survey are listed in the supplemental appendix 1. This study was supported by research grants from the Japanese Ministry of Health, Labor, and Welfare ["Study of quality of life and prognosis in childhood cancer survivors and establishment of the long-term follow-up system (Principal investigator: Yasushi Ishida)" and "Study to establish the standard treatment for childhood hematological malignancies (Principal investigator: Keizo Horibe)"].

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## V. 參考資料



# チャイルド・サポート のご案内

ご相談・ご質問がございましたら  
直接 CLS か外来・病棟スタッフに  
声をかけてください。

面談のお約束などは・・・  
e-mail:  
childlifespecialist@gmail.com

活動日: 平日 9時～17時半

CLS 三浦綾子、石田雪美  
院内 PHS 77201

聖路加国際病院

# 何をしますの？

## 何をするの？

### ① 患者様ご自身への支援

お子さまに関する様々なご相談にお応えする  
ことで、お父さま・お母さまの療養生活がより  
ストレスの少ないものとなるようサポートします。  
チャイルド・ライフ・スペシャリストによる  
支援を始めた。

お父さん・お母さんの調子はお子さんに  
とっても大きな出来事です。病院では大切な  
家族の一員としてお母さん・お父さんを支える  
子どもたちが、安心して毎日過ごすよう  
チャイルド・ライフ・スペシャリストによる  
支援を始めた。

### Child Life Specialist (CLS)

チャイルド・ライフ・スペシャリストは一人ひとりの  
子どもとご家族の「病院経験」がよりストレスの  
少ない、主体的なものとなるよう心理・社会的  
支援をおこなう専門の医療スタッフです。  
1950年代より日本で普及してきた専門資格  
で、発達心理学・心理学・教育学などを基盤に  
病院でストレスの多い環境におかれた子ども  
の発達や、ストレスへの対応に関する専門的  
知識を習得しています。

## 何をしますの？

### ② お子さまへの支援

大切な家族が特別な病気になってしまふ事  
は、子どもの心身に大きな影響を及ぼす事  
があります。

CLSはお子さんの遊びや命題を通して、  
お父さま・お母さまの病状や入院などの状  
況をお子さんがどのように感じているか、  
理解しているかを見極め、それをもとにご  
家族が、お子さんどのように過ごすことが  
できるか、を考えたお手伝いをいたします。

お子さんが内に抱える様々な感情や  
ストレスなども遊びを通して自然に表現し、  
お子さんなりに困難を乗り越える力を発揮  
できるように援助します

# 子どもたちはこんなことを 考えています。

★お父さん/お母さんは、  
どんな病気なの？  
★ばく/おちがきい子だから  
病気になったの？  
★これからどうなるんぼ33?

子どもたちは、病気について何も知らされてい  
なくても、いつもと違う何かを感じていることを  
敏感に感じ取ります。  
もしかしら、ひとりではいろいろな考え事をして  
いるかもしれません。

## がん患者さんのお子さんに関する 支援のご案内

お子さんに関するご相談をお受けします。  
ご希望がございましたら、  
主治医または看護婦へお伝えください。  
下記予約センターへのお電話、またはメールでも  
面談の予約を取ることができます。  
お気軽にご連絡ください。

●予約センター(遠隔電話)  
092-541-3262  
●Eメール(予約専用)  
nkcc.kodomo@shinetsu.ac.jp  
メールには必ず「がん患者さんのお子さんの支援」を記入してください

国 富 山 県 立 がん 研 究 会  
心 理 学 士 白 石 恵 子  
医 療 / 大 門 野 次 郎 弘 行

独立行政法人 国立病院機構  
九州がんセンター  
緩和ケアチーム  
TEL: 1366 福岡市東区東区1-1-1  
TEL: 092-541-3262 FAX: 092-541-4588  
URL: http://www.shinetsu.ac.jp

# 子どもたちに 病気についてどう伝えるか 話し合ひましよう

子どもたちに伝える時は・・・

## 1.今の状況を説明する

子どもたちは学校へ行ったり、遊んでいたりして、  
心のどこかで必ずお父さん・お母さんのことを心  
配っています。  
お子さんにかかわる医療で、今何が起きているのか  
を説明してください。

## 2.病気の話を誰のせいでもないことを伝える

お父さん/お母さんの病気は誰のせいでもないこ  
と、お子さんにはとらえられず伝えてください。

## 3.がんはうつらないことを伝える

子どもたちは、病気について知り始めると、次に  
「ばく/わたしも同じようになるのかな?」「近  
寄っても大丈夫?」と心配します。  
「がん」は風邪のようにうつらないことを説  
明してください。

## 子どもたちへどう話しかけるか できるのか?

子どもたちの反応が心配。  
どうなるの?

治療中、ご自身の気持ちの揺らぎや体調の  
変化も大きく、なかなか思うようにお子さんにお  
話しできないことがあるかもしれ  
ません。

患者さんへのサポート  
患者さん、またはご家族から、お子さん  
に関する疑問や不安、不安なことなど  
をお聞きします。一緒にお子さんの対応  
について考えたいきます。

子どもたちへのサポート  
私たちは  
患者さん、そして  
子どもたちをサポートします

子どもには、大人が思っている以上に理解力や適応力があります。  
子どもたちの不安を和らげ、それぞれのご家族らしく生活が出来るようにご支援いたします。

# 四国がんセンター チャイルドケアプロジェクト

お子さんがいらっしゃる患者さんが  
安心して療養生活を  
送ることができるように  
ご家族全体のサポートを考える  
プロジェクトです

Shikoku  
Cancer Center

独立行政法人国立病院機構  
四国がんセンター  
〒791-0820 愛媛県松山市南将木町甲160  
TEL 089-999-1114 FAX 089-999-1115

より安心して生活を送るために・・・  
お子さんがいらっしゃる  
患者さん・ご家族へ

独立行政法人国立病院機構  
四国がんセンター  
チャイルドケアプロジェクト

# お子さんがいらっしゃる患者さんへ

## 「お母さん、大丈夫かな」「お父さん、元気になるよね」

がんの治療はそれだけでも大きなストレスとなりますが、患者さんに子どもがいらっしゃる  
場合、その負担はより大きく感じられています。  
また、子どもにとっても親の病気の大きな出来事です。子どもは、たとえ病気のことを  
聞かされていなくても、普段とは違った家族の様子に気づいているといわれます。  
子どものストレス反応は、年齢、性格、環境などによってさまざまですが、  
周囲のサポートを得ながら、子どもはそれらの困難を乗り越えて行く力を持っています。  
当院では、患者さんができるだけ安心して療養生活を送ることができるよう、それぞれの  
ご家庭の状況に応じ、お子さんにも視野に入れたご家族全体の支援をおこなっています。

## 何をしますの？

### ① 大人（患者さん・ご家族）のつらさへ

子どもに接する様々なご相談に対応します。  
子どもへの関わり方、気になる事柄など、「  
事」に悩まされている方、療養の支障を最小限に  
抑えたい方、状況によっては、教育機関や  
小児科、福祉施設との連携も視野に入れて  
サポートします。

### ② 受診者さんへ

遊びや会話を通して、子どもの考えや感じて  
いることを引き出し、受け止めます。その上で、  
年齢に応じた療育の知見やストレスマネジメント  
などの心理療育をおこないます。  
また、院内療育などを通して、病気に  
対する情念の整理、子どもの持つ社会的な学習意  
欲を大切にします。

## 一緒に考えたいの？

がん相談支援・情報センター、または、病棟  
スタッフにお声かけください。子どもの心理、  
行動に詳しい臨床心理士などが対応します。





日本赤十字社 日本青年会議所  
 全国ボランティアセンター 緩和ケアチーム  
 TEL 1195 緩和ケアチーム（受付時間）  
 TEL 03-541-3331 FAX 03-541-4585  
 URL <http://www.ja-redcc.jp/>  
 (電子メール) サイコソングセンター



みんなで  
 本当によく がんばってきたね。

でも、もうこれ以上  
 なおらないみたい。



おとうさんが  
 うれしいときはあるから  
 心配いらないよ。



おとうさんは、  
 がんというびょうきなんだ。

うつることはないから  
 安心してね。

いま  
 今まで、いっぱい いっぱい  
 びょうきをやっつけようと  
 がんばってきたんだよ。



あなたも  
 よくがんばってきたね。



おとうさんのびょうきは  
 あなたのせいじゃないし、  
 だれのせいでもないんだよ。

何か困ったことがあったら  
 いつでも そばにいる看護師さんや  
 まわりのおとなに 聞いてね。



おとうさんが  
 あなたのことを とてもほめていたよ。  
 じまんの子なんだって。  
 あなたの話をきくときのおとうさんは  
 いつもとても楽しそう。

あなたは おとうさんと  
 いっしょにいてもいいし  
 つらいときは  
 別のことをしていてもいいんだよ。



さみしくなったら、会いにきてね。

手をぎってあげると  
おとうさんも安心して  
うれしいよ。



お話をできないの、  
どうしてかな？



おとうさんは今、  
がんばってきた体が弱って  
お話をできないの。

でもあなたの声は聞こえているし、  
あなたがそばにいることは  
目をとじていても  
分かっているよ。

来てくれたんだね…  
そばに来て大丈夫だよ。



うとうとねむっているから  
苦しくないよ。

だんだん息をする力が弱くなってくけど  
つらくはないよ。

今は声も聞こえるし、  
あなたがそばにいることもわかっている。  
だから話したいことがあったら  
言ってね。

みんなだいすきだよ…



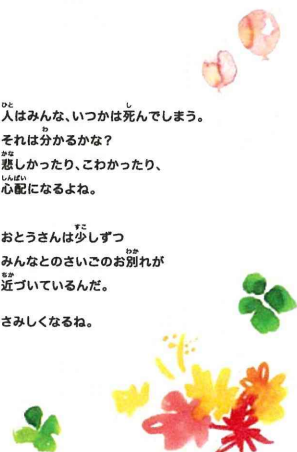
これからとても  
大事なことを  
お話するね。



人はみんな、いつかは死んでしまう。  
それは分かるかな？  
悲しかったり、こわかったり、  
心配になるよね。

おとうさんは少しずつ  
みんなとのさいこのお別れが  
近づいているんだ。

さみしくなるね。



いろいろ考えたり  
心が落ち着かなくなるのはみんな同じだよ。

すこし勇気があるかもしれないけど  
一人で考えこまずに  
まわりの人に話してみよう。



これからどうしたら  
いいのかな？



これからどうやって  
過ごしていけばいいのかわからないよ。

何にもしたくなかったり、  
おとうさんがいないことが悲しかったり、  
許せなかったりもするかな？





みんなで  
本当によく がんばってきたね。

でも、もうこれ以上  
なならないみたいなの。



おかあさんが  
つらいときのお薬はあるから  
心配いらないよ。

おかあさんのびょうき、  
心配だね。

おかあさんは、  
がんというびょうきなんだ。

うつることはないから  
安心してね。

今まで、いっぱい いっぱい  
びょうきをやっつけようと  
がんばってきたんだよ。



あなたも  
よくがんばってきたね。

おかあさんのびょうきは  
あなたのせいじゃないし、  
だれのせいでもないんだよ。

何か困ったことがあったら  
いつでも そばにいる看護師さんや  
まわりのおとなに 聞いてね。

ねえねえ、  
あのね...



おかあさんは  
あなたが  
大好きよ

うちの子たちね〜



おかあさんが  
あなたのことを とてもほめていたよ。  
じまんの子なんだって。  
あなたのことを話すときの おかあさんは  
いつもとても楽しそう。

あなたは おかあさんと  
いっしょにいてもいいし  
つらいときは  
別のことをしていてもいいんだよ。



さみしくなったら、会いに来てね。

手をにぎってあげると  
おかあさんも安心して  
うれしいよ。



お話ができないの、  
どうしてかな？

おかあさんは今、  
がんばってきた体が弱って  
お話ができないの。

でもあなたの声は 聞こえているし、  
あなたがそばにいることは  
目をとじていても 分かっているよ。



うとうとねわっているから  
苦しくないよ。



だんだん息をする力が弱くなってくるけど  
つらくはないよ。

今は声も聞こえるし、  
あなたがそばにいることも わかっている。  
だから話したいことがあったら  
言ってね。



みんな、だいすきだよ…

これからとても  
大事なことを  
お話するね。



人はみんな、いつかは死んでしまう。  
それは分かるかな？  
悲しかったり、こわかったり、  
心配になるよね。

おかあさんは少しずつ  
みんなとのさいごのお別れが  
近づいているんだ。

さみしくなるね。

いろいろ考えたり  
心が落ち着かなくなるのはみんな同じだよ。

すこし勇気があるかもしれないけど  
一人で考えこまずに  
まわりの人に話してみよう。



これからどうしたら  
いいのかな？



これからどうやって  
過ごしていけばいいのかわからないよね。

何にもしたくなかったり、  
おかあさんがいないことが悲しかったり、  
許せなかったりもするかな？