

# Impact of work-related changes on health-related quality of life in adolescent and young adult cancer survivors

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## Abstract

**Background:** Adolescent and young adult (AYA) cancer survivors often face unique work-related challenges and poor health-related quality of life (HRQOL). This study aimed to (1) assess work-related changes after cancer diagnosis in AYA cancer survivors and (2) explore the association between work-related changes and HRQOL.

**Methods:** In a cross-sectional web-based survey, AYA cancer survivors were assessed for work-related changes after cancer diagnosis and their HRQOL using the EuroQoL 5-Dimension 5-Level scale (EQ-5D-5L). The percentage of AYA cancer survivors who had experienced work-related changes was calculated. Multiple regression analysis was used to examine the association between EQ-5D-5L scores and work-related changes, demographics, and clinical variables.

**Results:** The participants were 206 AYA cancer survivors (180 women) with a mean age of 33.7 years (SD 4.3, range: 22–39 years). Among them, 115 (56%) had experienced work-related changes, including 53 (25.7%) who had quit their jobs after their cancer diagnosis. The EQ-5D-5L score (mean: 0.79) was lower in the AYA cancer survivors than in the general population. Moreover, AYA cancer survivors who experienced work-related changes had significantly lower EQ-5D-5L scores compared with AYA cancer survivors who did not (0.75 vs 0.84,  $P < .001$ ). Multiple regression analyses indicated that lower income, reduced working hours, and lower performance status, as measured by the Eastern Cooperative Oncology Group Scale, were associated with lower EQ-5D-5L scores.

**Conclusions:** More than half of the AYA cancer survivors reported work-related changes and had lower HRQOL. Identifying potential interventions supporting AYA cancer survivors with low physical and financial status may be useful for improving their HRQOL.

**Keywords:** adolescent and young adult cancer survivors, Health-related quality of life

## 1. Introduction

Adolescent and young adult (AYA; aged 15–39 years) cancer survivors represent 2.5%–5% of all patients with cancer in economically developed nations.<sup>1</sup> Today, their survival rates are

increasing and exceed 80% in developed countries.<sup>2,3</sup> AYA cancer survivors face a challenging development period characterized by physical, emotional, cognitive, and social transitions unique to this time of life.<sup>4</sup> During cancer treatment, they

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Availability of data and materials: The data sets used and analyzed in this study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate.

Potential participants first read introductory statements that summarized the contents of the questionnaire and explained that they could withdraw at any time if they wished. Responses were considered consent to participate. Those aged 16–19 years were asked to provide their parents' consent. This study was approved by the Institutional Review Board and Ethics Committee of the National Center for Neurology and Psychiatry, Japan, and was conducted in accordance with the principles of the Declaration of Helsinki.

Authors' contributions: The study design and assessments were conceptualized and developed by MF and YU. SG and MF analyzed and interpreted the adolescent and young adult cancer survivors (AYA) cancer survivor data regarding health-related quality of life (HRQOL) and associated factors. SG and MF wrote the manuscript outline, which was carefully revised, edited, and discussed by YI, MF, MO, KO, AS, and YU. All authors have read and approved the final manuscript.

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experience various significant life events, including starting a career, moving toward self-actualization and financial independence, and starting a family.

In addition, employment limitations are common among AYA cancer survivors. Those who quit work after a cancer diagnosis are more likely to report that cancer had a negative effect on their working life, given that AYA cancer survivors, being relatively inexperienced, must start their careers in a precarious position.<sup>5</sup> Among AYA cancer survivors who work full-time, more than half report work-related problems such as forgetfulness, difficulty focusing at work, and workplace errors because of feeling unwell.<sup>6</sup> In addition, 23.4% of AYA cancer survivors report unemployment status because of health issues compared with 13.7% of AYAs without a history of cancer.<sup>7</sup>

Employment status affects the health-related quality of life (HRQOL) in AYA cancer survivors, and unemployment is associated with a low HRQOL in AYA cancer survivors.<sup>8</sup> The employment status of AYA cancer survivors was compromised 24 months after primary diagnosis, and the HRQOL demonstrates relatively little observed improvement during the 12–24-month period after diagnosis.<sup>9</sup> Work-related changes link directly with the HRQOL in AYA cancer survivors.<sup>10,11</sup>

Previous studies that used the 5-level EuroQol-5D questionnaire found that AYA cancer survivors exhibited a low HRQOL with higher anxiety.<sup>12,13</sup> However, most previous research has focused on short-term cancer survivors (12–24 months),<sup>14</sup> and little is known about the status of work-related changes and HRQOL among AYA long-term cancer survivors in Japan. Lower HRQOL in AYA cancer survivors is associated with changes in work; maintaining a balance between work and treatment is important to improve HRQOL in AYA cancer survivors, which may require supporting patients with cancer during employment, from biological, psychological, and social perspectives. It is important to identify work-related parameters associated with lower HRQOL among AYA cancer survivors; however, previous studies have not examined them. Therefore, this study aimed to (1) assess work-related changes after cancer diagnosis and (2) explore the effects of such changes on HRQOL in AYA cancer survivors.

## 2. Materials and methods

### 2.1. Participants and procedure

A cross-sectional web-based survey was conducted, and the inclusion criteria were as follows: (a) patients with cancer who were being followed-up on an outpatient basis and (b) patients aged 16–39 years at the time of the survey. In April 2017, an Internet-based research company (Macromill Inc, Tokyo, Japan) recruited potential cancer survivors of 10 million registered people all over Japan and sent them questionnaires through the Internet over five days. Eligibility criteria were cancer survivors who were followed in outpatient clinics and aged between 16 and 39 years at the time of the survey. First, potential participants read a summarized content of the survey and informed that they could withdraw their consent to participate at any time if they wished. Responses were considered as consent to participate. Because the legal adult age at the time of 2017 in Japan is 20 years, respondents aged between 16 and 19 years were asked to confirm their parents' consent by ticking a box. Responses to the survey were voluntary, and confidentiality was maintained throughout all investigations and analyses. The survey was closed when 206 of

the 1026 AYA cancer survivors responded. The characteristics of patients who did not complete the survey were not determined because we used convenience sampling to analyze the responses through a web-based survey. This study was approved by the Institutional Review Board and Ethics Committee of the National Center for Neurology and Psychiatry, Japan, and was conducted in accordance with the principles set forth in the Declaration of Helsinki and its later amendments.

### 2.2. Measures

**2.2.1. Work-related changes after cancer diagnosis.** The participants' experience of work-related changes after cancer diagnosis was evaluated using the following question, and multiple answers were allowed: "Please select all applicable answers. From cancer diagnosis to the present, has your work changed because of your cancer?" Answers were scored four-point scale as follows: 0, no change; 1, reduced working hours; 2, leave of absence from work (absence from work means sick leave); 3, changed jobs; 4, quit their job; and 5, fired. The participants were allowed to choose between overlapping options. For example, those who took leaves of absence and resigned were counted as both. This item was developed with reference to previous literature,<sup>15</sup> and its content validity was confirmed in advance among researchers, health care professionals, and patients.

### 2.3. HRQOL: the EuroQol 5-dimension 5-level (EQ-5D-5L)

The EQ-5D-5L measures five dimensions of HRQOL: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D-5L enables the calculation of quality-adjusted life years (QALYs), a measure used to evaluate the incremental cost-effectiveness ratio (ICER).<sup>16</sup> The validity and reliability of the original and the Japanese version of the EQ-5D-5L have been confirmed.<sup>17,18</sup> The EQ-5D-5L has five severity levels from level 1 (no problems) to level 5 (high level of symptomatology and problems). The QOL-related score, which is the sum of the scores for the five dimensions, was transformed into a corrected score ranging from 0 (death) to 1 (complete health).

### 2.4. Demographic and medical characteristics

The participants were asked about their demographics and clinical information. Data on age, sex, marital status, education, years since diagnosis, cancer site, and occupational status were obtained from the basic monitoring system. The Eastern Cooperative Oncology Group (ECOG) performance status (PS) scale was used to assess each participant's performance status at enrollment. The ECOG scale ranges from 0 (healthy) to 5 (deceased).

### 2.5. Sample size calculations

We performed a multiple regression analysis to examine the factors related to health-related quality of life (HRQOL) and calculated that 10 times as many subjects as the number of independent variables would be required.<sup>19</sup> Considering missing data, the planned number of participants was 190. Previous research shows that the minimally important difference of the EQ-5D-5L in Japan is  $0.048 \pm 0.004$ .<sup>20</sup> The sample size of 206 gave a power of 100% to detect differences in the mean of

0.048 ± 0.004 for the EQ-5D-5L score using a two-group *t*-test with a two-sided significance level of  $P < .05$ .

## 2.6. Statistical analysis

Descriptive statistics were used to describe the participants' experienced work-related changes after cancer diagnosis; their demographic, medical, and social characteristics; and the EQ-5D-5L total scores of participants who experienced work-related changes and those who did not. A paired *t*-test was used to compare participant characteristics and EQ-5D-5L scores between participants who experienced work-related changes and those who did not. Univariate analysis using a correlation analysis and a  $\chi^2$  test was conducted to identify potential demographic, medical, and social factors associated with EQ-5D-5L. The independent variables were sex, age, age at first diagnosis, performance status, change in income and marital status, and chemotherapy experience, which demonstrated a *P*-value of less than .05 in the univariate analysis.<sup>4,21,22</sup> We considered associated factors (performance status, change in income and experienced work-related changes) which were reported in previous research as independent variables.<sup>7,8,11</sup> A backward stepwise selection was used to explore the factors associated with the EQ-5D-5L to reduce nonsignificant variables in the multiple regression analysis models. Data were analyzed using SPSS version 25.0 (IBM Corp, Armonk, NY), and all tests were two-tailed, with a *P*-value of less than .05.

## 3. Results

### 3.1. Participants' characteristics

In total, 1026 cancer patients (776 women, 75.6%) aged between 16 and 39 years were registered in the database of an Internet-based research company in April 2017. Of them, 206 AYA cancer survivors completed the survey (180 women, 87.4%). The mean age was 33.7 years (SD = 4.3, range: 22–39 years). The most common type of cancer was uterine cancer (40.8%), and Table 1 illustrates the sociodemographic and clinical characteristics of the participants.

### 3.2. Participants who experienced work-related changes after cancer diagnosis

A total of 115 (56%) AYA survivors experienced work-related changes after cancer diagnosis. Among them, 53 (25.7%) quit their jobs, 50 (24.3%) reported taking a leave of absence from work, 22 (10.7%) changed jobs, 20 (9.7%) reported reduced working hours, and two (1%) were fired. Seven (3%) participants reported taking a leave of absence from work and quitting their job, three (1%) took a leave of absence from work and reported reduced working hours, four (2%) took a leave of absence and changed jobs, and three (1%) reported reduced working hours and quit their job. Regarding marital status, people who were divorced and singles were more likely to experience work-related changes after a cancer diagnosis. Regarding children, the group with no children were more likely to experience work-related changes after cancer diagnosis. As illustrated in Table 1, the characteristics that significantly differed after a work-related change after cancer diagnosis were marital status (single or divorced;  $P = .012$ ), no children ( $P = .013$ ), decreased income after cancer diagnosis ( $P < .001$ ), lower performance status ( $P < .001$ ), and undergoing chemotherapy ( $P < .001$ ).

### 3.3. HRQOL of participants

The mean EQ-5D-5L total score for all AYA cancer survivors was  $0.79 \pm 0.14$ . The EQ-5D-5L total score after cancer diagnosis was significantly lower in AYA cancer survivors who experienced work-related changes than in those who did not ( $0.75 \pm 0.14$  vs  $0.84 \pm 0.13$ ,  $P < .001$ ). In those who experienced work-related changes, the severity of the scores for mobility, usual activities, pain/discomfort, and anxiety/depression, but not the self-care domains of the EQ-5D-5L, was also significantly lower (Table 2). The mean EQ-5D-5L total score was  $0.73 \pm 0.16$  in those who reported reduced working hours,  $0.73 \pm 0.13$  in those who reported a leave of absence from work,  $0.75 \pm 0.15$  in those who quit their job,  $0.72 \pm 0.16$  in those who changed jobs, and  $0.80 \pm 0.29$  in those who were fired.

### 3.4. Factors associated with HRQOL

Factors that were significantly correlated with low HRQOL scores were lower performance status ( $P < .001$ ), lower income ( $P = .013$ ), and reduced working hours ( $P = .039$ ; Table 3).

## 4. Discussion

This cross-sectional web-based survey revealed that 56% of the AYA cancer survivors experienced changes in their work status. All AYA cancer survivors exhibited low HRQOL; however, those who experienced work-related changes exhibited significantly lower HRQOL than those who did not. Several articles have reported a minimal important difference (MID) in the EQ-5D-5L, with a score of 0.039 in patients with cervical intraepithelial neoplasia and 0.071 in patients with coronary heart disease after percutaneous coronary intervention.<sup>13,23</sup> Previous research has shown the MID of the EQ-5D-5L index scores as follows: Canada,  $0.056 \pm 0.011$ ; China,  $0.069 \pm 0.007$ ; Spain,  $0.061 \pm 0.008$ ; Japan,  $0.048 \pm 0.004$ ; England,  $0.063 \pm 0.013$ ; and Uruguay,  $0.063 \pm 0.019$ .<sup>20</sup> The mean difference of 0.09 obtained in our study is considered clinically significant. Lower performance status, income, and working hours were associated with lower HRQOL.

In the United States, 64% of AYA cancer survivors experience negative work-related changes after cancer diagnosis. Our results are consistent with those of the previous studies. AYA cancer survivors with disrupted employment had a 17% higher burden of material conditions such as debt or bankruptcy resulting from cancer treatment or sequelae and an 8% higher burden of psychological distress compared with those without disruption.<sup>24</sup> Our results demonstrate that a higher percentage of AYA cancer survivors who experienced work-related changes had reduced income compared with AYA cancer survivors who did not experience work-related changes.

Financial distress—"financial toxicity," "economic hardship," and "financial burden"—is a particularly important factor in the HRQOL of patients with patients.<sup>25</sup> Honda et al.<sup>26</sup> reported that more than 60% of Japanese patients with cancer (median age 67 years) used alternative strategies, such as spending less money on food, clothing, or leisure, to cope with financial toxicity. Financial distress includes not only financial burdens but also psychological and behavioral burdens. Psychological burden includes anxiety about medical expenses, work, and family. Behavioral burden refers to delayed interrupted treatment and financial sacrifice. Cancer survivors cope with multiple problems by maximizing their use of social resources. Similar to older

**Table 1**  
**Patient characteristics and comparison of patients with and without work-related changes after cancer diagnosis.**

	All <i>N</i>	Work-related changes after cancer diagnosis				<i>P</i> -value
		Change		No change		
		<i>N</i>	%	<i>N</i>	%	
Sex	206	115	55.8	91	44.2	
Male	26	19	16.5	7	7.7	.058
Female	180	96	83.5	84	92.3	
Age group						
20–29	35	19	16.5	16	17.6	
30–34	68	36	31.3	32	35.2	
35–39	103	60	52.2	43	47.3	
Marital status						
Married	102	48	41.7	54	59.3	.012
Single or divorced	104	67	58.3	37	40.7	
Household size						
Living alone	45	27	23.5	18	19.8	.524
Two or more	161	88	76.5	73	80.2	
Having children						
None	128	80	69.6	48	52.7	.013
One or more	78	35	30.4	43	47.3	
Caring for parents						
No	192	105	91.3	87	95.6	.223
Yes	14	10	8.7	4	4.4	
Education						
Junior high school/high school	82	48	41.7	34	37.4	.747
Junior college/vocational school	54	27	23.5	27	29.9	
University/graduate school	62	36	31.3	26	28.6	
Others	8	4	3.5	4	4.4	
Occupational status						
Employed full-time	65	29	25.2	36	39.6	.394
Employed part-time	51	36	31.3	15	16.5	
Absence from work	16	11	9.6	5	5.5	
Homemaker	46	18	15.7	28	30.8	
Unemployed	23	17	14.8	6	6.6	
Others	5	4	3.5	1	1.1	
Income changes after cancer diagnosis						
No change	103	28	24.3	75	82.4	<.001
Decreased income	86	76	66.1	10	11.0	
Increased income	17	11	9.6	6	6.6	
Years since diagnosis						
<1 year	33	16	13.9	17	18.7	.171
1–5 years	105	61	53.0	44	48.4	
5–10 years	47	22	19.1	25	27.5	
≥10 years	21	16	13.9	5	5.5	
Performance status (PS)						
0	147	65	56.5	82	90.1	<.001
1	52	44	38.3	8	8.8	
2	4	4	3.5	0	0	
3	2	2	1.7	0	0	
4	1	0	0	1	1.1	
Cancer site						
Uterus	84	9	7.8	12	13.2	.544
Breast	25	10	8.7	15	16.5	
Thyroid	23	12	10.4	11	12.1	
Ovary	23	13	11.3	3	3.3	
Lymphoma	15	3	2.6	12	13.2	
Leukemia	13	3	2.6	10	11.0	
Intestine/rectum	13	5	4.3	8	8.8	
Age at first diagnosis						
<30 y	111	63	54.8	48	69.2	.771
≥30 y	95	52	45.2	43	57.1	
Chemotherapy						
Never	116	50	43.5	66	72.5	<.001
Yes (under/before)	90	65	56.5	25	27.5	

**Table 2**  
**Comparison of HRQOL scores and each domain between patients with and without work-related changes.**

	All		Work-related changes after cancer diagnosis				P
	Mean	SD	Change (N = 115)		No change (N = 91)		
			Mean	SD	Mean	SD	
EQ-5D-5L total score	0.79	0.14	0.75	0.14	0.84	0.13	<.001
Mobility	1.33	0.62	1.47	0.71	1.16	0.45	<.001
Self-care	1.10	0.41	1.14	0.44	1.05	0.38	.146
Usual activities	1.39	0.67	1.57	0.74	1.15	0.49	<.001
Pain/discomfort	1.61	0.75	1.76	0.86	1.42	0.52	<.001
Anxiety/depression	1.95	0.98	2.16	1.05	1.68	0.83	<.001

patients with cancer in Japan, the AYA cancer survivors in this study may have experienced financial distress, which negatively affected their HRQOL. Compared with older patients, AYA cancer survivors had fewer patients in the same age group. To support AYA cancer survivors, it is necessary to strengthen collaboration among patients and enhance the dissemination of information to the target patients.

We found that lower performance status, lower income, and reduced working hours were associated with lower HRQOL in AYA cancer survivors, suggesting the potential for interventions focused on balancing work and treatment toward maintaining employment, working hours, and income in AYA cancer survivors. As maintaining employment and establishing a comfortable work style are important for improving the HRQOL of AYA cancer survivors, the Japanese government has promoted a balance between work and cancer treatment of patients with cancer based on the Plan to Promote Cancer Control Programs.<sup>27</sup> Improvement in working styles, such as working from home, flexible working hour systems, and counseling by industrial physicians, would help improve HRQOL in AYA cancer survivors.

In this study, 25.7% of AYA cancer survivors quit their jobs, and 1% were laid off after a cancer diagnosis. In some countries such as the United States, AYA cancer survivors are known to experience loss of income, loss of medical insurance, and increased financial distress as a result of leaving their jobs.<sup>10,11</sup> Although Japan has a universal health insurance system that provides standard treatment for all patients with cancer, loss of income, loss of paid leave, and loss of employee benefits as a result of leaving their jobs are considered causes of financial distress. The burden of physical and psychological distress on AYA cancer survivors varied by job type and industry. It is important to improve the work environment for AYA cancer survivors according to their type of job and industry they work in. In this survey, participants' job types and industries were not tabulated. Future work is needed to investigate the association of HRQOL and economic burden taking into account

**Table 3**  
**Associated factors of HRQOL (EQ-5D-5L)—multiple regression analysis.**

EQ5D5L total score	B	SE	$\beta$	t	P
Reduced income after cancer diagnosis	0.035	0.027	0.155	2.503	.013
Reduced working hours after cancer diagnosis	0.06	0.029	0.123	2.079	.039
PS (0,1,2,3,4)	0.092	0.014	0.395	6.553	<.001

$\beta$ , standardized coefficient; B, coefficient; PS, ECOG performance status; SE, standard error.

occupational background, such as job type and industry. Our study will serve as a foundation for future interventional studies aimed at improving work-related social and employee support for AYA cancer survivors.

#### 4.1. Study limitations

This study has some limitations. First, this study had a sex imbalance, with more female participants than male participants. According to the Cancer Registry database of Japan, in 2016 and 2017, there were more female than male AYA cancer survivors older than 20 years, and 80% of the AYA cancer survivors in the 20–39-year age group were female.<sup>28</sup> In addition, breast and cervical cancers are predominant in women<sup>29</sup>; therefore, there may have been a sex imbalance in our study owing to this difference in incidence. Second, no participants were younger than 20 years, probably because parental consent was required from anyone younger than 20 years. There was one student participant in our survey, included in the “other” classification. There were few student participants because the survey primarily received responses from those between the ages of 20 and 39 years. There were few student participants because the survey received consent/responses from those between the age of 20 and 39 years. Third, it is unclear whether the respondents were unemployed or gainfully employed before the cancer diagnosis in this survey. There were 91 AYA cancer survivors whose jobs did not change before or after their cancer diagnosis; it is likely that some of these patients were unemployed before their cancer diagnosis. Future studies should investigate whether the patients were unemployed or employed before their cancer diagnosis and focus the analysis on patients who were unemployed before the diagnosis. While a national survey in Japan found that 18% of people in their 20s–30s had quit their jobs in 2022, our survey showed a higher trend among AYA cancer survivors, with 24.3% quitting their jobs.<sup>30</sup> Patients with AYA cancer may experience more negative work changes. Finally, the cross-sectional design of this survey meant that information regarding causal relationships could not be obtained.

#### 5. Conclusion

More than half of the AYA cancer survivors reported work-related changes and lower HRQOL. Identifying potential interventions supporting AYA cancer survivors with low physical and financial status may be useful for increasing their HRQOL. Our study provides a foundation for future interventional studies to improve work-related social and employee support for AYA cancer survivors.

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