

**A Pilot Study for the Development and Evaluation of an Educational Program to Reduce Stigma Towards
Cancer and Cancer Survivors: Focusing on Dating and Marriage After Cancer Diagnosis**

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ABSTRACT

The marriage rate of cancer survivors is lower than that of the general population and their siblings. This appears to be attributable to negative images and stigma in society regarding cancer and cancer survivors. In order to improve images and decrease stigma regarding cancer and cancer survivors, this study aimed to develop an educational program that primarily focuses on dating and marriage after cancer diagnosis. The education program was conducted for university students, and among 67 participants who attended the education program, 61 participants completed a self-report questionnaire both before and after the program. The questionnaire included measures to assess reluctance to date or marry a cancer survivor, attitudes toward marriage and having children, and level of empathy. Scores on most items assessing reluctance decreased after the program; however, only three items showed a significant decrease: reluctance to date a cancer survivor if cancer recurred or metastasized, and reluctance if one's family objects to dating a cancer survivor. Both before and after the program, disease severity was the main cause for reluctance to date. In addition, empathetic concern was associated with reduced reluctance to date or marry a cancer survivor, while conservative attitudes toward marriage was associated with greater reluctance which was a result of familial concerns regarding such relationships. Some of the reluctance could be attributable to socio-cultural values in Asia, where the choice of romantic partner is likely to be subject to familial influence.

INTRODUCTION

In the context of this study, cancer survivors are defined as those who received a cancer diagnosis. The rate of marriage for cancer survivors is lower than that of the general population and their siblings [e.g., 1, 2]. Research indicates that one of the major factors that inhibits cancer survivors from getting married is the anxiety of disclosing their cancer history to the potential partner [e.g., 3, 4]. Cancer survivors were concerned about when, what, and how to disclose their cancer history, changes in their appearance due to cancer treatments, and fertility issues. In fact, some survivors experienced negative reactions, such as potential partners stopped contacting them after learning of the cancer history [3]. The main contributory factor leading to negative reactions against cancer survivors is that cancer is typically associated with death [5]. In one example of negative attitudes toward cancer, 42.3% of the

general population in Korea indicated they were uncomfortable with a cancer survivor [6]. Although overt stigma against cancer survivors has not been reported in Japan, death or incurable illness was the most common belief associated with cancer [7]. The top information source on cancer in Japan is television [8]; however, Japanese TV dramas on cancer focus on terminally ill patients, which in turn impedes an accurate understanding of cancer [9].

There has been minimal research attention given to understanding how negative images and stigma regarding cancer and cancer survivors effect perceptions about romantic relationships and marriage with a cancer survivor. However, there are studies that have examined willingness or interest in dating or marrying a person who has a history of cancer. For example, in Korea, 48.1% of people without cancer did not want to marry a person whose family member has cancer [6]. Meanwhile, in the Netherlands, no difference was found among single people with regard to interest in dating cancer survivors versus those without a history of cancer [10]. Evidently, cultural factors can influence partner selection and marriage. Indeed, parental influence on children's spouse selection is found to be stronger in collectivist societies in Asia than in Western individualist cultures [11, 12]. Similar to Korean childhood cancer survivors being concerned about objection from future in-laws [13], in Japan marriage is not just a relationship between the couple but between families as well. In addition, filial piety (respect for parents and ancestors) remains a robust virtue in Asian societies and includes children's obligation to continue the family line by producing sons [14]. Although attitudes of the general population in Japan toward having a romantic relationship with a cancer survivor are unknown, cultural factors may be contributing to such attitudes.

Cancer is the leading cause of death in Japan, and in an effort to address negative and inaccurate attitudes toward cancer and cancer survivors, education on cancer has been promoted under the Cancer Control Act. Such educational efforts have demonstrated effectiveness with elementary and junior high school students in increasing the ratio of positive responses about cancer and cancer survivors [9]. The Japanese Ministry of Education, Culture, Sports, Science and Technology announced the policy to introduce cancer education in all elementary, junior high, and high schools in a step-by-step manner by 2020. However, young adults do not have the opportunity to have

cancer education, although young adults are in a developmental stage in which many important life events are likely to occur, such as employment, romantic relationships, marriage, and parenthood. To address the need for cancer education in general and young adults in particular, the purpose of this study was to develop and evaluate the effectiveness of a cancer education program to reduce stigma against cancer and cancer survivors with a focus on romantic relationships and marriage.

METHODS

The education program was conducted in a lecture hall for university students in December 2018 as part of a social psychology class. The program was designed with reference to the Cancer Education Guideline [15] and previous research on cancer education for school children [9]. This program had two parts, and each part was for one hour: a lecture by an oncologist, and a story told by a cancer survivor in his 20s who experienced cancer (that can affect both sexes) and returned to a normal life after receiving treatment. Question and answer sessions followed both parts. The lecturers and researchers had meetings to discuss the program content. More specifically, the lecture by the oncologist included basic cancer knowledge (cancer occurrence mechanism, genetic mutation, and cancer characteristics in pediatric and young populations), treatments, and side effects, whereas the content of the story by the cancer survivor focused on cancer trajectory, social support used, and psychosocial challenges post-diagnosis. The lecturers were asked to pay particular attention to lecture content regarding preventing stigma particularly against genetics, lifestyle, and fertility with reference to the Cancer Education Guideline [15]. A self-report questionnaire was administered immediately before (pre-survey) and after (post-survey) the education program. The participants gave their consent by answering the questionnaire.

Measures

The self-report questionnaire consisted of 26 total items with 3 subscales: 11-item Reluctance to Date or Marry, 8-item Attitudes Toward Marriage, and 7-item Empathetic Concerns.

To measure reluctance to date or marry a cancer survivor, 11 original items were prepared by referring to previous

studies that examined the impact of cancer on romantic relationships and marriage [3, 4, 13] and a survey item in a previous study on attitudes toward cancer and cancer survivors in Korea [6]. Participants responded to the items using a 5-point scale (1 = “Do not agree” to 5 = “Agree”). A factor analysis of the items yielded a one-factor structure with a Cronbach’s alpha of 0.94. The 11-item factor was named Reluctance to Date or Marry.

To measure attitudes toward marriage and having children, 8 original items were prepared by referring to a study regarding the psychological aspects of fertility issues among young Japanese cancer survivors [16]. Participants were asked to respond to the following items: “I want to get married in the future” (desire for marriage), “I want to have children in the future” (desire for children), “One becomes an adult only when one gets married and has a family” (one becomes an adult only when married), “Life is meaningless without leaving offspring” (meaninglessness without offspring), “One must have children and continue the family lineage” (family lineage), “I want to get married and reassure my parents” (reassure parents), “Marriage is not just between the couple but between two families” (marriage between two families), and “I want to give my parents grandchildren” (grandchildren for parents). Participants responded to the items using a 5-point scale (1 = “Disagree” to 5 = “Agree”). Two items (one becomes an adult only when married and meaninglessness without offspring) were removed after a factor analysis because their factor loadings were below the cutoff value of 0.35. The factor analysis without the 2 items yielded a one-factor structure with a Cronbach’s alpha of 0.88. The 6-item factor was named Attitudes Toward Marriage. A higher score indicates a more conservative attitude toward marriage and having children.

To measure level of empathy, the Japanese version of the 7-item Empathetic Concern subscale [17, 18] was used. An example item is “I often have tender, concerned feelings for people less fortunate than me.” Items were responded to on a 4-point scale where 1 = “Strongly disagree” and 4 = “Strongly agree.” A higher score indicates greater empathetic concern for others. Internal consistency reliability assessed with Cronbach’s alpha was 0.64.

Demographic information was collected and included participants’ gender, age, number of siblings, dating status,

history of cancer, as well as any history of cancer in people who are close to them.

RESULTS

The number of participants was 67 in the pre-survey and 66 in the post-survey. Among these participants, 61 completed both the pre- and post-questionnaire and were included in the analysis. The mean age was 20.9 years, and none of the participants had a history of cancer. Table 1 shows the demographic information of all participants. With regard to attitudes toward marriage, approximately 70% of the participants responded with “agree” or “somewhat agree” to having a desire for marriage, desire for children, and grandchildren for parents. More than 60% agreed or somewhat agreed with marrying to reassure parents.

Table 2 shows the paired *t*-test results for the pre- and post-means for the Reluctance to Date or Marry items. Among the 11 items, the highest means both pre- and post-survey were for reluctance if severe, reluctance if recurred, and reluctance if metastasized. After participation in the program, there was a significant decrease in the item means for reluctance if recurred, reluctance if metastasized, and reluctance with family objection.

As the result of a Pearson’s correlation analysis to examine the relationships between attitudes toward marriage and having children, empathy, and the Reluctance to Date or Marry items, two findings were of particular significance (Table 3). Firstly, Empathetic Concern subscale scores showed a significant negative partial correlation ($r = -0.37$) with reluctance if severe in the post-survey after controlling for the attitudes in the pre-survey. Secondly, Attitudes Toward Marriage scale scores showed a significant positive correlation ($r = 0.31$) with reluctance with family cancer history in the post-survey; after controlling for the attitudes in the pre-survey, the scores also showed a positive partial correlation ($r = 0.35$) with reluctance with family cancer history. In addition, Attitudes Toward Marriage scale scores significantly positively correlated with reluctance with family objection in both the pre- and post-survey ($r = 0.29$ and $r = 0.33$ respectively).

DISCUSSION

The purpose of this study was to develop and evaluate the effectiveness of a cancer education program to reduce stigma against cancer and cancer survivors with a focus on romantic relationships and marriage. Participants completed a questionnaire before and after the education program that assessed reluctance to date or marry a cancer survivor, attitudes toward marriage and having children, and level of empathy. The results indicate that most of the items assessing reluctance to date or marry a cancer survivor showed a decrease in the mean response after the program. Disease severity was the strongest or primary reason for reluctance in both the pre- and post-survey. Three items showed a significant decrease in the mean response: reluctance to date a cancer survivor if cancer recurred or metastasized, and reluctance if one's family objects to dating a cancer survivor. In addition, empathy and attitudes toward marriage and having children were differentially associated with specific items regarding reluctance to date or marry a cancer survivor both before and after the education program.

A possible reason for the decrease in reluctance is the education program provided the participants with accurate information on cancer and the opportunity to hear about a cancer survivor's experiences directly from a cancer survivor, thereby altering their perceptions about cancer and cancer survivors. Where the program had the most positive effect on reluctance (i.e., a decrease in reluctance) was with regard to information on cancer recurrence and metastasis, which are about the disease and the survivor, but also with regard to one's family objecting to dating a cancer survivor.

Empathetic concern was related to less reluctance to date a cancer survivor with a severe condition. After gaining cancer knowledge and meeting a cancer survivor in the program, people with strong feelings of empathy may have been more likely to imagine what a cancer survivor with a severe condition would be than those who are less empathetic.

The majority of the participants in this study indicated they want to get married to reassure their parents and to

give grandchildren to their parents. Clearly, the desire to please one's parents by marrying and having children are important influences and considerations. Nevertheless, after completing the education program participants reported significantly less reluctance to date a cancer survivor even if their family objected. In this regard, these findings suggest that learning about cancer and the experiences of a cancer survivor through the education program made them sympathetic to cancer survivors.

On the other hand, conservative attitudes toward marriage and having children were associated with reluctance to date a cancer survivor if one's family objects to it. The measure of attitudes toward marriage and having children includes items that focus on the family, such as "One must have children and continue the family lineage" and "Marriage is not just between the couple but between two families"; therefore, the findings revealed that participants who held conservative views were more likely to be subject to parental influences related to attitudes toward dating and marriage and as such may have traditional views of who they should date and marry in consideration of carrying on the family name [14]. The results are consistent with previous findings indicating that in Asian societies there is greater parental control over choice of marriage partners compared to Western countries [11, 12]. A similar finding with regard to conservative attitudes toward marriage and having children was its positive relationship to reluctance to marry a person whose family members had cancer. Because the significant correlation was a result that was found only after the program, it is possible that participants with conservative attitudes misunderstood the information provided about cancer being hereditary. Cancer and genetics are a topic that requires special attention in cancer education [15]. Genetics is a taboo topic in Japanese society even within an educational curriculum, because it is stigmatized due to its association with eugenics in Japan where producing a healthy offspring as an heir who carries a family name forward is important [19]. Thus, young people with a conservative view of marriage and family would be more likely to be reluctant to marry a person whose family members have cancer. In the future, the topic of family history and inherited cancer should be explained with special caution in an easily understood manner so that the education does not have an adverse effect on stigma against cancer and cancer survivors.

Results should be interpreted with consideration of the study's limitations. First, the single-session educational program did not allow for correcting any misunderstandings the participants may have had regarding the lecture information. In this regard, future educational interventions should provide a follow-up session to address any misunderstandings participants have regarding the content. Second, generalizability is limited because of the pilot study's small sample size. A further study, with a wider scope of young adults, could better assess effectiveness of cancer education. Finally, the low Cronbach's alpha for Empathetic Concern subscale may limit the correlations identified with reluctance to date or marry a cancer survivor. Despite its exploratory nature, this study offers insight into effectiveness of cancer education for young adults without opportunities to receive such education.

CONCLUSION

Reluctance to date or marry a cancer survivor decreased after a cancer education program, and disease severity was the main cause for the reluctance both before and after the program. Furthermore, empathetic concern was associated with reduced reluctance to date or marry a cancer survivor, while conservative attitudes toward marriage was associated with greater reluctance which was a result of familial concerns regarding such relationships. Some of the reluctance could be attributable to socio-cultural values in Asia, where the choice of romantic partner is likely to be subject to familial influence.

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Conflicts of interest/Competing interests

The authors have no conflict of interest, financial or otherwise.

Ethics approval

The study was conducted with an approval from the research ethics committee of Human Sciences, University of Tsukuba (Approval No. Tokyo 30-62).

Consent to participate

The participants gave their consent by answering the questionnaire.

Consent for publication (include appropriate statements)

Not applicable.

Availability of data and material (data transparency)

The datasets during and/or analyzed during the current study available from the corresponding author on reasonable request.

Code availability (software application or custom code)

All statistical analyses were performed using BellCurve for Excel version 2.00.

Authors' contributions

Both authors contributed to the study conception and design. Material preparation, data collection, analysis, and preparation of the first draft of the manuscript were performed by KY. YM contributed to interpretation of data and assisted in the preparation of the manuscript. Both authors read and approved the final manuscript.

Compliance with Ethical Standards**Disclosure of potential conflicts of interest**

The authors have no conflict of interest, financial or otherwise.

Research involving human participants

The study was approved by the appropriate institutional review board and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed consent

The participants gave their consent by answering the questionnaire.

Table 1. Demographic characteristics of participants

	n	%
	<i>N</i> = 61	
Age (years)	20.9	
Gender		
Male	18	29.5
Female	43	70.5
Sibling composition		
Male sibling (including mixed-gender siblings)	30	49.2
Female sibling	22	36.1
No sibling	9	14.8
Dating Status		
Partnered	32	52.5
Unpartnered	29	47.5
Cancer history		
Yes	0	0.0
No	61	100.0
Cancer history of significant others		
No	26	42.6
Yes*	35	57.4
Parents	9	14.8
Grandparents	23	37.7
Other	3	4.9

* The closest person was counted for multiple answers.

Table 2. Changes in reluctance to date or marry a cancer survivor

Items	Mean			
	Pre N = 61	Post	<i>t</i>	<i>r</i>
1. I am reluctant to date a cancer survivor. (Reluctance to date)	2.23	2.25	0.13	0.64
2. I am not reluctant to date, but reluctant to marry a cancer survivor. ^a (Reluctance to marry)	2.70	2.58	0.98	0.73
3. I would be reluctant to date a cancer survivor if the person is still receiving cancer treatment. (Reluctance if during treatment)	2.87	2.75	1.16	0.79
4. I would be reluctant to date a cancer survivor depending on the type of cancer. (Reluctance depending on cancer type)	2.15	2.10	0.49	0.67
5. I would be reluctant to date a cancer survivor if conditions are severe. (Reluctance if severe)	3.26	3.10	1.74	0.87
6. I would be reluctant to date a cancer survivor with recurrence. (Reluctance if recurred)	3.16	2.89	2.48*	0.80
7. I would be reluctant to date a cancer survivor with metastasis. (Reluctance if metastasized)	3.20	2.90	3.12*	0.86
8. I would be reluctant to a cancer survivor if the follow-up observation (approx. 5 years) has not passed. ^a (Reluctance if during follow-up)	2.42	2.25	1.69	0.78
9. I would be reluctant to date a cancer survivor if my family objects. ^a (Reluctance with family objection)	2.85	2.43	3.80**	0.76
10. I am reluctant to marry a person whose family members had cancer (the person does not have a cancer history). (Reluctance with family cancer history)	1.39	1.43	0.42	0.54
11. Cancer history has nothing to do with dating. (R)	2.38	2.43	0.40	0.69

Phrases in the parentheses are abbreviations for the items. R: reverse scored.

^a *n* = 60 responses. **p* < .05, ***p* < .001.

Table 3. Pearson's correlation analysis between reluctance to date or marry a cancer survivor and empathetic concern and attitudes toward marriage

Items	Empathetic concern		Attitudes toward marriage			
	Pre	Post ^a	Pre	Post ^a		
	<i>r</i>	<i>r</i>	<i>r</i>	<i>r</i>		
	n		n			
1 I am reluctant to date a cancer survivor. (Reluctance to date)	-0.15	-0.16 (-0.09)	0.01	-0.02 (-0.03)	61	60
2 I am not reluctant to date, but reluctant to marry a cancer survivor. (Reluctance to marry)	-0.08	-0.13 (-0.11)	0.01	-0.09 (-0.14)	60	59
3 I would be reluctant to date a cancer survivor if the person is still receiving cancer treatment. (Reluctance if during treatment)	-0.17	-0.21 (-0.13)	-0.02	-0.05 (-0.05)	61	60
4 I would be reluctant to date a cancer survivor depending on the type of cancer. (Reluctance depending on cancer type)	-0.08	-0.08 (-0.03)	0.02	0.03 (0.03)	61	60
5 I would be reluctant to date a cancer survivor if conditions are severe. (Reluctance if severe)	-0.02	-0.20 (-0.37**)	0.10	0.03 (-0.10)	61	60
6 I would be reluctant to date a cancer survivor with recurrence. (Reluctance if recurred)	-0.05	-0.14 (-0.17)	0.12	0.04 (-0.10)	61	60
7 I would be reluctant to date a cancer survivor with metastasis. (Reluctance if metastasized)	-0.08	-0.18 (-0.22)	0.09	0.04 (-0.09)	61	60
8 I would be reluctant to a cancer survivor if the follow-up observation (approx. 5 years) has not passed. (Reluctance if during follow-up)	-0.14	-0.12 (-0.02)	-0.11	-0.09 (-0.01)	60	58
9 I would be reluctant to date a cancer survivor if my family objects. (Reluctance with family objection)	0.12	-0.07 (-0.24)	0.29*	0.33* (0.18)	60	59
10 I am reluctant to marry a person whose family members had cancer (the person does not have a cancer history). (Reluctance with family cancer history)	-0.07	-0.08 (-0.05)	0.03	0.31* (0.35*)	61	60
11 Cancer history has nothing to do with dating. (R)	0.07	-0.08 (-0.18)	0.05	-0.08 (-0.16)	58	57

Phrases in the parentheses are abbreviations for the items. R: reverse scored.

^a Upper: correlation coefficient, Lower: partial correlation coefficient

* $p < .05$, ** $p < .01$.