

# Children's Perception of Cancer and Survivors After a Cancer Education Program Engaging with Survivors: A Qualitative Study

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## Abstract

**Background:** In Japan, cancer education utilizing external lecturers are being promoted as part of cancer control measures. The objective of this study was to clarify children's perceptions of cancer and survivors and their awareness of actions for early prevention and detection of cancer after participating in a cancer education program engaging with survivors.

**Methods:** This study was conducted during January and March 2020, using the qualitative analysis method. Homeroom teachers gave a lesson on cancer to sixth-grade students (n=69) at an elementary school in Japan. Two weeks later, a cancer survivor gave a follow-up class. Then an inductive content analysis was conducted on the content of the post-class reflection worksheets written by students.

**Results:** After analyzing the worksheets of 59 students, they learned that "to reduce the risk of developing cancer, one should lead a healthy lifestyle" and "strive for early detection through cancer screening" through the education program. As things they can do themselves in the future, they listed "encourage family members to get cancer screenings," "quit smoking," and "cut back on alcohol." In addition, children have deepened their understanding of cancer survivors and learned the importance of their own and others' lives.

**Conclusion:** The results suggested that children gained practical knowledge about cancer through the program and deepened their understanding of cancer and survivors by directly interacting with and listening to survivors.

**Keywords:** Health promotion, Child, Cancer survivors, Schools, Cancer education

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## 1. Introduction

Cancer is a serious medical problem and the leading cause of death worldwide. It is estimated that in 2020, 19.3 million people will be newly diagnosed with cancer worldwide, and approximately 10 million people will die from this disease (1). By 2040, the number of new cancer cases is expected to increase by 47% from 2020 to 28.4 million, which could be exacerbated by increasing risk factors associated with globalization and economic growth. In Japan, cancer has been the leading cause of death since 1981 (2), accounting for about 30% of all deaths. The number of new cancer cases in Japan in 2020 is reported to be 1,012,000 and is increasing (2).

The World Health Organization notes that about a third of cancer deaths are caused by smoking, high body mass index, alcohol intake, low fruit and vegetable intake, and lack of exercise (3). Since many of the health habits associated with

cancer and other diseases develop early in life (4), interventions that support the establishment of health-promoting behaviors in childhood, before adolescence, are needed to reduce cancer risk in adults (5). There have been many surveys regarding knowledge and awareness about cancer and its prevention among children, adolescents, and others in various countries, including Japan (6-13). However, it has been pointed out that children and adolescents have insufficient knowledge about cancer and its prevention; therefore, the frequency of preventive behaviors is also low. It has also been reported that the level of knowledge and awareness is closely related to health-related behaviors and cancer-related risk behaviors (10-13).

Schools are unique venues for preventive interventions in promoting youth health, and the school years are critical for developing healthy behaviors that contribute to lifelong health promotion (14). The American Cancer Society states the importance of comprehensive health

education programs in primary cancer prevention (4) In this regard, since the late 1970s, educational programs on health habits for preschool and elementary school children have been developed (15). Others have reported that cancer education programs have been developed and offered to students from elementary through high school by school personnel, cancer hospitals, and charities (5, 11-13, 16-19). These programs' content is designed to provide knowledge about cancer and its prevention for school teachers, trained leaders, and high school students. The usefulness of school-based cancer education has been reported, as scores indicating the degree of students' knowledge and awareness of cancer and cancer prevention significantly increased after the intervention of cancer education programs (5, 11-13, 16-19).

In Japan, the Cancer Control Act was enacted in 2006, and since then, a basic plan to promote cancer control has been developed every five years. In the Second-term Basic Plan to Promote Cancer Control Programs formulated in 2012, "promotion of cancer education" was included as a basic measure for the first time (2). Furthermore, in December 2016, a new article entitled "The national and local governments shall take necessary measures to promote cancer education in school and social education" was added to the partially revised Cancer Control Act (2). The Third-term Basic Plan to Promote Cancer Control Programs (FY 2017–2022) indicates that "a system to utilize external lecturers, such as cancer survivors (survivors) and medical professionals, should be established according to local conditions, and cancer education should be enhanced after ascertaining the status of implementation nationwide" (20). However, according to a 2018 survey conducted by the Ministry of Education, Culture, Sports, Science, and Technology of Japan (MEXT), the implementation rate of cancer education in elementary schools nationwide is 56.3%, while in Okinawa Prefecture it is less than half, at 24.5% (20). Furthermore, the implementation rate of cancer education using outside instructors is low, at 3.9% (11/282 schools) in Okinawa Prefecture, compared to 8.3% (1690/20420 schools) nationwide (20). Training courses that involve cancer survivors as outside instructors is rarely implemented in Okinawa Prefecture or Japan. These statements indicate the need to develop a system for cancer education in collaboration with school teachers and outside instructors, such as survivors, in the future.

A report that quantitatively compared the cancer prevention knowledge and perceptions of cancer patients among elementary school students who received cancer education from outside instructors suggested that children's knowledge of cancer prevention may be improved, but the outside instructors were not identified as survivors (21). The studies mentioned above are also not cancer education programs that engage with survivors (6, 11-13, 16-19). Although promoting cancer education involving outside instructors is necessary for Japan, no research reports evaluate cancer education programs engaging with survivors. In addition, since evaluations before and after cancer education program interventions (6, 11-13, 16-19, 21) have been conducted only by quantitative comparisons, specific learning contents, perceptions, and changes in children's verbal expression have not been clarified. Therefore, the objective of this study was to clarify children's perceptions of cancer and survivors as well as their awareness of actions for early prevention and detection of cancer after participating in a cancer education program engaging with survivors. Another purpose of the study was to obtain suggestions for creating outcome measures for the cancer education program through qualitative analysis of reflection worksheets written by children. These findings also examine the possibility of children's proactive involvement in cancer control by providing cancer education programs in collaboration with teachers and survivors.

## 2. Methods

This study was conducted using the qualitative content analysis method.

### 2.1. Participants and Data collection

The primary selection used convenience sampling to recruit participants (22); primary school A was selected among the target primary schools, where cancer education had not been conducted before. The school principal and two sixth-grade teachers explained the study's purpose and method, and their consent was obtained. The study population was 69 students from two sixth-grade classes at an elementary school in Okinawa Prefecture, Japan. The inclusion criterion for this study was that the subjects were sixth grade students at primary school A who had attended

a cancer education program with homeroom teachers and a cancer survivor, and the exclusion criterion was that the students had not obtained consent from their parents.

Data were collected from reflection worksheets written by children after participating in the cancer education program. In addition, to observe the children's responses to the cancer survivor's class, the researcher participated as an observer in two classes provided by the survivors.

### 2.2. Cancer Education Program procedures

The program content was structured under the two goals of (1) to understand cancer correctly and (2) to think independently about the importance of life and health, discussed by the Ministry of Education, Culture, Sports, Science, and Technology of Japan (MEXT) (23). First, a meeting was held between the homeroom teacher, the cancer survivor, and the researcher to outline considerations for the children before the class (23). We checked with the homeroom teacher to determine if there were pediatric cancer

patients, students who had cancer, students who had family members with cancer, or students who had lost family members to cancer in the class. Furthermore, the homeroom teachers notified students' parents by letter two weeks before the start of class, informing them that the class would focus on cancer.

In January 2020, the cancer education program was implemented in two separate classes. The homeroom teachers conducted a 45-minute class providing basic knowledge about cancer (Table 1). At the end of the class, the children were asked to write down any questions they would like to ask the survivor, and these were sent to the survivor conducting the class. Approximately two weeks later, the cancer survivor provided the class (Table 1). A cancer survivor with seven years of experience providing cancer education to elementary school students in another prefecture offered the same lesson to two classes of children. The first half of each class consisted of answering questions about survivors' experiences based on the questions sent in advance. In the second half, the survivor talked about the importance of life, introducing a friend

**Table 1:** Overview of the cancer education program for sixth-grade students

Objectives	The classes are designed to provide students with correct information about cancer and opportunities to think independently about the importance of life and health.
Contents of class by homeroom teacher (45 minutes)	Contents of class by cancer survivor (45 minutes)
<p>1. What is cancer (including factors of cancer)</p> <ul style="list-style-type: none"> <li>Human cancer development</li> <li>Causes of cancer</li> </ul> <p>2. Types of cancer and their course</p> <p>3. Status of cancer in Japan</p> <ul style="list-style-type: none"> <li>Epidemiology of cancer</li> </ul> <p>4. Cancer prevention</p> <ul style="list-style-type: none"> <li>Evidence-based prevention of cancer in Japan</li> </ul> <p>(12 new tips to reduce the risk of cancer)</p> <p>5. Early detection of cancer / cancer screening</p> <ul style="list-style-type: none"> <li>In Japan, few people undergo cancer screening.</li> </ul> <p>6. Cancer treatments</p> <ul style="list-style-type: none"> <li>Surgery, radiation therapy, drug therapy</li> </ul> <p>7. Palliative care in cancer treatment</p> <ul style="list-style-type: none"> <li>Relieve pain in the mind and body</li> </ul> <p>8. What's life like for cancer patients?</p> <ul style="list-style-type: none"> <li>Able to live the unchanged life while being treated for cancer.</li> </ul> <p>9. How to find out about cancer</p> <ul style="list-style-type: none"> <li>How can I get the correct information on cancer?</li> </ul>	<p>1. Cancer Stories (25 minutes)</p> <p>The cancer survivor talked about how she felt when she found out she had cancer, the cause of her cancer, and what was challenging and helpful during her treatment experiences, according to the "What you want to ask cancer patients" questions provided by the students in advance.</p> <p>Actual classroom scenes</p> <ul style="list-style-type: none"> <li>➤ The survivor, in response to preliminary questions from the students, stated that she had breast cancer, that she had never smoked or drunk heavily, and that her doctor had told her that he did not necessarily know what caused the cancer.</li> <li>➤ She further explained the symptoms (lumps in the breast) when cancer is detected, and stated that while cancer that can be touched from the surface can be noticed, cancer in internal organs has no pain or other symptoms and is difficult to self-diagnose.</li> <li>➤ She shared her treatment experience, showing pictures of her own hair loss, and said that her family and friends supported her, and that it is still hard when people feel sorry for her.</li> <li>➤ She also talked about how her doctors have not yet told her that she is cured of cancer, but that she is now living a normal, healthy life while undergoing checkups.</li> </ul> <p>2. Story of a friend who died of cancer (20 minutes)</p> <ul style="list-style-type: none"> <li>➤ The survivor shared with the students a story of a cancer survivor who was involved in a cancer education class until his passing, faced cancer, and lived to describe it, emphasizing the importance of life.</li> </ul> <p>Actual classroom scenes</p> <ul style="list-style-type: none"> <li>➤ She used slides to tell the story of one of her friends. These slides included his message to the students: "It is amazing that you are alive now, and it is a blessing to be able to live a normal life," "Take care of those who are by your side," "I pass the baton of life to you all," and "Enjoy your life, which is irreplaceable."</li> </ul>

**Table 2:** Categories and codes extracted from responses to each question theme on the worksheet

Themes	Categories	Codes (number of codes)
What I learned about cancer	Cancer characteristics	Cancer may be noticed by pain or lumps, or it may go unnoticed (delayed recognition) (17)
		Cancer can occur anywhere in the body and can be of many different types (11)
		Cancer is a disease that can develop even if one is careful about lifestyle (9)
		Cancer does not always kill you, if detected early, it can be cured (7), When it is not curable, cancer can kill you (3)
		Some cancers are hereditary, but the effect of heredity is small (6)
		Associated with lifestyle habits such as smoking and drinking (4)
		Familiar disease affecting 1 in 2 people (8), It is common among the elderly (4), More males than females are affected (1)
	Cancer treatment and the effects	There are various treatment options, but they are both time and physical burdens (8)
		Cancer treatment may cause hair to fall out, but not always (5)
What I view about cancer patients	Negative view before the classes	The image was gloomy, listless, and painful (20)
		I had an image of him/her in a wheelchair (9)
		I thought all cancer patients would lose their hair (7)
	Change in view of cancer patients after the classes	Cancer patients can be cheerful and positive about life (53), Many people with cancer can live a normal life (18)
		My fear of "cancer = death" has disappeared (3), Even if we have cancer, it doesn't mean we'll always be unhappy (1)
	Cancer patients' bodies are at war against themselves (1), Having cancer makes it hard to enjoy one's life (1)	
What I can do to prevent or detect cancer early	Live a healthy lifestyle	Maintain a healthy lifestyle or regular life (9), Do not smoke (9), Do exercise (6)
		Avoid drinking too much alcohol (6), Maintain a nutritionally balanced diet (6)
		Aim to get a good night's sleep and not overexerting oneself (4)
		Tell family members to quit smoking or encourage sobriety (5)
	Medical checkups and consultations	Take a cancer screening or health checkup (38), Undergo regular checkups or if an abnormality is found (10)
	Encourage family members to undergo cancer screenings and health checkups (8)	
	Take out cancer insurance (1)	
What I can do to understand cancer and patients	Learning together	Share what I learned about cancer with my family (22)
		Continue to learn more about cancer (19)
		Create opportunities to discuss and interact with the community about cancer (5)
	Having compassion	Have a compassionate attitude toward cancer patients (17)
	Interact with and listen to cancer patients (7)	
What I can do if my loved one has cancer	Support my loved one	Talk to my loved one to encourage them and support them in their treatment (26),
		Help take care of things (household chores) that my loved one is unable to do (7), Support what he/she wants to do (3),
		Stay by their side and support them as much as possible (6), Listen to my loved one (3), Go visit a loved one (3)
	Respect my loved one	Having a good time together, telling good stories, having fun (7)
		Don't feel sorry for him/her (4), Treat them the same way I have always treated them (2)
		I will let my loved ones do whatever they want to do (2)
Understanding cancer	Research on my own or listen to his/her doctor to understand (5)	
	I will talk to those around me about my loved one and make sure they understand (3)	
What I want to do in the future after the classes	Take care of myself and those around me	I will choose not use hurtful words to others (12)
		I will act with consideration for the value of my own life and the lives of those around me (10)
		If I see a friend in need, I want to help (4)
		I want to convey the importance of life to those close to me (3)
		I want to express my gratitude to those close to me (1)
	Spend my life meaningfully	I want to make the most of each day and do what I want to do while I'm still alive (8)
		I want to do something for the benefit of others in the future (5)
		I want to live positively and confidently (2)

who had been engaged in cancer education classes until just before his death and a friend who had faced cancer and lived on his terms. After the class, the homeroom teacher distributed a worksheet for reflection and asked the students to fill it out freely. The worksheet included six items: 1. what they learned about cancer, 2. what they viewed about cancer patients, 3. what they can do to prevent or detect cancer early, 4. what they can do to understand cancer and patients with cancer, 5. what they can do if their loved one has cancer, and 6. what they would like to do after taking the class.

### 2.3. Data Analysis

The students' free-response statements to the six questions on the worksheet were analyzed using inductive content analysis (24). At the beginning of the analysis, as a preparatory step, we read the students' worksheet descriptions to understand what they were describing. Next, the following steps were taken in the analysis. We focused on words and sentences representing semantic content as the unit of analysis for each question, and extracted them as codes. After open coding, we grouped similar codes and formulated general descriptions for the question themes by creating categories as abstractions.

Data analysis was refined by repeating the analysis until discrepancies in interpretation among researchers were resolved. Particular attention was paid to the selection of analysis units through discussions among the researchers to ensure that the semantic content of the descriptions was not lost or fragmented. Two elementary school teachers also participated in the peer-checking process to confirm the authenticity of the data. In addition, the entire process of analysis was supervised by an expert in qualitative research.

### 3. Results

The participants were 59 sixth-grade students whose parents' consent was obtained from the 69 students who participated in the cancer education program. The actual classroom scenes provided by the survivor are shown in Table 1. The analysis results of the 59 children's worksheets are shown in Table 2.

In response to question 1, "What I learned about cancer," the children understood that cancer

is a familiar disease that affects one out of two people, its cause is related to lifestyle habits such as smoking and drinking, and it is possible to develop cancer even if the person is careful about lifestyle. They also realized that there are various treatment options and that these treatments may be harmful to the body. Regarding question 2, "Views about cancer patients," they had an image of cancer patients as gloomy, listless, in pain, in wheelchairs, with hair loss, and so on, before the course. Through interaction with the cancer survivor, they changed their opinion to "even if they have cancer, they can live a normal, cheerful, and positive life and that they are not necessarily unfortunate". In response to question 3, "What I can do to prevent or detect cancer early" they mentioned maintaining a healthy lifestyle, including quitting smoking, moderating alcohol consumption, exercising, and having a well-balanced diet. They said they would encourage their families to receive cancer screening and regular checkups. For question 4, "What I can do to understand cancer and cancer patients," they responded, "Sharing what I learned about cancer with my family," "Continue to learn more about cancer," and "Have compassion for cancer patients." In response to question 5, "What I can do if my loved one has cancer," students answered that they should support treatment, help with household chores, have fun together, not feel sorry for them, and treat them the same way they have always treated each other. In response to question 6, "What I want to do now that I have finished the cancer education class," students answered, "Think about the importance of my own life and the lives of those around me," "Do something useful for others such as volunteer activities," and "Cherish each day and live positively." Throughout class time, students listened intently to the cancer survivor's story.

### 4. Discussion

The present study focused on students' descriptions of what they learned and found that through cancer education programs engaging with survivors, they gained more practical knowledge about cancer and cancer prevention through a cancer education program engaging with cancer survivors and deepened their understanding of cancer and survivors. A spillover effect of children acting as health promoters to inform their families about cancer screening and cancer-related lifestyle modification was also predicted, suggesting the

possibility of promoting children's proactive participation in cancer control.

A national survey of Japanese school students conducted before cancer education was introduced in schools reported that television and parents were the top sources of information about health and cancer at 87% and 68%, respectively (25). In terms of awareness of who is eligible for cancer screening, 76% were "those with subjective symptoms," 70% were "those recommended by a doctor," while 60.9% were reported as "healthy people" (26).

After examining the learning from the free descriptions of the children who participated in this cancer education program, the children were able to accurately express in their own words what they understood about cancer, cancer patients, and cancer prevention behaviors and thus were evaluated as having a good understanding of cancer. While smoking and infectious diseases are the main causes of cancer in Japan, more than half of all cancers have no known reason (27); It is believed that the children were able to acquire more practical knowledge in addition to the above general knowledge through the survivors' experience.

Furthermore, Kobayashi (28), who has been involved in health education in Sri Lanka for many years, revealed that a smoking cessation campaign targeting adults in Sri Lanka was not effective in preventing oral cancer, and he described how educating elementary school students about cancer prevention reduced smoking rates in the community. Similarly, our findings also showed that children could contribute as health promoters by expressing what they can do, such as encouraging their families to undergo cancer screening, quit smoking, and reduce alcohol consumption.

Regarding cancer-related risk behaviors among adolescents, the Japanese government has established a goal in Cancer Control Act to reduce the youth smoking rate to zero by 2022 (29). The youth smoking rate (at least once in the past 30 days) in Okinawa Prefecture has decreased over time (30). However, in 2016, this rate was 4.4% for boys and 1.7% for girls (30), considerably higher than the national rates of 0.5% and 0.2%, respectively (31). Similarly, the prevalence of alcohol use (at least once in the past 30 days) has also shown a decreasing trend over time, but the

frequency in Okinawa is 9.8% for boys and 8.6% for girls (30), also higher than the national rates of 5.1% and 4.3%, respectively (31). Given this situation, early intervention in cancer education for children is necessary for Okinawa Prefecture to raise awareness of risk behaviors related to cancer among the youth from an early age.

On the other hand; however, Yako-Suketomo and colleagues (21) pointed out that there are concerns about that improvement in cancer prevention knowledge may lead to the promotion of prejudice against cancer patients. According to the results of a questionnaire for Japanese children who received cancer education, the percentage of those who answered "excessive smoking and drinking" was significantly higher after the course than before in terms of their image of cancer patients (21). Overemphasizing to children that "cancer is caused by lifestyle" may lead to a false perception of cancer. Therefore, it would be appropriate to inform children that several factors contribute to cancer development, and having a healthy lifestyle can help prevent cancer and other diseases. Furthermore, providing support that focuses on establishing healthy habits and lifestyles is also paramount.

In this study, the students had a negative image of cancer patients before the class, which was thought to be influenced by information from mass media such as TV and movies. However, the results of the children's descriptions revealed that their negative images of the disease were considerably reduced through direct interaction with a cancer survivor. In a survey of Japanese elementary school students, Sugisaki and colleagues (32) reported that students whose parents or relatives had cancer were more likely to think that "cancer is scary" or "I think I will get cancer in the future" and less likely to think that "cancer is preventable," but their attitudes changed to positive as their understanding of cancer increased. The findings supported our results by stating that such negative attitudes may decrease as cancer education increases the knowledge of cancer. To prevent negative images of cancer, providing opportunities to interact with survivors through cancer education programs, starting at an early age, may help reduce prejudice against cancer and cancer patients. In this study, the students who participated in our educational program engaging with a survivor were intentionally asked and given the opportunity to think about "what I

can do to understand cancer patients” and “what I can do when my loved one has cancer.” Providing opportunities to interact with survivors may reduce prejudice against cancer patients and help them face cancer positively, even when a family member has cancer. In cancer education for children, who will be future leaders, it is important to provide not only knowledge about cancer and cancer prevention but also opportunities to learn about building a society where people can live with cancer to reduce the burden caused by cancer in the future. Therefore, in cancer education at schools, it is significant to incorporate programs in which teachers and survivors collaborate to deepen correct knowledge about cancer and the understanding of cancer patients. Considering that one out of every two people will be diagnosed with cancer, the number of survivors is expected to increase. In the future, survivors are expected to play an important role as outside instructors in cancer education at schools and as peer supporters in the community. Through school education and interaction with students in the community, we believe that disseminating survivors’ experiences, thoughts, and issues to society will help promote survivorship in society.

The unique aspect of the study was to assess children’s perceptions of cancer and cancer patients and their awareness of actions for prevention and early detection through qualitative analysis of worksheets written by the children. By analyzing the children’s verbal expressions, we found that even sixth-grade children have sufficient potential to deepen their understanding of cancer. The findings of this study have significant implications for future cancer education practices engaging with survivors.

#### 4.1. Limitations

However, this study has several limitations. Firstly, the sampling strategy may have introduced a selection bias of students from one school in a limited geographic area. Second, because this cancer education program was implemented once cross-sectionally, it is necessary to continue evaluating the educational content by examining changes in children’s interests, attitudes, about cancer and survivors, as well as changes in their knowledge and understanding of cancer. In addition, further studies involving more students and schools are needed to examine the long-term educational effects and address sampling limitations.

## 5. Conclusions

In this study, a cancer education program was provided to sixth-grade students in collaboration with school teachers and a survivor. The children’s perception of cancer and survivors after participating in the program was studied through inductive content analysis of their worksheets. As a result of the analysis, the children understood “the significance of developing healthy lifestyle habits that minimize the risk of developing cancer” and “the importance of undergoing cancer screening.” Their learning can be expected to spill over into their families as health promoters. In addition, through interaction with cancer survivors, children may have deepened their understanding of cancer patients, learned the importance of their own and others’ lives, and had an experience that affected their sensibilities. Based on the above, the implementation of cancer education programs engaging with cancer survivors in schools is expected to lead to the acquisition of more practical knowledge about cancer, the development of the ability to address health issues and cancer control proactively, and the fostering a sense of coexistence, ultimately leading to improved cancer literacy and the promotion of survivorship in the entire community.

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## Ethical Approval

This study was reviewed by the University of the Ryukyus Research Ethics Committee (approval No. 1552), which approved the following process for obtaining informed consent from the children to be studied and their parents/guardians. Parents were informed by letter of the purpose of this study, its methods, whether they were willing for their children’s written reflection worksheets to be included in the study, and that they could decline to participate in the study. Written responses were obtained from each parent regarding whether or not the reflection sheets could be utilized.

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