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Research Article

Dietary Events for Social Activity in Children, Adolescents and Young Adults Cancer Patients

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Abstract

Background and Objectives: The role of social activities through dietary events in pediatric patients, adolescents and young adults remains unknown. This study aimed to evaluate the composition of participants in patient-led dietary events and to evaluate the importance of social activities among children, adolescents and young adults. **Materials and Methods:** In this prospective study, the number of dietary events held was assessed, targeted number of hospitalized patients, number of participating hospitalized patients (the participation rate was based on these results), participant's characteristics (sex, age; children: Age 0-14 years, adolescent and young adults: Age 15-39 years), frequency of dietary events in which pediatric and adolescent and young adult patients participated together, number of families that participated, number of staff members that participated and number of outpatients between January, 2013 and October, 2017. **Results:** One hundred and fifty-five patients participated in the meal events (84 males, age 9 [1-31 years]). The median number of events attended per patient was 2 (1-18). Sixty-six dietary events were hosted; 430 (93.9%) out of 458 targeted patients participated and 92% of events had both pediatric and adolescent and young adult patients participating, with no statistical difference ($p = 0.136$). A total of 398 families and 237 staff participated. **Conclusion:** Patient-led dietary events for children, adolescent and young adult patients with cancer had a high socialization rate, without any differences based on age; this may serve as a social activity for patients.

Key words: Social activity, cancer, patient-led, dietary event, paediatrics, adolescents and young adults, multidisciplinary collaboration

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Data Availability: All relevant data are within the paper and its supporting information files.

INTRODUCTION

Although the 5-year survival of childhood cancer has reached 70% in recent years, the 5-year survival of Adolescent and Young Adult (AYA, age: 15-39 years) patients is approximately 50%^{1,2}. In the United States, with the National Cancer Institute, the Lance Armstrong Foundation formed the AYA Oncology Progress Review Group (AYAO PRG) that clarified the characteristics and problems of AYAs. Since then, reports on cancer in AYAs have been published^{3,4}. On the other hand, in Japan, data on the epidemiology of cancers in AYA and related interventions are limited⁵⁻⁸. Treatment adherence is also low⁹. To address these issues, research involving AYA patients with cancer primarily in Europe and the United States is ongoing^{10,11}.

There has been no report on social activity among pediatric and AYA patients, despite the many studies conducted in this patient group^{12,13}. At the Shizuoka Cancer Center (SCC), in working towards our goal of "we support patients and their families thoroughly," the pediatric nurses and Child Life Specialists (CLS) monitor the therapeutic progress of patients and collaborate with Registered Dietitians (RD) to host patient-led dietary events as a social activity using the playroom in the pediatric (AYA) ward¹⁴. Loss of appetite is inevitable during cancer treatment. No efforts have been reported to support eating through such collaboration among medical professionals¹⁵. Regarding achieving adherence through RD-only nutritional interventions, efforts to improve eating have limits¹⁶. It is thought that patient-led communication and socialization can be created by having patients eat the same food at the same table. It may make sense to use meals for events that both growing children and AYAs have in common.

So far, no hospital dietary event for children and AYAs has been reported. The effects of dietary events in collaboration with medical professionals have not also been reported.

This study aimed to elucidate the composition of participants of patient-led dietary events and to evaluate the importance of social activities among pediatric and AYA patients.

MATERIALS AND METHODS

Study subjects: This prospective study (Approval No.: 28-J65) was approved by the SCC Institutional Review Board (IRB). Patient consent was obtained using in-hospital notices of the Institutional Review Board (IRB) at SCC. All dietary events hosted between January, 2013-October, 2017 at the

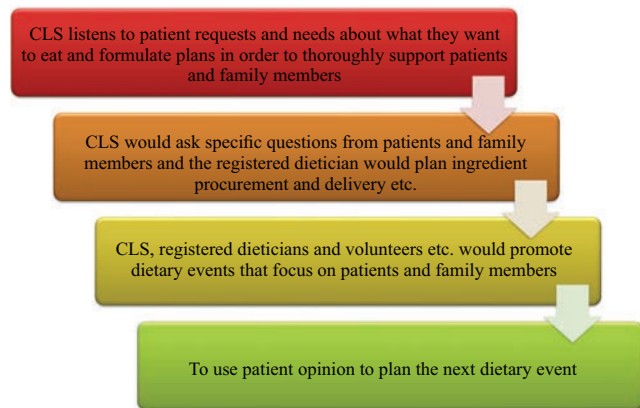


Fig. 1: Steps involved in the organization of a dietary event
AYA: Adolescent young adult, CLS: Child life specialist

children's (AYA) ward in SCC (9 beds) (The study was carried out at the Division of Pediatrics and the AYA Generation, Shizuoka Cancer Center, Japan) was studied.

Methods: The data of Fig. 1 shows the steps that were followed in organizing dietary events at the children (AYA) ward in SCC with the permission of a paediatrician.

We assessed the number of dietary events held, targeted number of hospitalized patients, number of participating hospitalized patients (the participation rate was based on these results), participants' characteristics (sex, age; children: age 0-14 years, AYA: age 15-39 years)^{1,2}, frequency of dietary events in which children and AYA patients participated together, number of families that participated, number of staff members that participated and number of outpatients. Data of the study items mentioned above were extracted from the CLS and RD electronic medical charts after each dietary event. The dietary events were conducted with permission from all the physicians and compliance with the Hazard Analysis and Critical Control Points (HACCP)¹⁷ for food sanitation. Besides, the cost of food ingredients that were used for meals are eaten by anyone other than the patients during the dietary events was covered by donations.

Statistical analysis: All results are expressed as medians. The ratios of the participating pediatric and AYA patients in the dietary events were compared using Pearson's chi-square test. JMP® 12 software (SAS Institute Inc., Cary, NC, USA) was used for all the statistical analyses. A two-sided level of significance was used and set at 5%.

RESULTS

All the data in Table 1 shows all the patients who participated in each dietary event.

More than 10 ingredients were used in making takoyaki, hand-rolled sushi, crepes and pizza. Out of the 66 dietary events held, children and AYA patients participated together in 61 (92%). The result of Fig. 2 shows the breakdown of

participants of each dietary event. There was no difference between the proportion of children and AYA in each dietary event ($p = 0.136$). There were 11 dietary events in which no patient participated due to bone marrow suppression (cytopenia) associated with cancer treatment. No food incident or accident occurred. The data of Table 2 shows the patients' and family members' opinions during the events.

Table 1: Background during dietary events

Total number of patients	145 (84 males, 61 females)
Age (range)	9 (1-34) years
Number of events attended per participant (range)	2 (1-34)
Disease	Bone and soft tissue tumours (n = 69) Brain tumors (n = 46) Blastomas (n = 19) Others (n = 21)
Treatment options	Radiation therapy (n = 68; of which 65 were on proton therapy) Chemotherapy (n = 49) Surgery (n = 19) Observation (n = 7) Palliative treatment (n = 4) Hematopoietic stem cell transplantation (n = 2) Others (n = 6)
Total number of dietary events	Sixty-six dietary events were organized during the study period (58 months), with at least one event per month
Composition of hospitalized participants	Out of the 458 targeted hospitalized patients, a total of 430 participated in the events (93.9%; 175 females and 255 males). 291 were children (110 boys and 181 girls). 139 were AYA patients (65 females and 74 males)
Ages of hospitalized participants (range)	12 (1-32) years, Male: 11 (1-31) years, Female: 12 (1-32) years
Other members	398 families, 237 staff members, 13 outpatients (including 3 AYA patients)
The food leftover rate (range)	0.5% (0-0.5)
The type of dietary events	Birthday parties (n = 24), Takoyaki (n = 10), Hand-rolled Sushi (n = 6), Crepe (n = 6), Pizza (n = 5), Gyoza (n = 5), Ramen, fried rice and yakisoba, okonomiyaki (n = 2), Cookies and cupcakes (n = 2), Pancakes (n = 2), Sukiyaki/kimchi hot pot (n = 1), Valentine's Day Chocolate preparation (n = 2), Picnic (Sandwiches, n = 8)

AYA: Adolescents and young adults

Table 2: Opinions and observations of the patients and family members during the dietary events

Dish of the event	Observations of dietitian during each event and opinions of the patients and family members
Okonomiyaki	Nori (dried seaweed) topping was popular
Hand-rolled sushi	Patients recognized the front and back of the Nori sheets and were able to make inside-out rolls. The Yakiniiku sauce flavour for ground beef, which was a requested ingredient, was widespread. Prawns and cheese were said to go well together
Pizza	10 or more types of topping ingredients requested were well-received by all the participants. Teriyaki chicken and dessert pizzas were famous
Gyoza	Each participant was wrapping up around 10 gyozas and eating them silently
Takoyaki	Onion and red ginger used as toppings were unpopular. The participants liked cheese Bonito stock, used as diluting water, was widespread. Participants were eating Takoyaki and fried eggs sandwiched in Ebisen (prawn crackers) (Takosen)
Crepe	Children with problems swallowing, who are used to eating chopped or thickened meals, enjoyed this mainly and even asked for second servings With the 15 types of toppings requested, we saw that patients who usually do not even eat hospital meals ate 6 crepes. A two-year-old ate 4 crepes. Some participants said that they would prefer slightly thinner crepes or crepes without holes. They also expressed their wish to bake the crepes themselves. There was a child who regained his/her appetite and ate 3 crepes. As this child was used to eating chopped up/thickened meals, he could eat the meal provided with some of the crepes and chopped ingredients
Cookies	Patients shaped the cookies into their desired shapes and showed them to the staff
Baked cheesecake	Since there was a request to make the cake fresher in taste, we used granulated sugar, which was well-received
Gateaux chocolat	Many siblings who participated in shaping the cake shared 10 equal portions among children alone. There were requests for the recipe
Pancakes	There were many female participants and sweet flavours were popular. The idea was raised by a child who did not have much appetite, an adverse effect of radiation therapy. This child was able to eat 3 pancakes. Wieners and ham were well-received and considered excellent accessories to the dish
Christmas party	There were requests for Calpico (Calpis) and carbonated drinks, such as syrup for the fruit punch, which was well-received
Summer festival	Sauce for grilled corn (7:1:1 by soy sauce, mirin and sugar, respectively) was well-received. The female AYA patients ate up the beef skewers in no time
Monjayaki	Even patients with gastrostomies were able to eat this dish. Mochi (rice cake) and cheese made the dish heavier, which was well-received. Baby star (crispy ramen noodles) was also well-received. Weiner was more popular than bacon

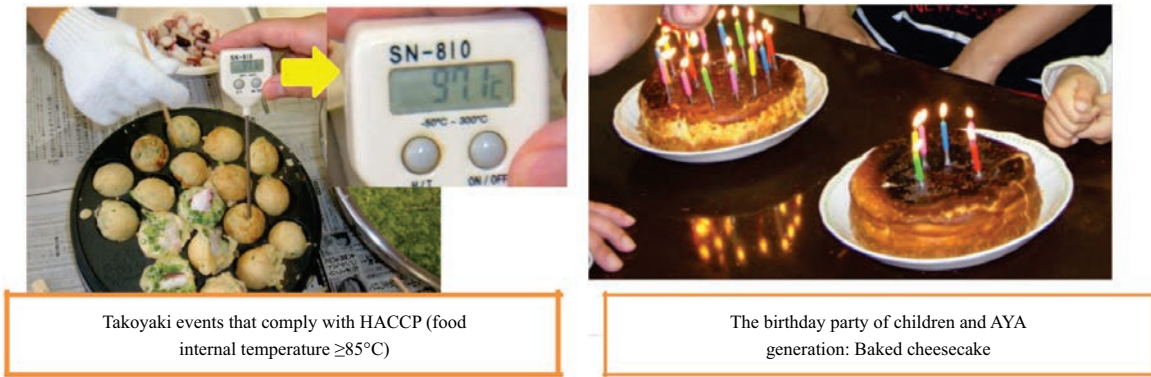
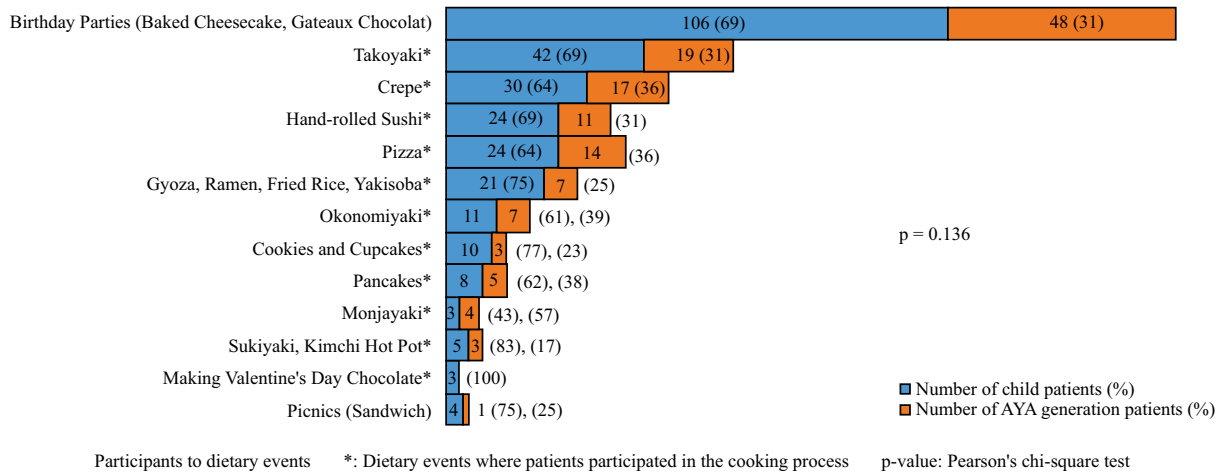


Fig. 2: Breakdown of participants in each dietary event

There was no difference in the proportion of the number of children and AYAs in each event and the dietary events showed the right blend of the generations. AYA: Adolescent young adult, HACCP: Hazard analysis and critical control points

DISCUSSION

By cooperating with SCC's medical care team, we have maintained a high participation rate and continuous meal events for five years. A total of 145 patients participated approximately twice in the 66 meal events (Table 1). The participation rate of hospitalized patients in the dietary events organized within approximately 5 years was 93.9%. The AYA patients accounted for 30% (139 patients) of the total participants. A total of 648 participants were family members, staff and outpatient visitors. The dietary events for which both children and AYA patients participated accounted for 92% of all events. There were no differences between the proportion of participating children and AYA patients in each event ($p = 0.136$; Fig. 2). These results suggested that dietary events held in the children's (AYA) ward in SCC had high participation rates without gaps in participation levels between children and AYA patients. There have been reports of depression and loss of appetite and nutritional

interventions in patients with cancer, but none on of patient-led dietary events^{18,19}. We believe that the high participation rate in the dietary events, as observed in this study, as a result of the cooperation between pediatric nurses and CLS, who set arbitrary dates for the dietary events considering the patients' therapeutic progressions so that they could participate in the events unfailingly. Additionally, the RD added examples of food requests from patients in the past (Table 2) in the menu proposal for each dietary event. The pediatric nurses and CLS stayed close to the patients and family members throughout these events.

Of the dietary events mentioned, the most frequently held and most popular event in terms of the number of participants was the birthday parties for which the RD cooked (Fig. 2). In preparing the cakes used for birthday parties, it was possible to choose between baked cheesecake or chocolate cake, which needed to be cooked such that the internal temperature of the food was above 85°C to comply with HACCP¹⁷, in consideration of bone marrow suppression that

patients may have been experiencing due to treatment. The food items incorporated patient requests using caster sugar for children who preferred sweeter cakes, granulated sugar for AYA patients who preferred a fresher taste; Other ingredients, such as Grand Marnier, orange peels and lemon juice were also used. The next most popular dietary events in terms of the number of participants were cooking participatory events involving takoyaki, hand-rolled sushi, crepe and pizza. The procurement of food ingredients requested by patients for each dish by the contracted RD resulted in the participants enjoying the events more and participating more often. We were able to appreciate the dietary events better based on the food options provided by the patients and family members during the dietary events. We inferred that they were good due to the input from the pediatric nurses, CLS and RD. They responded to various patient backgrounds and tastes. All participants enjoyed and devised ways to enjoy the events (Table 2). The dietary events intended for children and AYA patients in SCC met each patient's wishes and requests. They provided a specific meal environment that is otherwise difficult to attain with regular hospital meals. This active approach takes a step further than conventional approaches.

In Japan, a proverb goes, "Eat out of the same pot," (used to describe a close relationship formed through living together for long and overcoming various challenges together) which is supported by the previous reports¹².

This study showed no age gap in the participants' composition of patient-led dietary events intended for children and AYA patients. Group work involved in these dietary events may have served as social activities for the patients (Fig. 2). Furthermore, dietary events were held at least once a month over the 5-year study duration through collaboration between pediatric nurses, CLS and RD, while maintaining safety and high quality (participation rate). However, we did not study the influence of the dietary events on the treatment of the children and AYA patients with cancer and how sharing problems individually could effectively provide psychological relief and patient support^{20,21}. This study had some limitations. First, no scale²² could scientifically evaluate whether the dietary events raised patient motivation and adherence to treatment²³. Second, the transmission of contact infections was not discussed²⁴. Third, the patients' satisfaction was not assessed; this should be clarified in future studies. In our study, the medical team (CLS, Ns, RD) continued organizing desirable dietary events for children and AYA patients that could not be achieved with hospital diets; these events had high participation and low residual diet rates. Its application has not been reported worldwide; however, it is considered to be significant as a new method of nutritional intervention.

CONCLUSION

Patient-led dietary events for children and AYA patients with cancer had a high socialization rate among the participants, without any differences according to age and they may serve as a social activity for patients. Collaboration between pediatric nurses, CLS and RDs may support these patient-led dietary events. Patient-led dietary events can change themes and be fun for patients.

SIGNIFICANCE STATEMENT

This study aimed to elucidate the composition of participants in patient-led dietary events and to evaluate the importance of social activities among pediatric and AYA patients. We analyzed all dietary events hosted from January, 2013-October, 2017. In all the dietary events, we provided flexible meals that considered the requests made by patients with cancer and their family members that are otherwise difficult to attain through regular hospital meals. Among the subjects during the 5-year study period, a high participation rate and eating rate were maintained. There were no differences in the participation rates between children and AYA patients. These meal events provided a platform for socialization among the participants. Furthermore, adequate food sanitation was ensured.

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