A Hospital-Based Online Patients Support Program, Online Adolescent and Young Adult Hiroba, for Adolescent and Young Adult Cancer Patients at a Designated Cancer Center in Japan

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Adolescent and young adult (AYA) patients with cancer have few opportunities to interact with peers in their lives. To meet peers safely during the coronavirus disease 2019 (COVID-19) pandemic, a hospital-based online patients support program called Online AYA Hiroba was launched for AYA patients with cancer and held regularly by the National Cancer Center Hospital in Japan. This retrospective study suggested the degree of satisfaction with this program and issues about facilitating the sessions that are unique to the online environment. Our findings potentially contribute to the establishment of a hospital-based online patients support program for AYA patients with cancer at other hospitals.

Keywords: adolescent and young adult, online, peer support, survivorship care, psychosocial support

Introduction

More than 20,000 adolescent and young adult (AYA) patients are newly diagnosed with cancer each year,1 representing ~2.3% of all people diagnosed with cancer in Japan. Various clinical departments provide medical care for these patients because there are few AYA patients with cancer at each designated cancer center and the primary cancer site varies.2 Although AYA patients with cancer have reported that the opportunity to meet and receive support from other survivors of a similar age is more important than the support they receive from family and friends,3 these patients have few opportunities to interact with patients in same generation in their daily lives.

The National Cancer Center Hospital (NCCH) is a high-volume cancer center that treats >1000 AYA patients with newly diagnosed cancer each year. An in-hospital patients support program for AYA patients with cancer named AYA Hiroba was launched in 2016. It is operated by the AYA support team consisting of multidisciplinary experts. Hiroba originally means the place or space to gather in Japanese.

From October 2017 to March 2020, AYA Hiroba was held 30 times in a face-to-face format and a cumulative total of 161 patients participated.4 However, AYA Hiroba was interrupted owing to the coronavirus disease 2019 (COVID-19) pandemic. Holding sessions in a face-to-face format is associated with the potential risk of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) transmission because patients gather and talk in close proximity.

For safety reasons during the COVID-19 pandemic, AYA Hiroba has been held online since June 2020. Online peer support is reported to have positive effects such as lower...
1. Program preparation

1) Leaflets with the program’s URL and QR code were posted inside the hospital, including in the outpatient department. Leaflets were also distributed to inpatients by AYA support team staff. An application form was completed and submitted by patients wishing to participate in the program. This form was distributed via the staff mailing list. The staff in charge of operations obtained the applicant’s email address. To confirm whether the patient belongs to the Online AYA Hiroba program, the staff in charge of operations referred to the section entitled “With or without patient registration card for NCCH” on the application form. Before the program began, the staff in charge of operations asked participants about topics that they would like to talk about on the application form.

The e-mail addresses were only used for contacting participants about the Online AYA Hiroba program and strictly managed by the staff in charge of operations.

2) A program notice was sent by e-mail to patients who had previously participated in the program and opted to receive notifications from the program. The notice was delivered by e-mail several days before the program.

3) Hospitalized applicants were informed that they could attend the program via Zoom at the NCCH Patient Support Center when they have difficulty participating and need private space because they are in a shared patient room. Suitable rooms were reserved for program operations at the Patient Support Center on the day before or of the session.

4) The following were sent to participants by noon on the day of the session: (1) URL for the session, (2) rules of the program, and (3) instructions on how to use Zoom.

A final meeting with facilitators was held at 2:40 p.m. on the day of the session, to start on time.

2. How to conduct the meeting

1) Opening remarks:

“Hello everyone. Can you activate your camera?”

“Several more people are going to participate. Please wait a few minutes.” Or “There may be some participants joining later. It is now time to start the meeting.”

Confirm that the usernames of the participants on Zoom are the names that they want to use during the sessions. Some cameras cannot be activated in certain Wi-Fi network settings—this information should be shared with the participants.

2) Describe the rules of the meeting (using slides through a shared screen)

“There are some rules for the Online AYA Hiroba program. I will present these rules and the agenda for this session to you.”

3) Provide an introduction and other information about each participant, including the participants’ usual activities, favorite things, concerns, or interests.

“Let’s begin by introducing ourselves. Tell us three things about yourself: your name, type of cancer and ongoing treatment, and your favorite things.”

4) Have an open conversation or give the participants some choices for discussion topics.

Engage in an open discussion or give the participants some choices for discussion topics (a flip chart to talk from 10 conversation topics prepared in advance by the AYA support team may be used). Provide the topics that participants reported that they would like to discuss on the application form when there is little open discussion.

Flip chart contents (some topics can be related to illness or treatment, and other topics can be related to daily life):

1. What do you do when you have free time?
2. What do you want to recommend to everyone?
3. How do you refresh when you feel depressed?
4. If you win the lottery, what would you buy?
5. What is one thing you couldn’t stop doing within the last year?
6. Who did you first tell about your illness?
7. Who can you tell about your illness? Who can’t you tell?
8. What has changed since you got sick? What hasn’t changed?
9. How do you change your mood in the hospital?
10. What would you like to ask everyone?

Provide a 5-minute warning before the end of the session (this can be provided via chat, if needed).

5) Ask the participants for brief feedback before closing the session.

“It is almost time to close the session. Can you give us a short comment about this session?” (It will run smoothly if the facilitator calls on the participants in order.)

6) Ask the participants to complete the post-meeting questionnaire (tell the participants that a survey link will be sent after the session).

“To use your feedback to improve meeting facilitation in the future, we will send you a questionnaire via e-mail after this session. It would be appreciated if you could answer it. Thank you in advance for your cooperation.”
prevalence of depression and perceived stress for patients with cancer.\textsuperscript{5–8} An online AYA community reportedly helped AYA patients with cancer express feelings, exchange information, exchange peer support, and cope with cancer.\textsuperscript{9}

NCCH’s hospital-based online patients support program called Online AYA Hiroba provides online get-together opportunities for AYA patients with cancer. The purpose of this retrospective study was to investigate the degree of satisfaction and issues with the online patients support program for AYA patients with cancer at a designated cancer center in Japan.

**Methods**

**Online AYA Hiroba content**

Online AYA Hiroba and AYA Hiroba have essentially the same content.\textsuperscript{4} Two facilitators from the AYA support team participate in each session. Table 1 provides the facilitator’s manual unique to online sessions based on actual operations. This program was held monthly for 1 hour (3 p.m. to 4 p.m.). Participants consisted of AYA patients with cancer aged 15 to 39 years who are inpatients or outpatients at NCCH. Patients who participate in the program may talk freely about any theme they wish. Participation rules are as follows: (1) “You will never be forced to talk about anything you do not feel comfortable sharing with other participants,” (2) “Do not disclose anything you heard or learned from this program,” and (3) “Do not criticize other participants’ opinions. Show respect.”

**Retrospective study**

This study was retrospective study of medical records and questionnaires that were clinically conducted at the end of each session of Online AYA Hiroba from June 2020 to September 2021.
Information collected in the questionnaire included: (1) participation experience (first time or not), (2) thoughts about program timing, (3) thoughts about program duration, (4) thoughts about program frequency, (5) desire to participate again, (6) Net Promoter Score (NPS), (7) whether the program met expectations (0–10 points), (8) opinions about the content (0–10 points), (9) whether the program helped the participant cope with cancer (0–10 points), (10) satisfaction with the online program, and (11) whether it is easier to attend sessions online versus face-to-face. In addition to these questions, a free-text field for impressions and issues about the program was included.

NPS, a single item measure of consumer satisfaction, was used to assess trial performance across conditions. NPS has been used as an overarching measure of patient experience with health care delivery. Patients were asked, “How likely would you recommend taking part in this program to another patient like you?” Participants with scores of 0–6 were considered detractors; 7–8, passive; and 9–10, promoters.

Participant characteristics were collected from medical records retrospectively. Information included age, gender, treatment type (outpatient or inpatient), cancer type, cancer stage, and treatment setting.

This study was approved by the NCCH ethics committee (approval number, 2019-215) and conducted in accordance with the principles of the Declaration of Helsinki. The requirement for informed consent was waived owing to the retrospective design, and opt-out information was published on the NCCH website.

Analysis

Descriptive statistics were used to evaluate participant demographics. Simple tabulation was performed for the 10 question items, except for (6) NPS. For NPS, the percentage of promoters minus the percentage of detractors was calculated. NPS could range between −100 and 100. To respect the valuable opinions of the participants, all results of the questionnaire were analyzed.

Differences in survey responses for question items (2) to (5) by the participation experience (first time or not) were compared using the chi-square test. Differences in survey responses to items (7) to (11) by the participation experience (first time or second time) were compared using the paired t-test. The free-text descriptions were classified based on similarities and differences.

Results

From June 2020 to September 2021, Online AYA Hiroba was held 16 times. A total of 23 patients participated. On average, there were 2.9 participants at each session (a cumulative total of 47 participants). Characteristics of the respondents attending for the first time are given in Table 2.

Based on the questionnaire responses (Table 3), 31 (66.0%) participants thought that it was easy to participate during the hours of 3 p.m. to 6 p.m. and 42 (89.4%) participants reported that they wanted to participate in 1-hour sessions. Twenty-eight (59.6%) participants answered that they want to participate once a month. The proportion of participants who responded as described above was significantly higher among those participating multiple times than among first-time participants. Forty-three (91.5%) participants answered that they want to attend the program again.

NPS was 52, 71, and 62 for respondents attending for the first time, multiple times, and total times, respectively. There were no significant differences in survey responses to question items (7) to (11) between first-time and second-time among 9 participants attending multiple times.

Regarding free-text responses, discussion topics for the future were classified into four categories: physical problems, social problems, relationships and communication, and other.

Table 2. Characteristics of the Participants

| No. of patients | Proportion (%) |
|-----------------|----------------|
| Age, years (median age, 32 years) | |
| 15–19 | 0 | 0 |
| 20–24 | 2 | 8.7 |
| 25–29 | 6 | 26.1 |
| 30–34 | 5 | 21.7 |
| 35–39 | 10 | 43.5 |

| Gender | |
|--------|----------------|
| Male | 13 | 56.5 |
| Female | 10 | 43.5 |

| Treatment type | |
|----------------|----------------|
| Outpatient | 8 | 34.8 |
| Inpatient | 15 | 65.2 |

| Cancer type | |
|--------------|----------------|
| Ewing sarcoma | 4 | 17.4 |
| Leukemia | 3 | 13.0 |
| Rhabdomyosarcoma | 2 | 8.7 |
| Malignant lymphoma | 2 | 8.7 |
| Osteosarcoma | 1 | 4.4 |
| Liposarcoma | 1 | 4.4 |
| Germ cell tumor | 1 | 4.4 |
| Breast cancer | 1 | 4.4 |
| Cervical cancer | 1 | 4.4 |
| Colorectal cancer | 1 | 4.4 |
| Malignant melanoma | 1 | 4.4 |
| Squamous cell cancer | 1 | 4.4 |
| Submandibular adenocarcinoma | 1 | 4.4 |
| Malignant glioma | 1 | 4.4 |
| Hemangiopericytoma | 1 | 4.4 |
| NUT carcinoma | 1 | 4.4 |

| Cancer stage | |
|--------------|----------------|
| I | 5 | 21.7 |
| II | 1 | 4.4 |
| III | 1 | 4.4 |
| IV | 8 | 34.8 |
| Recurrence | 3 | 13.0 |
| Unknown | 5 | 21.7 |

| Treatment setting | |
|-------------------|----------------|
| Under treatment | |
| Surgery (within 1 month after surgery) | 4 | 17.4 |
| Surgery and chemotherapy (within 1 month after surgery) | 1 | 4.4 |
| Chemotherapy | 11 | 47.8 |
| Chemotherapy and radiation | 4 | 17.4 |
| Observation (after treatment) | 3 | 13 |

NUT, nuclear protein of the testis.
### Table 3. Questionnaire Answers

| No. of times participating in the event | First time (n=23) | Multiple times (n=24) | Total times (N=47) | p  |
|--------------------------------------|-------------------|-----------------------|--------------------|----|
| (2) At what times are you available to attend these sessions? (multiple answers allowed) |                   |                       |                    |    |
| 10 a.m.–12 p.m.                      | 4 (17.4%)         | 5 (20.8%)             | 9 (19.2%)          | <0.001 |
| 1 p.m.–3 p.m.                        | 10 (43.5%)        | 16 (66.7%)            | 26 (55.3%)         |    |
| 3 p.m.–6 p.m.                        | 15 (65.2%)        | 16 (66.7%)            | 31 (66.0%)         |    |
| 6 p.m.–8 p.m.                        | 6 (26.1%)         | 5 (20.8%)             | 11 (23.4%)         |    |
| (3) For how long do you want to participate in a session? (multiple answers allowed) |                   |                       |                    |    |
| 30 minutes                            | 4 (17.4%)         | 0 (0%)                | 4 (8.5%)           | 0.001 |
| 1 hour                               | 19 (82.6%)        | 23 (95.8%)            | 42 (89.4%)         |    |
| 1.5 hours                             | 8 (34.8%)         | 4 (16.7%)             | 12 (25.5%)         |    |
| 2 hours                               | 1 (4.4%)          | 1 (4.2%)              | 2 (4.3%)           |    |
| (4) How many times a month do you want to participate? |                   |                       |                    |    |
| Once a month                          | 12 (52.2%)        | 16 (66.7%)            | 28 (59.6%)         | 0.001 |
| Twice a month                         | 9 (39.1%)         | 8 (33.3%)             | 17 (36.2%)         |    |
| Four times a month (weekly)           | 2 (8.7%)          | 0 (0%)                | 2 (4.2%)           |    |
| (5) Do you want to attend another online session? | Yes               | 19 (82.6%)            | 24 (100%)          | 43 (91.5%) |
|                                       | 0 (0%)            | 0 (0%)                | 0 (0%)             | NA  |
|                                       | Unknown           | 4 (17.4%)             | 0 (0%)             | 4 (8.5%) |

Provide a score out of 10. The highest score is 10 (exceeded expectations) and the lowest score is 0 (did not meet expectations).

(6) NPS (Do you want to invite your acquaintances to the online program?)

|               | 52 | 71 | 62 | NA |
|---------------|----|----|----|----|

(7) Was the online program what you expected?  8.0 (1.66)  8.3 (1.20)  8.2 (1.43)  NA
(8) How did you feel about the online program?  8.5 (1.04)  8.5 (1.14)  8.5 (1.08)  NA
(9) Did the online program help you cope with your disease?  8.6 (1.08)  8.4 (1.44)  8.5 (1.27)  NA
(10) Were you satisfied with the online program?  8.7 (1.02)  8.8 (1.15)  8.7 (1.07)  NA
(11) Do you find it is easier to attend the program online compared to face-to-face?  8.7 (1.49)  8.7 (1.94)  8.7 (1.72)  NA

Please tell us if you have any topics you want to discuss in future Online AYA Hiroba sessions.

Physical problems
- How to cope with treatment
  - What you started to do to improve your health or what you are taking care of in your daily life
  - Usual infection prevention behavior
  - Change in appearance (how did you cope with the change in your appearance? For example, have you been using a wig or a hat?)

Social problems
- Incentive to work and how to approach work
- Job assistance, disclosure of the cancer diagnosis to family members and friends, and communication with family members
- How to cope with work
- When to return to work
- How to work and get married
- To what extent do we use social resources, such as the health insurance system and health support system
- Problems associated with return to work, including conflicts between the expectations of coworkers and my poor physical condition

Relationships and communication
- How to disclose the cancer diagnosis to family members and friends; how specific should the explanation be
- Disclosure of the cancer diagnosis to family members and friends, and communication with family members

Other
- Positive things patients have experienced from having cancer
- Delicious foods sold at convenience stores in NCCH
- Basically, I would like to have an open conversation
- I think there is no problem with how the sessions are currently conducted.
- I can discuss the topics that the other participants want to talk about.
- Changes in your life before and after the onset of cancer, including your way of thinking, values, and human relationships
- I would like to provide useful information to the other participants.

Please write down your requests or suggestions for improvement with respect to Online AYA Hiroba, if applicable.

(continued)
Table 3. (Continued)

| No. of times participating in the event | First time (n=23) | Multiple times (n=24) | Total times (N=47) | p |
|----------------------------------------|-------------------|----------------------|--------------------|---|

Content
- I wish I had an opportunity to talk with other patients who have the same cancer as me.
- The advantage of an online program is that we can attend from anywhere. However, the Zoom session was more difficult than a face-to-face meeting for those like myself who are not familiar with using Zoom.
- I thought that it could be easier to talk with the other participants about some topics after disclosure of their disease, if they do not mind. I felt the meeting could have run more smoothly if we knew whether or not we could have a deeper conversation about our disease in advance.
- It would be better if the participants took turns speaking after choosing a specific topic.
- I have to work during the day on weekdays. If session are held after 6 p.m. on weekdays or on weekends, I would want to join more often.
- It would be better if we had more than 30 minutes.
- If you could increase the number of participants, I believe that it would be better to change the participants after half an hour by dividing the meeting into two halves. This will allow those who are busy to participate in the online program even for half an hour.

Facilitation
- It would be better if the chair could not only facilitate the conversation but also provide sympathy or advice.
- The chair can facilitate discussions between the participants by presenting a topic. I think the method for conducting discussions is better today.
- It is not clear when we can speak in the online program. It would be easier to continue the discussion if the chair asks someone for an opinion when nobody is going to say anything about the topic. This will make the program more fun and productive.
- I think it was very good that the chair asked “How about you, Mr./Ms. O O?” to facilitate discussion.

Online connection environment
- I found it was easier to attend the online program. Thank you very much for your support. But I could not catch what some participants said due to poor signal quality and I felt sorry about that. This makes it difficult for us to communicate well with others online.
- If I was attending the program during hospitalization, I think it would be difficult to communicate due to the poor Wi-Fi signal quality.
- Please avoid microphone feedback between the facilitators.
- Please provide any other comments that you have about Online AYA Hiroba.

Content
- It was a very fun meeting because the participants were all hospitalized or have been hospitalized. I was encouraged by the other participants who are coping with cancer in a different ward. I wish I could have a chance to talk with other AYA cancer patients with a similar type of cancer or treatment stage in the future. The word “cancer” refers to many various types. It seems that cancer patients should be able to easily understand each other, but I often think it is rather unexpectedly difficult. I have no idea what to expect of my future cancer treatment. I personally feel that I want to join a meeting of AYA sarcoma patients or patients who have cancer with a poor therapeutic effect in response to non-operative treatment.
- Please share useful information obtained from previous Online AYA Hiroba sessions with us. This may be difficult because you held a one-time session.
- I was able to bring myself to focus on the conversation because some patients told us the name of their disease during their self-introduction. Thank you very much.
- I want to be listened to firsthand by pharmaceutical companies or industrial physicians.
- I was impressed by what the participants discussed. I want to join subsequent sessions whenever possible.
- As mentioned during the session, I hope to have a meeting with hospitalized AYA patients.
- I was able to observe the changes in appearance or words and actions of the participants who had attended the previous sessions because I had participated in other sessions.
- I was not able to catch the name of the band that A said that he listens to while driving in the car, etc., in the self-introduction. If you know the name, please let me know. Thank you in advance for your kind support.
- There were more female participants than male participants in this meeting and I found it so easy to talk with them. Generally, males are not good at talking with others. I think we will have a more lively conversation when the attendance rate of females is higher.
- I think it is appropriate (i.e., not too small or large) to have a friendly conversation with five or six participants.

Format
- I hope that you will continue to hold these sessions.
- I wish you could hold the sessions four times a month. This may be unrealistic but I think a 1-month interval is too long of a period to wait for the next session, if I missed the last one. If we have four chances in a month, there may be only few participants. On the other hand, we will have more chances to attend when we are in good shape after treatment. In addition, I hope we have some kind of matching system to facilitate communication with a specific participant directly, if desired. This system would allow us to develop a network and to lean on each other.

(continued)
The opinions they requested or suggested for improving this program were classified into three categories: content, facilitation, and online connection environment. Requests and suggestions for improving this program were classified into four categories: content, format, online connection environment, and other.

**Discussion**

This study was the first about a hospital-based online patients support program for AYA patients with cancer at a designated cancer center in Japan. The study has two strengths. First, this retrospective study identified the needs and challenges of a hospital-based online patients support program for AYA patients with cancer. Second, the hospital-based online patients support program we created could be a model for other hospitals.

The average number of participants and clinical characteristics of the participants (Table 2) were compared with data from the face-to-face AYA Hiroba program. Ease of access is one advantage of the online program. For face-to-face sessions, participants need to be hospitalized or go to the hospital on the day of the event, but for online sessions, they can participate from their home or anywhere they like. Furthermore, the AYA generation in Japan has a high internet utilization rate with smartphones or personal computers. However, the average number of participants per session decreased from 5.4 with the face-to-face format to 2.9 with the online format. It is necessary to verify the factors that make it difficult for AYA patients with cancer to participate online.

Although adolescents and young adults have reported that they have high digital communication needs, adolescents did not participate in this online program. It is necessary to verify the factors that make it difficult for adolescents to participate and identify ways to recruit them.

Men participated more than women, which is different from the results of previous online support studies in other countries. According to the Cancer Registry of Japan, there are more female than male patients with cancer older than 20 years of age and 80% of patients with cancer aged 20–39 years are women. This result suggests that Japanese men are more likely to participate in online patients support program. With the face-to-face format, women had a higher participation rate and men seemed to have less need for patients support program. However, if access is improved with an online format, it will be easier for men to participate, and men might in fact have previously unrecognized needs for patients support program. This finding might lead to male cancer peer support care for the AYA generation.

Inpatients participated more than outpatients. This finding was thought to be owing to the relative ease of accessing information about the program. In addition, recruitment of outpatients was challenging.

There were patients with various cancer types, including rare cancers, who participated, reflecting the various cancer types in the AYA generation. The proportion of patients with stage IV cancer was high. The online format allowed patients with progressive cancer who have restricted mobility to meet peers.

Most participants were undergoing treatment because they had easier access to information about the program. Providing patients support program to long-term survivors and posttreatment patients is another issue to address in the future.

Based on responses to the questionnaire (Table 3), the need for this program is high and the format of this program is generally appropriate because evaluations such as NPS or other items remained at a high level even after multiple sessions.

On the contrary, this program faced two main challenges. The first challenge was facilitation challenges unique to the online format. Unlike the face-to-face format, it was difficult for participants to grasp the timing of speaking. The facilitator needed to actively ask participants to speak in the appropriate order. Furthermore, facilitators needed to make big gestures, reactions (e.g., nodding, empathizing, laughing, or being surprised), and actively use the reaction emojis in Zoom, and to encourage participants to do so as well because it was difficult to understand reactions (positive or negative) to the discussion. It was important to give some brief feedback after the participant’s remarks to move on to the next participant. The second challenge was the online connection environment. To provide a stable program, at a minimum, the online connection environment on the operating side must be stable. For participants in the hospital, it is also necessary to provide a wireless environment in the hospital and tablets.

This study has several limitations. First, it was a single-center retrospective study with a small number of participants. It might be difficult to generalize these results to other countries.
facilities. Second, the effect of the online patients support program in terms of satisfaction and usefulness could not be measured using validated scales or instruments other than NPS. Further prospective studies are needed to evaluate the effect of the online patients support program on satisfaction and usefulness using validated scales or instruments. Finally, this program is intended only for NCCH patients. The online program can be implemented for a wide range of outpatient. However, it is difficult to identify whether an outpatient is really a patient with cancer or a member of the AYA generation with the current system.

Despite these limitations, our findings can potentially contribute to the establishment of a hospital-based online patients support program for AYA patients with cancer at other hospitals. To increase opportunities for AYA patients with cancer to interact with peers in their lives and improve their quality of life, we intend to further develop this program.

Conclusion

This study suggested the degree of satisfaction and issues for Online AYA Hiroba, a hospital-based online patients support program for AYA patients with cancer. Further evaluation and the establishment of an online patients support program for AYA patients with cancer that could be held at other hospitals are needed.

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