

## Possible Significance of a Café-style Event to Introduce Advance Care Planning for General Citizens

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**Objectives:** We conducted a survey to determine whether the general public who participated in a café-style event to raise awareness of advance care planning (ACP) actually implemented ACP after attending the event. **Methods:** On February 20, 2020, a café-style event (Tokai Blue Café: TBC) was held at the Tokai University Hospital. The TBC consisted of a lecture about ACP, “The Go-Wish Game,” and a tea party. A questionnaire-based survey was conducted on ACP implementation after one month of TBC. **Results:** Of the 14 participants (three males and 11 females), 11 agreed to answer the questionnaire and eight responded. Two respondents were male and six were female. Six of the respondents were aged  $\geq 60$  years. Seven of the eight respondents implemented ACP with their family members, while none did so with their family doctor, even though all of them indicated that they had a family doctor. Several respondents reported that they were uncomfortable discussing the issue with their doctors. **Conclusion:** The results indicate that a café-style event as an awareness-raising activity may have a significant effect on ACP implementation, although it suggests that there are some challenges in involving family doctors.

**Key words:** Advance care planning, awareness-raising activity, café-style event, go-wish game

### INTRODUCTION

The Ministry of Health, Labour, and Welfare of Japan (MHLW) states that “the process of thinking in advance, repeatedly discussing, and sharing your wishes for healthcare in the event of an emergency is called Advance Care Planning (ACP)”, and “it is important that your family doctor provides you and your family with appropriate information and explanations according to your physical and mental condition” [1]. MHLW revised its “Guidelines on the Decision-Making Process for Healthcare at the End of Life” (Process Guidelines) in March 2018, and recommends healthcare professionals conduct ACP [2]. Additionally, the MHLW has begun publicizing ACP to the general public, giving it the nickname “*Jinsei Kaigi*” [3].

The MHLW is also promoting the establishment of a “dementia café,” where people with dementia and their families can share information with local people and specialists and gain mutual understanding under the Comprehensive Strategy for Dementia Policies (New Orange Plan) [4]. The dementia café is expected to bring people together as if they were enjoying a casual café and allow people with dementia, their families, and healthcare professionals to share information and understand each other. The dementia café is also held by the local government where our institution is located and is called the “Orange Café” after the “New Orange Plan” [5].

Therefore, the authors came up with the idea that events such as the Orange Café could also be effective

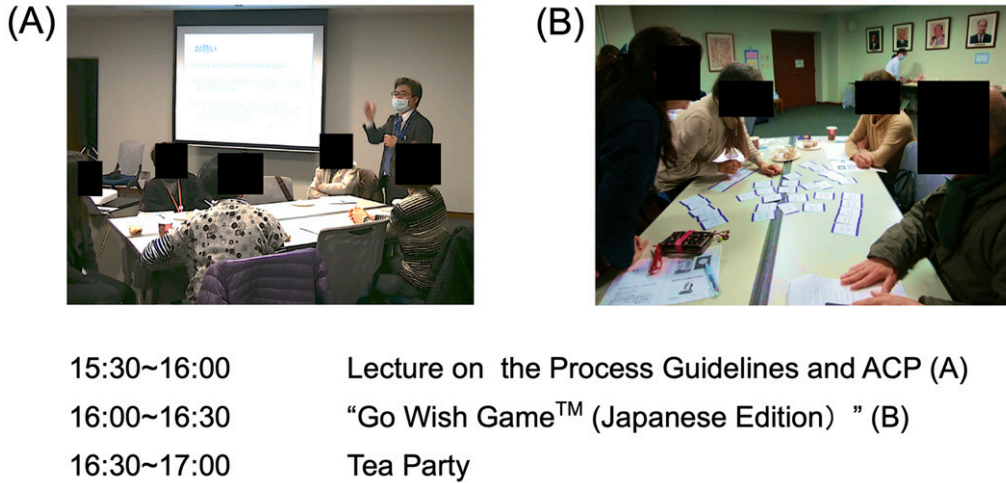
in raising awareness of the ACP and held the Tokai Blue Café (TBC) for the general public who were interested in end-of-life care on February 20, 2020. This study was conducted to investigate the potential influence of TBC on participants’ implementation of ACP.

### METHOD

#### TBC

The TBC was announced in December 2019 by publishing it in the public relations paper of Isehara City, Kanagawa Prefecture, Japan. Twenty people participated in the TBC, and 14 people participated in the TBC held in February 2020 (Figure). At the TBC, one of the authors, an expert in medical ethics with extensive experience in home healthcare, gave a half-hour lecture on the process guidelines and ACP. Next, the participants were divided into several groups and played the Japanese version of the “Go-Wish Game™”, which was originally developed by the Coda Alliance, SA, USA, and translated and published in Japanese by iACP as the “*Moshi Bana Game*”. The participants then talked freely for about 30 minutes while enjoying tea, coffee, and other beverages, as well as light snacks. All the authors participated as facilitators.

In the lecture, the following explanations were given regarding the process guidelines and ACP: 1) healthcare professionals have an ethical obligation to respect your wishes and to determine end-of-life care based on those wishes; 2) it is important to share your view of life and values, including how you like to live your life,



**Figure** The Scene of the TBC in progress  
The TBC began with a lecture (A), followed by the game (B). A tea party was then held on the spot.

with your family and doctor; and 3) it is advisable to appoint a proxy or a trusted person, such as a family member, who can speak on your behalf.

**Questionnaire Survey**

At the end of the TBC, we explained the questionnaire to the participants. Those who gave written consent and also provided a mailing address for the questionnaire were mailed a consent form, a questionnaire, and a stamped envelope one month after the TBC and were asked to answer the questionnaire and then drop it in the mail.

The items included in the questionnaire were as follows: (1) age (by decade), (2) gender, (3) past medical history, (4) presence of the family doctor, (5) whether they knew about ACP before attending the TBC, (6) whether they discussed about ACP with family members after the TBC, (7) whether they discussed about ACP with their family doctor after the TBC, (8) whether they documented ACP, and (9) who they thought should introduce ACP to patients.

**Ethical Consideration**

When administering the questionnaire survey, no information that could identify participants, such as their names and dates of birth, was collected. This study was approved by the Institutional Review Board for Clinical Research at Tokai University (19R198).

**RESULTS (Table 1)**

**The attributes of the respondents**

Of the 14 TBC participants (three males and 11 females), 11 agreed to participate in the questionnaire survey, eight of whom actually responded. Six respondents were aged ≥ 60 years, one in her 50s, and one in her 20s. Two patients were male and six were female. Three of the respondents reported a history of life-threatening illnesses, including malignancy, heart disease, and stroke. Only one respondent indicated that she was aware of ACP prior to attending the TBC. All the respondents indicated that they had a family doctor.

**Implementation with family members**

Regarding the question of whether they had discussed their views on life and values, discussed proxies, or discussed end-of-life care with their families, only one (No. 5) of the eight respondents had not had discussions with their families on all topics. He indicated that he felt it was too early to talk to family members.

Six respondents indicated that they had discussed their views on life and their values. Five of the respondents discussed their proxies. Seven respondents discussed end-of-life care. The respondent who discussed views of life, values, and specific end-of-life care but did not discuss proxies (No. 7) stated that she discussed these topics with all family members, which eliminated the need to select a proxy. One respondent (No. 6) stated that he had only discussed end-of-life care with his family.

**Implementation with family doctors**

None of the respondents reported discussing their views of life and values, proxies, or end-of-life care with their family doctor. Two respondents stated that they had not seen their family doctor at the time they responded to the survey. Three respondents (Nos. 2, 3, 5, and 8) did not think it was necessary to discuss it with their family doctors. For at least three respondents (Nos. 4, 5, and 6), it appeared that the doctor was a factor in the lack of discussion.

**Documentation of the ACP**

One respondent wrote that he was in the process of documentation of the ACP, but none indicated that they had actually documented an ACP after TBC. As for the reasons for not documenting ACP, one respondent (No. 3) commented that he had already prepared an "Ending Note," two (Nos. 2 and 8) commented that they did not know how to do it, and two other people (Nos. 4 and 5) said they did not feel the need to do so.

**Who should introduce ACP to patients?**

Three of the respondents cited family members as triggers for ACP; two cited doctors; and the care

managers, the patients themselves, and seminars in the community were cited by one patient each.

## DISCUSSION

The following factors have been reported as relevant to the dissemination of ACP to the general public: (1) being aware of the term ACP and its contents, (2) having a family doctor and knowledge about ACP, and (3) being provided with opportunities to discuss ACP [6]. In Japan, local governments have held lectures for residents to promote and educate the general public about ACP, and they have also been invited by Isehara City, Oiso Town, and Ninomiya Town in Kanagawa Prefecture to give lectures to local residents. Such lectures may be effective in disseminating knowledge about ACP to a large number of people simultaneously, but it is not certain whether or not the audience will actually implement ACP.

TBC is characterized by the fact that participants can learn about ACP through interactions with each other, similar to the Orange Café conducted for people with dementia and their supporters to learn about dementia and care for dementia. Unlike mere lectures, in which lecturers unilaterally convey information to the audience, interactive discussions among lecturers, facilitators, and participants are the best part of the TBC. Another example of an initiative similar to TBC that promotes interaction among related parties is the “Cancer Salon,” which requires core cancer hospitals nationwide to conduct [7].

This time, the authors used the “*Moshi Bana Game*” as an opportunity for participants to think about the ACP as their own. The game has been used in training ACP implementation for healthcare professionals as well as in the introduction of ACP to patients and the general public [8–10]. Although it has not been verified whether the game promoted understanding of ACP and communication among participants, it is believed that the game was effective in encouraging people who had never met each other before to talk frankly about ACP. However, some participants shared their experiences of having recently lost family members during the TBC. Although no participant complained of emotional distress this time, it was considered necessary to take care not to make the game and discussion among participants too painful for them, for example, by asking them to leave the room as soon as they felt distress.

Three of the eight respondents had a history of serious illness, and all had a family doctor. These facts suggest that people who usually work in some way with medical care attended the TBC, suggesting the need for consideration of participants.

It is worth mentioning that seven out of the eight respondents indicated that they had some kind of discussion related to ACP with their families after participating in the TBC. It is possible that the experience of gaining knowledge from the lecture, confronting their own preferences regarding end-of-life care in the game, and discussing freely with other people may have facilitated discussions with their families.

On the other hand, it is also noteworthy that none of the respondents had discussions related to ACP, including end-of-life care, with their family doctor, which is not surprising since the survey was conducted one

month after the TBC was conducted. Unfortunately, even among those who saw a family doctor, some stated that they did not need to discuss it with their family doctor, or that they felt their family doctor would not listen to them. The MHLW and the Japan Medical Association seem to ask family doctors to take on the responsibility of spreading ACP awareness [11], but they should first educate doctors about the importance of willingly accepting ACP when patients want it and maintaining a good doctor-patient relationship on a routine basis as a precondition for such acceptance.

Documentation of ACP is an important process for sharing the patient’s view of life, values, a proxy that the individual considers desirable, or a preference for end-of-life care. However, none of the respondents reported ACP after TBC. One respondent stated that she had already created an “*Ending Note*,” which is a kind of living will format in Japanese and is distributed by local governments, medical institutions, or funeral service providers independently. For example, Yokohama City in Kanagawa Prefecture has created a booklet on living wills and distributed it to citizens, and has produced a drama about ACP featuring famous actors, which is available for free on YouTube [12]. It has been pointed out that the items in an “*Ending Note*” are unique depending on the entity that prepares it. Specifically, those prepared by local governments provide more detailed information on adult guardianship and wills. Those prepared by medical institutions provide more detailed information on end-of-life medical treatment and care preferences, and those prepared by funeral homes provide more detailed information on funeral rites and cemetery selection [13]. It is necessary to verify separately how useful the living wills represented by “*Ending Note*” are in respecting the wishes of the person concerned. However, it may be useful to hold discussions regarding ACP while using such a document or to write the ACP process in such a document.

Regarding who should bring up ACP, one respondent each said the patient themselves and a seminar in the community, while three respondents expected family members and two said medical care providers, such as doctors and care managers, should take on the role. Although this was a survey of a small number of people, it may be fair to say that the MHLW’s idea of promoting ACP to the general public and healthcare professionals is reasonable.

## CONCLUSION

Since the TBC was suspended after one implementation due to the coronavirus disease 2019 pandemic, the survey could only be administered to a small number of people. It is also assumed that those who participated in the TBC were biased in that they were originally interested in end-of-life care. Despite these limitations, our results indicated that a café-style event that consists of a lecture, the “*Go-Wish Game*,” and a tea party may have some effect on ACP implementation and suggest that there are many challenges in involving family doctors. As a university hospital that plays a central role in the community, the authors intend to promote and educate not only the general public but also healthcare professionals about ACP.

**Table 1** Please see the attached file (xlsx) separately

Age	Sex	Medical history of life-threatening diseases	Knowledge of ACP before attending TBC	Presence of family doctor	Implementation with Family Members			Comment	
					After TBC, did you discuss your views on life and values with your family and others around you?	After TBC, did you discuss the proxy with your family and others?	After TBC, did you discuss with your family and others about end-of-life care?		
1	60s	F	None	No	Yes	Yes	Yes	Yes	
2	70s	F	None	No	Yes	Yes	Yes	Yes	
3	50s	F	None	No	Yes	Yes	Yes	Yes	
4	70s	M	Heart disease	No	Yes	Yes	Yes	Yes	
5	70s	M	Stroke and malignancy	No	Yes	No	No	No	I think it is still too early to have such a discussion.
6	80s	F	Malignancy	No	Yes	No	No	Yes	
7	20s	F	None	No	Yes	Yes	No	Yes	Since I've talked to all the family members, I don't think I need to choose a proxy.
8	60s	F	None	Yes	Yes	Yes	Yes	Yes	

Implementation with Family Doctors			Documentation of ACP			
After TBC, did you discuss your views on life and values with your family doctor?	After TBC, did you discuss the proxy with your family doctor?	After TBC, did you discuss with your family doctor about end-of-life care?	Comment	Have you documented an ACP after TBC?	Comment	Who do you think should bring up ACP to the patient?
No	No	No	Not seen the doctor until questionnaire.	No		Patients themselves
No	No	No	I told the doctor that I attended TBC, but did not discuss the specifics. Someday I would like to tell the doctor how I feel.	No	I would like to see instructions on how to prepare advance directives and samples of advance directives.	The physician who is in charge when a patient hospitalizes
No	No	No	I spent a lot of time just talking to doctors about treatment. I already have a documented advance directive, so there is no need to speak with a doctor.	No	I had already prepared a documented advance directive (so called "Ending Note").	Seminars in the community
No	No	No	The doctor was not open to tangents. I myself am not in the right frame of mind to talk about such things, nor do I feel the need to.	No	I still don't think I need a documentation of ACP because I believe I can be cured from my disease.	Family and others around a patient
No	No	No	I am finding it difficult to talk to that doctor about such things, and I think that it is too early to talk about them.	No	I still think it's premature to write advance directives.	I do not know.
No	No	No	I couldn't get through to that doctor, and I doubt that we can discuss it.	No	Preparing now.	Family doctor, family and others around a patient
No	No	No	Not seen the doctor until questionnaire.	No	The content of the advance directive is not clearly defined.	Family and others around a patient
No	No	No	It sees no need to do so.	No		Care manager

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## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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