

The Effect of Educational Intervention regarding Advance Care Planning for Advance Directives

Yae Takeshita^{1*}, Mika Ikeda², Sayaka Sone³, Michiko Moriyama³

¹Graduate School of Biomedical & Health Sciences, Hiroshima University, Hiroshima, Japan

²Osakikamijima Town Government, Toyota-gun, Japan

³Institute of Biomedical & Health Sciences, Hiroshima University, Hiroshima, Japan

Email: *takeshita0307@rice.ocn.ne.jp

Received 14 July 2015; accepted 4 August 2015; published 7 August 2015

Copyright © 2015 by authors and Scientific Research Publishing Inc.

This work is licensed under the Creative Commons Attribution International License (CC BY).

<http://creativecommons.org/licenses/by/4.0/>



Open Access

Abstract

This study aimed to examine the effects of empowerment and education intervention to promote Advance Care Planning (ACP) for residents in a highly aged and depopulated region. The study utilized a single-group pre- and post-test design and was conducted in Osakikamijima, Hiroshima, Japan. The researchers and town officials together formed an ACP committee and created an intervention framework. An ACP workshop was held for the participants and a self-administered questionnaire was carried out before, immediately after, and 3 months after the workshop. A total of 125 residents participated in the workshop and 87 of them completed more than 80% of the questionnaire items, whose responses were analyzed as valid responses. The number of participants who completed the AD increased significantly three months after the workshop ($p = 0.008$). There was a slight increase in the frequency of consultation with the family, but no change was observed in terms of consultation with healthcare providers. The educational intervention increased the respondents' awareness and knowledge of ACP but did not affect the autonomous decision-making process regarding end-of-life care. This strategic process of ACP empowered the residents' awareness and attitude towards end-of-life care with an increased completion rate of AD. On the other hand, cognitive barriers remained toward communication and decision-making shared with healthcare providers. Insufficient consultation with family members also became evident. Therefore, a new intervention strategy which helps increase communication with healthcare providers needs to be formulated and guidelines for consultation with the family and others need to be prepared.

*Corresponding author.

Keywords

End-of-Life, Advance Care Planning, Advance Directives, Community Empowerment

1. Introduction

In Japan, the rate of aging is currently at 25.1% and is advancing faster than any other rate in the world [1]. In addition, the population has started to decrease as of 2005, and the society entered a new stage where the death rate exceeded the birth rate [2]. Inevitably, Japan's healthcare system, known for their excessive number of hospital beds, must prepare for this change and the government has begun reforming medical care to shift from a hospital-focused to a home care-focused system [3]. On the other hand, community and people's preparations for dying at home are inadequate. While the rate of those who wanted to die at home was 49.5% [4], that of death at home was only 12.8% in 2012 [5].

What is causing this gap and why are dying at home not more prevalent? Several factors have been discussed. 1) The large number of hospital beds [6] makes hospitalized treatment easier, and Japan has become used to this as a reality. 2) The number of families with three generations cohabiting has decreased, leading to an increase in those living alone or only with the elderly [7]. Although the public long-term care insurance system is available, the reality is that there is inadequate service for those living alone [8]. 3) There exists anxiety over care provided by the family, the burden of caregiving work involved, and fear regarding responses during emergencies, even if they live with families. Therefore, dying at home is avoided and, instead, people choose to die in hospitals [9]-[11]. 4) Finally, a care manager responsible for service arrangements and health/nursing care providers themselves consider that dying at home can be difficult if the family cannot provide adequate care [12]. 5) Additionally, advance directives (AD), which are legislated in the West, are not legislated in Japan [13] and there is no effective, legal method of carrying out the wishes of an elderly person. Moreover, medical and nursing care providers have lack of knowledge regarding AD [14], and people in Japan lost learning opportunities and experiences to have natural death without having any invasive medical treatment.

Despite these limitations, Japan is currently compensating for the lack of knowledge of both its citizens and health/nursing care providers through a concept called advance care planning (ACP), designed to promote dying at home. ACP is being promoted in community through the integrated community care system, which is a system designed to support regional home care system by 2025 when Japan's elderly population is expected to peak [15]. ACP is defined as "process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions" [16] with AD at its center. ACP programs that have demonstrated effectiveness are being developed [17] and they have proven popular in England, USA, and Australia; interestingly, this popularity has been limited in Japan.

One reason for this slow uptake is the aforementioned psychological resistance of both health/nursing care providers and citizens. Other reasons include the lack of promotion for the ACP process in order to compensate for the lack of knowledge of both citizens and health/nursing care providers, and that topics regarding end-of-life care tend to be avoided because they conjure images of death.

Community empowerment is effective for widespread awareness of the concepts of ACP and to tie these to implementation. This is a process by which a region's citizens critically assess their own situation, realize common issues, and take action to improve and resolve the causes of these issues by creating societal change [18]. Awareness of issues by all citizens in a region and subsequent proactive action against these issues will be effective in order to reform society, even with factors preventing the spread of ACP.

Therefore, in this study, we selected one region and performed community awareness activities directed to health/nursing care providers and citizens alike in order to promote ACP in the integrated community care system, and we have reported on the changes to awareness and behavior based on this intervention. Furthermore, we measured promotion through the completion of written AD and discussions about end-of-life care with family and health care professionals as goals for the development of ACP.

1.1. Literature Review of ACP in Japan

In an awareness survey conducted in 2014 by the Ministry of Health, Labour and Welfare on 2179 people in the

general population, those with completed AD comprised 3.2%. Meanwhile, 42.2% responded that they had discussed with their families, but only 2.8% responded that they spoke in detail [19]. Amidst these conditions, the proportion of those responding in favor of living wills (LW) rose from 47.6% in 1998 to 61.9% in 2008 [19], indicating a gradual increase in awareness of the importance of indicating one's preferences toward end-of-life care.

Searching literature databases (MEDLINE, the Cumulative Index to Nursing and Allied Health Literature [CINAHL], and the Japan Medical Abstracts Library) for ACP and AD in Japan revealed most studies regarding the awareness of AD or LW. Several studies focused on the complete rate of AD or the practicality of AD [11] [20]-[22], as well as the compliance and content of AD and LW [23]-[25]. However, there was only one interventional study regarding the creation of LW [26]. In this educational intervention for AD, a lecture was given to the interventional group comprised of the regional elderly population and who discussed AD in small groups; meanwhile, the control group were given handouts. In comparing the two groups, the proportion of those who discussed with their families and health care providers increased significantly; however, a significant increase was not observed for writing a LW (5.7%).

As demonstrated above, Japan has not yet reached a stage where it can facilitate awareness of study-focused, practical interventions from a community empowerment perspective, despite the fact that the importance of ACP is well known.

1.2. Characteristics of Osakikamijima as a Research Field

Osakikamijima has a population of 8207 and is designated an isolated island. The proportion of elderly people is 45.4%, while those aged over 75 years comprise 26.7% (as of January 1, 2014) [27]. In 2012, the total number of deaths was 165, with 92.1% of those experiencing death outside their home (51.7% in the hospital, 19.4% in the clinic (with beds), and 15.8% in nursing homes) [28]. While the proportion of those wishing to live out their lives in the comfort of their own homes is high, the actual number of those able to do so is low.

2. Methods

2.1. Participants and Recruitment

Participants were non-hospitalized residents aged over 20 years living in the region. A notice was sent to all residents of Osakikamijima, where a workshop was given (Figure 1), and the workshop participants were used in this study. The person whose cognitive function declined was excluded.

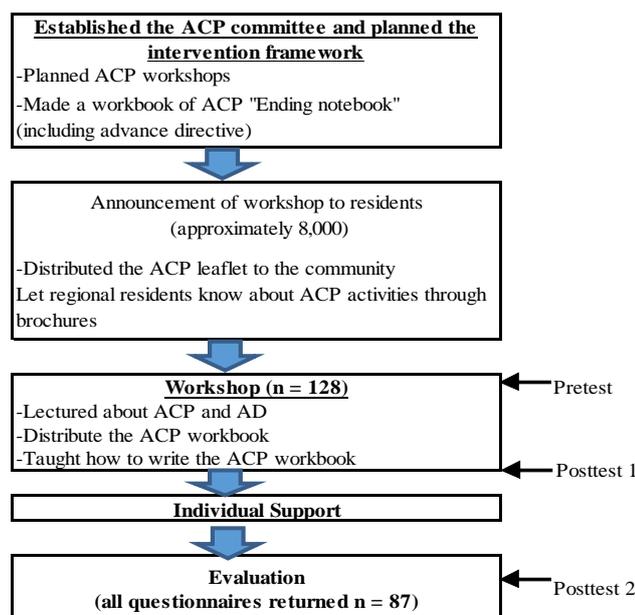


Figure 1. Project framework.

2.2. Research Design

Single-group pre and posttest study.

Intervention method: We outlined the framework and performed the intervention at the corresponding step in **Figure 1**.

Step 1: Established ACP committee and planned intervention framework: A joint committee between Osakikamijima and the researchers was established in order to create a region where it was possible to live out one's life on the island. The participating members were the Mayor of Osakikamijima, government employees from Osakikamijima, the town's medical association, the town's Council of Social Welfare, the community comprehensive care center, the nursing care service office, the home-visiting nursing station, and an informal municipal organization.

Step 2: Created an ACP workbook: We created a workbook "Ending Notebook" to help guide the ACP process. The contents included wishes for how to live in the future, personal history, messages to important people, preference of medical/nursing care, management of money and assets, and funeral arrangements. For medical/nursing care, participants noted the disease diagnoses and remaining life, if they were given the information from the healthcare provider. Questions regarding palliative care such as pain management and the use of life-prolonging treatments (artificial feeding, cardiopulmonary resuscitation, use of artificial respirator) were answered with one of three options: yes, no, and unsure. Space was included for free comments, as well as in-putting the names of each participant's family physician and the proxy decision makers. Additionally, space was included to record the date when discussions with the healthcare provider and family took place.

Step 3: Announcement of the workshop to residents: We created a leaflet explaining ACP and announced the workshop for the promotion of ACP in the town's PR brochure, which was distributed to all residents of Osakikamijima. The public health nurse of the town urged opinion leaders, such as the regional welfare commissioner and heads of neighborhood associations, to participate; at the same time, the public health nurse urged citizen participation through door-to-door canvassing.

Step 4: Implemented the workshop: The workshop was implemented over four sessions (60 minutes/session, 2 days). There was a two-week gap between the two workshop sessions (**Figure 2**). The workshop was structured to take into account learning elements based on Bloom *et al.* [29]: affective domain (attitude), cognitive domain

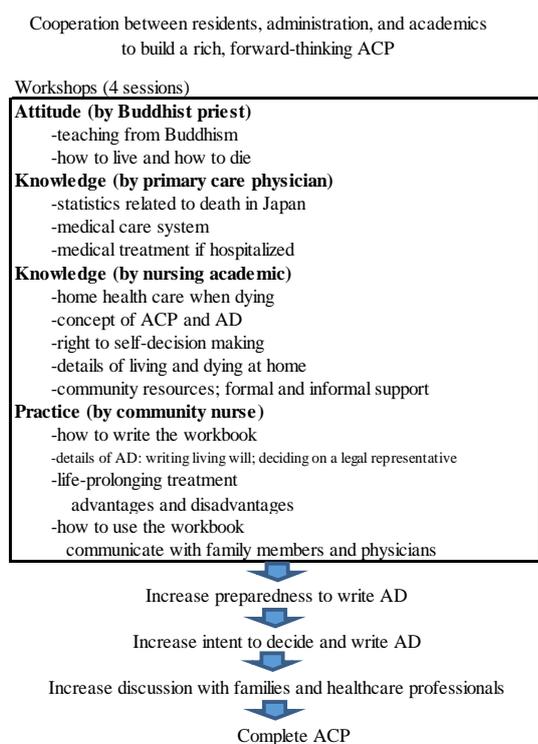


Figure 2. Process of completing ACP.

(knowledge), and psychomotor domain (behavior). We employed a regional key person to increase participant awareness. The regional head priest of the Buddhist temple gave a lecture on living and dying from the perspective of Buddhism. A physician for the head of the town's medical association gave a lecture on the current state of end-of-life care in Japan, as well as medical knowledge pertaining to end-of-life and life-prolonging treatment. Additionally, the physician shared their thinking regarding end-of-life care. A nursing academic, who was a member of the ACP committee, explained dying in a familiar environment, concepts and processes of ACP and AD, the importance of autonomous decision-making and caregiving at home using social resources. A public health nurse promoting ACP explained the contents of the ACP workbook and provided specific guidance on how to complete it. Additionally, the nurse explained frequently-asked questions while completing the workbook. Finally, to make AD effective, the nurse explained the importance of discussions with family and health care providers.

2.3. Evaluation and the Process

Theoretical process of having effects in this study is shown in **Figure 2**. Participation in the workshop led to an increase in knowledge about ACP (knowledge). The number of people endorsing ACP increased (attitude) as awareness about its importance spread, which subsequently led to greater autonomy regarding decisions about end-of-life care (attitude). These factors helped to prepare for ACP. As a result of autonomous decisions about end-of-life care, the completion rate of AD and discussions with family and health care providers increased (behavior), ultimately leading to popularization of ACP.

In order to demonstrate these effects, the AD completion rate was set as the primary endpoint and the number of discussions with health care providers and family as the secondary endpoint. Additionally, the tertiary endpoints were the degree of awareness of ACP, AD knowledge scale, endorsement of ACP, awareness of the importance of ACP, Autonomy Preference Index (API), and preferences toward end-of-life care. Questions regarding awareness and preferences were constructed by the researcher using previous studies as a reference [26].

2.4. Data Collection

We performed self-administered questionnaires according to the 3 points shown in **Figure 1** and collected data. We asked prior to the workshop (pretest: baseline) and 3 months after (posttest 2), questions whether “completed the AD” and “had discussions with family or healthcare providers about end-of-life care.” We asked about ACP awareness, the AD knowledge scale, endorsement of ACP, awareness of the importance of ACP, API, and preferences toward end-of-life care before and after the workshop (pretest, posttest 1).

For awareness of ACP, we asked whether they had knowledge of AD, LW, and legal representatives (yes/no). For testing AD knowledge, the advance directive knowledge test [30] was administered. This scale was developed to evaluate the effect of interventions promoting the education of AD writing. Japanese version of this test contained 8 true-false items dealing with concepts and facts related to AD [31]. The test includes themes such as legal considerations, importance, communication with others, appropriate use, and timing. This scale score was calculated by assigning a score of 1 and 0 to correct and incorrect answers, respectively. More correct answers indicated a higher degree of knowledge (score range = 0 - 10). Reliability and validity were tested.

Attitudes toward ACP were evaluated by asking whether they agreed with writing an AD or discussing this with healthcare providers and family (endorsement of ACP), as well as whether they thought this was important (awareness of the importance of ACP). API is a measure of the degree of decision-making regarding medical procedures [32]. There are two subscales for API, but the Japanese version was classified into three independent subscales of “information seeking” “case-based decision making” “non case-based decision making.” In this study, the generalized subscale measuring the degree of decision-making was used. This 4-item API (non case-based decision making) subscale uses a 5-point Likert scale with responses ranging from 1 (strongly agree) to 5 (strongly disagree). In accordance with prior research, a score was rated from 100 for “strongly disagree” to 0 for “strongly agree” and was converted the scores at each step of the analysis so that a higher degree of autonomy led to higher scores. Reliability and validity were tested [33].

To ascertain their end-of-life preference, participants were asked the following: If there is no chance of recovery from your illness, would you like to receive the following treatments? (Examples given were cardiopulmonary resuscitation, artificial ventilation, and artificial nutrition.) Participants chose one of four answers: 1) yes, I would; 2) leave it to the physician to decide; 3) leave it to my family to decide; or 4) no, I would not.

2.5. Data Analysis

In order to make comparisons before and after the workshop (before and 3 months after the workshop), McNemar's test was used for the completion of AD, discussions, ACP awareness and endorsement of ACP. The t-test was used for total scores of AD knowledge Scale, the Wilcoxon rank sum test was used for the awareness of importance of ACP and API, and the marginal homogeneity test was used to analyze preferences toward end-of-life care. Statistical significant level was set at $p < 0.05$.

2.6. Ethical Considerations

This study was approved by the Ethics Committee of Hiroshima University. A written consent form was taken from all workshop participants. Before signing, all participants were explained the purpose of this project, that study participation was voluntary, that they could withdraw at any time, that personal information would be secure, and the method of publication with protection of privacy.

3. Result

3.1. Outlines of Participants

A total of 125 people participated in the workshop; 90 participants responded to all three evaluation points, and 87 who completed >80% of items were analyzed as valid responses.

The basic characteristics of the participants are shown in **Table 1**. The average age was 64.1 (SD = 13.4), 54.2% were aged over 65 years, 63 participants (75.0%) were female, 18.4% lived on their own, 81.6% lived with another, 87.2% had a family physician, 56.0% had experience with major operations or hospitalization, and 77.0% had experience of care giving for their family. A total of 77.3% of participants over 65 years of age rated their subjective degree of health as good.

3.2. Educational Effects on Making Advance Directives

Tables 2-5 show the changes before and after the workshop.

3.2.1. Behavior: Change of Behavior toward Developing AD

The completion rate of making AD is the primary endpoint of this study. The number of participants who responded that they had completed the AD was 1 out of 72 (1.4%) before the workshop, which rose to 9 out of 72 (12.5%) at three months after the workshop ($p = 0.008$) (**Table 2**).

Table 1. Participant demographics.

	N	Mean (\pm SD) or N (%)
Age (years)	83	64.1 (13.4)
Sex (female)	84	63 (75.0)
Living arrangement		
Couple		36 (41.4)
Parents and children	87	28 (32.2)
Alone		16 (18.4)
With others		7 (8.0)
Has primary physicians	86	75 (87.2)
Health condition		
Very good		10 (11.7)
Good	85	57 (67.1)
Fair		9 (10.6)
Poor		8 (9.4)
Very poor		1 (1.2)
Past medical history of surgery/hospitalization	84	47 (56.0)
Caregiving experience for terminally ill or serious conditions	87	67 (77.0)

Table 2. Attitude, cognition, and behavior change after the workshop.

	N	Pre		Post		p-value
		Yes	(%)	Yes	(%)	
Change of behavior toward developing advance directives						
Completed writing advance directives	72	1	(1.4)	9	(12.5)	0.008 ^a
Discussed with the family	74	29	(39.2)	37	(50.0)	0.057 ^a
Discussed with the physician	72	5	(6.9)	4	(5.6)	1.000 ^a
Change of knowledge of advance care planning						
Was aware of advance directives	86	35	(40.7)	72	(83.7)	<0.001 ^a
Was aware of living wills	84	23	(27.4)	62	(73.8)	<0.001 ^a
Was aware of durable power of attorney	79	52	(65.8)	66	(83.5)	0.001 ^a
The advance directives knowledge test score: Mean (±SD)	76	5.1	(2.2)	6.2	(1.8)	<0.001 ^b
Change of attitude toward ACP: Endorsement of ACP						
Agreed with making advance directives	79	76	(96.2)	77	(97.5)	1.000 ^a
Agreed with discussing end-of-life care	86	85	(98.8)	85	(98.8)	1.000 ^a

^aMcNemar test, ^bt-test.

Table 3. Change of attitude toward ACP: Awareness of importance of ACP.

	Total	Pre		Post		p-value
		N	%	N	%	
Making advance directives is important						
Strongly agree	76	32	(42.1)	41	(53.9)	0.129
Agree		41	(53.9)	33	(43.4)	
Disagree		3	(3.9)	2	(2.6)	
Strongly disagree		0	(0.0)	0	(0.0)	
Discussion about end-of-life care is important						
Strongly agree	85	72	(84.7)	67	(78.8)	0.157
Agree		11	(12.9)	16	(18.8)	
Disagree		2	(2.4)	1	(1.2)	
Strongly disagree		0	(0.0)	1	(1.2)	

Wilcoxon rank sum test.

Table 4. Score of the change of Autonomy Preference Index (N = 64).

	Pre		Post		p-value
	Mean	(±SD)	Mean	(±SD)	
The important medical decisions should be made by your physician, not by you.	43.8	(30.5)	46.9	(35.2)	0.344
You should go along with your physician's advice even if you disagree with it.	51.2	(28.3)	55.1	(31.9)	0.132
When hospitalized, you should not be making decisions about your own medical care.	50.8	(33.6)	50.8	(31.8)	0.917
If you were sick, as your illness became worse, you would want your physician to take greater control.	41.0	(30.0)	43.8	(31.8)	0.392

Wilcoxon rank sum test.

Discussing end-of-life care with healthcare providers and family are the secondary endpoints of this study. Participants who had discussed end-of-life care with family before the workshop totaled 39.2%, which rose to 50% at three months after the workshop; however, this difference was not significant ($p = 0.057$). Participants who had discussed end-of-life care with healthcare providers before the workshop totaled 6.9%, and this was 5.6% at three months after the workshop; therefore, there was no change ($p = 1.000$).

Table 5. Changes in life-saving treatment preferences (N = 80).

	Pre		Post		<i>p</i> -value
	N	(%)	N	(%)	
Cardiopulmonary resuscitation					
Yes, I would	14	(17.5)	8	(10.0)	0.486
Leave it to the physician	26	(32.5)	29	(36.3)	
Leave it to my family	9	(11.3)	13	(16.3)	
No, I would not	26	(32.5)	26	(32.5)	
I cannot decide	5	(6.3)	4	(5.0)	
Mechanical ventilation					
Yes, I would	4	(5.0)	5	(6.3)	0.893
Leave it to the physician	24	(30.0)	21	(26.3)	
Leave it to my family	11	(13.8)	12	(15.0)	
No, I would not	37	(46.3)	39	(48.8)	
I cannot decide	4	(5.0)	3	(3.8)	
Artificial nutrition					
Yes, I would	6	(7.5)	7	(8.8)	0.275
Leave it to the physician	17	(21.3)	13	(16.3)	
Leave it to my family	13	(16.3)	9	(11.3)	
No, I would not	41	(51.3)	47	(58.8)	
I cannot decide	3	(3.8)	4	(5.0)	

Marginal homogeneity test. Question “If there is no chance of recovery from your illness, would you like to receive the following treatment?”

3.2.2. Knowledge: Awareness of ACP and Changes to the Degree of AD Knowledge

Awareness and acquisition of knowledge are the tertiary endpoints of this study. A total of 40.7%, 27.4%, and 65.8% of participants responded that they were aware of ACP (AD/LW/durable power of attorney) before the workshop, which rose to 83.7%, 73.8%, and 83.5%, respectively after the workshop. These differences were statistically significant ($p < 0.001$, $p < 0.001$, $p = 0.001$, respectively) (Table 2). The scores of AD knowledge was an average of 5.1/10 (SD = 2.2) before the workshop, which rose significantly to 6.2 (SD = 1.8) after the workshop ($p < 0.001$) (Table 2).

3.2.3. Attitudes: Endorsement of ACP, Awareness of Importance, API

Most participants agreed prior to the workshop that end-of-life care and AD writing should be discussed; this percentage did not change post-workshop ($p = 1.000$, $p = 1.000$, respectively) (Table 2). Over 95% of participants before and after the workshop responded that writing the AD and discussing it with family and healthcare providers are important and there were no changes between pre and post-workshop ($p = 0.129$, $p = 0.157$, respectively) (Table 3). In all four questions measuring the degree of autonomy regarding medical treatment by API, there was no significant difference before and after the workshop ($p = 0.344$, $p = 0.132$, $p = 0.917$, $p = 0.392$, respectively) (Table 4).

3.2.4. Preferences toward End-of-Life Care

Preferences for life-prolonging treatment—such as cardiopulmonary resuscitation, artificial respiration, and artificial nutrition—did not change before or after the workshop ($p = 0.486$, $p = 0.893$, $p = 0.275$, respectively) (Table 5).

4. Discussion

4.1. The Effect of Patient Characteristics on the Results

Compared to the rate of aging for Osakikamijima, the proportion of the elderly in this study was 54.2%, suggesting that a greater number of elderly participated in the workshop. Among participants aged over 65 years, a high proportion answered that their subjective health was good, which, when compared to prior studies [34], suggests that the elderly in this study were healthier. Additionally, the percentage of workshop participants living alone was 18.4%, which is similar to the same percentage for Osakikamijima (17.2%) [35], indicating that common people participated in the study.

The workshop was announced widely in the town's PR brochure and given that participation was voluntary, we surmise that the participants were an active group of individuals with a high degree of interest in end-of-life care. This group comprised people who were older but healthy and who did not live alone. The proportion of participants with a family physician exceeded 80%. Compared to the percentage obtained through an investigation of 5667 people over 20 (32.8%) [36], the study participants have adequate access to a family physician, despite being elderly. Moreover, because we selectively informed the regional welfare commissioners, we infer that the participants include those with a role in the region or with high consciousness. These individuals are likely to be opinion leaders in the region, and their involvement and effect on group dynamics is important for future promotion and popularization.

4.2. Effect of This Interventional Project

The primary endpoint of the AD completion rate increased significantly as a result of the educational intervention in this study. Compared to the completion rate of 5.7% after intervention reported by Matsui [26], our study showed a higher completion rate. Given that the Ministry's investigation showed an increasing trend of citizens in favor of the LW [19], the changing preferences of citizens could also have influenced our results.

Additionally, there are three reasons that might explain our results: 1) Ease of instructions and provision of examples; we distributed a model AD after the workshop. 2) Selection of influential people as the presenters. 3) Ease of writing the AD; AD from Five Wishes [37] or Caring Connections [38], and LW from the Japan Society for Dying with Dignity [39] used in previous references are all limited to a Do/Do not selection regarding life-prolonging treatments and do not allow for a non-decision. The AD we developed for this study allows answers other than Do/Do not, and can be completed even if a decision has not yet been made.

As a result of investigating methods through collaboration and coordination with the town government from the planning phase, we believe that the group dynamics on the island foster region-wide concerns, ultimately leading to an increase in the number of people writing AD. In other words, resident participation and empowerment were effective in producing the results. Before the workshop, fewer than half of the participants knew the specific methods of ACP, such as AD and LW; this knowledge increased significantly after the workshop. Familiarity with legal representatives and the knowledge scale for AD also increased significantly, suggesting that changes in attitude toward writing are possible.

Knowledge and completion rate increased, on the other hand, the degree of autonomous decisions about API and preferences for life-prolonging treatment did not change before and after the workshop. Even after the workshop, 26% - 50% of participants responded that the decision for life-prolonging medical treatment is up to the family or healthcare provider, and no improvement to autonomy was observed. Even though autonomy is an important factor for promoting ACP [40], there have been no civil rights movements regarding medical procedures in the past in Japan, possibly leading to lower autonomy [41]. Therefore, it is necessary for Japanese people to aware the importance of critically considering their belief system and attitude regarding medical procedures they are going to take. As a fact, participants who responded that they discussed end-of-life care with family and healthcare providers before the workshop reevaluated their discussion as inadequate after being shown more specific content. There is no clear guidance on what type of end-of-life care requires discussion in Japan. For this reason, it is possible that people do not know what to discuss regarding end-of-life care. Therefore, it will be necessary to standardize the quality of discussions using the AD as a tool so that discussions reflect the preferences of a patient at their end of life.

4.3. Obstacles Preventing the Effective Function of ACP: The High Barriers of Communication between Citizens and Healthcare Providers

This study revealed some issues regarding ACP education in Japan. The results showed a slight increase in the number of discussions with family, whereas this number did not change for discussions with healthcare providers. The mentality to defer decision-making to the healthcare provider on specific medical procedures did not change. One reason for this may be that AD is not legislated. In Japan, there is no opportunity for patients to obtain information on AD or to create one, as regulated by the Patient Self-determination Act. Additionally, there is some paternalism when healthcare providers made decisions because patients were dependent on healthcare providers as "citizens do not know any better regarding medical treatment" [42]. Therefore, the fact that someone else was making decisions about a medical treatment that one was receiving was never questioned. This de-

pendent model is gradually changing to an autonomous decision-based model [43]; however, legislation mandating information regarding AD to elderly patients over the age of 75 years may be required to break through this psychological dependency. In parallel, providing a common forum within the region for health care providers, care managers, and citizens to discuss successful dying at home will also lead to reformation of awareness.

4.4. Future Consideration

Promoting ACP without organized legislation may be difficult; however, citizens deserve the best medical care, and the mentality that one cannot consider their own QOL at the end-of-life and that it is the responsibility of the healthcare provider must be changed. For this to happen, efforts cannot fall strictly on citizens (patients) and healthcare providers must be willing to facilitate information exchange regarding end-of-life care, including providing the time for discussions. Both sides must make an effort toward autonomous decision-making. In fact, some studies suggest patients who asked to complete AD or receiving an explanation about AD have a higher AD completion rate [44], suggesting that a two-sided effort by patients and healthcare providers alike can move ACP forward.

5. Conclusions

- Given that the AD completion rate increased in Osakikamijima, the empowerment and education intervention for the region's citizens was effective.
- There was a slight increase in discussions with family, but no change regarding discussions with health care providers.
- The education intervention increased awareness and knowledge regarding ACP, but did not change the autonomous decision-making process regarding end-of-life care.
- In Japan, the legislation does not yet provide a forum for thinking about ACP; however, in the future, citizens will have to change their mentality in order to decide their own medical treatment during their end-of-life stage. At the same time, it will be important for health care providers to approach these issues from their perspectives as well.

References

- [1] Statistic Bureau, Ministry of Internal Affairs and Communications (2014) Statistical Handbook of Japan 2014. <http://www.stat.go.jp/english/data/handbook/c0117.htm#c02>
- [2] Ministry of Health, Labour and Welfare (2014) Summary of Vital Statistics. <http://www.mhlw.go.jp/english/database/db-hw/populate/dl/02.pdf>
- [3] Ministry of Health, Labour and Welfare (2013) Annual Health, Labour and Welfare Report 2012-2013 Health and Medical Services. <http://www.mhlw.go.jp/english/wp/wp-hw6/dl/02e.pdf>
- [4] Ministry of Economy, Trade and Industry (2012) A Report of the Study Group on Publicity and Enlightenment of Creating a Peaceful and Reliable End-of-life Stage. For Better Lives and Better Farewells. <http://www.meti.go.jp/press/2012/04/20120426006/20120426006-3.pdf>
- [5] Ministry of Health, Labour and Welfare (2013) Handbook of Health and Welfare Statistics 2013 Number of Deaths and Percentage Distribution by Place of Occurrence, by Year. <http://www.mhlw.go.jp/english/database/db-hh/1-2.html>
- [6] Organisation for Economic Co-Operation and Development (2013) Health Care Resources. http://stats.oecd.org/index.aspx?DataSetCode=HEALTH_STAT#
- [7] Ministry of Health, Labour and Welfare (2008) Trends in Households with Persons Aged 65 Years and Over by Household Structure, 1975-2008. <http://www.mhlw.go.jp/english/database/db-hss/cslc-tables.html>
- [8] Watanabe, M., Kono, K., Kawamura, K. and Matsuura, T. (1998) Factors Influencing Admission to Nursing Homes among Frail and Bedridden Elderly Persons Receiving Public Health and Welfare Services. *Japanese Journal of Public Health*, **45**, 45-55.
- [9] Yamagishi, A., Morita, T., Miyashita, M., Yoshida, S., Akizuki, N., Shirahige, Y., Akiyama, M. and Eguchi, K. (2012) Preferred Place of Care and Place of Death of the General Public and Cancer Patients in Japan. *Supportive Care in Cancer*, **20**, 2575-2582. <http://dx.doi.org/10.1007/s00520-011-1373-8>
- [10] Fukui, S., Fujita, J. and Yoshiuchi, K. (2013) Associations between Japanese People's Concern about Family Caregiver Burden and Preference for End-of-Life Care Location. *Journal of Palliative Care*, **29**, 22-28.
- [11] Miyashita, M., Sato, K., Morita, T. and Suzuki, M. (2008) Effect of a Population-Based Educational Intervention Fo-

- cusing on End-of-Life Home Care, Life-Prolonging Treatment and Knowledge about Palliative Care. *Palliative Medicine*, **22**, 376-382. <http://dx.doi.org/10.1177/0269216308090073>
- [12] Ministry of Health, Labour and Welfare (2004) The Place of End-of-Life Care. <http://www.mhlw.go.jp/shingi/2004/07/s0723-8d8.html>
- [13] Mendelson, D. and Jost, T.S. (2003) A Comparative Study of the Law of Palliative Care and End-of-Life Treatment. *The Journal of Law, Medicine & Ethics*, **31**, 130-143. <http://dx.doi.org/10.1111/j.1748-720X.2003.tb00063.x>
- [14] Minooka, M. (2008) The Importance of the Advance Directive and the Difficulties of Its Prevalence. *Japanese Journal of Cancer and Chemotherapy*, **35**, 41-42.
- [15] Nagura, M. (2013) To Aim at Better Home Medical Care. *Clinical Neurology*, **53**, 1296-1298. <http://dx.doi.org/10.5692/clinicalneuro.53.1296>
- [16] Teno, J.M., Nelson, H.L. and Lynn, J. (1994) Advance Care Planning Priorities for Ethical and Empirical Research. *The Hastings Center Report*, **24**, S32-S36. <http://www.jstor.org/stable/3563482?origin=crossref>
<http://dx.doi.org/10.2307/3563482>
- [17] Detering, K.M., Hancock, A.D., Reade, M.C. and Silvester, W. (2010) The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial. *British Medical Journal*, **340**, c1345. <http://dx.doi.org/10.1136/bmj.c1345>
- [18] Israel, B.A., Checkoway, B., Schulz, A. and Zimmerman, M. (1994) Health Education and Community Empowerment: Conceptualizing and Measuring Perceptions of Individual, Organizational, and Community Control. *Health Education & Behavior*, **21**, 149-170. <http://dx.doi.org/10.1177/109019819402100203>
- [19] Ministry of Health, Labour and Welfare (2014) Attitude Survey Report about the Medical Care in the End-of-Life. <http://www.mhlw.go.jp/bunya/iryuu/zaitaku/dl/h260425-02.pdf>
- [20] Iwata, K. (2008) Advance Directive at General Medicine Outpatient Clinic. *The Japanese Journal of Family Practice*, **14**, 18-24. (In Japanese)
- [21] Sato, T. and Makigami, K. (2008) Terminal Care Education and Consultation Activities in Advance of the Critical Stage of Disease by Attending Physicians at a Rehabilitation Unit. *Japanese Journal of Geriatrics*, **45**, 401-407. <http://dx.doi.org/10.3143/geriatrics.45.401>
- [22] Kawamoto, T., Sunada, S., Shigematsu, K., Tamura, R., Matsuda, M., Hatanaka, N., Sanemori, N., Nakanishi, T., Okuda, M. and Kamiike, W. (2014) Comparison of the Registration of Living Will and Advance Directives between Cancer and Non-Cancer Patients in Electronic Medical Records. *Iryo*, **68**, 392-398.
- [23] Mayumi, T., Watanabe, I., Arishima, T., Onodera, M., Takahashi, H., Takezawa, J. and Katsumata, Y. (2008) Living Will in Abdominal Acute Medicine in Japan. *Journal of Abdominal Emergency Medicine*, **28**, 673-677.
- [24] Fukuda, T. (2012) DNAR in Out-of-Hospital Cardiopulmonary Arrest. *Japanese Association for Acute Medicine*, **23**, 101-108. <http://dx.doi.org/10.3893/jjaam.23.101>
- [25] Uchiyama, T., Atsumi, T., Suzuki, M., Ito, M., Shimizu, T. and Ohashi, T. (2010) Efficacy of a Novel Format for the Advance Directive in Amyotrophic Lateral Sclerosis. *Neurological Therapeutics*, **27**, 77-81.
- [26] Matsui, M. (2010) Effectiveness of End-of-Life Education among Community-Dwelling Older Adults. *Nursing Ethics*, **17**, 363-372. <http://dx.doi.org/10.1177/0969733009355372>
- [27] Hiroshima Prefectural Government (2014) Population Aging Rate in the City Area of the Hiroshima. <https://www.pref.hiroshima.lg.jp/soshiki/63/1279598930406.html>
- [28] Hiroshima Prefectural Government (2012) The Number of Deads and Place of the Death in the City Area of the Hiroshima. <http://www.pref.hiroshima.lg.jp/site/toukei/24-jinnkoudoutaitoukeinennpou.html>
- [29] Bloom, B.S., Hastings, J.T. and Madaus, G.F. (1971) Handbook on Formative and Summative Evaluation of Student Learning. McGraw-Hill Inc., New York.
- [30] Murphy, C.P., Sweeney, M.A. and Chiriboga, D. (2000) An Educational Intervention for Advance Directives. *Journal of Professional Nursing*, **16**, 21-30. [http://dx.doi.org/10.1016/S8755-7223\(00\)80008-3](http://dx.doi.org/10.1016/S8755-7223(00)80008-3)
- [31] Hamayoshi, M. and Kono, A. (2014) Reliability and Validity of the Advance Directive Knowledge Test and Attitude Survey for Japanese Local Older Residents. *Journal of Japan Academy of Community Health Nursing*, **16**, 32-40.
- [32] Ende, J., Kazis, L., Ash, A. and Moskowitz, M.A. (1989) Measuring Patients' Desire for Autonomy: Decision Making and Information-Seeking Preferences among Medical Patients. *Journal of General Internal Medicine*, **4**, 23-30. <http://dx.doi.org/10.1007/BF02596485>
- [33] Ohki, M. and Fukuhara, S. (1995) Development and Validation of the Autonomy Preference Index for Japanese Subjects. *Japan Health Psychology*, **3**, 11-24.
- [34] Mitoku, K., Takahashi, T. and Hosi, T. (2006) Health Relation Factors of Elderly People and Subjective Feeling of

- Health. *Kawasaki Medical Welfare Journal*, **15**, 411-421.
- [35] Statistic Bureau, Ministry of Internal Affairs and Communications (2014) Statistical Observations of Shi, KU, Machi, Mura 2014. <http://www.e-stat.go.jp/SG1/estat/List.do?bid=000001053740&cycode=0>
- [36] Japan Medical Association Research Institute (2014) Attitude Survey Report about the Medical Care in Japan. <http://www.jmari.med.or.jp/download/WP331.pdf>
- [37] Aging with Dignity (1998) Five Wishes. <https://www.agingwithdignity.org/five-wishes.php>
- [38] Caring Connections (2004) Advance Directives. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>
- [39] Japan Society for Dying with Dignity (1976) Living Will. http://www.songenshi-kyokai.com/living_will.htm
- [40] Hoshino, K. (1995) Autonomous Decision Making and Japanese Tradition. *Cambridge Quarterly of Healthcare Ethics*, **4**, 71-74. <http://dx.doi.org/10.1017/S0963180100005661>
- [41] Johnstone, M. and Kanitsaki, O. (2009) Ethics and Advance Care Planning in a Culturally Diverse Society. *Journal of Transcultural Nursing*, **20**, 405-416. <http://dx.doi.org/10.1177/1043659609340803>
- [42] Munakata, T. (1996) Health and Disease Analyzed by Behavioral Science. Medical Friend Co. Ltd., Tokyo.
- [43] Hayashi, M., Hasui, C., Kitamura, F., Murakami, M., Takeuchi, M., Katoh, H. and Kitamura, T. (2000) Respecting Autonomy in Difficult Medical Settings: A Questionnaire Study in Japan. *Ethics & Behavior*, **10**, 51-63. http://dx.doi.org/10.1207/S15327019EB1001_4
- [44] Alano, G.J., Pekmezaris, R., Tai, J.Y., Hussain, M.J., Jeune, J., Louis, B., El-Kass, G., Ashraf, M.S., Reddy, R., Lesser, M. and Wolf-Klein, G.P. (2010) Factors Influencing Older Adults to Complete Advance Directives. *Palliative & Supportive Care*, **8**, 267-275. <http://dx.doi.org/10.1017/S1478951510000064>