Effects of an Education Program to Promote Advance Directive Completion in Local Residents

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Purpose: An educational program was developed to facilitate advance directive (AD) completion, using the situation of end-of-life care for people with dementia. The aim of the study was to examine the effects on AD completion rates of an education program conducted for local community residents.

Methods: The design was a quasi-experimental study with intervention and control groups, respectively. The study population included local welfare officers from two cities in Osaka Prefecture, Japan, of whom 81 persons were allocated to an intervention group and 60 persons to a control group. A 70-minute intervention program was performed twice for the intervention group. Primary outcomes included AD completion and intention to complete an AD, as indicated by binary “Yes” or “No” responses, and secondary outcomes included knowledge of AD, attitudes towards AD, and knowledge of dementia.

Results: The intervention group exhibited a significant increase in the number of people who completed an AD from the baseline assessment compared to the four-month reassessment (odds ratio = 5.0, 95% confidence interval = 1.0–25.0, $p = 0.04$). The results showed that the interactions between group and time were statistically significant for scores of both the AD Attitude Survey Test ($F = 4.1$, $p = 0.04$) and the Dementia Knowledge Scale ($F = 4.6$, $p = 0.04$).

Conclusions: The results suggest that this education program to facilitate AD completion may promote 1) AD completion, 2) favorable attitudes towards AD, and 3) knowledge of dementia among local residents.

Keywords: advance directives, end-of-life care, dementia

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BACKGROUND

Among Organization for Economic Co-operation and Development (OECD) nations, 14 million people aged 60 years and over are reported to suffer from dementia according to a 2009 estimate.¹ In Japan, this number surpassed an estimated 3.05 million in 2012,² with the prevalence of dementia steadily increasing with advancing age. In recent years, there has been research on end-of-life care for elderly patients with dementia,^{3–5} which identified the necessity of advance directives (ADs) for such persons.^{6,7} An AD is defined as a document that establishes directives for treatment preferences during end-of-life care and designates a proxy decision maker.⁸

In the United States, ADs were enacted into law by the 1990 Patient Self-Determination Act. This legislation recognizes the right to self-determination of the patient, and AD completion is currently being established as a nursing standard of care for elderly patients.⁹ However, even in the United States, AD completion rates are not high, and interventions to facilitate AD completion through randomized clinical trials have been undertaken in recent decades.^{10–12}

According to a research report by the Japanese Ministry of Health, Labour and Welfare concerning end-of-life care,¹³ 69.7% of the general population endorsed the statement “I agree that a document like a living will should give instructions about medical care.” Although those in favor of ADs are increasing in number,¹³ research on methods to promote ADs has not yet clarified the best approach in Japan.

Previous research on education promoting AD completion in Western countries has demonstrated the necessity of providing this education through medical professionals,¹⁴ or of including interactions with others.^{15,16} Current research suggests that multimodal intervention is needed for improving AD completion rates. Incorporating models of health behavior change to promote ADs^{17–19} and the Theory of Planned Behavior (TPB) have both been used to complete advance care planning and ADs.²⁰ The author developed an AD completion promotion program that uses a behavior prediction model based on the TPB, where “behavioral intention” and “subjective norms” shape “perceived behavioral control.” These three elements

working together can positively support undertaking goal-oriented actions. The programs based on this theory can help form proactive attitudes towards AD completion with the purpose of encouraging participants to take action.

It is desirable that an AD should be completed at a stage when people’s decision-making abilities are competent so that the documents can accurately indicate well-considered wishes for their future end-of-life care.^{21,22} It is necessary that this be done before they become “old-old” to thereby adequately reflect their actual intentions.

The aim of this study was to examine the effects on local community residents, without cognitive decline, of an education program based on the Theory of Planned Behavior to determine AD completion rates, attitudes towards AD, and knowledge of dementia.

METHODS

Procedure and participants

The study design was a non-randomized quasi-experimental study with an intervention and a control group. The data were collected from June to December 2012, inclusive.

The study participants were local welfare officers from two cities in Osaka, Japan: Neyagawa, as the intervention group, and Izumiotsu as the control group. Local welfare officers are community officials appointed by the Minister of Health, Labour and Welfare who support elderly people living alone, with the number of these proportional to the municipality’s population. They are usually retired employees and housewives, with an average age of over 60 years.

The study participant flow chart is shown in **Figure 1**. On 1st July 2012, the population of Neyagawa was 242,792 and that of Izumiotsu was 77,350; the total number of local welfare officers of Neyagawa was 368, and that of Izumiotsu was 90, respectively. Welfare officers from two districts in Neyagawa and all 90 officers in Izumiotsu were invited to participate in this study. The final study population comprised 106 officers from Neyagawa and 63 from Izumiotsu. The follow-up measurements were collected from 81 subjects in Neyagawa, and 60 in Izumiotsu (see **Figure 1**). Because the concept of ADs is not common knowledge

Figure 1. Derivation of study participants

in Japan, a 60-minute lecture, the contents of which were related to ADs and dementia, was provided to both the intervention and control groups before baseline data collection. Initial baseline data were collected immediately after this lecture, and the follow-up data were collected four months after baseline at a meeting for the intervention group and via postal mail for the control group. The data collection method differed between groups because there was no regular meeting at the time of follow-up for the control group. All data were collected via a self-administered written questionnaire. The four-month endpoint was chosen in keeping with other studies on AD which had similar endpoints.¹²

Statistical analysis

Based on applied multiple regression analysis²³ for a significance level α of 0.05 and detection power of 0.8, a sample size of 63 individuals per group was considered to be effective for detecting a moderate size effect. Accordingly, a total of 126 individuals were chosen as the sample population size. Eighty indi-

viduals were recruited for both the intervention group and the control group, with an assumed 20% drop out rate.

Outcome measures

1) Primary outcome

The primary outcomes were measured via two indicators of AD completion and intention to complete an AD, which were the responses to the questions “Did you complete an AD?” and “Do you think that you will complete an AD?”, respectively; these questions were scored as 1 for “Yes” or 0 for “No.” In this study, an AD was defined as a document that established directives for treatment preferences during end-of-life care and which designated a proxy decision maker. An AD booklet was distributed and explained at the time of the baseline lecture about ADs and dementia.

2) Secondary outcome

The secondary outcomes included knowledge of ADs, attitudes towards ADs, and knowledge about dementia. Knowledge of ADs and positive attitudes towards ADs were anticipated to be closely associated with AD

completion rates from the results of our previous study.²⁴ In addition, it was considered that knowledge about dementia and AD completion would be closely associated, because knowledge about dementia promotes recognition of the disabling of self-determination caused by it.

Knowledge about ADs was measured by the eight items from the Japanese version²⁵ of the AD Knowledge Test.²⁶ The original AD Knowledge Test is scored in terms of binary, correct/incorrect responses to items; the scale is calculated by giving each correct item a score of 1 and each incorrect item a score of 0. Higher scores indicate a greater extent of knowledge with the range of scores being from 0 to 10, inclusive. The internal consistency of the original scale, using Cronbach's alpha, was 0.79.²⁷ Prior to the present study, these scales were translated into Japanese with the consent of the authors, and which was administered to 102 members of an elderly association as a pretest.²⁵ As a result of verifying the correlation coefficients between each item and the total scale (I-T coefficients), two items were removed from the AD Knowledge Test whose coefficients fell below 0.3; finally eight items were used for the Japanese version of the scale, with a Cronbach's alpha of 0.67 from the preliminary data.²⁵ Attitudes towards ADs was measured by the 11 items of the Japanese version²³ of the AD Attitude Test.²⁵ The original AD Attitude Test items are scored ranging from 1 (strongly agree) to 4 (strongly disagree); for purposes of analysis, 'strongly agree' and 'agree' responses were combined into one 'agree' response category and 'disagree' and 'strongly disagree' were combined into one 'disagree' response category. The response to each item was scored as 1 for 'agree' or 0 for 'disagree'. The total scores range from 0 to 13 points, and higher scores indicate more favorable attitudes toward ADs. The internal consistency of the original scale, using Cronbach's alpha, was 0.80.²⁶ Prior to the present study, as a result of verifying the correlation coefficients between each item and the total scale (I-T coefficients), two items were removed from the AD Attitude Scale whose coefficients fell below 0.3 and 11 items were used for the Japanese version of the scale. Cronbach's alpha was 0.86 in the preliminary data.²⁵

Knowledge about dementia was measured by the Dementia Knowledge Test.²⁶ This uses a three-point scale of "agree", "disagree", and "I don't know." The response to each item was scored as 1 for 'agree' or 0 for either 'disagree' or 'I don't know'. The total number of correct responses indicates the extent of knowledge about dementia. Scores range from 0 to 15 points and higher scores show greater knowledge about dementia. The Cronbach's alpha of the Dementia Knowledge Test was 0.71.²⁷

AD Completion Program

The AD Completion Program for the intervention group used the framework of a behavior prediction model based on the Theory of Planned Behavior.²⁸ A 70-minute intervention program was performed twice for the participants in the intervention group. This full program consisted of two lectures including the following themes: "Who will have durable power of attorney if you get dementia?" and "When a family member cannot eat food, what kinds of decisions do you have?"

Explanations were provided about a proxy decision maker and the requirement of a percutaneous endoscopic gastrostomy (PEG) tube towards the end of life. Each program consisted of three elements according to the TPB: a short lecture aimed at facilitating favorable attitudes towards ADs; use of a case example scenario to facilitate subjective behavioral norms; and group work or feedback aimed at facilitating perceived behavioral control, so that participants recognized behavioral decision-making processes (see **Table 1**).

An AD booklet describing how to fill in the form for an AD was distributed to both control and intervention groups at the time of the baseline assessment, and the process was explained in the knowledge portion of the lecture.

The intervention was conducted after regular meetings of the local welfare officers in citizen centers.

Ethical approval

Participants gave informed consent via signed documents after a thorough explanation of the study. Study subjects were allowed to withdraw from the study at any time. The study was approved by the Ethics

Table 1. Program protocol

Subject matter	Framework of Program	Attitude toward behavior (Facilitating favorable attitudes to ADs)	Subjective norm (Facilitating subject behavioral norms)	Perceived behavioral control (Facilitating behavioral decision-making processes)
Program 1:		Short lecture about acquiring AD-related information (15 minutes)	Experiencing a scenario to evoke an emotional response, and individual work (25 minutes)	Building consensus with group work and general feedback (30 minutes)
Who will have durable power of attorney if you develop dementia?		Durable power of attorney & its role in ADs.	Uses a case example of a scenario of necessary decision-making for a family member.	Discussion about who is given durable power of attorney and why, conducted in groups.
Program 2:		Short lecture about acquiring AD-related information (15 minutes)	Experiencing a scenario to evoke an emotional response, and individual work (25 minutes)	Building consensus with group work and general feedback (30 minutes)
When a family member cannot eat food what kinds of decisions do you have?		How it can become impossible for a person to eat & undergo percutaneous endoscopic gastrostomy.	Uses a case example of a scenario where it has become impossible for a family member to eat.	Discussion about the decision from the family's perspectives, conducted in groups.

Committee of the Graduate School of Nursing, Osaka City University.

Statistical analysis

Statistical analysis was performed using Statistical Analysis System (SAS) software version 9.2 (SAS Institute, Cary, NC, USA). The level of statistical significance was set with a p-value of <0.05.

To compare characteristics at baseline between the two groups, the students t-test was used for continuous variables and χ^2 -tests for categorical variables. Odds ratios were calculated by logistic regression analysis adjusted for age and sex to find the primary outcomes of changes in AD completion behavior and intention between groups. Score changes in the AD Knowledge Test, AD Attitude Test, and Dementia Knowledge Scale were examined by repeated measures two-way analysis of variance (ANOVA) after adjusting for age and sex, using the SAS procedure "proc mixed" with pre- versus post-intervention (time) and intervention versus control (group), respectively.

RESULTS

Characteristics of participants at baseline

Characteristics of participants at baseline are shown in **Table 2**. The mean age of the study participants was 66.7 years (SD = 6.5) for the intervention group and 66.1 years (SD = 6.6) for the control group; these were not significantly different. The percentage of females in the intervention group (85.1%) was significantly higher than that in the control group (53.3%). There were no significant differences between the groups in respect of educational background, a history of having been a family caregiver, experience in having discussed end-of-life topics with family members, a history of serious illness, or the belief in a specific religion (see **Table 2**).

Effects on primary outcomes

At baseline, no participant in the intervention group and one participant in the control group had completed an AD. Fourteen participants in the intervention group and two participants in the control group had completed an AD at four-months of follow-up. The

Table 2. Characteristics of participants at baseline (*N* = 141)

Characteristics	Intervention (<i>n</i> = 81)	Control (<i>n</i> = 60)	<i>p</i> -value
Age, Mean (SD)	66.7 (6.5)	66.1 (6.6)	0.57 ²⁾
Years of experience as local welfare commissioners, Mean (SD)	12.2 (11.2)	11.4 (8.9)	0.63 ²⁾
Sex, <i>n</i> (%)			
Male	9 (11.1)	27 (45.0)	<0.0001 ¹⁾
Female	69 (85.1)	32 (53.3)	
Education, <i>n</i> (%)			
High school or lower	36 (44.0)	28 (46.6)	0.57 ¹⁾
College or higher	42 (51.7)	28 (45.6)	
Have experience as a family care giver, <i>n</i> (%)	67 (82.7)	48 (76.1)	0.33 ¹⁾
Have discussed end-of-life topics with family, <i>n</i> (%)	56 (69.1)	44 (69.8)	0.92 ¹⁾
Have suffered a serious illness or surgical operation, <i>n</i> (%)	14 (17.2)	14 (22.2)	0.38 ¹⁾
Have a specific religion, <i>n</i> (%)	24 (29.0)	11 (17.1)	0.09 ¹⁾

Note: 1) Chi-square test; 2) Student's *t*-test

Table 3. Group comparison of number of ADs completed and intention to complete an AD (*N* = 141)

	Group	Baseline				4-month follow-up			
		N (%)	OR	95%CI	<i>p</i> value	N (%)	OR	95%CI	<i>p</i> value
AD completion ^{a)}	Intervention ^{a)}	0	NA	NA	.96	14 (17)	5.0	1.0–25.0	.04
	Control	1 (1)				2 (3)			
AD intention-to-complete	Intervention ^{a)}	51 (65)	0.5	0.2–1.2	.07	65 (81)	2.0	0.8–4.9	.09
	Control	47 (79)				41 (68)			

Note: Multivariate logistic regression analysis; Adjusted variables = Age, Sex

NA: Not Analyzed; OR = Odds Ratio; CI = Confidence Interval

Age: 47–64 years old = Age 1; 65–69 years old = Age 2; 70–76 years old = Age 3

^{a)}Missing Variable: *n* = 1

intervention group showed a significant increase in the number of people who had completed an AD compared to the control group (odds ratio = 5.0, 95% confidence interval (CI) = 1.0–25.0, *p* = 0.04).

For the intention to complete an AD, the affirmative responses in the intervention group increased by 15 but decreased by six in the control group, when compared to their respective baseline values, although these findings were not statistically significant (odds ratio = 2.0, 95% CI = 0.8–4.9, *p* = 0.09; see **Table 3**).

Effects on secondary outcomes

To validate the effectiveness of the intervention program, pre-intervention and four-months post-inter-

vention average scale scores were compared for the intervention group and the control group in terms of the changes in secondary outcomes, respectively.

The results showed that the interaction between group and time were statistically significant for scores of both the AD Attitude Survey Test (*F* = 4.1, *p* = 0.04) and the Dementia Knowledge Scale (*F* = 4.6, *p* = 0.04). Scores of the Attitude Survey Test increased in the intervention group (mean = 0.4, SD = 2.0) but decreased in the control group (mean = –0.5, SD = 1.4); scores of the Dementia Knowledge Scale increased in the intervention group (mean = 1.1, SD = 2.2) while those in the control group remained unchanged (mean = –0.1, SD = 2.5) over time.

Table 4. Change in AD Knowledge Scale, AD Attitude Scale, and Dementia Knowledge Scale (N = 141)

	Possible score Range	Group	N	Assessment period, Mean (SD)		Effect		
				Baseline	4-months	Group, <i>F</i> value	Time, <i>F</i> value	Group × Time, <i>F</i> value
AD Knowledge Scale	0–8	Intervention^{a)}	81	6.5 (1.2) ^{a)}	7.0 (1.1) ^{a)}	10.1**	7.0*	0.7
		Control	60	6.1 (1.4)	6.4 (1.4)			
AD Attitude Scale	0–11	Intervention^{b)}	81	8.9 (1.8) ^{b)}	9.3 (1.8) ^{a)}	2.7	0.03	4.1*
		Control^{c)}	60	9.0 (2.2)	8.5 (2.2) ^{b)}			
Dementia Knowledge Scale	0–15	Intervention^{d)}	81	11.4 (2.2) ^{a)}	12.6 (2.0) ^{c)}	9.0*	3.9*	4.6*
		Control^{e)}	60	10.9 (2.4) ^{b)}	10.9 (2.5) ^{b)}			

Note: Two-way repeated measures analysis of variance; Adjusted Variables = Age, Sex

^{a)}Missing Variable: n = 1

^{b)}Missing Variable: n = 2

^{c)}Missing Variable: n = 3

*p < .05, **p < .001

The AD Knowledge Test results showed that the interactions between group and time were not statistically significant ($F = 0.7$, $p = .38$; see **Table 4**).

DISCUSSION

Many previous studies have shown that AD completion rates have increased by 5% to 20% through intervention.¹² The results of this study show similar results with a statistically significant increase from 0% to 17% in the intervention group, versus just 1% to 3% in the control group.

The results suggest that an AD completion promotion program may promote AD completion as well as favorable AD attitudes and improved knowledge about dementia among local residents.

These results also suggest that the present program using a TPB model can be effective in promoting AD completion among local residents. In particular, group work or interaction counseling with healthcare providers demonstrated a high efficacy in promoting an increase in the AD completion rate, which was consistent with previous studies.^{29–31}

One possible reason for the score increases on the AD Attitude Survey and Dementia Knowledge Test was that the program focused on dementia issues specifically using case scenarios. After acquiring accurate knowledge about dementia, and considering potential problems with it, participants could evaluate for

themselves the necessity for creating an AD and could also develop positive attitudes towards them.

One strength of the present study is that it is one of only a few intervention research investigations related to AD completion conducted in Japan that has established a target comparison group. Reported results of systematic reviews suggest that there is no evidence for increased completion rates in previous studies that used only knowledge providing-type interventions.^{11,12,31} Accordingly, in the present study a program was developed using the TPB as a framework and its efficacy was evaluated. The results showed that AD completion behavior significantly increased in the intervention groups, as did proactive attitudes toward ADs. Intervention effectiveness was low only for the knowledge-provision and paper medium approach. Having an interactive outreach likely leads to improved AD completion rates, results that are consistent with those of previous studies.^{15,16,28}

A second strength of this study was the high adherence of participants to the intervention. Those in the intervention group who agreed to the study but did not attend were absent because of scheduling conflicts but not because of program refusal. There were no participants who refused the program in the present study. Thus, this type of program appears acceptable to Japanese citizens.

There were several limitations of the present study. One

limitation is that the AD completion rate, the primary outcome, was based on self-reports, as other studies have also pointed out.^{11,12,14}

A second limitation of the study is that the study population was composed of local welfare officers of just two cities, limiting the generalizability of the results. This group might have more knowledge about guardians or elderly suffering from dementia compared to the general public. Although AD completion was increased in the intervention locations, this study was not a randomized controlled trial (RCT). There is also a limit to such generalization because of the differences of the subject baseline demographic information between the two cities, and with the intervention group having a significantly greater proportion of females. Since there was a suggestion that women are more likely to complete an AD, as in our previous study,²⁵ the influence of this in the present research must be considered. RCT or cluster RCT research designs have been conducted in other countries that have evaluated the efficacy of interventions for AD completion, and intervention evaluations in which uniformity in research populations is attempted are also becoming more numerous.^{11,30–32} To more rigorously confirm the effects of this program in the Japanese population, several future residential or outpatient studies should adapt a RCT or cluster RCT design.

A third limitation of this study was in the control group assessments. Replying by mail may have promoted a more negative attitude to AD completion.

CONCLUSIONS

The AD completion promotion program developed in the present study appeared to be effective in promoting AD completion among local residents. Furthermore, the creation of positive attitudes towards ADs appeared to encourage AD completion. This was one of the first intervention studies in Japan related to AD completion, and it is hoped that larger studies in the development of promotion and completion of ADs are undertaken hereafter.

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