

# Research Article

# Association between Advance Care Planning for Older Adults and Family Caregivers' Sense of Security in Home Care Settings: A Prospective Cohort Study

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Received 28 October 2022; Revised 27 January 2023; Accepted 18 March 2023; Published 3 April 2023

Academic Editor: Gianpiero Greco

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Family caregivers' sense of security benefits older adults who receive home care. Advance care planning (ACP) is reported to affect family caregivers' experience positively, but it might differ depending on family caregivers' kin relationships with the older adults. This study aimed to investigate whether ACP for older adults in home care settings is associated with family caregivers' sense of security and whether such an association depends on the family caregivers' status as spouses or adult children. Clarifying this association may offer practical support for implementing ACP while maintaining family caregivers' sense of security. This study was part of a prospective cohort study in Japan. The participants were older adults who used home-visit nursing services, their family caregivers, and the nurses who cared for them, recruited through the professional associations of home care nurses across Japan. Family caregivers answered a sense of security questionnaire, and the nurses were asked whether ACP was conducted. Data were collected three times from nurses and twice from family caregivers over a three-month period from August 2019 to June 2020. Multivariate logistic regression analyses were performed to examine the association between ACP implementation and positive changes in the sense of security scores after three months. Data from 169 cases were analyzed; 28.1% of the family caregivers were men and 55.6% were spouses. ACP was performed in 53.8% of the cases. The multivariate analysis showed an interactive effect between ACP implementation and family caregivers' kin relationships. For spouses, ACP was significantly associated with a positive change in their sense of security. For adult children, such an association was not found. Thus, ACP might have a positive effect on caregiving spouses' sense of security. Adult child caregivers, who often have multiple responsibilities and have difficulties facing their parents' physical decline, may need support in addition to ACP.

## 1. Introduction

Family caregivers play an essential role in providing longer homestays according to the preferences of older adults. According to a 2019 survey in Japan, 43.8% of caregivers living with older adults were spouses and 38.1% were children [1]. For family caregivers, it is reassuring to know that adequate support will be provided by healthcare professionals whenever needed, which gives them a sense of security [2, 3]. A previous study indicated that sense of security consists of three dimensions: (1) feeling secure that health care services will be provided by competent professionals; (2) feeling secure in their timely access to required care, services, and information; and (3) feeling secure in their own identity and self-worth as a caregiver and individual [2]. In the present study, we focus on dimensions (1) and (2), which are directly related to the continuity of home care. We define the sense of security as the sense that adequate support is provided by competent professionals when necessary and that one can safely continue home care. Family caregivers' sense of security is related to older adults' home death, older adults' quality of life from family caregivers' perspective, and the burden they carry as family caregivers [4]. Sense of security itself is a crucial aspect of a better caregiving experience and increasing and maintaining it leads to the continuity of home care [2, 3]. Despite its importance, few reports have elucidated approaches for maintaining and improving family caregivers' sense of security regarding home care.

The sense of security of family caregivers may be affected by advance care planning (ACP), that is, discussing the goals and preferences for future medical treatment and care [5]. The rapidly aging population underscores the importance of ACP, given that aging may be accompanied by serious illness, symptom distress, functional dependence and frailty, considerable family support needs, and the use of extensive healthcare resources [6]. Some studies suggest that when discussing ACP, caregivers can initially feel guilty of being linked to their perceived responsibility for protecting the care recipient [7]. However, ACP for older adults has been reported to positively impact patient outcomes and bereaved family caregivers' satisfaction, anxiety/depression levels, quality of life, and grief reaction [8, 9]. Bereaved relatives appreciated ACP conversations because of the clarity provided concerning the decision-making and patients' preferences [10]. In Japan, ACP is defined as a process that supports the decisions regarding future care with respect for the person, and constant discussion and understanding of the person's values and wishes are considered essential to ACP [11]. In the present study, we defined ACP implementation as the situation in which an older adult's desired care and support are constantly discussed and shared among family members, as well as medical and care professionals. Through this constant discussion and sharing, the family caregivers can be reassured that they can always expect adequate support for realizing the desired care. As a result, ACP may lead to a practical sense of security, such as the availability of various services or appropriate relief for the older adult's pain. Despite the possibility of ACP increasing family caregivers' sense of security, few studies have reported on it.

Moreover, among households with older adults in Japan, the number of those with only couples or only parents and unmarried children is increasing [12]. Family caregivers' experience differences depending on whether the caregiver is a spouse or a child [13–15]. Although nurses are now expected to support family caregivers considering this difference in experience, few studies have examined this aspect.

This study investigated whether ACP for older adults receiving home care is associated with family caregivers' sense of security. We also investigated whether the association depends on family caregivers' kin relationship with the older adult (spouse or adult children).

The research questions were as follows: (1) Is the implementation of ACP for older adults in home care settings associated with family caregivers' sense of security? (2)

Does the association depend on the family caregivers' status as spouse or adult children? Examining these factors may offer practical support for the implementation of ACP while maintaining family caregivers' sense of security.

# 2. Materials and Methods

2.1. Study Design and Settings. This study was a part of the Visualizing Effectiveness of Nursing & Long-term Care (VENUS) project [16]. The VENUS project was a prospective cohort study for evaluating the quality of long-term care in home-visit nursing services in Japan. Forty-seven home-visit nursing agencies from all over Japan participated in this project. These include 23 agencies from the National Capital Region (Tokyo and the seven surrounding prefectures) [17] and 24 agencies from other areas. As ACP conversations should be updated regularly through discussions [5], we used longitudinal data from the VENUS project to examine the effect of repeated ACP implementation.

Home-visit nursing services in Japan provide care for clients, such as observing health conditions, nutrition management, and rehabilitative care, and support the informal caregivers [18]. Two-thirds of home-visit nursing agencies have fewer than five nurses, and the average number of clients per agency is 68.5 [19]. As home care nurses have a long-term relationship with clients and their family caregivers, understanding and supporting the family caregivers is one of their key roles [18].

2.2. Participants and Data Collection. The participants of the VENUS project were individuals aged 75 years and older who used home-visit nursing services, their family caregivers (if available), and the nurses who cared for them. Participants were recruited through the National Association for Visiting Nurse Service. The association invited home-visit nursing agencies throughout Japan, and each agency voluntarily decided to participate. The questionnaire survey was conducted from August 2019 to June 2020. We used data from surveys for family caregivers and nurses. For nurses, data were collected online three times: the first time (T0), one month later (T1), and three months later (T2). For family caregivers, data were collected by mail twice: T0 and T2. In the VENUS project, family surveys were conducted less frequently than the surveys for nurses to reduce the burden of responses for family caregivers. Information obtained from family caregivers and nurses concerning one older adult were treated as belonging to the same case.

In this investigation, the target population was represented by the cases with family caregivers. We included participants of the project who met the following criteria: (1) family caregiver who responded to the sense of security questionnaire entirely in both the T0 and T2 surveys; (2) family caregiver who were identified as a spouse or adult child; and (3) no onset or worsening of diseases during the data collection period. We included clients whose conditions had been stable (i.e., there had been no onset or worsening of diseases) during this study, under the assumption that ACP should be implemented earlier to benefit patients [20]. Data from different family caregiver survey respondents for the T0 and T2 surveys were excluded.

#### 2.3. Measures

2.3.1. Dependent Variable: Family Caregivers' Sense of Security Regarding Home Care. Based on the previous literature, we define the sense of security as the sense that adequate support is provided by competent professionals when necessary and that one can safely continue home care [2]. To measure family caregivers' sense of security regarding home care for older adults, we adopted a scale from a previous study on the sense of security regarding cancer care among the general population of 3,730 people [21]. To develop specific scale items for this study, the researchers initially conducted repeated discussions about appropriate statements for family caregivers' sense of security regarding home care for older adults. Then, the authors of the original scale were consulted, and permission was obtained to modify the scale for our purpose. The statements were as follows: (1) "I feel secure about the treatment and support that the client receives;" (2) "The client's pain is relieved appropriately;" (3) "Medical staff adequately respond to my concerns;" (4) "I feel secure because a variety of services are available;" and (5) "I feel secure in taking care of the client at home." Family caregivers were asked to rate their agreement on a scale (1 = *strongly disagree* to 5 = *strongly agree*); the total score of all five questions was then calculated (score range: 5-25) (the response format is described in Figure 1). Higher scores indicated a stronger sense of security. The face validity was assessed based on the agreement of the researchers. We confirmed construct validity using exploratory and confirmatory factor analyses. In the exploratory factor analysis, family caregivers' sense of security had the same singlefactor structure as the original version. In the confirmatory factor analysis, the single-factor structure of family caregivers' sense of security showed good data fit ( $\chi^2 = 16.1$ , df = 5, p = 0.007; CFI (comparative fit index) = 0.97; SRMR (standardized root mean square residual) = 0.032). The testretest reliability of the questionnaire was also confirmed. Cronbach's alpha for internal consistency was 0.832 in this study, compared to 0.91 in the original study.

2.3.2. Independent Variable: Whether ACP Was Conducted or Not. By developing one item based on a previous study [22], we asked the nurses whether ACP was conducted: "Do you or other health care professionals regularly discuss the care and support that the client wants to receive (including advance care planning) and share this information with others (including family members and health care professionals)?" Furthermore, nurses were asked which of the following would be the most appropriate: "discuss and share," "discuss but do not share," "do not discuss," or "don't know."

ACP conversations should be updated regularly [5] through constant discussions about clients' changing preferences. Based on the definition of ACP implementation in this study, those cases in which nurses answered "discuss and share" at all time points (T0, T1, and T2) were categorized as ACP implementation, whereas others were classified as ACP nonimplementation. Although the specific content, duration, and frequency appropriate for ACP differ from person to person, a situation in which constant discussion and information sharing occurred at each time point during the study period was considered ACP implementation.

2.3.3. Independent Variable: Nurse-Appraised Family Caregiver Burden. A previous study has shown that caregiver burden is significantly associated with family caregivers' sense of security [4]. In the present study, we considered it an important confounding factor that should be adjusted for. Information on family caregiver burden was obtained by asking home care nurses, "Has the family caregiver been exhausted for care within 30 days?" They were asked to respond "yes," "no," or "don't know." Family caregiver burden was confirmed when the nurses answered "yes" to this question in at least one T0, T1, or T2 survey. In the VENUS project, this item was included in the nurses' survey to reduce the number of responses required in the family survey, thereby reducing the burden of the responses for the family caregivers.

2.3.4. Independent Variables: Characteristics of Clients and Family Caregivers. We obtained the characteristics of clients at T0 from the home care nurses: age, gender, household composition, diseases, physical function, cognitive impairment level, medical procedure, and use of home care services. Physical function was assessed using the bedridden levels of the Ministry of Health, Labour, and Welfare [23] (Ranks J and A–C) dichotomized as Ranks J (independent) and A (mild) vs. Ranks B (moderate) and C (severe). Cognitive impairment level was assessed using the dementia rating of the Ministry of Health, Labour, and Welfare [23] (Grades I–IV and M) dichotomized as no grade (no dementia) and Grades I (slight impairment) and II (moderate) vs. Grades III (somewhat severe), IV (severe), and M (very severe).

Family caregivers' characteristics at T0 were obtained from family caregivers themselves: age, gender, kin relationship with the client, employment status, and current economic situation.

2.4. Sample Size Calculations. Sample size for the logistic regression analysis was calculated using G \* Power (version 3.1.9.4) set for chi-square tests. The power was set at 0.8,  $\alpha$  level at 0.05. To the best of our knowledge, no previous study examined the association between ACP and family caregivers' sense of security. Thus, to estimate the effect size, we have referred to a previous study, which examined the impact of community-wide interventions to distribute information about palliative care on bereaved family members' sense of security [24]. In this study, the proportions of respondents with a high sense of security score in pre- and post-intervention were 34% and 39%, respectively. In the present study, we estimated a larger effect size because ACP

(1) I feel secure about the treatment and support that the client receives	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
(2) The client's pain is relieved appropriately	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
(3) Medical staff adequately respond to my concerns	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
(4) I feel secure because a variety of services are available	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
(5) I feel secure in taking care of the client at home	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

Family caregivers' sense of security questionnaire Please indicate your own feelings about each statement.

FIGURE 1: Response format of the sense of security questionnaire (English translation).

implementation in our study was via individual and direct communication with the client and their family caregivers rather than through community-wide dissemination of information. We set the proportions of family caregivers who increase or maintain their sense of security for the ACP implementation group and ACP nonimplementation group as 34% and 45%, respectively, resulting in a sample size of 146.

2.5. Statistical Analyses. To examine how to deal with the absence of follow-ups, participant characteristics, ACP implementation rate, and sense of security score at T0 were compared between all respondents at T0 and those that we were able to follow-up with until T2. Since there were no significant differences, loss to follow-ups was excluded from subsequent analyses. In addition, there were some cases with missing data for the sense of security score, and since there were no significant differences in the participant characteristics and ACP implementation rate from all other eligible cases, these were also excluded from the analyses. COVID-19 began to proliferate all over Japan in March 2020; the disruption of home care services could have started during this period. To confirm potential impacts on the results, we statistically examined the sense of security score difference before and after March 2020.

The main outcome of the current study was the improvement or maintenance at a high level, of family caregivers' sense of security. Before the analysis, we divided the participants into a "positive" or "negative" group based on changes in family caregivers' sense of security from T0 to T2. Then, we investigated whether ACP was related to the identified "positive" or "negative" domains. This step was to properly evaluate the increase in the sense of security and the maintenance of the high sense of security during the study period as a positive outcome. "Positive" and "negative" outcomes were determined by referring to the classification method of Whitlatch et al. [25] and Kurasawa et al. [26]. Factors considered in determining the criteria for positive and negative outcomes were as follows: regression toward

the mean is to be expected with extreme scores, and therefore, the amount of change defining a positive or negative outcome would be more significant for those with extreme scores, than for those with less extreme scores; positive and negative indicators were based on what was considered a clinically meaningful change. The process of determination was as follows. We divided family caregivers into quartiles based on their sense of security score at T0. Caregivers in the lowest quartile were classified as "positive" if their sense of security score increased by  $\geq 1$  standard deviation (SD) unit (4 points). If the score increased by <1SD unit or decreased, caregivers were classified as "negative." Caregivers assigned to the medium-low quartile at T0 were considered "positive" if their sense of security score increased by  $\geq 0.5$  SD unit (2 points). All others were classified as "negative." Given that caregivers assigned to the mediumhigh quartile were those already with a high sense of security, any increase or the absence of change indicated a "positive" outcome. Conversely, all others were grouped in the "negative" category. Those in the highest quartile whose scores increased, remained unchanged or decreased by  $\leq 0.5$ SD unit were classified as "positive" and all others as "negative" (Figure 2).

Subsequently, the following analyses were performed. First, we used descriptive statistics to present the characteristics of the study population and ACP implementation rate. Furthermore, chi-square tests, Fisher's exact tests, and Welch's t-tests were conducted to compare the participants' characteristics by caregivers' kin relationship (spouses or adult children). Second, bivariate binary logistic regression analyses were conducted to examine the associations between all items and the main outcome. Finally, multivariate binary logistic regression analyses were conducted to examine the impact of ACP on the main outcome. The following variables were entered into the model using the forced entry method: (a) whether ACP was conducted (yes = 1 or no = 0); (b) family caregiver's kin relationship with the client (spouse = 1 or adult child = 0); (c) interaction term between (a) and (b); (d) the variables related to family caregivers' sense of security in the literature (clients' age, gender, family caregivers' financial situation, and family caregiver burden) [4, 27]; and (e) variables that showed p < 0.05 in the bivariate analyses. In the case of a significant interaction between ACP and family caregivers' kin relationships, we additionally performed stratified multivariate regression analyses by family caregivers' kin relationship with the client. The significance level was p < 0.05 (two-tailed). SPSS (version 27.0) was used for all statistical analyses.

2.6. *Ethical Consideration*. Written consent was obtained from all participants after explaining the purpose, voluntary nature of participation, and privacy protection. Home-visit nursing agencies received compensation of 4,000 yen per participant. The Research Ethics Committee of the Graduate School of Medicine, the University of Tokyo (2019087NI-(3)) approved this study.

#### 3. Results

#### 3.1. Participant Characteristics and ACP Implementation Rate

3.1.1. Analyzed Cases. Among 1,120 cases enrolled in the VENUS project from home-visit nursing agencies (including cases in which family caregivers might have been unavailable), 325 family caregivers responded to the sense of security questionnaire entirely in both the T0 and T2 surveys (response rate: 29.0%). Based on the inclusion and exclusion criteria, 169 cases were analyzed (Figure 3). There were no statistically significant differences in participant characteristics, ACP implementation rate, and sense of security score at T0 between the cases included in the present analysis and those excluded. There was no statistically significant difference in sense of security score before and after March 2020, showing that COVID-19 did not significantly impact the results of this study.

3.1.2. Older Adults' Characteristics. Table 1 shows the participants' characteristics and ACP implementation rates. The mean age of the clients was 85.6 years, and about half (49.7%) were men. Of the 169 clients, 38.5% had dementia, and 33.7% used home help services. Clients cared for by spouses were significantly younger (82.4 years old vs. 89.7 years old, p < 0.001), men (72.3% vs. 21.3%, p < 0.001), less diagnosed as having dementia (25.5% vs. 54.7%, p < 0.001), having lower physical and cognitive impairment level (37.2% vs. 64.0%, p = 0.001; 27.2% vs. 56.0%, p < 0.001, respectively), and using less home help service (23.4% vs. 46.7%, p = 0.001) compared with those cared for by adult children.

3.1.3. Family Caregivers' Characteristics and Sense of Security. The mean age of family caregivers was 71.9 years, and about one-third (28.1%) were male. About half (55.6%) were spouses, and 44.4% were adult children. More than a third (35.5%) of family caregivers was reported to have a care burden. Spouses were significantly older (79.7 years old vs. 62.3 years old, p < 0.001) and more unemployed or absent (92.0% vs. 64.0%, p < 0.001) compared with adult

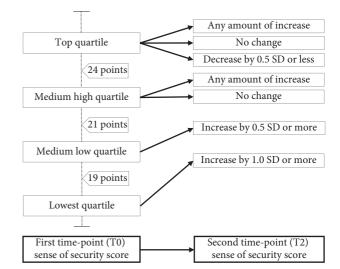


FIGURE 2: Definition of successful group. T0 = first time-point; T2 = three months later time-point; SD = standard deviation.

children. Family caregivers' sense of security scores were 21 points on average, both in the T0 and T2 surveys, and positive changes occurred in about half (49.7%) of the cases. We found no significant differences in the sense of security scores and positive change rates between the two groups.

3.1.4. ACP Implementation Rate. ACP was conducted in approximately half (53.8%) of all cases, and it was significantly more common in cases where family caregivers were adult children (46.8% vs. 62.7%, p = 0.040).

3.2. Factors Associated with Positive Changes in Family Caregivers' Sense of Security. In the bivariate analyses, not receiving medical procedures (p = 0.007) and lower caregiver burden (p = 0.013) showed significant associations with a positive change in family caregivers' sense of security. We entered the variable "not receiving medical procedure" into the multivariate analysis, in addition to the variables related to family caregivers' sense of security identified in the literature, including caregiver burden [4]. Cases in which any one of these variables was missing were excluded from the multivariate analysis; in one case, a variable (financial status) was missing and was, therefore, excluded.

In the multivariate logistic regression analysis for the overall samples of this study (Table 2), a statistically significant interaction was found between ACP and family caregivers' kin relationships with clients (adjusted odds ratio (AOR), 5.01; 95% confidence interval (CI), 1.28–19.66; p = 0.021). The results also revealed the following significant items: clients' higher age (AOR, 1.07; 95% CI, 1.01–1.14; p = 0.028), not receiving medical procedure (AOR, 2.15; 95% CI, 1.04–4.41; p = 0.038), and family caregivers having lower caregiver burden (AOR, 0.39; 95% CI, 0.19–0.79; p = 0.009).

To examine how ACP and other variables were associated with spouses' and children's sense of security, the study conducted stratified analyses by family caregivers' kin

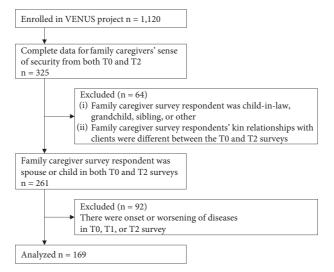


FIGURE 3: Flowchart of participants. T0 = first time-point; T2 = three months later time-point.

	Total (n = 169)	Family caregivers		
	<i>n</i> (%) Mean ± SD	Spouses $(n = 94)$ n (%) Mean ± SD	Children ( <i>n</i> = 75) <i>n</i> (%) Mean ± SD	Р
Characteristics of clients				
Age	$85.6 \pm 6.4$	$82.4 \pm 5.7$	$89.7 \pm 4.8$	< 0.001 <sup>c</sup>
Gender				
Male	84 (49.7)	68 (72.3)	16 (21.3)	< 0.001 <sup>a</sup>
Family composition	. ,			
Living alone	11 (6.5)	0 (0.0)	11 (14.7)	$< 0.001^{b}$
Living with spouse	65 (38.5)	63 (67.0)	2 (2.7)	< 0.001 <sup>a</sup>
Living with others (other than spouse)	93 (55.0)	31 (33.0)	62 (82.7)	< 0.001 <sup>a</sup>
Diseases (multiple answers allowed)	· · · ·	· · · · ·	( ),	
Dementia	65 (38.5)	24 (25.5)	41 (54.7)	< 0.001 <sup>a</sup>
Cerebrovascular disease	58 (34.3)	35 (37.2)	23 (30.7)	$0.372^{a}$
Heart failure	34 (20.1)	18 (19.1)	16 (21.3)	$0.725^{a}$
Cardiovascular disease (other than heart failure)	28 (16.6)	20 (21.3)	8 (10.7)	$0.065^{a}$
Cancer	26 (15.4)	14 (14.9)	12 (16.0)	0.843 <sup>a</sup>
Diabetic/metabolic/endocrine disease	25 (14.8)	15 (16.0)	10 (13.3)	0.633 <sup>a</sup>
Digestive system disease	21 (12.4)	8 (8.5)	13 (17.3)	$0.084^{a}$
Chronic obstructive pulmonary disease	20 (11.8)	12 (12.8)	8 (10.7)	$0.675^{a}$
Neurological disease	20 (11.8)	15 (16.0)	15 (6.7)	0.063 <sup>a</sup>
Musculoskeletal disease	14 (8.3)	5 (5.3)	9 (12.0)	$0.117^{a}$
Fractures	10 (5.9)	2 (2.1)	8 (10.7)	$0.024^{b}$
Pneumonia	9 (5.3)	5 (5.3)	4 (5.3)	$0.628^{b}$
Urologic disease	8 (4.7)	6 (6.4)	2 (2.7)	$0.225^{b}$
Renal disease	7 (4.1)	2 (2.1)	5 (6.7)	$0.140^{b}$
Psychiatric disorder (other than dementia)	6 (3.6)	2 (2.1)	4 (5.3)	$0.241^{b}$
Refractory skin ulcer	5 (3.0)	2 (2.1)	3 (4.0)	$0.394^{b}$
Autoimmune disease	3 (1.8)	1 (1.1)	2 (2.7)	$0.416^{b}$
Others	2 (1.2)	0 (0.0)	2 (2.7)	$0.195^{b}$
Physical function <sup>d</sup>				
Moderate and severe	83 (49.1)	35 (37.2)	48 (64.0)	$0.001^{a}$
Cognitive impairment level <sup>e</sup>	. ,			
Severe	67 (40.1)	25 (27.2)	42 (56.0)	< 0.001 <sup>a</sup>
Medical procedure	· · ·			
Not receiving medical procedure	112 (66.3)	62 (66.0)	50 (66.7)	0.923 <sup><i>a</i></sup>
Service use				

	TABLE 1: Continued.						
	Family caregivers' relationship with						
	Total (n = 169)	cli					
	n (%)	Spouses $(n = 94)$ n (%)	Children $(n = 75)$ n (%)	Р			
	Mean $\pm$ SD	Mean $\pm$ SD	Mean $\pm$ SD				
Welfare equipment	110 (65.1)	60 (63.8)	50 (66.7)	0.701 <sup>a</sup>			
Outpatient visit	81 (47.9)	50 (53.2)	31 (41.3)	0.125 <sup><i>a</i></sup>			
Regular home-visit by physicians	68 (40.2)	31 (33.0)	37 (49.3)	0.031 <sup><i>a</i></sup>			
Adult daycare	64 (37.9)	29 (30.9)	35 (46.7)	0.035 <sup>a</sup>			
Home help service	57 (33.7)	22 (23.4)	35 (46.7)	$0.001^{a}$			
Home-visit rehabilitation	44 (26.0)	22 (23.4)	22 (29.3)	0.383 <sup>a</sup>			
Home medical treatment management instruction	35 (20.7)	18 (19.1)	17 (22.7)	0.575 <sup>a</sup>			
Short stay	28 (16.6)	12 (12.8)	16 (21.3)	$0.137^{a}$			
Daycare with rehabilitation	23 (13.6)	16 (17.0)	7 (9.3)	$0.148^{a}$			
Home bathing service	20 (11.8)	6 (6.4)	14 (18.7)	$0.014^{a}$			
Home-visit dental care	12 (7.1)	6 (6.4)	6 (8.0)	$0.684^{a}$			
Home-visit by pharmacists	8 (4.7)	4 (4.3)	4 (5.3)	$0.509^{b}$			
Temporary home-visit by physicians	8 (4.7)	4 (4.3)	4 (5.3)	$0.509^{b}$			
Outpatient rehabilitation	2 (1.2)	2 (2.1)	0 (0.0)	$0.308^{b}$			
Characteristics of family caregivers							
Age	71.9 (10.4)	$79.7 \pm 5.5$	$62.3 \pm 6.0$	< 0.001 <sup>c</sup>			
Gender							
Male	47 (28.1)	26 (28.0)	21 (28.4)	0.952 <sup>a</sup>			
Relationship with the clients (spouse or child)		. ,	. ,				
Spouse	94 (55.6)						
Employment status							
No employment or absent	129 (79.1)	81 (92.0)	48 (64.0)	< 0.001 <sup>a</sup>			
Economic situation							
Having sufficient financial resources	21 (12.5)	15 (16.1)	6 (8.0)	0.113 <sup>a</sup>			
Family caregivers having burden	60 (35.5)	27 (36.0)	33 (35.1)	$0.904^{a}$			
Family caregivers' sense of security regarding home care							
Sense of security score (T0)	$20.7 \pm 3.7$	$20.3 \pm 4.0$	$21.2 \pm 3.2$	0.108 <sup>c</sup>			
Sense of security score (T2)	$20.8\pm3.6$	$20.4 \pm 3.9$	$21.3 \pm 3.0$	0.089 <sup>c</sup>			
Positive change in the sense of security score	84 (49.7)	45 (47.9)	39 (52.0)	$0.594^{a}$			
ACP was conducted	91 (53.8)	44 (46.8)	47 (62.7)	$0.040^{a}$			

ACP = advance care planning; SD = standard deviation; T0 = first time-point; T2 = three months later time-point. <sup>*a*</sup>Chi-square test. <sup>*b*</sup>Fisher's exact test. <sup>*c*</sup>Welch's *t*-test. <sup>*d*</sup>Assessed using the bedridden levels of the Ministry of Health, Labour, and Welfare (Ranks J and A–C); Moderate and Severe: Ranks B and C. <sup>*e*</sup>Assessed using the rating of dementia of the Ministry of Health, Labour and Welfare (Grades I–IV and M); and Severe: Grades III, IV, and M.

TABLE 2: Factors associated with positive change in family caregivers' sense of security: multivariate logistic regression analyses.

	Positive change in family caregivers' sense of security								
	Overall sample $(n = 168)$		Family caregivers were spouses $(n = 93)$		Family caregivers were children $(n = 75)$				
	AOR	[95% CI]	Р	AOR	[95% CI]	Р	AOR	[95% CI]	Р
ACP was conducted	0.54	[0.19-1.48]	0.227	3.19	[1.15-8.85]	0.026	0.62	[0.21-1.79]	0.374
Family caregivers were spouses <sup>a</sup>	0.65	[0.20-2.09]	0.466						
ACP was conducted $\times$ family caregivers were spouses <sup><i>a</i></sup>	5.01	[1.28–19.66]	0.021						
Clients' characteristics									
Age	1.07	[1.01 - 1.14]	0.028	1.11	[1.02 - 1.22]	0.021	1.09	[0.98 - 1.22]	0.117
Gender	0.84	[0.38-1.86]	0.669	0.41	[0.13 - 1.34]	0.140	2.30	[0.63 - 8.34]	0.205
Not receiving medical procedure	2.15	[1.04 - 4.41]	0.038	2.00	[0.70 - 5.74]	0.198	1.86	[0.63 - 5.48]	0.259
Family caregivers' characteristics									
Having sufficient financial resources	0.64	[0.23 - 1.78]	0.396	0.23	[0.06-0.95]	0.042	5.62	[0.58 - 54.42]	0.136
Family caregivers having burden	0.39	[0.19-0.79]	0.009	0.35	[0.12 - 1.04]	0.060	0.28	[0.09-0.82]	0.021
Nagelkerke <i>R</i> <sup>2</sup>		0.172			0.250			0.238	

ACP = advance care planning; AOR = adjusted odds ratio; CI = confidence interval. "Reference: family caregivers were adult children.

TABLE 1: Continued.

relationship subgroups (Table 2). In the spouse subgroup, the association between ACP and positive change in the sense of security was statistically positively significant (AOR, 3.19; 95% CI, 1.15–8.85; p = 0.026). Clients' higher age (AOR, 1.11; 95% CI, 1.02–1.22; p = 0.021) and family caregivers having insufficient financial resources (AOR, 0.23; 95% CI, 0.06–0.95; p = 0.042) were also significantly associated with the outcome. Lower family caregiver burden also tended to be associated with the outcome, although not to a significant degree.

In the adult children subgroup, no significant association was found between ACP and positive change in the sense of security. Lower family caregiver burden was the only significant item (AOR, 0.28; 95% CI, 0.09–0.82; p = 0.021).

#### 4. Discussion

This study investigated the association between ACP for older adults and family caregivers' sense of security, that is, the sense that adequate support is provided by competent professionals when necessary and that one can safely continue home care. To the best of our knowledge, this study is the first to report an association between ACP and family caregivers' sense of security. Furthermore, this is the first study to examine whether the association between ACP and family caregivers' sense of security differs by their kin relationship with the clients. These findings indicate that the association differed between spouses and adult children. ACP had a significant association with positive changes (improvement or the maintenance of a high level) in the sense of security of spouses but not of adult children. The results indicate that when professionals implement ACP for older adults in home care settings, paying attention to family members' kin relationships to improve and maintain family caregivers' sense of security will be helpful.

4.1. ACP Implementation Rate. ACP was implemented in 53.8% of the cases. In a previous study with outpatients aged 65 years and older living in the community, the percentage of those who had an ACP discussion with family members or a primary care doctor was 61.1% [28]. In this study, ACP was defined as an ongoing discussion and information sharing over a period of 3 months, not a one-time event, which may explain the relatively low rate of ACP implementation. In addition, since the sample was limited to clients whose conditions had been stable during this study, the ACP implementation rate might have been lower than if the sample had included more people with unstable conditions.

4.2. Association Between ACP and Spouse Caregivers' Sense of Security. ACP was associated with positive changes in caregiving spouses' sense of security. In a previous qualitative study that interviewed spouses who cared for older adults with a memory disorder, the caregivers wanted to take care of their spouses at home for as long as possible, despite the obstacles they faced [29]. Discussing and sharing issues to continue their marital lives through ACP seemed meaningful for spouses, and therefore, may have led to a positive change in their sense of security.

ACP itself may have a positive effect on spouses' sense of security. Healthcare providers are advised to discuss and offer the support the older adults want to receive. Providers' concern about the potential impact of end-of-life discussions on both patients and their loved ones is reported as one of the barriers to ACP [30]. Therefore, communicating this result to professionals will lead to them developing positive attitudes toward ACP for older adults. Communication training for professionals, education for clients and their families, and system improvement, such as setting reminders for ACP discussions on the medical records, would also be helpful for ACP implementation.

4.3. Association Between ACP and Adult Child Caregivers' Sense of Security. As for adult children, ACP was not associated with a change in their sense of security. According to a previous qualitative study investigating adult daughters' experiences of caring for frail older parents living at home, caring was experienced as a constant process of seeking a balance between caring for an aging parent and other responsibilities [31]. In another study, caregivers of parents with heart failure struggled and expressed their desire for help to prevent further decline [32]. These studies provide two possible reasons why ACP did not lead to an increase or maintenance of adult children's sense of security. First, they may have been facing difficulty in addressing the issues of their parents while also fulfilling their other roles, such as work and parenting. ACP may have led them to specifically contemplate their parents' care, which could have added to those difficulties. Second, it may have been challenging for them to acknowledge that their parents, whom they had always depended on, were inevitably declining, through ACP discussions. When implementing ACP for older adults cared for by their adult child, it might help to address both these points to provide the support that can enhance the caregiver's sense of security. Future studies are needed to identify effective support types for this subgroup.

Many countries have recently been implementing policies to promote ACP to achieve end-of-life care consistent with people's values, goals, and preferences. The results of the present study suggest that the policies to promote ACP for older adults need to consider how ACP is perceived by family caregivers, especially how it affects adult child caregivers' sense of security for continuing home care. Policies to assist adult child caregivers in facing their parents' ACP could be helpful for them. For example, national or local governments can disseminate information to the community about the trajectory of aging, care needed for end-of-life, how to discuss ACP with their parents, and available resources for balancing their various roles at home and in society. Also, governments can have a public consultation service for family caregivers struggling with ACP. It is also important to enhance public awareness about ACP and create a social atmosphere in which family members talk to each other regularly about their goals, values, and preferences about future lives. This may help adult child caregivers address issues regarding their parents' ACP. These policies could help increase and maintain family caregivers' sense of security, leading to the continuity of home care.

4.4. Other Factors Related to Family Caregivers' Sense of Security. The present study also identified other factors that were associated with the positive change in family caregivers' sense of security: clients' older age (in the overall samples and the spouse subgroup), caregiver burden (in the overall samples and both spouse and adult children subgroups), not receiving medical procedure (in the overall samples), and economic situations (in the spouse subgroup). The result for age was consistent with those in a previous study that found a positive association between the patients' higher age and family members' sense of security during ongoing palliative care [27]. The result for family caregiver burden was also comparable to that in a previous study on families of cancer patients, in which a lower care burden was associated with a higher sense of security [4]. Care burden may reduce family caregivers' confidence and motivation to continue home care, and therefore, lower their sense of security. In order to increase and maintain the sense of security for continuing home care for both spouse and adult child caregivers, it is vital to alleviate the care burden by improving the quality and quantity of public medical and care services. The association between the absence of medical procedure and family caregivers' sense of security has not been mentioned in previous studies. It can be explained by the anxiety regarding the future among family caregivers of older adults undergoing a medical procedure because of the time and effort required for the care or due to the stressful situations caused by the life-threatening procedure the older adults are undergoing. The result of this study suggests that healthcare providers must pay specific attention to family caregivers of older adults receiving medical treatment to enhance their sense of security. For example, it may be helpful to provide sufficient information about medical treatment, identify and address any concerns, and consider ways to reduce the time and effort required for care.

On the other hand, sufficient financial resources were associated negatively with a positive change in the sense of security among spouses. This is inconsistent with the results of a previous study that showed a negative association between family members' worries over private finances and their sense of security during ongoing palliative care [27]. Financial leeway might lead to consideration of the use of higher-end services (e.g., luxury nursing homes), thereby reducing spouses' sense of security regarding current home care. In addition, people with higher age and higher socioeconomic status may be affected by social desirability bias. They possibly reported a heightened sense of security in the first survey.

4.5. *Limitations and Future Directions*. This study had several limitations. First, there may have been a self-selection bias: home-visit nursing agencies motivated to care for clients and family members may have participated in this study. This may limit the generalizability of the study results. Second, the

response rate for this study may be underestimated. Of the 1,120 participants in the VENUS project, 325 were included in the analysis of the current study. However, given that the percentage of Japanese people who were unmarried at age 50 in 2015 was 23.4% for men and 14.1% for women [33], it is likely that some of the 1,120 participants in the VENUS project had neither spouses nor children; therefore, they were not eligible for this study. This means that the true response rate may be higher. Third, since the participants were limited to home-visit nursing service users, their physical condition may have affected their sense of security. Fourth, we asked nurses whether ACP was conducted using a single question; thus, the exact details of the ACP discussions (who initiated it, what was discussed, and who was present) were not collected. Fifth, the implementation status of ACP outside the observation period (three months) is unknown. Sixth, although we considered as many potential confounders to family caregivers' sense of security as possible, there may be other unadjusted potential factors. Finally, statistical power for the subgroup analyses may be insufficient due to the small sample sizes.

Despite these limitations, this study is the first to examine the association between ACP for older adults in the home care setting and family caregivers' sense of security. Future research is needed to determine what kind of ACP affects family caregivers' sense of security in detail.

# 5. Conclusions

ACP implementation for older adults with stable conditions in home care settings was associated with a positive change in spouse caregivers' sense of security. On the other hand, it was not associated with the change in that of adult-child caregivers in our study. The results suggested that while ACP might support spouses' wishes to continue their lives with their partners and bolster their sense of security, there may be a need for care (in addition to ACP) for adult children to improve and maintain their sense of security. This result should be emphasized when developing ACP guidelines and nursing education in the future.

#### **Data Availability**

The prospective cohort study data used to support the findings of this study have not been made available by The Research Ethics Committee of the Graduate School of Medicine, the University of Tokyo, in order to protect patient privacy.

#### Disclosure

This paper is a revised version of a master's thesis submitted to the Graduate School of Medicine, the University of Tokyo. The abstract of this paper was presented at the Gerontological Society of America (GSA) 2021 Annual Scientific Meeting, November 10–14, 2021, in Phoenix, AZ, USA (online), as an oral presentation [34].

#### **Conflicts of Interest**

The authors declare that there are no conflicts of interest regarding the publication of this paper.

## Acknowledgments

The authors express sincere gratitude to all the participants and collaborators for their cooperation. This work was supported by a Geriatric Health Promotion Project grant provided by the Japanese Ministry of Health, Labour and Welfare; and a research grant offered by the Yuumi Memorial Foundation for Home Health Care.

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