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Pre-post Evaluation of a Dementia-Specific Advance Care Planning Toolkit for Japanese Primary Care Clinicians

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Abstract

Background: The population of people living with dementia (PLwD) continues to grow in Japan where advance care planning (ACP) for PLwD is relatively new. Our aim was to evaluate the feasibility and cultural acceptability of a dementia-specific ACP communication skills toolkit for Japanese primary care clinicians.

Methods: We delivered 13 training sessions in primary care clinics across central Japan and conducted a post-training survey to assess whether the toolkit increased confidence in dementia-specific ACP communication skills and the acceptability of the toolkit with the following 4 statements: 1) The language in the sessions was clear, 2) The sessions took an appropriate amount of time to complete, 3) The design of the sessions was an effective educational method, and 4) The sessions were culturally appropriate for communication with Japanese patients with dementia and their family members. We asked participants to respond using a 5-point Likert scale from strongly agree to strongly disagree.

Results: All participants were Japanese and included 80 physicians (mean age 39.8 years), 33 nurses (mean age 45.7 years), and 58 other participants (mean age 42.9 years), who were 30.0%, 87.9%, and 55.2% female respectively. Most participants practiced in rural settings. In pre-post-comparisons, participant confidence increased in determining capacity, understanding dementia prognosis, goals of care, eliciting surrogates, recommending self-care practices to families, and leading family meetings (all $p < 0.001$). Most participants strongly agreed or agreed that the toolkit was an effective method (96.9%), took an appropriate amount of time (94.5%), contained clear language (89.8%), and was culturally appropriate (73.6%).

Conclusions: Dementia-specific ACP communication skills toolkit can be delivered in Japan. Japanese primary care generally felt the dementia-specific ACP toolkit increased their confidence in ACP communication skills and was acceptable. The language, time, and design were well received, though further work is needed to improve the cultural appropriateness of the toolkit.

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Key Points: Dementia-specific ACP communication skills toolkit can be delivered in Japan and was generally well-received except cultural appropriateness could be improved.

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INTRODUCTION

Japan is experiencing a steady increase in the prevalence of dementia.[1] Within the next 25 years, 2 in every 7 people in Japan over the age of 65 will suffer from dementia.[2] With world's oldest population and a high prevalence of dementia, in 2007, the Japanese Ministry of Health, Labour, and Welfare (MHLW) released the "Guidelines for the Decision-Making Process of End-of-Life Medical Care" to increase interest in advance care planning (ACP).[3] ACP is a process defined by discussions and documentation of a patient's preferences for future medical treatment in serious illness. [4] These discussions can take place with family, friends, or healthcare professionals.

As in Western nations, increased clinician training focused on ACP communication skills may be a solution to expand ACP practice among Japanese healthcare professionals. A survey conducted by the Japanese Ministry of Health, Labour, and Welfare (MHLW) in 2022 found that 60% of physicians reported practicing ACP at some level, but those who do not practice ACP cited lack of skills, time, and confidence to initiate ACP conversations.[5] A prior study by the MHLW found that even among those with limited familiarity with ACP, once the concept was explained, most participants felt that ACP was important.[6] Of note, "primary care" is not an established specialty in Japan, and while Family Medicine is gaining popularity as a specialty, most physicians train within a specialty but practice in their communities as general practitioners without formal primary care training.[7] Per Noda *et al*, "Generally speaking, under the existing medical care system, most dementia cases are clinically diagnosed and treated by primary care physicians."[8] Understandably, Japanese physicians in primary care have reported challenges with a lack of ability to coordinate care for people with dementia.[9] Thus, there is a great need for more education for healthcare professionals on ACP in Japan, especially for physicians caring for dementia patients.[10] Suggested solutions include implementing ACP trainings which emphasize "assertive professional communication skills" for healthcare providers.[11]

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The overarching goal of our work is to enhance the care of people with dementia in Japan. To accomplish this goal, we evaluated a dementia-specific ACP toolkit developed in the United States, after linguistic and cultural adaptation for Japanese primary care clinicians. This paper presents the feasibility and acceptability of the new dementia-specific ACP toolkit.

METHODS

Study Design- Linguistic and Cultural Adaptation of Dementia-specific ACP Toolkit

We translated an existing ACP training toolkit, called AD-ACP Toolkit, consisting of didactic lectures, videos, roleplay activities, and action planning into Japanese. The AD-ACP Toolkit was developed and evaluated with primary care clinicians in North Carolina.[12] Initially, a researcher (AK) who is a native Japanese-speaking, US-trained Family Medicine physician, board-certified in Palliative Medicine and Geriatric Medicine and a VitalTalk trained faculty, provided the initial translation of the didactic materials. Two other researchers, Japanese-trained Family Medicine physicians (MI and TM) currently practicing in Japanese primary care and a sociologist in intercultural communication (MA) reviewed and edited the didactic materials.[13] Subsequently the videos were subtitled and roleplay scenarios and action planning were translated and modified (CK and MA). Our interdisciplinary research team with expertise in Japanese culture, ACP, and Japanese clinical practices sat together to discuss the modifications required for the AD-ACP tool kit for Japanese patients and decided on these two modifications. All researchers then reviewed the final training materials and made suggestions for content changes. The study was exempt from review by the UNC IRB.

Japanese AD-ACP Toolkit Intervention Design

Since ACP priorities evolve across the progression of dementia, the Global Deterioration Scale (GDS) stages[14] were used to define four modules addressing different elements of ACP at each stage of dementia. The toolkit consisted of in-person training with short didactic lectures for each module, video

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scenarios demonstrating ACP communication by module, two role-playing scenarios, and lasted approximately 3 hours (Supplementary Figure S1). The videos portrayed clinical encounters in the United States, and were subtitled in Japanese. The intervention has been described previously,[12] but two major changes were made. In the POLST and goals of care in late-stage dementia (GDS 4-6) module, we modified this section to focus on the elements in the POLST form that should be discussed since Japanese practitioners would not use the actual POLST form. POLST forms are not used in Japan, but Japanese practitioners are generally familiar with them. We modified the hospice and hospitalization in end-stage dementia (GDS 7), because, in Japan, dementia is not a hospice-eligible diagnosis but U.S. guidelines on dementia and hospice were included for explanation. This section was also modified to discuss nutritional needs and gastrostomy tube feeding, which is widely used in Japan.[15]

Study Participants and Recruitment

We recruited primary care clinicians from both urban and rural areas in central Japan. Clinicians were recruited by contacting clinical leadership such as medical directors who elicited volunteers for training. Hamamatsu University's Department of Family and Community Medicine leads the Shizuoka Family Medicine program and its associated clinics which provided a large pool of primary care clinics for outreach and their connections with the Japanese Primary Care Association provided the rest. We opened the training to physicians, physicians-in-training, care managers, social workers, nurses, physical therapists, medical students, and interested community members. Interested community members were allowed to participate in the spirit of collaboration and transparency with local communities but training was not targeted to this group. Training participation was not dependent on completion of the surveys and all data were anonymized. Participants were asked to complete the pre-training survey immediately before the training and the post-training survey immediately after the training. However, as the clinics were busy medical practices, some staff came late or had to leave early and could not finish the surveys. Additionally, we discovered that some participants struggled with the use of their smart phones for the

surveys, and we provided hard copy surveys for participants after the first training. Participants were not reimbursed for their time but received a certificate of completion.

Survey Measures

Data collection utilized pre- and post-training surveys to evaluate the effect of the toolkit on confidence in skills. Participants provided demographic and education-level data in the pre-training survey. Toolkit evaluation items were modified from ACP communication training for critical care.[16] Survey items addressed participants' confidence in dementia-specific ACP skills (rated on a 4-point Likert-type scale, from ''not very confident'' to ''very confident''), including determining capacity, exploring dementia prognosis, exploring goals of care, eliciting surrogates, recommending self-care practices to families, leading family meetings about goals of care, and leading family meetings about hospice. Post-training, participants were asked four questions to address acceptability of the toolkit, rated on a 5-point Likert-type scale, from ''strongly disagree'' to ''strongly agree'': 1) The design of the sessions was an effective educational method, 2) The language in the sessions was clear, 3) The sessions took an appropriate amount of time to complete, and 4) The sessions were culturally appropriate for communication with Japanese patients with dementia and their family members.[17]

Analysis

We used descriptive statistics to report the demographic and education-level data. Confidence responses were dichotomized as ''not very confident'' or ''somewhat confident'' (0) versus ''confident'' or ''very confident'' (1). Then differences between pre- and post-training clinicians' confidence were compared by using McNemar's test on population with both pre-training and post-training responses, using a within participant comparison. Acceptability statements were presented as frequencies. All statistical analysis was performed in R 4.2.1.

RESULTS

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Feasibility of The Toolkit

We conducted 13 of 15 planned training sessions from June 2022 to August 2022 for a total of 153 participants (Supplementary Figure S2). Trainings were conducted across central Japan. Several were conducted in Hamamatsu city and in the larger Shizuoka prefecture. The remainder were conducted in central Honshu (the main island of Japan). One training was held on Zoom, and two were canceled due to COVID-19. All other training was held in person, though some had a few participants on Zoom due to COVID-related illnesses.

Participant Characteristics

In total, 171 surveys were completed before the trainings and 130 were completed after trainings, with 105 participants completing both surveys, though not all 105 participants completed all items within each survey. Most participants (n=112) were referred by a coworker. The learned about the training through advertising, online search, or other methods. In total, 53.1% of participants were female and 59.4% of participants stated they were from a rural area (Table 1). Though a variety of participants were trained, 46.8% of participants were physicians and 19.3% were clinic nurses. When asked about their specialty, 56.3% of physicians identified as family medicine doctors, 27.5% specialized in internal medicine, and 16.3% identified as “other.”

ACP Communication Skill Confidence and Toolkit Acceptability

When comparing ACP communication skill confidence pre- and post-training, participants’ confidence significantly increased in all areas, except increased confidence in making a diagnosis of dementia was marginally significant (from 17.1% confident pre-training to 31.4% confident post-training, p=0.0521) (Table 2). Sensitivity analysis of this domain by occupation (physician, nurse, or other) found a significantly increased confidence in physicians though not in nurses or other groups (Supplementary Table S1). Most participants agreed or strongly agreed that the toolkit was an effective educational method, had clear

language, and took an appropriate amount of time to complete (Figure 1). However, evaluation of cultural acceptability was more mixed. While a majority (73.6%) of participants agreed it was culturally appropriate, others (26.4%) were neutral or disagreed.

DISCUSSION

This study demonstrates the feasibility of translating, adapting, and delivering an existing toolkit on dementia-specific ACP communication skills across central Japan in community-based primary care clinics. Most participants had increased confidence in a variety of ACP skills and found the toolkit to be clear, timely, and effectively designed. However, to respond to less positive evaluation of cultural appropriateness, new work by our group of investigators is underway using video scripting and acting by Japanese participants, to optimize cultural acceptability.

The AD ACP toolkit is an important first step to meet the need for more education for healthcare professionals in Japan, with a focus on those who are caring for dementia patients. In a recent report on current barriers to ACP in practice, suggested solutions include ACP trainings which emphasize "assertive professional communication skills" for healthcare providers. However, these authors also report that other strategies may be necessary to address barriers, such as better defining ACP for the Japanese people and improving public literacy on the topic.[11]

In recognition of the need for similar education, modification of a serious-illness communication training for a Japanese physicians was recently conducted through VitalTalk.[18] VitalTalk was initially developed as a serious-illness communication training workshop for United States clinicians.[19] A qualitative analysis of responses from 24 Japanese physicians who completed the modified VitalTalk training revealed an overall positive experience; however, two of their common complaints were discomfort with English mnemonics, discomfort with "naming the emotion" and overall disbelief with the emotional reactions of Japanese patient actors.[18] Similar to the modified VitalTalk training, the Japanese AD ACP training reported here

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was co-designed by Japanese-trained primary care clinicians currently practicing in Japan. The vignettes and didactics were modified by these clinicians (MI, TM) to focus on Japanese clinical practice. For example, all emotion naming skills were changed to "recognizing and accepting" emotions to be more culturally relevant for our Japanese audience.

The AD ACP Toolkit is the first evidence-based training to focus on PLwD through a non-dyadic communication lens. In the United States, incorporating family caregivers into ACP has been shown to improve communication with their physicians and ACP documentation.[20] The intervention in this study contextualizes dementia-relevant topics within the Japanese culture. In Japan, ACP is influenced by the concept of "omakase", in which important decision-making is entrusted in family or to the doctor.[21] "Omakase", while prioritizing the family surrogate decision-maker, does not provide a pathway for the family to know a patient's desires for end-of-life care, and decisional conflicts still arise.[21] A recent consensus definition of ACP in Japan focused on the support of a trusted physician and in supporting individuals who are hesitant to express opinions with their families [22] In Japan, two major factors, which are included in our training, appear to reduce decisional conflict for Japanese families making end-of-life choices: 1) previous guidance from physicians and 2) previous discussion with the physician on the future care needs of their relative.[23,24] A systematic review of ACP in Japan reported on the importance of properly eliciting patient's preferences that are best for both patients and families.[25] ACP communication training in primary care may be an important palliative care component of a national dementia strategy for Japan.[26] This study offers evidence that non-dyadic ACP communication training for Japanese primary care providers increases their confidence, though future work is needed to enhance its cultural appropriateness.

One of the reasons we included the primary care team members (and not just physicians) in the training was that primary care physicians are remarkably busy in Japan. There is a Japanese saying ""Sanjikan machi, sanpun shinsatsu" which means "three hours wait, three-minute visit". Japanese

primary care physicians may see a patient every 5 minutes, averaging between 60 to 100 patients per day.[27] However, Japan has a robust long-term care insurance program, "Kaigo Hoken", that provides a variety of in-home and community-based services with nursing, pharmacists, aides, physical therapists, and others.[28] One potential solution to the short visit times is that the Japanese primary care physician may be raise issue of ACP and its and then the home visit nurse can more fully explore the patient and family's wishes. In Japan, nurses have been found to have more favorable attitudes to ACP in general than physicians.[29] Once the ACP is discussed, the physician can then confirm their ACP values and plan at a subsequent visit. More work is needed on how to incorporate ACP communication for PLwD in primary care but our work represents an important step.

This study has several limitations. These limitations include an inability to capture changes in actual clinical behavior. While the study of the US training workshop was able to monitor ACP practices before and after training, the lack of a unified EMR, the need for IRB approval in Japan, and large number of sites made obtaining this information unobtainable. The study was also conducted only in central Japan and primary care providers in other parts of Japan may have different training needs. The providers trained in this study may also be more enthusiastic for ACP communication than general primary care providers, given the affiliation with an academic institution. In general, primary care physicians are less enthusiastic for advance care planning than other groups in Japan.[30] Additionally, video scenarios that have native Japanese speakers in realistic Japanese clinical contexts may increase confidence and cultural appropriateness. Lastly, the current training may be more relevant to physicians than to nurses or other primary care staff, and future efforts should examine the best process to incorporate nurses and other clinical staff in the ACP process for PLwD.

Conclusion

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In conclusion, a dementia-specific ACP communication skills toolkit for primary care physicians, nurses, and others was feasible, and increased confidence in a variety of ACP skills. The training toolkit was clear, timely, and effectively designed, though requires continued cultural adaption. Future work should include developing more Japanese specific videos, measuring clinical outcomes such as ACP documentation, and dissemination across Japan.

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Figure 1. AD ACP Toolkit Acceptability

Supplementary Materials. Table of Changes in the Confidence Level for Physicians, Figure of the Training Content and Timeline, and Figure of the Workshop Locations Across Central Japan.

Table 1. Participant Characteristics, n (%)

Participant Characteristics	Physicians, n = 80	Nurses, n = 33	Other*, n =58
Age, mean ± SD	39.8 ± 13.3	45.7 ± 9.95	42.9 ± 11.2
Female	(30%)	(87.9%)	(55.2%)
Place of Origin			
Urban	19 (23.8%)	4 (12.1%)	2 (3.4%)
Suburban	26 (32.5%)	0 (0%)	14 (24.1%)
Rural	35 (43.8%)	29 (87.9%)	31 (53.4%)
Frontier	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	11 (19.0%)
Work Setting			
Urban	12 (15.0%)	4 (12.1%)	5 (8.6%)
Rural	56 (70.0%)	28 (84.8%)	35 (60.3%)
Both	9 (11.3%)	0 (0%)	1 (1.7%)
Other	3 (3.8%)	1 (3.0%)	17 (29.3%)
Specialty			
Family Medicine	45 (56.3%)	3 (9.1%)	2 (3.4%)
Internal Medicine	22 (27.5%)	2 (6.1%)	0 (0%)
Other	13 (16.3%)	2 (6.1%)	4 (6.9%)
Sub-Specialty			
Geriatrics	2(2.6%)	0 (0%)	0 (0%)
Hospice & palliative care	2(2.6%)	0 (0%)	0 (0%)
Other	14 (17.5%)	0 (0%)	0 (0%)
Years Practicing/Working			
<2 years	3 (3.8%)	2 (6.1%)	0 (0%)
2-5 years	27 (33.8%)	2 (6.1%)	2 (3.4%)
6-10 years	14 (17.5%)	1 (3.0%)	7 (12.1%)
11-15 years	5 (6.3%)	3 (9.1%)	3 (5.2%)
16-20 years	7 (8.8%)	1 (3.0%)	3 (5.2%)
>20 years	12 (15.0%)	7 (21.2%)	5 (8.6%)
Percentage of Patients Living with Dementia (PLwD)			
<25%	40 (50.0%)	9 (27.3%)	3 (5.2%)
25-50%	27 (33.8%)	6 (18.2%)	11 (19.0%)
51-75%	4 (5.0%)	2 (6.1%)	4 (6.9%)
76-100%	5 (6.3%)	1 (3.0%)	5 (8.6%)
Missing	4 (5.0%)	15 (45.5%)	35 (60.3%)

*"Other" includes care managers, physical therapists, students, and community members.

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Table 2. ACP Communication Skill Confidence Pre- and Post-training, n (%)

Confidence	Pre-training	Post-training	p-value
Confidence in Making the Diagnosis of Dementia, n=87			
Confident	18 (17.1%)	33 (31.4%)	0.0521
Not Confident	74 (70.5%)	67 (63.8%)	
Confidence in Determining the Decisional Capacity of a Person with Dementia, n=89			
Confident	10 (9.5%)	33 (31.4%)	<0.001
Not Confident	84 (80.0%)	67 (63.8%	
Confidence in Understanding the Prognosis of a Person with Early Dementia, n=90			
Confident	9 (8.6%)	33 (31.4%)	<0.001
Not Confident	86 (81.9%)	67 (63.8%)	
Confidence in Understanding the Prognosis of a Person with End-stage Dementia, n=89			
Confident	16 (15.2%)	43 (41.0%)	<0.001
Not Confident	78 (74.3%)	57 (54.3%)	
Confidence in Discussing goals of care with a person with early dementia, n=91			
Confident	10 (9.5%)	39 (37.1%)	<0.001
Not Confident	86 (81.9%)	61 (58.1%)	
Confidence in Discussing goals of care with the family members of a person with dementia, n=91			
Confident	17 (16.2%)	38 (36.2%)	0.004
Not Confident	78 (74.3%)	63 (60.0%)	
Confidence in Eliciting surrogate decision-maker choice from a person with early dementia, n=92			
Confident	12 (11.4%)	43 (41.0%)	<0.001
Not Confident	84 (80.0%)	58 (55.2%)	
Confidence in Recommending self-care practices to prevent burnout and fatigue to a family caregiver for a person with dementia, n=91			
Confident	20 (19.0%)	46 (43.8%)	<0.001
Not Confident	76 (72.4%)	54 (51.4%)	
Confidence in Leading a family meeting about prognosis and goals of care for a person with dementia, n=92			
Confident	11 (10.5%)	36 (34.3%)	<0.001
Not Confident	85 (81.0%)	65 (61.9%)	
Confidence in Leading a family meeting discussion about hospice and hospitalization decisions for a person with dementia, n=92			
Confident	15 (14.3%)	37 (35.2%)	0.001
Not Confident	81 (77.1%)	64 (61.0%)	

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Table 1. Participant Characteristics, n (%)

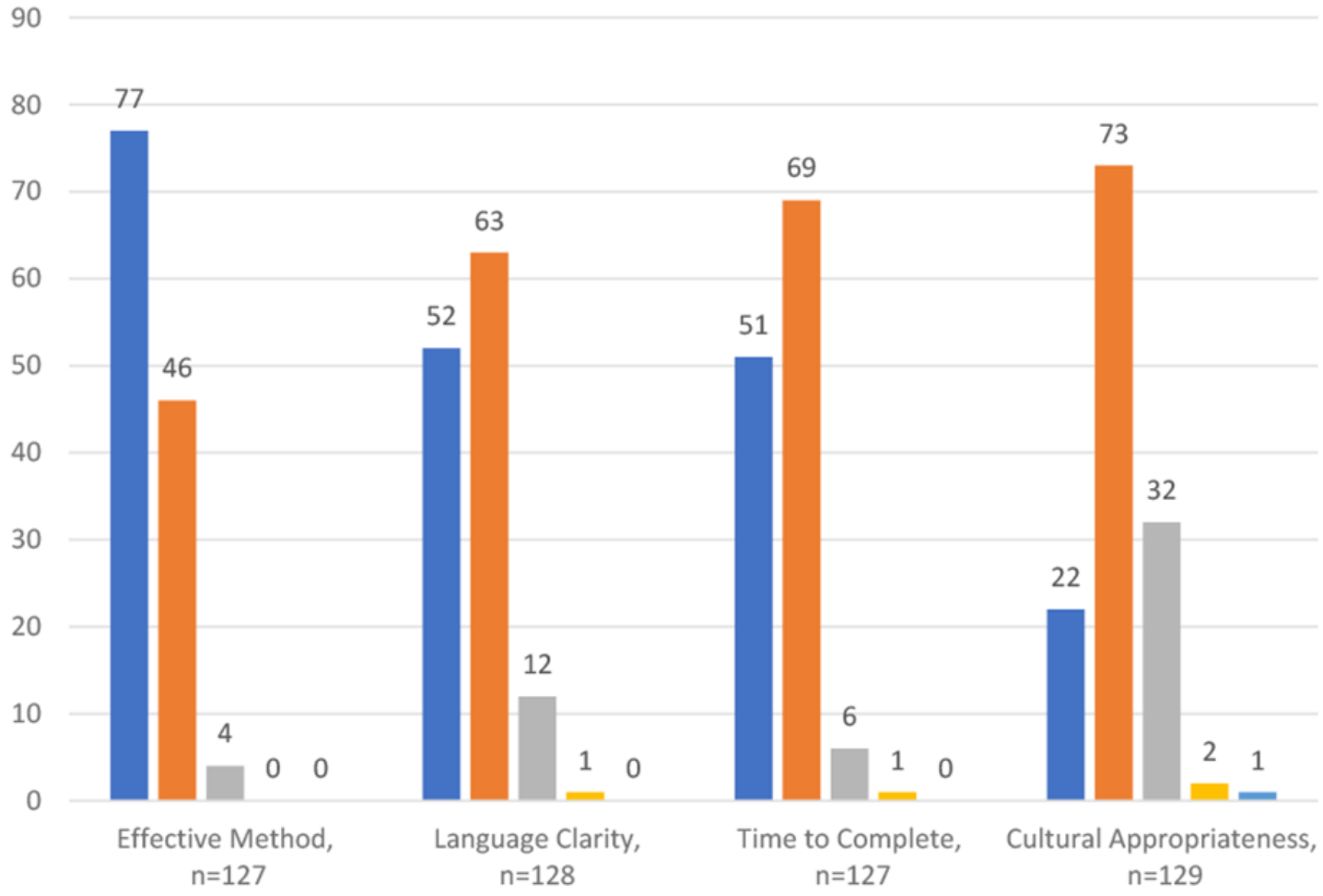
Participant Characteristics	Physicians, n = 80	Nurses, n = 33	Other*, n =58
Age, mean ± SD	39.8 ± 13.3	45.7 ± 9.95	42.9 ± 11.2
Female	(30%)	(87.9%)	(55.2%)
Place of Origin			
Urban	19 (23.8%)	4 (12.1%)	2 (3.4%)
Suburban	26 (32.5%)	0 (0%)	14 (24.1%)
Rural	35 (43.8%)	29 (87.9%)	31 (53.4%)
Frontier	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	11 (19.0%)
Work Setting			
Urban	12 (15.0%)	4 (12.1%)	5 (8.6%)
Rural	56 (70.0%)	28 (84.8%)	35 (60.3%)
Both	9 (11.3%)	0 (0%)	1 (1.7%)
Other	3 (3.8%)	1 (3.0%)	17 (29.3%)
Specialty			
Family Medicine	45 (56.3%)	3 (9.1%)	2 (3.4%)
Internal Medicine	22 (27.5%)	2 (6.1%)	0 (0%)
Other	13 (16.3%)	2 (6.1%)	4 (6.9%)
Sub-Specialty			
Geriatrics	2(2.6%)	0 (0%)	0 (0%)
Hospice & palliative care	2(2.6%)	0 (0%)	0 (0%)
Other	14 (17.5%)	0 (0%)	0 (0%)
Years Practicing/Working			
<2 years	3 (3.8%)	2 (6.1%)	0 (0%)
2-5 years	27 (33.8%)	2 (6.1%)	2 (3.4%)
6-10 years	14 (17.5%)	1 (3.0%)	7 (12.1%)
11-15 years	5 (6.3%)	3 (9.1%)	3 (5.2%)
16-20 years	7 (8.8%)	1 (3.0%)	3 (5.2%)
>20 years	12 (15.0%)	7 (21.2%)	5 (8.6%)
Percentage of Patients Living with Dementia (PLwD)			
<25%	40 (50.0%)	9 (27.3%)	3 (5.2%)
25-50%	27 (33.8%)	6 (18.2%)	11 (19.0%)
51-75%	4 (5.0%)	2 (6.1%)	4 (6.9%)
76-100%	5 (6.3%)	1 (3.0%)	5 (8.6%)
Missing	4 (5.0%)	15 (45.5%)	35 (60.3%)

*"Other" includes care managers, physical therapists, students, and community members.

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Table 2. ACP Communication Skill Confidence Pre- and Post-training, n (%)			
Confidence	**Pre-training**	**Post-training**	**p-value**
Confidence in Making the Diagnosis of Dementia, n=87			
Confident	18 (17.1%)	33 (31.4%)	0.0521
Not Confident	74 (70.5%)	67 (63.8%)	
Confidence in Determining the Decisional Capacity of a Person with Dementia, n=89			
Confident	10 (9.5%)	33 (31.4%)	<0.001
Not Confident	84 (80.0%)	67 (63.8%	
Confidence in Understanding the Prognosis of a Person with Early Dementia, n=90			
Confident	9 (8.6%)	33 (31.4%)	<0.001
Not Confident	86 (81.9%)	67 (63.8%)	
Confidence in Understanding the Prognosis of a Person with End-stage Dementia, n=89			
Confident	16 (15.2%)	43 (41.0%)	<0.001
Not Confident	78 (74.3%)	57 (54.3%)	
Confidence in Discussing goals of care with a person with early dementia, n=91			
Confident	10 (9.5%)	39 (37.1%)	<0.001
Not Confident	86 (81.9%)	61 (58.1%)	
Confidence in Discussing goals of care with the family members of a person with dementia, n=91			
Confident	17 (16.2%)	38 (36.2%)	0.004
Not Confident	78 (74.3%)	63 (60.0%)	
Confidence in Eliciting surrogate decision-maker choice from a person with early dementia, n=92			
Confident	12 (11.4%)	43 (41.0%)	<0.001
Not Confident	84 (80.0%)	58 (55.2%)	
Confidence in Recommending self-care practices to prevent burnout and fatigue to a family caregiver for a person with dementia, n=91			
Confident	20 (19.0%)	46 (43.8%)	<0.001
Not Confident	76 (72.4%)	54 (51.4%)	
Confidence in Leading a family meeting about prognosis and goals of care for a person with dementia, n=92			
Confident	11 (10.5%)	36 (34.3%)	<0.001
Not Confident	85 (81.0%)	65 (61.9%)	
Confidence in Leading a family meeting discussion about hospice and hospitalization decisions for a person with dementia, n=92			
Confident	15 (14.3%)	37 (35.2%)	0.001
Not Confident	81 (77.1%)	64 (61.0%)	

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