

The Current Status and Issues of the Advance Care Planning in the Primary Care Domain in Japan

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Abstract

Introduction: Japan is not only an aging society, but also a society with a high death rate, and end-of-life care is an urgent issue, as well as support for the lives of the elderly. Advance Care Planning is one of the important decision-making supports for maintaining and improving the quality of life (QOL) and quality of dying and death of patients. Therefore, this study will investigate the implementation status and issues of ACP in primary care facilities in Japan. **Methods:** A cross-sectional survey study in which 1444 facilities of home care support clinics in Japan were randomly selected. **Results:** One hundred-eleven responses (7% response rate) were received, with a valid response rate of 100%. Seventy-three facilities (65.7%) were implementing ACP and 38 (34.2%) were not. The support needed for implementation was prioritized as knowledge, information and understanding of the people involved. Reasons for difficulties in implementation included lack of knowledge, skills and experience of medical professionals and lack of understanding of patients and their families. **Conclusion:** With 37.8% of participants not having received training and 34% not implementing ACP, it cannot be said that implementation of ACP is widespread in primary care domain. Lack of knowledge and skills regarding ACP and difficulty in finding time are issues for the implementation and continuation of ACP, and the need for support in terms of opportunities to attend training and provision of specific information at a practical level was suggested.

Keywords

Primary Care, ACP (Advance Care Planning), Support for Decision Making, Japan

1. Introduction

While Japan's total population has been declining since 2011, the total population of those aged 65 and over has continued to rise, and the country is now an ultra-aged society. An ultra-aged society is also a society with a high death rate. The number of deaths among those aged 65 and over in 2020 is estimated to be 1.25 million, a 65% increase compared to 20 years ago. According to the National Institute of Population and Social Security Research's future estimates (2023), the number of deaths among people aged 65 and over is estimated to increase by 26% to 1.57 million by 2040 [1]. Alongside support for the lives of the elderly, end-of-life care is also an urgent issue in Japan. The Nippon Foundation conducted a nationwide survey on how to face the end of life, targeting parents aged 67 to 81 and their children aged 35 to 59. According to the results, 70.4% of the parents responded that they wanted to "live life as themselves", and 58.8% of them wanted to spend the final days of their lives "at home". When considering where they would like to spend the final days of their lives, 95.1% of respondents said that it was important that it should "not be a burden on their families". On the other hand, 85.7% of the younger generation said that it was important that "their parents should be able to spend sufficient time with their families", indicating a gap in the way parents and children think [2]. Against this background, the actual place of death for people who died in Japan in 2023 was "hospital" 64.5% and "home" 17.4% [3].

Advance Care Planning (ACP) is a process in which patients, their families, and medical professionals share the individual's values through discussion and clarify goals and preferences for future treatment and care [4]. ACP is one of the important decision-making support methods for maintaining and improving patients' quality of life and quality of death, and various research and educational activities are being conducted in various countries to promote its widespread use [5]-[7]. In Japan, the Ministry of Health, Labour and Welfare published the "Guidelines for the Medical Care Decision-Making Process in the Final Stages of Life" [8] in 2018, and in the hope that the meaning of ACP will be clearly communicated to Japanese people and that it will become a part of everyday life, efforts are being made to promote awareness of ACP, using the nickname "Life Conference".

However, according to the results of a 2022 awareness survey [9], only 5.9% of the general public, 45.9% of doctors, 45.8% of nurses, and 47.5% of care managers responded that they were aware of ACP, and the percentage of people who had discussed medical care and care at the end of life was less than 30% of the general public, while it was around 60% of medical and care workers, showing a large difference between the general public and medical and care workers, and the concept has not yet become widespread. On the other hand, the percentage of people who responded in favor of promoting Life Conference was 57.3% of the general public, 76.1% of doctors, 87.0% of nurses, and 81.8% of care managers, showing a high level of awareness of the necessity of these systems. The factors preventing

the spread of ACP despite its necessity include the cultural tendency of Japanese people to avoid talking about death, which makes it difficult to communicate honestly with family members due to feelings of restraint and awkwardness [10], and the fact that medical and nursing care workers are anxious and nervous about confirming the wishes of patients and users at the final stage of life, which is a great psychological burden for them [11], and so they are unable to create opportunities or environments for discussion, and ACP is not being implemented. The decision-making process is influenced by culturally formed values, and there are cultural differences between Japan and the United States in terms of the healthcare system, legal foundations, and respect for the right to self-determination [12]. Therefore, it is necessary to consider ACP practices that are appropriate for Japan.

In the United States, a country where ACP is advanced, ACP is often carried out during home care when patients' conditions are relatively stable, before they worsen or require hospitalization, and primary care medical professionals are becoming the main providers of ACP. In order to increase the implementation rate and popularize ACP, the development of ACP intervention programs in the field of primary care, such as Sharing and Talking about My Preference (hereinafter referred to as STAMP) [13], has begun. In Japan, too, it is hoped that primary care medical professionals who are involved with patients on an ongoing basis from the stage when they are fully capable of discussing the issue will be the ones to implement ACP. However, the actual situation regarding the implementation of ACP in the field of primary care in Japan has not been clarified. Therefore, we decided to examine the implementation status and issues of ACP in primary care facilities nationwide as a basic survey toward the development of an ACP support program in primary care in Japan.

2. Materials and Methods

2.1. Study Design

A cross-sectional survey was employed in the current study.

2.2. Selection of Subjects

Of the 14,439 home care support clinics registered nationwide as clinics with a track record of home visits, house calls, and end-of-life care, 1444 clinics, or 10%, were randomly selected to be the survey subjects.

2.3. Questionnaire Composition

The questions were created independently through discussion among researchers with the aim of clarifying the awareness of ACP, its implementation status, and the issues that need to be overcome in order to implement it in home care support clinics across the country. In order to obtain responses from as many clinics as possible, we considered questions that could be answered concisely without interfering with work, and decided on a total of 30 items. The main content included basic data (age, occupation, clinic classification, whether or not home visits/house

calls were conducted, number of years they were conducted, and details of implementation), knowledge of ACP (awareness, experience participating in training), implementation status of ACP (whether or not it was conducted, number of years it was conducted, time required per session), requirements considered necessary for implementing and continuing ACP, and difficulties and benefits of implementing ACP. The survey questionnaire was created by researchers after consulting specialized books on social research and questionnaire surveys [14]-[16], and after undergoing a pre-test, the final survey questionnaire was completed (See **Appendix**).

2.4. Data Collection Procedure

A survey request form was sent by mail, and facility representatives who agreed were asked to complete an online survey using Google Forms to collect the data. The survey period was from July to August 31, 2023. The reason for choosing a web survey was to reduce the resistance to cooperation in answering the survey, as many clinics are busy. In addition, the results of the survey were analyzed early on, in order to proceed with the next step of this research, which is to develop an ACP support program in the field of primary care in Japan.

2.5. Data Analysis

Basic data and knowledge and implementation status of ACP were simply tallied for each item. Items that asked for free-form responses were analyzed in accordance with Berelson B.'s content analysis [17] introduced by Funashima (2007), to maintain objectivity and avoid the analyst's subjectivity or bias. All written content was systematically analyzed, and classified and categorized according to the written language and its similarity of meaning.

2.6. Ethical Considerations

Approval was obtained from the ethical review committee of the affiliated institution (approval number: 2023-9-A). After indicating ethical considerations in the survey request, such as anonymity, strict adherence to information management, and voluntary participation, responses to the survey were deemed to have given consent for research cooperation.

3. Results

Of the 1444 facilities, 111 facilities (response rate: 7%) cooperated in participating, giving a valid response rate of 100%.

3.1. Demographics of study participants (Table 1)

The demographics of participants and their affiliated clinics are shown in **Table 1**. The largest group was those in their 50s with 33 people (33%) and doctors with 79 people (71.2%). Regarding the classification of clinics, 103 (92.8%) were clinics without beds, and 108 (97.3%) were clinics that provided home visits or house

calls. The largest number of clinics, 66 (61.1%), have been conducting home visits and house calls for more than 10 years (**Table 1**), and Many of the reasons given for the implementation of ACP were the needs of the residents, a sense of role and satisfaction in contributing to community health care, and succession from the predecessor.

Table 1. Demographics of study participants.

Item	Classification	number (%)
Age	20s	2 (1.8)
	30s	7 (6.3)
	40s	26 (23.4)
	50s	33 (29.7)
	60s	31 (27.9)
	Over 70s	11 (9.9)
	No answer	1 (0.9)
Occupation	Doctor	79 (71.2)
	Nurse	14 (12.6)
	Medical social worker	3 (2.7)
	Administrative staff	14 (12.6)
	No answer	1 (0.9)
Treatment category	Clinic with beds	8 (7.2)
	Clinic without beds	103 (92.8)
Home visits/house calls	Yes	108 (97.3)
	No	3 (2.7)
Years of implementation of home visits/house calls	1	6 (5.6)
	2	3 (2.8)
	3	7 (6.5)
	4	5 (4.6)
	5	6 (5.6)
	6	6 (5.6)
	7	3 (2.8)
	8	3 (2.8)
	9	3 (2.8)
	over 10	66 (61.1)

In terms of facility staffing, the majority of facilities had a single doctor (46 people, 46.8%). For nurses, 26 facilities (23.4%) had six or more nurses, followed by around 15% with 1 - 5 nurses. Around 80% had no therapists such as social workers, caregivers, or physical therapists, and the proportion of administrative staff was similar to that of nurse (**Table 1**).

3.2. Knowledge and Interest in ACP (**Table 2(a)**)

Knowledge and interest in ACP were shown in **Table 2(a)**. Forty-seven people (42.3%) were familiar with ACP, 47 people (42.3%) knew about it, 10 people (9.0%) had heard of it but were not familiar with it, and 6 people (5.4%) did not know of it, meaning that 84.6% of people were familiar with it or knew about it. Regarding experience of participating in ACP-related training or programs at conferences, 69 respondents (62.1%) and/or facility staff had participated, while 42 respondents (37.8%) had not.

3.3. ACP Implementation Status (**Table 2(b)**)

ACP implementation status was shown in **Table 2(b)**. Fifty-five people (49.5%) were taking the initiative in implementing ACP, 18 people (16.2%) were involved in ACP but not the initiative, 10 people (9%) were considering it, and 28 people (25.2%) had not implemented ACP. Of the 73 people who were implementing or involved in ACP, the highest number of years was 33 people (45.2%) who had been implementing ACP for 5 years or more, followed by 22 people (30.1%) who had been implementing ACP for 1 - 3 years (**Table 2(b)**). Regarding the monthly number of ACP implementations, 44 people (60.3%) had 20 cases or more ACPs, followed by 10 people (13.7%) with 5 - 10 cases or less, and 7 people (9.6%) with 10 - 20 cases or more. In the case of short sessions, the time required for each ACP session was 5 minutes or less in 24 people (32.9%), 10 minutes in 23 people (31.5%), 20 minutes in 14 people (19.2%), 30 minutes in 9 people (12.3%), and 60 minutes or more in 2 people (2.7%). In the case of longer sessions, the time required for each ACP session was 30 minutes in 29 people (39.7%), and 60 minutes or more in 22 people (30.1%), followed by 20 minutes in 13 people (17.8%), 10 minutes in 6 people (8.2%), and 40 minutes in 2 people (2.7%).

Table 2. (a) Knowledge and interest in ACP; (b) ACP implementation status.

(a)		
Item	Classification	number (%)
Do you know ACP	Familiar with	47 (42.3)
	Knew	47 (42.3)
	Heard but not familiar with	10 (9.0)
	Didn't know	6 (5.4)
	No answer	1 (0.9)

Continued

	Yes both of facility staff and respondents	27 (24.3)
Participating in ACP-related training or programs at conferences	Yes respondents	36 (32.4)
	Yes facility staff	6 (5.4)
	No both	42 (37.8)
(b)		
Item	Classification	number (%)
ACP implemented	Initiative in	55 (49.5)
	Involved in	18 (16.2)
	Not	28 (25.2)
	Consider	10 (9.0)
Number of years of ACP implementation	Less than 1 year	4 (5.5)
	1 year to less than 3 years	22 (30.1)
	3 years to less than 5 years	13 (17.8)
	More than 5 years	33 (45.2)
	No answer	1 (1.4)

3.4. Requirements Considered Necessary for the Implementation and Continuation of ACP

We asked 73 people who are implementing or involved in ACP to respond. The priorities for the requirements for implementing and continuing ACP were, in order, “Knowledge and information about ACP”, “Understanding of those involved (patients and families)”, and “Cooperators within the facility (people who understand)” (**Figure 1**). Similarly, 28 people who answered that they had not implemented ACP or were considering it were asked about the factors necessary for implementing ACP. The highest priorities were “Knowledge and information about ACP”, “Understanding of those involved (patients and families)”, “Time”, and “Cooperators within the facility (people who understand)”.

3.5. Difficulties in implementing ACP (Table 3)

Difficulties in implementing ACP were shown in **Table 3**. Nine categories (indicated in brackets []) and 23 subcategories (indicated in brackets < >) were generated from the written responses obtained from 48 participants.

The researchers discussed the matter repeatedly in order to improve the validity of the study. As a result, the following three issues emerged from the categories that were generated.

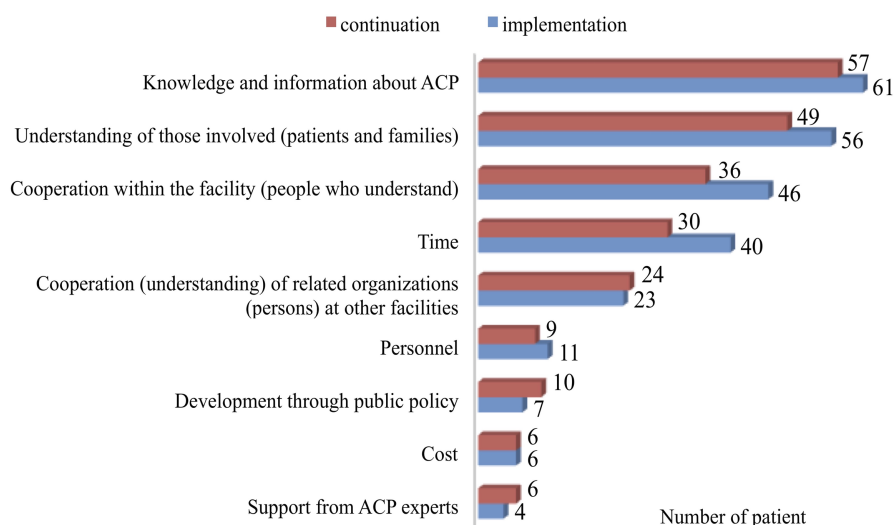


Figure 1. Requirements for implementation and continuation of ACP.

Table 3. Difficulties in implementing ACP.

Category	Subcategory	Free description
Not institutionalized	Not established as a system	<i>Public intervention is difficult</i>
		<i>Administrative guidance needs to be strengthened</i>
	Not included in medical fees	<i>Since it is not a stakeholder meeting, not all job types are involved.</i>
Low convenience and lack of common tools	Not included in medical fees	<i>If you are busy and cannot claim medical fees and there is no benefit at all, your work priority will be low. C1</i>
	Need for tools	<i>I have to use some kind of paper</i>
	Lack of standardized tools	<i>A tool with a common format, such as the “Attending Doctor’s Opinion”, is essential. C2</i>
	Convenience of online management, etc.	<i>Each municipality and facility uses its own unique tools.</i>
Low awareness of ACP	Convenience of online management, etc.	<i>Definitions and implementation methods vary by facility and region.</i>
	Not recognized in society	<i>If it can be managed online, it will no longer be necessary to have “Life Conference” with everyone, and it will be useful to be able to submit information to the hospital in the event of a sudden change such as hospitalization. C3</i>
	Publicity activities conducted but not implemented	<i>Questions are too specialized and detailed</i>
	Not recognized in society	<i>There is also a lack of recognition in society.</i>
	Publicity activities conducted but not implemented	<i>It has not penetrated yet</i>
	Publicity activities conducted but not implemented	<i>Although I have been promoting ACP for more than 8 years, it is still a “Pie in the sky”.</i>

Continued

		<i>There is a trend that preparing for death is bad luck.</i>
	Taboo consciousness regarding the topic of death	<i>Creating an atmosphere where people can express their opinions proactively</i> <i>Domestic citizens' views on life and death are vague to begin with.</i>
Negative feelings toward preparations for and discussion of death	Unable to face death	<i>There are many cases where families are unable to accept the current situation and are unable to make up their minds.</i> <i>acceptance of death</i> <i>Patients and families want to avoid facing the problem</i> <i>Stubbornly rejected, unable to think about his own death</i>
	Unable to imagine the future	<i>It is difficult for patients and their families to imagine the future.</i> <i>If you don't want to think too far ahead</i> <i>future design</i>
The patient/family is not interested in or understands ACP	Gaining the patient/family's understanding	<i>Lack of basic knowledge of patients and families. C4</i> <i>Understanding of the words ACP and Life Conference</i> <i>Difficult to gain understanding from patients and their families</i>
	Lack of interest from the patients/family	<i>There was a low sense of involvement, and it ended without a sense of reality. C5</i> <i>family is uncooperative</i> <i>Everyone is indifferent to the person's presumed intentions.</i>
	The patient/family's wishes cannot be confirmed	<i>Decline in cognitive function is seen in the person concerned or in their family</i> <i>The person has dementia</i> <i>Due to medical conditions, etc., it is difficult to hear the person's thoughts directly.</i>
The patient/family cannot agree on their opinion	The patient/family cannot agree on their opinion	<i>When the person and his or her family have different orientations, such as when the person has not been notified.</i> <i>Family members also have different opinions</i> <i>The person and his family have different opinions</i> <i>Disagreements within the family</i>
	Opinions change depending on the person or situation	<i>Requirements change depending on the person</i> <i>Caregivers' caregiving burden increases and their feelings change</i>

Continued

		<i>Hospitalizing doctors and nurses do not understand ACP knowledge and practice methods</i>
	There are differences in knowledge and understanding among medical professionals	<i>Difficulties may arise depending on the care manager and the quality of the facility.</i>
		<i>The skills of the people considered to be experts are inconsistent.</i>
		<i>How to tell the other person. C6</i>
	Lack of interview skills among medical professionals	<i>Family expectations are excessive</i>
Lack of knowledge, skills, and experience among medical professionals		<i>There are some situations where it is difficult to explain in detail. C7</i>
	Building relationships with the patient and their family	<i>Building trusting relationships with patients and their families</i> <i>If you don't have a relationship, it will be difficult and you won't be able to have honest discussions.</i>
	Difficulty in responding to each case	<i>Even for ACP targets, the content of the story differs depending on whether the situation is dire (terminal cancer) or not, making it difficult to find materials suitable for each person.</i>
		<i>It's case by case</i>
		<i>Unable to find a facility with a system that matches the patient's wishes</i>
	Determining which targets need to be introduced	<i>Selecting whether to be a target person or not</i>
Timing of introduction and implementation during intervention		<i>The timing of implementation is difficult. C8</i>
	Implementation according to the illness or condition	<i>It is better to do it as many times as necessary, as it depends on the situation at the time, but</i> <i>it is difficult to know when that timing is. C9</i>
		<i>I feel the timing is too late. C10</i>
	Adjusting time	<i>Time coordination for participants</i>
Securing time and adjusting schedules		<i>Adjusting the time</i>
		<i>There isn't enough time for everyone. C11</i>
	Securing time	<i>Finding time C12</i>
		<i>It is difficult to reach a conclusion.</i>

3.5.1. Social Issues [Not Institutionalized] Has Two Subcategories

<Not established as a system> and <Not included in medical treatment fees>.

[Low convenience and lack of common tools] has three subcategories: <Need for tools>, <Lack of standardized tools>, and <Convenience of online management, etc.>, [Low awareness of ACP] has two subcategories: <Not recognized in society> and <Publicity activities conducted but not implemented>, and [Negative feelings toward preparations for and discussion of death] has three subcategories: <Taboo consciousness regarding the topic of death>, <Unable to face death>, and <Unable to imagine the future>.

3.5.2. Issues for Patients and Their Families

[The patient/family is not interested in or understands ACP] consists of two subcategories: <gaining the patient/family's understanding> and <the patient/family is not very interested>. [The patient/family cannot agree on their opinion] consists of three subcategories: <the patient/family's wishes cannot be confirmed>, <the patient/family cannot agree on their opinion> and <opinions change depending on the person or situation>.

3.5.3. Issues for Medical Professionals

[Lack of knowledge, skills, and experience among medical professionals] consists of four subcategories: <Difficulties in knowledge and understanding among medical professionals>, <Lack of interview skills among medical professionals>, <Building relationships with the patient and their family>, and <Difficulty in responding to each case>. [Timing of introduction and implementation during intervention] consists of two subcategories: <Determining which targets need to be introduced> and <Implementation according to the illness or condition>. [Securing time and adjusting schedules] consists of two subcategories: <Adjusting time> and <Securing time>.

3.6. Benefits of Implementing ACP (Table 4)

Benefits of implementing ACP were shown in **Table 4**. Six categories (indicated in brackets []) and 21 subcategories (indicated in brackets < >) were generated from the written responses obtained from 41 participants. The researchers discussed the matter repeatedly in order to improve the validity of the study. As a result, the following three elements emerged from the categories that were generated, which led to the resolution of the three issues mentioned above.

3.6.1. Confirmation of Intention and Common Understanding Can Be Obtained

[It provides an opportunity for the patient, their family, and medical professionals to confirm their wishes] is made up of three subcategories: <facing the patient's wishes>, <being able to confirm one's own wishes>, and <feeling at ease when expressing one's own wishes>. [Family and related parties gain a deeper understanding of the patient and reach an agreement] is made up of two subcategories: <family and staff gain a deeper understanding of the patient> and <everyone is able to reach a consensus>.

Table 4. Advantages of implementing ACP.

Category	Subcategory	Free description
It provides an opportunity for the patient, their family, and medical professionals to confirm their wishes.	Facing the patient's wishes	<i>You can check</i>
		<i>I was able to know his thoughts</i>
	Being able to confirm one's own wishes	<i>I had never thought about how he wanted to spend his time, but I was able to hear his thoughts. D1</i>
		<i>I was able to confront the patient's honest feelings.</i>
Feeling at ease when expressing one's own wishes	Elderly people who had many vague complaints said they felt relieved and mentally calmed down after being able to express their feelings. D2	<i>Ensuring the patient's own identity</i>
		<i>The patient said that it was good to be able to talk to me.</i>
		<i>From a basic understanding, the family's understanding deepens with each session. D3</i>
Family and related parties gain a deeper understanding of the patient and reach an agreement	Family and staff gain a deeper understanding of the patient	<i>Through ACP, family and staff can understand the medical care and nursing care that the individual wants.</i>
		<i>By providing ACP to dementia patients, it is possible to provide end-of-life treatment that satisfies the family.</i>
	Everyone is able to reach a consensus	<i>It is easy to get everyone to agree and reach a consensus.</i>
Able to respond in a way that respects the patient's wishes, both in normal times and in emergencies	Able to have a common understanding and respect the patient's wishes	<i>When the patient, their family, and medical professionals reach a consensus</i>
		<i>Providing medical care and nursing care that is in line with the wishes of patients and their families</i>
	Able to utilize this in determining future policies at the hospital	<i>The patient communicated his wishes to his family in advance, and the family respected his decisions on a daily basis.</i>
		<i>We were able to fulfill the wishes of patients with non-cancer diseases.</i>
Able to respond smoothly in an emergency based on the patient's wishes	Able to respond smoothly in an emergency based on the patient's wishes	<i>During his hospitalization, he was told about the gastrostomy tube insertion, but by expressing his wishes, he has been able to continue oral intake, although it is still insufficient, even after being discharged from the hospital.</i>
		<i>When conditions change, we can provide consultation based on past intentions.</i>
		<i>Things can go smoothly</i>
		<i>Quick response when needed</i>

Continued

		<p><i>When the patient's condition suddenly worsened, the family used ACP to care for him.</i></p> <p><i>Even after the patient was no longer able to express his/her wishes, the family and medical staff were able to provide care at home while estimating the patient's wishes.</i></p> <p><i>Terminally ill patients and their families were able to spend time at home in a way that closely matched their wishes.</i></p> <p><i>I was able to care for him at home, surrounded by my family, instead of in a hospital.</i></p> <p><i>Increased family satisfaction</i></p> <p><i>A satisfying end for all involved, including the patient and their family</i></p> <p><i>Satisfaction even after death</i></p> <p><i>When the patient was able to spend the final days of their life at home, feeling satisfied (or so they thought).</i></p> <p><i>Families will be very happy if they are able to care for their loved one at home, including the preparations required.</i></p>
<p>Able to provide satisfactory end-of-life care for the family based on the patient's wishes</p> <p>Satisfying end-of-life care</p>	<p>Able to infer the patient's wishes and provide end-of-life care for the family</p> <p>Able to provide end-of-life care at home and the family is pleased</p>	<p><i>During the care at home, I was told that it was good that he was able to spend the last moments at home.</i></p> <p><i>Patient's family thanked me and said they were happy to be able to stay at home until the end.</i></p>
<p>Family members can rest in peace after their final moments</p> <p>Peace of mind for the family</p> <p>Final letter to the family</p>	<p>The patient and family were able to spend the final days peacefully</p>	<p><i>The family expressed their sincere gratitude many times, saying they were so glad that they were able to spend the final days of their loved one peacefully together.</i></p> <p><i>He passed away peacefully at home surrounded by his family.</i></p> <p><i>The family's expressions remained clear even after the death</i></p> <p><i>Gain peace of mind for your family</i></p> <p><i>We were able to share how we wanted to spend our final moments together and spend time together in a relaxed atmosphere.</i></p> <p><i>There was a person who wrote down "things he wanted to convey" to each family member in a letter-like format, as if it were a will.</i></p>
<p>Leading to improved awareness, knowledge and experience among medical professionals</p>	<p>It is almost always done in the terminal stage</p> <p>It is very important in terms of consideration and communication</p>	<p><i>Living will consent is obtained and is almost always done in the final stages.</i></p> <p><i>In the case of the end of life of young patient with malignant tumors, etc., more consideration and communication is necessary, and ACP is very important and meaningful.</i></p>

Continued

Awareness of providing sufficient explanations	<i>By providing sufficient explanations in elderly care facilities, end-of-life care can be provided within the facility.</i>
Experience of staff	<i>The number of cases of end-of-life care at home has increased.</i>
Knowing that life does not always go as planned	<i>I feel like life isn't going the way I want it to.</i>
Clarified policy	<i>The treatment plan becomes clear.</i>
No need to call the police	<i>I didn't have to call the police.</i>

3.6.2. Realizing Care and End-of-Life Care Based on the Individual's Own Decisions

[Able to respond in a way that respects the patient's wishes, both in normal times and in emergencies] consists of three subcategories: <Able to have a common understanding and respect the patient's wishes>, <Able to utilize this in determining future policies at the hospital>, and <Able to respond smoothly in an emergency based on the patient's wishes>. [Able to provide satisfactory end-of-life care for the family based on the patient's wishes] consists of three subcategories: <Family members can provide end-of-life care by understanding the patient's wishes >, <Satisfying end-of-life care>, and <Able to provide end-of-life care at home and the family is pleased>. [Able to remain at peace even after the family's final moments] consists of three subcategories: <The patient and family were able to spend the final days peacefully>, <Peace of mind for the family>, and <Final letter to the family>.

3.6.3. Improved Experience and Skills of Medical Professionals

[Leading to improved awareness, knowledge and experience among medical professionals] consists of seven categories: <It is almost always done in the terminal stage>, <It is very important in terms of consideration and communication>, <Awareness of providing sufficient explanations>, <Experience of staff>, <Knowing that life does not always go as planned>, <Clarified policy> and <No need to call the police>.

4. Discussion

We will discuss the three issues involved in implementing ACP in the primary care domain.

4.1. Social Issues

Training of implementers is underway, including the suitability of social workers and visiting nurses as ACP implementers [18] [19] and the effectiveness of ACP implementation by ACP facilitators [20].

However, the primary care field is busy, requiring a wide range of roles from preventive medical care to end-of-life care for residents [21]. The results of this study showed that while 97.3% of clinics carried out home visits and house calls

(Table 1) in addition to regular clinical duties, the staffing ratio of each clinic ranged from 1 to a maximum of 6 nurses, and around 60% of clinics did not employ social workers. This means that the burden on the doctors and nurses who are the main caregivers is considerable when it comes to carrying out ACP in addition to their regular duties, including home visits and house calls. As for [not institutionalized], the fact that <it is not institutionalized in medical fees> not only means that *implementing ACP is given a low priority within work* (Table 3, C1), but it does not reduce the burden on each staff member and they do not have the time to do so, which is thought to be an influence on the result that only 69 people (62.1%) had experience participating in ACP-related training or programs at conferences (Table 2(a)). When asked what is necessary to implement and continue ACP, the most common answer was “knowledge and information about ACP implementation” (Figure 1). Because *it is difficult to find the time, despite feeling the need* (Table 3, C12), we think that setting up a learning environment through online formats and e-learning, etc. [22] [23], as well as participating in training sessions and academic conferences, would be effective in promoting the implementation of ACP. In addition, there are *opinions calling for convenience such as a common format and online management* (Table 3, C2, C3), but [the lack of convenience and common tools] is putting a burden on the work. In order to improve convenience, attempts have been made to develop interactive websites, which are useful for understanding ACP and sharing information among those involved, but there are issues regarding the promotion of discussions among those involved, such as the use of online functions [24]. Based on the Ministry of Health, Labor and Welfare’s Life Conference [18], each prefecture and municipality has created its own record sheets for ACP tools. In addition, there are a variety of tools that emphasize ease of use for those involved, such as ACP implementation tools for target patients and ACP tools by companies, along with explanations of treatment and pathological progression by disease by medical institutions. Based on the Ministry of Health, Labor and Welfare’s Life Insurance Conference [25], each prefecture and municipality has created its own record sheets for ACP tools. In addition, there are a variety of tools that emphasize ease of use for those involved, such as ACP implementation tools for target patients and ACP tools by companies, along with explanations of treatment and pathological progression by disease by medical institutions. To promote widespread adoption and implementation, ease of use for medical professionals will also be important.

4.2. Issues for Patients and Their Families

When implementing ACP, there are many problems, such as *patients lacking basic knowledge* (Table 3, C4) and *a low sense of involvement* (Table 3, C5). Difficulties were felt in [a lack of interest or understanding in ACP from patients and their families], and the public awareness is still low [9]. Similarly, in the primary care domain, we feel that patients and families have [a low awareness of ACP], and it is difficult for medical professionals to have opportunities to discuss it due

to [preparations for death and negative feelings towards the topic]. It turns out that.

What makes it difficult to deal with this issue is that [the opinions of the individual and their family cannot be determined], such as: <The wishes of the individual and their family cannot be confirmed>, <The individual and their family do not agree on anything>, and <Opinions change depending on the person and situation>.

On the other hand, the positive aspects of implementing ACP include the fact that *it allows the patient to sort out their feelings and have them known, which brings relief* (Table 4, D2), and that by <facing the person> through discussion, it allows them to think about *things they had never considered before* (Table 4, D1) [providing an opportunity for the patient, their family, and medical professionals to confirm their wishes].

Even when the patient and family are not ready to have a discussion, it is believed that medical professionals can provide opportunities for discussion and hold multiple meetings, which will lead to <family and staff gaining a deeper understanding of the patient> (Table 4, D3), and [family and other related parties gaining a deeper understanding of the patient and reaching an agreement].

4.3. Issues for Medical Professionals

They felt there were difficulties with [a lack of knowledge, skills, and experience on the part of medical professionals] such as <a lack of interview skills on the part of medical professionals> and <building relationships with the patient and their family> as well as difficulties with <the timing of implementation during introduction and intervention>. In terms of the requirements considered necessary for implementing and continuing ACP, [knowledge and information on implementing ACP] was given the highest priority, followed by [support from experts] at the lowest (Figure 1).

ACP implementers are expected to be skilled medical and care providers who work with patients, their families, and other relevant parties to facilitate person-centered expression of wishes and dialogue for decision-making in order to realize medical and care decisions that are in line with the patient's values and wishes [26] [27]. However, it was apparent that there is *a need for interview skills in implementing ACP* (Table 3, C6, C7), and that in addition to knowledge and information about ACP, there is a need for support in the form of advice and consultation at a concrete practical level.

Regarding [securing time and adjusting schedules] for implementing ACP, the time required for each ACP session is adjusted according to the situation, in the long case with 60% of sessions lasting at most 30 - 90 minutes or more and in the short case with 60% of sessions lasting 5 - 10 minutes or less. However, *there is not enough time to implement it for all necessary targets* (Table 3, C11), and it is difficult to schedule and implement stakeholder meetings at the necessary times (Table 3, C8, C9, C10).

Because ACP interviews are based on communication skills, it is not easy to master the skills by simply acquiring knowledge through training, etc. It is therefore advisable to receive practical training and feedback, including role-playing. However, in the field of primary care, it is difficult to find time for training while performing regular duties. Therefore, in the future, we believe it will be necessary to consider training methods that allow the time and place to be selected, such as online training, and that also include objective evaluation.

5. Limitations of This Study

The low response rate (7%) raises concerns about the possibility of response bias, limiting the representativeness of the sample. This time, we did not conduct a follow-up survey of non-respondents, so it is not possible to compare respondents and non-respondents. The low response rate may be due to the fact that the implementation of ACP is not widespread and that people are busy with their work. We would like to work with the medical institutions that have responded to our request for cooperation but have not yet implemented ACP, and deepen our discussions on measures to promote its implementation.

6. Recommendations

It is necessary to provide opportunities for ordinary citizens to think about ACP as something that concerns them personally in their daily lives. Many older people want to live their lives as they are until the end of their lives, and they are also highly interested in health. The participation rate in health courses at sports gyms and public institutions is also high. We think that it would be effective to work on educational activities in places that promote health in the future. We will continue to research effective approaches to promoting ACP.

At present, researchers are working to promote ACP by creating videos of ACP in practice and holding ACP training sessions [28]. Based on the results of this study, we will create a specific, practical-level educational support program that can be used in the primary domain. To this end, we will consider the format of training and support programs so that participants can consult about effective intervention cases and difficult cases in practice.

7. Conclusion

When implementing ACP, it is difficult to gain the understanding of patients and families who have little awareness or interest, and there is a sense of lack of knowledge and technical experience, and there is a need to acquire more knowledge and information. However, only 62.1% had ever participated in training sessions or conferences. In the field of primary care, which has a limited number of personnel and is responsible for everything from preventive medical care to end-of-life care for local residents, adjustments to the learning environment, such as holding training sessions in a variety of formats, are necessary. In addition, there is a need for interview techniques that can promote dialogue for patients to express

their wishes and make decisions, and it was suggested that there is a need for support that responds to advice and consultations at a concrete practical level.

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Conflicts of Interest

There are no conflicts of interest to disclose in relation to this paper.

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Appendix

Basic survey of ACP in primary care

Please answer the following questions to the best of your ability.

We apologize for the inconvenience, but please answer by August 11, 2023.

Thank you for your cooperation.

1) Please tell us about your age. Please select (✓) the appropriate one.

20 s

30 s

40 s

50 s

60 s

over 70 s

2) Please tell us about your gender. Please select (✓) the appropriate one.

male

female

no answer

3) Please tell us about your occupation. Please select (✓) the appropriate one.

Doctor

Nurse

Medical social worker

Caregiver

Therapist (Physical/Occupational/Speech)

Medical administration

Others

4) We would like to ask you about the number of employees by job type at your employer. Please check (✓) one of the following for each item.

0 1 2 3 4 5 over 6

Doctor

Nurse

Medical social worker

Caregiver

Continued

Therapist
(Physical/Occupational/Speech)

Medical administration

Others

5) Please answer the following questions about your medical treatment category. Please select (✓) the appropriate one.

Clinic with beds

Clinic without beds

Other

6) Approximate monthly average number of outpatients? (Example: 735)

Number of outpatients

7) Do you make home visits or house calls?

Yes

No

If you answered “yes” to 7., please go to 7-2.

If you answered “no” to 7., please go to 8.

7-2) How long have you been conducting home visits and house calls? Please select (✓) the appropriate one.

Less than 6 months

1 year

2 years

3 years

4 years

5 years

6 years

7 years

8 years

9 years

More than 10 years

7-3) How did you get started with home visits and house calls? (Free description)

7-4) What is the average number of medical visits and house calls per month? (Example: 20)

Number

8) Are you familiar with ACP? Please select (✓) the appropriate one.

familiar with

knew

heard of it but not familiar with

don't know

9) Have you participated in any ACP-related training or programs at conferences? Please select (✓) the appropriate one.

Both facility staff and respondents

Respondents only

Facility staff only

No respondents and no facility staff

If you answered "yes" to 9., please go to 9-2.

If you answered "no" to 9., please go to 10.

9-2) What were the main training sessions you attended? (Free description)

10) Do you implement ACP? Please select (✓) the appropriate one.

Initiative in implementing

Involved in it, but not the initiative

Not implemented

Under consideration

If you answered "10." and you are implementing or involved in ACP, please go to 11.

If you answered “10.” as not implementing or considering ACP, please go to 18. 18. is the end of the questionnaire. Thank you for your cooperation.

11) How was the ACP implemented? (Multiple answers allowed)

Felt it was necessary

Wanted by the individual or family

Related institution (hospital, nursing home, home nursing service, etc.)

Other

12) How many years has the ACP been in place? Please select (✓) the appropriate one.

Less than 6 months

6 months to less than 1 year

1 year to less than 3 years

3 years to less than 5 years

More than 5 years

13) What is the number of ACPs implemented to date (total number)? Please select (✓) the appropriate one.

0 cases

1 to less than 3

3 to less than 5

5 to less than 10

10 to less than 20

More than 20

14) How long (minutes) per ACP? Please check (✓) one of the following for each item.

	5 or less	10	20	30	40	50	60 or more
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Short cases

Long cases

15) When should the ACP be implemented? (Multiple answers allowed)

-
- Periodically
 - When the implementer deems it necessary
 - When requested by the person or their family
 - When requested by related organizations or supporters
 - Other
-

16) Who are the main implementers of the ACP? Please select one of the following (✓).

-
- Doctor
 - Nurse
 - Medical social worker
 - Caregiver
 - Therapist (Physical/Occupational/Speech)
 - Medical administration
 - Staff at the hospital or facility that the person is using or has used
 - Other
-

17) Who participates in ACP? Please check all that apply.

-
- The person
 - Family
 - Doctor
 - Nurse
 - Medical social worker
 - Caregiver
 - Therapist (Physical/Occupational/Speech)
 - Medical administration
 - Staff at the hospital or facility that the person is using or has used
 - Other
-

18) Please tell us the top three most important things you think are necessary to implement ACP, such as support and systems.

Knowledge and information about ACP
Cooperators (people who understand) within the facility
Staff
Cost
Time
Understanding of those involved (patients and families)
Support (understanding) from related organizations (people) at other facilities
Support from ACP specialists
Improvements through public policy
Other

19) Please tell us the top three most important things you think are necessary to continue ACP, such as support and systems.

Knowledge and information about ACP
Cooperators (people who understand) within the facility
Staff
Cost
Time
Understanding of those involved (patients and families)
Support (understanding) from related organizations (people) at other facilities
Support from ACP specialists
Improvements through public policy
Other

20. Please tell us about any difficulties you have encountered in implementing ACP. (Free response)

21. Please tell us about any good points you have encountered in implementing ACP. (Free response)

This concludes the survey. Thank you for your cooperation.