

Japanese citizens' attitude toward end-of-life care and advance directives: A qualitative study for members of medical cooperatives

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Abstract

Background: Japanese citizens are interested in choosing their own end-of-life care, but few have created their own advance directive. This study examined changes among Japanese citizens' attitudes toward end-of-life care and advance directives and explored factors that affected these attitudes.

Methods: We conducted five focus groups with 48 participants in 2009 and 2010. All participants were members of health cooperatives in Tokyo.

Results: We identified many barriers and reasons for creating and writing down advance directives. Experience caring for dying people and having a serious disease affected attitudes toward advance directives. Some participants changed their attitude toward end-of-life care by writing their own advance directive.

Conclusions: When someone is writing advance directives, asking about his/her past experience of caring may be helpful. And learning about or filling out advance directives may help to break down resistance to using these documents.

KEYWORDS

advance directives, end-of-life care, qualitative study, steps for coding and theorization

1 | INTRODUCTION

Medical decisions about end-stage patients are made every day in many primary care settings in Japan, but these decisions are associated with a number of problems. The most serious dilemma is that many decisions are made without considering the patients' preferences because the patients are already incapable of expressing their wishes.¹ In particular, the use of life-sustaining devices such as ventilators and feeding tubes for frail elderly patients is a controversial and ethical problem. Patients' families and health professionals are then forced to undertake the burden of making a difficult decision about the patient's life.

Advance care planning is an ongoing process that offers the patient the opportunity to deliberate with his or her family members and physician regarding the choices for end-of-life care. Advance directives consist of a person's oral and written instructions about his or her future medical care, in case he or she becomes unable to communicate,

becomes incompetent to make healthcare decisions (during a terminal illness), or is in a persistent vegetative state²

A survey conducted by the Ministry of Health, Labor and Welfare in 2013 indicated that 69.7% of Japanese citizens approved of writing advance directives. However, people who have talked about their end-of-life was only 42%, those who have already created an advance directives was only 3.2% of the general public.³

In Japan, there is no law supporting advance directives, and format has not been determined. A "Living Will" of the Japan Society for Dying with Dignity⁴ is a typical one, but not widespread. The number of members registered in the Japan Society for Dying with Dignity has increased annually since 1990, only 113 600 people are currently registered. This number accounts for only 0.5% of the population older than 65 years.⁵

Bitto et al. conducted a qualitative study about end-of-life care and advance directives among Japanese citizens living in Japan and Japanese Americans who had immigrated to the United States. They

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conducted the focus groups in 1996 and 1997. The results showed that advance directives were generally accepted among both groups. However, Japanese participants saw written directives as intrusive, whereas Japanese Americans viewed them mainly as tools to reduce conflict between a dying person's wishes and the hopes of family members.⁶ Another study showed that 85% of English-speaking Japanese Americans preferred to be informed about impending death with words, but only 36% of Japanese living in Japan expressed such a desire.⁷ These cultural differences could be one of the factors contributing to the low use of advance directives in Japan.

Twenty years have passed since the focus groups conducted by Bito et al. and Matsumura et al., and the need to pass bad news on to patients has become even more common in Japan during this time. More and more doctors have become conscious of clinical ethics and tend to respect patients' preferences and autonomy.⁸ Furthermore, it is likely patients' awareness of their rights and the diffusion of medical knowledge has increased patients' ability to make decisions themselves.

The purpose of this study was to elucidate changes in Japanese citizens' attitudes toward end-of-life care and advance directives. And also we intended to find out the key to disseminating advance directives. We conducted focus groups after participants wrote their advance directives to analyze barriers and reasons for creating and writing down advance directives.

2 | METHODS

2.1 | Design

This was a qualitative study in which we conducted five focus groups with 48 participants in 2009 and 2010. The themes of discussion comprised decision making on end-of-life care and advance directives. In focus group, we used new advance directives produced by reference to "My Wills about End-of-life Care" made by National Center for Geriatrics and Gerontology.⁹ Advance directives contain two sections: The first covers the patient's written wishes regarding administration of life-sustaining medical devices such as ventilators and tube feeding, and the second is the healthcare proxy, which lists the name of the person who determines the type or amount of treatment in case the patient can no longer express his or her wishes.

The study protocol was approved by the IRB of Tokyo Hokuto Medical Cooperative. The application number is 30.

TABLE 1 Participant characteristics

Group	Description	No. of participants	Age composition	M:F
A	Elderly neighborhoods	10	60s, 1; 70s, 5; 80s, 4	1:9
B	Members of several "Han" groups (participants were divided into two focus groups)	19 (10 were analyzed)	60s, 5; 70s, 11; 80s, 2; 90s, 1	1:18
C	Women living in the same apartment	5	60s, 1; 70s, 3; 80s, 1	0:5
D	Housewives with experience of nursing care	4	50s, 1; 60s, 3	0:4
E	Group enjoying table tennis for health	10	60s, 3; 70s, 7	3:7

M, males; F, females.

2.2 | Participants

Participants were recruited through the members of health cooperatives in Tokyo. All participants belonged to "Han," that is a group of members of medical cooperatives who hold health promotion meetings regularly. Most participants were residents of urban areas and were not medical professionals. Group members were acquainted with each other. Each group had a different age and gender composition (see Table 1). The participants gathered voluntarily after they were informed that the aim of the meeting was to investigate their attitude toward end-of-life care and advance directives.

2.3 | Data collection and analysis

The author conducted all focus groups, and all dialogues were recorded with an IC (Integrated Circuit) recorder and transcribed verbatim. The following guide topics were used, with additional questions added depending on the context: (i) experiences with end-of-life care and decisions for relatives and friends; (ii) images about life-sustaining treatment and devices; (iii) ideal end-of-life care; and (iv) attitudes toward advance directives (after writing their own directives). All participants read and wrote down their advance directives during the focus groups.

Data analysis was carried out using SCAT (Steps For Coding and Theorization).¹⁰⁻¹³

In this method, coding and theorizing processes are divided into several steps. Specifically, we put segmented data into a matrix, and then, we (1) picked up notable words in the data; (2) paraphrased the words in another way; (3) gave meaning and interpretation to items in (2); and (4) described themes and constructive concepts arising from item (3). After these four steps, we created storylines weaving the themes and constructive concepts together. Theoretical descriptions were drawn from the storylines.

A theoretical description is not a general theory that includes the whole study, but rather includes small and particular findings derived from the themes and constructs identified. As a result of this study, several themes were derived and typical dialogues could be determined.

3 | RESULTS

Focus group discussion averaged 1 hour and 30 minutes in length, and each group contained 4-10 participants. Table 1 shows information

on the participants. Group B had a large number of participants, so we divided the members into two groups. One focus group was conducted by a participant, but the meeting room was so noisy that we could not record the discussion clearly. In addition, participants were noted to only voice their own opinions and no group dynamics occurred. As a result, this group was excluded from the analysis and only data from Group B in which the focus group was conducted by the author were included.

Data on two primary themes were gathered: attitudes toward end-of-life care, and advance care planning and advance directives. Subcategories of each of the themes are presented below along with a sample dialogue that was recorded.

3.1 | Attitudes toward end-of-life care

3.1.1 | End-of-life care of a family member

Many participants talked about the last hours of a family member's life. Positive themes included "Continuing daily life as a factor of a 'good death'" and "Caregiver's sense of accomplishment affecting peaceful acceptance of the family member's death." Negative themes were "Family's burden of supporting a long-time survivor with tube feeding" and "Experience of withdrawal from caring for a family member as a barrier to active involvement in end-of-life care decision making."

1.1.1 Continuing daily life as a factor of a "good death"

I could see my father off in July 200X at home. It was good for us that my mother said that my father died in his bed without suffering. Though my father was bed-bound, he could drink a glass of alcohol mixed with a lot of water on his last days. That was the way my mother took care of him.

(Group E, 61-year-old female)

1.1.2 Caregiver's sense of accomplishment affecting peaceful acceptance of the family member's death

I have no regrets because I dedicated myself to the care of my husband. I took care of him for 13 years; he was bed-bound for the last 3 years....I readily accepted his death because I was deeply dedicated to him.

(Group A, 89-year-old female)

1.1.3 Family's burden of supporting a long-time survivor with tube feeding

My brother's wife was bed-bound for 3 years. She got nutrition through intestinal tube feeding. This was a huge burden on her family and was very expensive.

(Group B, 91-year-old female)

1.1.4 Experience of withdrawal from caring for a family member as a barrier to active involvement in end-of-life care decision making

My husband died. He had colon cancer. First, I took care of him, but it was too difficult for me to continue caring for him. I asked the ward office for help. He was admitted to S hospital for more than half a year, and died in T hospital. The telephone rang and they said he was in danger, and within 5 minutes, "He died". He might have suffered, but I don't know. (Facilitator: Did he receive life-sustaining treatment?) I don't know.

(Group C, 70-year-old woman)

3.1.2 | Participants' preferences for their own end-of-life care

Many participants talked about their ideal way of dying. Some wished for "pokkuri" death, which refers to dying immediately without suffering from disease nor bothering their family. Others wished for a natural death surrounded by their family at home. Themes about decision making regarding end-of-life care included "Experience of family member's life-sustaining treatment as a background for refusal of their own life-sustaining treatment"; "Independent life history as a background for wishing to be independent just before death"; and "Acceptance of death as a background of active decision making about end-of-life care." One theme about participants' appreciation of their own death was "Loved one's illness/death as an opportunity for realistic appreciation of death."

1.2.1 Experience of family member's life-sustaining treatment as a background for refusal of their own life-sustaining treatment

My wife's father had stomach cancer. He was admitted to a hospital and underwent surgery. But the cancer was too advanced so the surgeon closed the abdomen after injecting drugs, without performing a resection. After that, for about 3 months, he was unconscious and couldn't eat. But the doctor continued his life support... Knowing this, I prefer not to receive life support therapy... Though he had no possibility of being cured, he continued breathing with the help of multiple devices.

(Group E, 77-year-old male)

1.2.2 Independent life history as a background for wishing to be independent just before death

If I become sick, I can't live without someone's help, because I live alone. I have been living earnestly as beautician since the 1940s. I prefer to die in the blink of an eye. It's my policy.

(Group B, 91-year-old woman)

1.2.3 Acceptance of death as a background of active decision making about end-of-life care

First, when the doctor said I had an aortic aneurysm, I couldn't sleep for two days. But I changed my mind and thought "It is a good way to die." I will die just after the aneurysm ruptures. ... So I am happy I have such a disease.

(Group A, 89-year-old female)

1.2.4 Illness experience as an opportunity for realistic appreciation of death for oneself and the surrounding people

I'm feeling that death is imminent. This year I experienced a stroke and a heart attack. I was admitted to the hospital and underwent an operation. So such things (death and dying) became one step closer for me.

(Ms. A, Group D, 57-year-old female)

Yes, her illness made us feel death was a realistic thing.

(Ms. B, Group D, 66-year-old female)

1.2.5 Refusing to be told he/she has cancer based on a fear of facing death

Well, these days, does a doctor tell his patient that he or she has an early cancer? (Facilitator: Yes, he tells even if it is not an early one.) Oh, does he? For myself, I don't want to be told, I'll die of shock. It's a real shock. So I always tell my wife never to inform me if I have any possibility of having cancer. I never want to have surgery. I want her to keep quiet, and hide the truth even if I begin to experience pain. I don't want to know, if I hear that, I'll really become crazy in shock.

(Group E, 77-year-old male)

3.2 | Advance care planning and advance directives

3.2.1 | Barriers to creating and writing down advance directives

Several barriers to completing advance directives were identified. These included "Attitude to avoid facing death," "Dependency on others about decision making regarding treatment," and "Difficulty talking about end-of-life care caused by distant family relationships." In addition, while some participants indicated a desire to provide advanced care planning, there were several barriers to actually writing down their wishes. These barriers included "Resistance to filling out all the items and writing things down," "Suspicion of doctor's compliance with advance directives" and "Worry that asking for an advance directive will be mistaken as encouraging a family member to die."

2.1.1 Attitude to avoid facing death or malignant illness

(Facilitator: Don't you think about having a malignant disease?) No. (Facilitator: Don't you usually think about death at all?) In my daily life, I never think about death. I don't intend to.

(Group E, 68-year-old female)

2.1.2 Dependency on others about decision making regarding treatment

(About herself) When the time comes, the doctor will do good for me. If I die, they will contact the ward office and my children.

(Group C, 70-year-old female the same person as 1.1.4)

2.1.3 Difficulty talking about end-of-life care caused by distant family relationships

(My family) rarely come to see me so we have never talked about that. They live far away, and I have difficulty talking about such an evil topic at a new year.

(Group C, 78-year-old female)

2.1.4 Resistance to filling out all the items and writing things down

It is bothersome to fill out all the items. I tend to think simply. I go to see the doctor every month, is it right if I hand over a written document saying that I do not want life-sustaining treatment to be put on my chart?

(Group B, 91-year-old female)

2.1.5 Suspicion of doctor's compliance with advance directives

Even if I write this down (advance directives), treatment of the patient is a doctor's duty. So they will do it no matter what I write down.

(Group B, 73-year-old female)

2.1.6 Worry that asking for an advance directives will be mistaken as encouraging a family member to die

I understand. It sounds like we are compelling death. She may feel like I am saying "Please die early."

(Group D, 57-year-old female)

3.2.2 | Positive factors for creating and writing down advance directives

The merits of creating and writing down advance directives included "Clarity and consistency of written directives is better than oral communication," "A way to resolve anxiety that the family may affect one's way

of dying with no reference to his/her wishes," "A way to support one's will beyond the family's wishes," "A way of sharing and talking about one's end-of-life care with all family members," "A way to stabilize and reassure one's mental state by delivering one's wishes about end-of-life care," and "Advance directives are a source of decision making and security for one's family." As mentioned earlier, some people worry that a recommendation to create an advance directive may be misunderstood as hoping that the person dies early. However, resolution of this worry was conceptualized as "Writing one's own advance directives first is a good way to recommend it to someone." (2.2.7).

2.2.1 Clarity and consistency of written directives is better than oral communication

This (advance directives) is a good thing. We will forget spoken words even if we stamp them in our minds. We can show this to other people. Ideas will change when we talk about it next time, but this will not change.

(Group A, 72-year-old female)

2.2.2 A way to support one's will beyond the family's wishes

I can't be tolerant if I get a treatment that opposes what I have written down with no respect for my will. She is my only child, and I worry about being resuscitated at my daughter's wishes. I don't want to bother her. So I put my wishes on this paper.

(Group A, 82-year-old female)

2.2.3 A way of sharing and talking about one's end-of-life care with all family members

I will take this paper (advance directives) home and ask my family "I am going to write this down on this paper, what do you think of it? How about writing yours?" I think talking about end-of-life care is a task for the family.

(Group D, 57-year-old female)

2.2.4 Writing one's own advance directive first is a good way to recommend it to someone

If I say "I have written this (advance directives), so how about you, aunt?" It is a better way to recommend this.

(Group D, 69-year-old female)

3.2.3 | Experience that affects attitudes toward advance care planning and advance directives

Based on an evaluation of the dialogue of several participants, past experience affected their attitude toward advance care planning

and advance directives. This is described as "Positive experience of caring for a dying person as a background of active writing of advance directives" (2.3.1). For example, a 61-year-old female who talked about "Continuing daily life as a factor of a 'good death'" (1.1.1) also discussed advance directives as a communication tool within the family to talk about end-of-life care. Participants who had experienced serious diseases such as myocardial infarction, aortic aneurysm, or Parkinson's disease recognized the possibility of their own death and had proactive attitudes toward advance directives. This is described as "Appreciation of one's own illness and death as a background of active writing of advance directives" (2.3.2). For example, a 57-year-old female who experienced myocardial infarction (1.2.4) characterized advance directives as "a task for the family" (2.2.3).

2.3.1 Positive experience of caring for a dying person as a background of active writing of advance directives

My mother is now 90 years old. I will go to see her soon. ...I can not only talk with her about her end-of-life care but also record it using this advance directive. That's good.

(Group E, 61-year-old female the same person as 1.1.1)

2.3.2 Appreciation of one's own illness and death as a background of active writing of advance directives

See the section 1.2.4 and 2.2.4.

3.2.4 | Possibility of changing ideas about death and dying and its acceptance by writing advance directives

As mentioned above, there are various barriers to writing advance directives. However, there were several impressive cases in this study. For example, a 77-year-old male refused to be told bad news (1.2.5) and avoided serious topics like death and end-of-life care. However, after writing advance directives, he recognized the need to think about such topics and changed his mind about talking with his family. We named this theme "Writing advance directives as an awareness-raising factor to consider one's death and discuss with the family."

2.4.1 Writing advance directives as an awareness-raising factor to consider one's death and discuss with the family

Well, I have been comparatively healthy, so this is the first time I think of such a serious problem... I have been keeping away from such serious topics, and I have never talked about it. Because I feel depressed if I think of such serious things... But today after writing this (advance directives), I think I should prepare myself to talk with my wife about this kind of topic. Yes, I should prepare to do this.

(Group E, 77-year-old male the same person as 1.2.5)

4 | DISCUSSION

Experiences caring for dying people have a profound effect on individuals' realistic appreciation of death, acceptance of death, and attitudes toward advance directives. One 89-year-old woman who did her best and took care of her dying husband was satisfied with her care (1.1.2). She also had a fatal disease (aortic aneurysm), and she had already prepared advance directives and accepted that her own death was coming in the near future (1.2.3). Another 61-year-old woman whose father died at home peacefully (1.1.1) actively fulfilled her own advance directives. Independent life history (1.2.2) and family's burden of supporting a long-time survivor with tube feeding (1.1.3) were also promoting factors of fulfilling documents.

On the other hand, a 70-year-old woman who withdrew from the care of her dying husband and decision making of his treatment (1.1.4) had little interest in her own end-of-life care and had not written down any advance directives (2.1.2).

These facts suggest that we can predict the person's attitude toward advance directives by knowing their experience of caring dying people or their own experience of illness.

Bito et al. found that Japanese living in Japan and Japanese Americans living in the United States had different ideas about

advance directives. The former were reluctant to provide advance directives and disliked the concept of written documents, whereas the latter readily accepted advance directives and viewed them as a way to relieve the family's burden.⁷ In contrast, in the present focus group, not a few participants agreed to write an advance directive and mentioned many advantages of these documents, including having written documentation to make their wishes clear (2.2.1). Some described advance directives as a tool to end life in one's own way even though they knew their family's hopes that they should be kept alive (2.2.2).

One participant characterized advance directives as a task for the family (2.2.3). She also mentioned the usefulness of advance directives as an opportunity to talk about end-of-life care.

Various studies have been conducted investigating promoting factors and barriers of filling out advance directives. Known promoting factors are the presence of pain and deteriorating health of their own.¹⁴ Known barriers of physician are lack of time, perceived low health literacy of patients, lack of necessary skills, lack of privacy for discussion, and patients not sick enough.

Barriers of patient side are deferring to family members or physicians, inconsistency with religious beliefs, too distressing to think about, difficulty completing documents, and planning to do it later.¹⁵

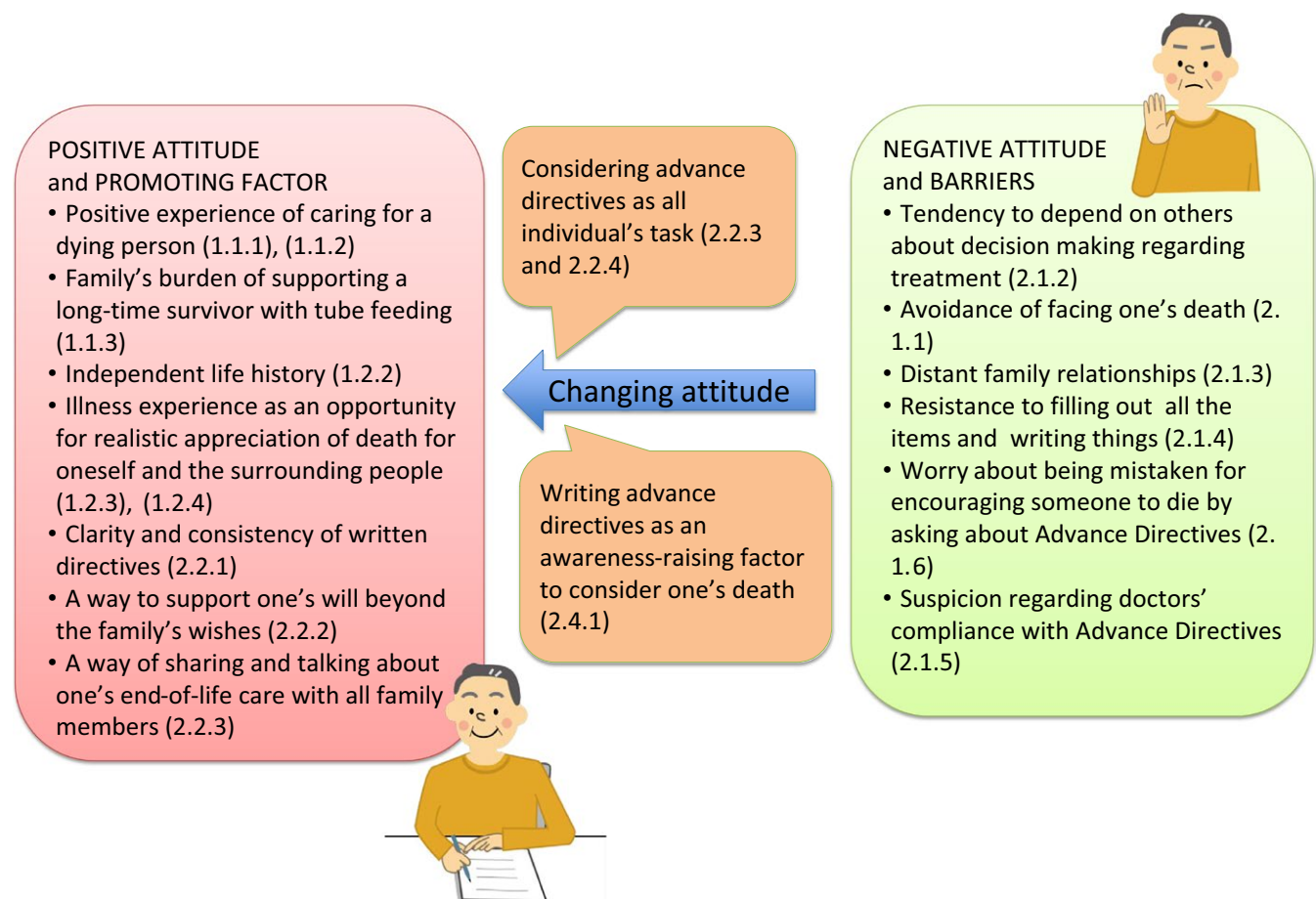


FIGURE 1 Japanese citizens' attitude toward advance directives

In this study, there are still various barriers to writing advance directives, including tendency to depend on others about decision making regarding treatment (2.1.2), avoidance of facing one's death (2.1.1), distant family relationships (2.1.3), bother associated with writing all the information down (2.1.4), and worry about being mistaken for encouraging someone to die early by asking them to create an advance directives (2.1.6). Some participants mentioned their suspicion regarding doctors' compliance with advance directives (2.1.5), which raises the concern about hidden problems in the doctor-patient relationship.

What should be noted is participants who had avoided talking about death (eg 77-year-old male at 1.2.5) made up their minds to talk to their family by writing an advance directive and through the experience of the discussion in this focus group (2.4.1). That is, learning about or filling out advance directives itself may help to break down barriers. Also, it is likely that death became familiar even without experience of own illness or nursing dying person, by sharing experiences of others. Furthermore, to avoid the idea that advance directives "compel death," (2.1.6) we recommend that advance directives be considered all individual's task and not for only elderly or sick person (mentioned at 2.2.3 and 2.2.4). All of findings are shown in Figure 1.

One limitation of this study was that all participants were members of medical cooperatives. All participants were learning about medical topics and health promotion on a daily bases and had a greater interest in medical service and health promotion than common Japanese citizens. Thus, these results may not be able to be generalized to a larger population. In the future, it will be necessary to conduct focus groups with participants from various segments of society.

Other limitation was the predominance of female participants (43-5 men). This is because the older women are the majority of the members of the cooperatives. And there is a tendency that women are more interested in end-of-life care, through their nursing experience.

Age structure is 50's: 1 person, 60's: 13 people, 70's: 27 people, 80's: 7 people, 90's: 1 person. This is biased toward the elderly, especially in the 70's, and further investigation targeting the younger generation is necessary in the future. In addition, the survey was conducted in urban areas of Tokyo where the aging of the population is progressing, but it may also be different in other areas with different population composition.

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DISCLOSURE STATEMENT

YH is a member of Centre for Family Medicine Development (CFMD) practice based research network. YH was a former trainee of Jikei Clinical Research Program for Primary-care. TO is a lecturer of Jikei Clinical Research Program for Primary-care. TO received the lecture and travel fee from Jikei Clinical Research

Program for Primary-care. MM received the lecture fee and travel fee for lecture from CFMD of Japanese Health and Welfare Co-operative Federation. MM is an adviser of CFMD practice based research network. MM is a program director of Jikei Clinical Research Program for Primary-care. There is no potential competing interest to be declared relevant to this work other than the above description.

AUTHORSHIP CRITERIA

As corresponding author, YH made design and concept, held focus group interviews, performed data collection. MM joined the discussion at the stage of conception, he made some important advise to YH. After data analysis, he discussed with YH again at the stage of consideration of the results, he contributed to the preparation of the final manuscript. TO participated in discussions at the stage of conception, made data analysis with YH. Contributed greatly to the theory constitution after the analysis. All of the three authors check the final manuscript and agreed the contents of it.

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