

# End-of-life care management for older adults at home by multidisciplinary professionals in Japan

Akiko Kaneda PhD  | Yuka Kanoya PhD

School of Medicine Nursing Course, Public University Corporation Yokohama City University, Japan

## Correspondence

Akiko Kaneda, School of Medicine Nursing Course, Public University Corporation Yokohama City University, 3-9 Fukuura Kanazawa-ku Yokohama City 226-0004, Japan.  
Email: [akaneda@yokohama-cu.ac.jp](mailto:akaneda@yokohama-cu.ac.jp)

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## Abstract

**Background:** Population aging is a global phenomenon, and there is an urgent need to establish community-based integrated care systems for a sustainable society. In particular, the needs of home-dwelling older adults are multifaceted, encompassing areas such as medical care, nursing care, and welfare. Therefore, it is necessary to implement comprehensive care management that utilizes social resources suitable for diverse needs. This study aims to comprehensively describe care management practices by various professionals for home-dwelling older adults in the end-of-life (EOL) period.

**Methods:** This study adopted a qualitative analysis method using conventional content analysis. We conducted semi-structured interviews of 20 multidisciplinary professionals from February to March 2020.

**Results:** Multidisciplinary professionals ensured continuity of care by implementing care management as necessary when providing care to older adults who desired to stay at home until the end. Seven categories of EOL care management practices for home-dwelling older adults by multidisciplinary professionals were generated: (1) support to enable discharge to home; (2) decision-making support that captures the intention of the older adult without missing opportunities; (3) building a team system to realize the desired life and EOL; (4) family support for the entirety of the EOL period, (5) symptom control aimed at the realization of wishes; (6) emotional support for acceptance of the EOL period; (7) spiritual support.

**Conclusions:** Multidisciplinary professionals, including care managers, collaborating in a mutually complementary manner by sharing a comprehensive understanding of care management might prevent knowledge fragmentation and ensure that older adults receive home-based EOL care.

## KEYWORDS

care management, end-of-life, homecare, multidisciplinary professionals, older adult

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## 1 | INTRODUCTION

With the extension of humans' lifespan, it is anticipated 75 years and older population group will increase, resulting in an expected increase in the number of deaths in the future.<sup>1</sup> In many countries, population aging is expected to have a significant impact on social protection systems.<sup>2-4</sup> Therefore, for a sustainable society, it is necessary to ensure that older adults can receive diverse care in the community.<sup>4,5</sup> In Japan, public long-term care insurance (LTCI) became mandatory in 2000 to meet the needs of the rapidly aging society.<sup>4</sup> The goal of the LTCI was to develop a social system of older adults to live independently regardless of disability.<sup>4</sup> In LTCI, care managers (CMs) provide care management.<sup>6</sup> The function of care management is to comprehensively assess the needs of home-dwelling older adults and coordinate, planning, and support their continuous life in the community by utilizing appropriate social resources. CMs are important professionals who are responsible for care management.<sup>6</sup> In the United States and the United Kingdom, many CMs are nurses or social workers.<sup>7</sup> In Japan, CMs come from various professional backgrounds. Approximately 70% of CMs are qualified care workers and social workers.<sup>8</sup> Previous studies have identified difficulties of Japanese CMs in responding to physical emergencies and coordinating with medical professionals.<sup>9,10</sup>

In Japan, by the year 2025, it is estimated that one in seven people will be 80 years and older.<sup>11</sup> With the extension of life expectancy and care provided over a longer time span, a new concept known as end-of-life (EOL) care has emerged, which specifically focuses on the final stage of life.<sup>12</sup> The EOL period is the period from the time when one starts contemplating death, regardless of health status, specific illness, and age.<sup>13</sup> It encompasses palliative and terminal care.<sup>13</sup> In Japan, 69.2% of individuals express a desire to spend their EOL period at home.<sup>14</sup> However, the home death rate remained at 17.3%.<sup>15</sup> In the case of older adults, 66.3% of deaths occurred in hospitals.<sup>16</sup> Older adults wish to spend their EOL period at home but are concerned about the burden it may place on their families.<sup>17,18</sup> Indeed, as the caregiving period for older adults in need of care extends, there is an expected increase in the physical, psychological, and social burdens faced by caregivers.<sup>19</sup> Therefore, to support home-dwelling older adults during the EOL period, it is necessary to cover diverse needs using different sectors such as medical, nursing, and social care to alleviate the burden on families. CMs collaborate with various professionals, older adults, and their families to provide optimal medical, nursing, and social care.<sup>20</sup> Previous studies have shown that during the EOL period, various professionals (such as visiting physicians, visiting nurses, visiting caregivers, homecare workers, discharge nurses, and medical social workers) offer care management as necessary to facilitate the continued community living of older adults.<sup>21-25</sup> However, we were unable to comprehensively describe the care management of home-dwelling older adults during the EOL period by multidisciplinary professionals.

The aim of this study is to comprehensively describe care management of home-dwelling older adults during the EOL period by multidisciplinary professionals. The significance of this study lies in the potential for promoting collaboration and cooperation among

multidisciplinary professionals, including CMs, through the shared understanding of comprehensive care management. This study may contribute to enabling home-dwelling older adults that require long-term care to live at their home until the end of their lives.

### 1.1 | Definition of terms

In this study, care management was defined as to comprehensively assess the needs of home-dwelling older adults and coordinate, planning, and support their continuous life in the community by utilizing appropriate social resources.<sup>6</sup> CMs are defined as professionals who are responsible for care management.<sup>6</sup>

## 2 | METHODS

### 2.1 | Sampling and recruitment

The participants were visiting physicians,<sup>23</sup> visiting nurses,<sup>21</sup> visiting pharmacists,<sup>23</sup> discharge nurses,<sup>22</sup> CMs,<sup>6</sup> homecare workers,<sup>25</sup> and medical social workers,<sup>22</sup> who often assist home-dwelling older adults during the EOL period. One of the researchers, AK, contacted a visiting nurse who provides EOL care at home. Then, the snowball sampling method was used to recruit participants, which started with the visiting nurse. Participants were informed about the study details and that they could withdraw their consent at any time during the study. Additionally, participants received a gift certificate worth 2000 yen for participating in the study. Recruitment was concluded once the data reached saturation (i.e., at a point of no additional data provision regarding care management practice of home-dwelling older adults).

### 2.2 | Study design

This study adopted a qualitative analysis method using conventional content analysis.<sup>26</sup> Conventional content analysis was adopted to directly derive codes and categories from textual data.<sup>26,27</sup> Additionally, this study conducted an inductive analysis to describe fragmented care management practices by multidisciplinary professionals.<sup>27</sup>

### 2.3 | Exclusion criteria

Multidisciplinary professionals with no experience in providing care for home-dwelling older adults in the EOL period were excluded.

### 2.4 | Data collection

Data collection was conducted using semi-structured interviews. On the semi-structured interviews, the questions were prepared in advance, and changes in the order of questions or the addition of new

ones were allowed based on the participants' reactions.<sup>28</sup> We were chosen this approach with the expectation of eliciting practices and perspectives of the interviewees.<sup>28</sup> Semi-structured, face-to-face personal interviews were conducted by the first author (AK) from February to March 2020 for 20 participants. AK conducted interviews lasting 40–60 min. AK interviewed participants with questions on their specific care management practices, and care management practices for the physical, psychological, and social well-being of the home-dwelling older adults who wish to spend their EOL period at home. Before the interview, AK defined care management and EOL period for the participants.

## 2.5 | Data analysis

The recorded interviews were transcribed into written text. In conventional content analysis, coding categories are derived directly from the text data.<sup>26</sup> These text data were read repeatedly to ensure a comprehensive understanding of the overall content, and specific sections describing the care management during the EOL period of older adults requiring long-term care at home were extracted.<sup>27</sup> Next, the extracted sections were carefully read and transformed into concise expressions to create codes.<sup>27</sup> The codes were compared for differences and similarities, and subcategories and categories were generated from multiple codes.<sup>27</sup> The initial coding and analysis were independently conducted by the first author (AK) and second author (YK). Subsequently, the two authors engaged in discussions and organized the coding, replacing it with more

appropriate codes.<sup>27</sup> During the process of discussing the similarities and differences in the codes and abstracting them into categories, AK and YK conducted the analysis to ensure reliability and validity.

All interviews were conducted by AK. AK and YK analyzed the same data from the categorization and arrived at the same conclusion.<sup>27</sup> AK and YK are researchers in gerontological nursing, and both hold qualifications as CMs. Additionally, to ensure the reliability of the data, the entire analysis process was reviewed by another two researchers. The two researchers were experts in nursing care of older adults and qualitative research.

## 3 | RESULTS

### 3.1 | Participants' characteristics

A summary of the study participants is shown in Table 1. The participants included three visiting physicians, three visiting nurses, three visiting pharmacists, four CMs, two home care workers, three discharge nurse, and two medical social workers. The average interview time was  $48.3 \pm 5.22$  min.

### 3.2 | End-of-life care management for older adults at home by multidisciplinary professionals

The comprehensive practices by multidisciplinary professionals from the care management perspective for older adults in need of care at

Occupation	Age	Sex	Years of experience (years in current position)	Interview time (min)
Visiting physician	46	Man	20 (5)	45
Visiting physician	51	Man	26 (12)	45
Visiting physician	46	Man	20 (10)	54
Visiting nurse	59	Woman	36 (18)	45
Visiting nurse	50	Woman	28 (16)	42
Visiting nurse	52	Woman	30 (15)	50
Visiting pharmacist	55	Man	31 (10)	45
Visiting pharmacist	36	Man	13 (6)	48
Visiting pharmacist	45	Woman	21 (17)	42
Care manager	44	Man	11 (11)	46
Care manager	50	Man	25 (25)	52
Care manager	63	Woman	12 (20)	58
Care manager	48	Woman	20 (20)	52
Home care worker	54	Woman	25 (20)	44
Home care worker	44	Woman	14 (11)	60
Discharge nurse	47	Woman	25 (2)	41
Discharge nurse	50	Woman	29(7)	49
Discharge nurse	46	Woman	24 (8)	48
Medical social worker	30	Woman	8 (8)	47
Medical social worker	28	Woman	6 (6)	53

TABLE 1 Participants' characteristics.

home during the EOL are shown in Table 2. These results consist of 7 categories and 29 subcategories. In this paper, square brackets, [], indicate a category, double quotation marks, "", indicate a subcategory, italics indicate a narration, and () indicate their respective occupations.

### 3.2.1 | [Support to enable discharge to home]

This category was generated from four subcategories as follows: "Not missing the chance to be discharged home," "Preparing welfare equipment for care at home according to the older adult's physical condition before discharge," "Proposing services considering the older adult's economic background with a focus on the entire EOL period," and "Expanding the network of social resources on a regular basis to be able to propose various local services."

In terms of activities of daily living (ADL), we assess what the individual is unable to do as compared to before hospitalization. Based on their social situation and making predictions about how they will progress, we then propose a care plan.

(Discharge nurse).

There are various reasons, like if they have not received instructions on using the total parenteral nutrition port, they cannot go home... But more importantly, we cannot miss the opportunity for them to return home.

(Visiting physician).

I consider having a network as a skill of a care manager... It would be beneficial for the older adults to have access to a wide range of social resources.

(Care manager).

### 3.2.2 | [Decision-making support that captures the intention of the older adult without missing opportunities]

This category was generated from four subcategories as follows: "Eliciting the older adult's feelings about the way he/she wishes to spend his/her life from the early stage of involvement," "Assessing the timing of decision-making support," "Providing older adults with information on the prediction of symptoms," and "In cases where the older adult and family members disagree regarding the older adult's wishes, providing information on medical knowledge and prognosis, and supporting the older adult as he/she comes to terms with the situation."

I make sure to facilitate discussions early on about how older adults want to live and what their preferences

are for their final moments. It's important to draw out those conversations effectively.

(Visiting nurse).

When there is a discrepancy between the individual's and the family's wishes... we make an effort to explore and find potential areas of compromise.

(Visiting physician).

### 3.2.3 | [Building a team system to realize the desired life and desired EOL]

This category was generated from eight subcategories as follows: "Allowing the older adult to actively participate in his/her own care management," "Fostering an atmosphere in which the care team collaborates to support the older adult in realizing his/her wishes," "Conferences for those in charge of services to discuss the prognosis and treatment plan" "Establishing a system for smooth coordination among service providers in case of sudden changes," "Establishing a 24-hour contact system," "Working with medical staff to disseminate information to the care team on noticing changes in physical conditions," "Complementing each other with necessary support without drawing boundaries between themselves and other professionals," and "Reducing the anxiety of other members of the care team."

Care management is inherently about designing it according to one's own desires and preferences.

(Visiting nurse).

I believe it's good for the older adults themselves to actively participate in their own care management.

(Visiting physician).

For example, it would be great if we could propose solutions across various professionals to help elderly people who want to go see cherry blossoms in Atami.

(Visiting physician).

I have met CMs who hold meetings with various professionals to extract their challenges and proposals, actively seeking prognostications, and solutions for the issues.

(Home care worker).

Sharing emergency contact information within the multidisciplinary professionals' team supporting the home-dwelling older adult is crucial.

(Visiting pharmacist).

There are often situations where care workers notice changes in the condition but are unable to inform the doctor.

(Visiting physician).

TABLE 2 End-of-life care management for older adults at home by multidisciplinary professionals.

Category	Subcategory	Informant's occupation						
		A <sup>1)</sup>	B <sup>2)</sup>	C <sup>3)</sup>	F <sup>4)</sup>	D <sup>5)</sup>	E <sup>6)</sup>	G <sup>7)</sup>
【Support to enable discharge to home】	Not missing the chance to be discharged home	○			○			
	Preparing welfare equipment for care at home according to the older adult's physical condition before discharge	○		○				
	Proposing services considering the older adult's economic background with an eye on the entire end-of-life period		○					
	Expanding the network of social resources on a regular basis to be able to propose various local services	○						○
【Decision-making support that captures the intention of the older adult without missing opportunities】	Eliciting the older adult's feelings about the way he/she wishes to spend his/her life from the early stage of involvement	○	○	○	○	○	○	○
	Assessing the timing of decision-making support	○	○			○		
	Providing older adults with information on the prediction of symptoms	○			○			○
	In cases where the older adult and family members disagree regarding the older adult's wishes, providing information on medical knowledge and prognosis, and supporting the older adult as he/she comes to terms with the situation	○			○	○	○	○
【Building a team system to realize the desired life and desired end-of-life】	Allowing the older adult to actively participate in his/her own care management	○	○					
	Fostering an atmosphere in which the care team collaborates to support the older adult in realizing his/her wishes	○				○	○	○
	Conferences for those in charge of services to discuss the prognosis and treatment plan					○	○	
	Establishing a system for smooth coordination among service providers in case of sudden changes	○	○	○				
	Establishing a 24-h contact system	○	○					
	Working with medical staff to disseminate information to the care team on noticing changes in physical conditions	○		○				○
	Complementing each other with necessary support without drawing boundaries between themselves and other professionals	○		○		○	○	○
	Reducing the anxiety of other members of the care team							
	Helping to ensure that there are no regrets for the family members left behind				○			
	Providing appropriate support after assessing the family's caregiving ability	○	○	○				○
【Symptom control aimed at the realization of wishes】	Explaining the process of dying with the intention of preparing the family emotionally	○	○	○	○	○	○	○
	Cooperating with medical professionals to share with the care team the outlook on the course of symptoms due to disease trajectories (cancer, failure, dementia, and senility)	○	○	○	○	○	○	○
	Not overlooking signs of sudden changes in daily life so that care is not too late	○	○	○				
	Predicting changes in the older adult's physical condition and quickly developing care plans	○	○		○			
	Sufficiently alleviating painful symptoms so that the older adults can stay at home without feeling pain	○	○	○				
	Prioritizing the older adult's comfort when treatment is given	○	○	○				

TABLE 2 (Continued)

Category	Subcategory	Informant's occupation						
		A <sup>1)</sup>	B <sup>2)</sup>	C <sup>3)</sup>	F <sup>4)</sup>	D <sup>5)</sup>	E <sup>6)</sup>	G <sup>7)</sup>
【Emotional support for acceptance of the end-of-life period】	Listening to feelings	○	○	○	○	○	○	○
	Developing a care plan in tune with the changing feelings of the older adult	○	○	○	○	○	○	○
	Respecting the older adult's faith	○	○	○	○	○	○	○
【Spiritual support】	Listening to the older adult without denying what they are saying	○	○	○	○	○	○	○
	Empathizing with the older adult's anguish over death	○	○	○	○	○	○	○

Note: The checkmark (○) indicates that there was mention of the conversation. A<sup>1)</sup>: visiting physician; B<sup>2)</sup>: visiting nurse; C<sup>3)</sup>: visiting pharmacist; D<sup>4)</sup>: care manager; E<sup>5)</sup>: homecare worker; F<sup>6)</sup>: discharge nurse; G<sup>7)</sup>: medical social worker.

We must eliminate the mindset of professionals limiting themselves to their specialized field and believing that certain tasks are not their responsibility.  
(Visiting physician).

Not being fixated on specific professions is crucial. Valuable insights often arise from different professional perspectives.  
(Visiting pharmacist).

When the older adult shows a painful expression while moving their body, the helpers become anxious about whether it is appropriate for us to move them... The care manager consults with medical professionals and relays information to the helpers.  
(Care manager).

### 3.2.4 | [Family support for the entirety of the EOL period]

This category was generated from three subcategories as follows: "Helping to ensure that there are no regrets for the family members left behind," "Providing appropriate support after assessing the family's caregiving ability," and "Explaining the process of dying with the intention of preparing the family emotionally."

As the caregiving burden on families increases, the need for family members to take a break becomes necessary. By enabling home-dwelling older adults to access short-stay services, it allows families to have the opportunity for rest and relaxation.  
(Care manager).

The family is very anxious because they have never witnessed a death at home. To prepare them mentally, it would be helpful to discuss home-based palliative care and share stories of similar caregiving experiences.  
(Care manager).

Even after the passing, the experience remains within the family, so I believe it is important to leave it as a positive experience, if possible.  
(Care manager).

### 3.2.5 | [Symptom control aimed at the realization of wishes]

This category was generated from five subcategories as follows: "Cooperating with medical professionals to share with the care team the outlook on the course of symptoms due to disease trajectories (cancer, organ failure, dementia, and senility)," "Not overlooking signs

of sudden changes in daily life so that care is not too late,” “Predicting changes in the older adult’s physical condition and quickly developing care plans,” “Sufficiently alleviating painful symptoms so that the older adults can stay at home without feeling pain,” and “Prioritizing the older adult’s comfort when treatment is given.”

Unexpected events do not happen very often. There is usually something beforehand that gives us an indication. It is crucial how we pick up on those signs and respond.

(Visiting physician).

Being proactive and responsive to changes in condition is crucial, but it can be challenging due to the need for speed and quick decision-making.

(Care manager).

We offer advice on how to approach the end of life, including the decision between aggressive treatment and pain management. Based on our observations of the level of pain, we suggest the appropriate dosage of medication to the doctor.

(Visiting pharmacist).

The main priority is the older adult’s comfort rather than treatment. Some cases, particularly those with respiratory issues, may not have an appetite and prefer not to eat to avoid breathing difficulties.

(Visiting physician).

### 3.2.6 | [Emotional support for acceptance of the EOL period]

This category was generated from three subcategories as follows: “Listening to feelings” “Developing a care plan in tune with the changing feelings of the older adult,” and “Respecting the older adult’s faith.”

Thoughts and perspectives naturally change as we are human beings. It is influenced by the situation and family dynamics at that time. Therefore, we should avoid making prescriptive statements about what should be done.

(Visiting physician).

Decisions can be changed at any time. Even if faced with unexpected challenges and a change in feelings, nurses embrace everything and provide support.

(Visiting nurse).

### 3.2.7 | [Spiritual support]

This category was generated from two subcategories as follows: “Listening to the older adult without denying what they were saying” and “Empathizing with the older adult’s anguish over death.”

In spiritual care, it is crucial to listen wholeheartedly without denying the older adult’s thoughts and feelings.

(Homecare worker).

Amidst various pains, I contemplate what happiness means to the older adult and strive to ensure they can embrace death in a state of happiness according to their own definition.

(Care manager).

## 4 | DISCUSSION

This study comprehensively described care management conducted by multidisciplinary professionals, including CMs, for home-dwelling older adults during the EOL period. In previous studies, care management had three functions: directly addressing the needs of older adults and caregivers, intermediary and coordination function, and collaboration with social resources.<sup>29</sup> In this study, it was found that various professionals assess the situation and, if necessary, provide direct or indirect care management to enable home-dwelling older adults to stay at home until the end of their lives. Multidisciplinary professionals, with a care management perspective, work to achieve home-dwelling older adults’ goals, such as [Support to enable discharge to home], [Decision-making support that captures the intention of the older adult without missing opportunities], [Building a team system to realize the desired life and desired EOL], [Family support for the entirety of the EOL period], [Symptom control aimed at the realization of wishes], [Emotional support for acceptance of the EOL period], and [Spiritual support].

On [Support to enable discharge to home], effective collaboration between discharge nurses and visiting physicians is crucial in identifying opportunities for discharge and ensuring timely referrals to CMs without missing the chance to facilitate discharge to home. In [Decision-making support that captures the intention of the older adult without missing opportunities], it is important to provide medical care and caregiving information necessary for decision-making through multidisciplinary collaboration on early time by visiting physicians during the EOL period and to facilitate alignment between the preferences of the family and the older adult. In providing home care, it is necessary to [Build a team system to realize the desired life and desired EOL]. It is important to collaborate with professionals from different disciplines while considering their perspectives and working together with a shared understanding of the goals. The results from this study were consistent with results of previous studies that demonstrated the need for a team approach<sup>4,30,31</sup> in bridging between and among care providers,<sup>31</sup> accepting diverse values, and reducing family caregivers’ anxiety about medical aspects of care.<sup>32</sup> The [Family support for the entirety of the EOL period] category highlighted the importance of considering the family’s capabilities and providing discharge instructions tailored to their abilities, enabling them to provide care at home without difficulty. Additionally, consistent with prior research, it is important to prepare for EOL in

a way that prevents regrets for family members.<sup>32</sup> For the category [Symptom control aimed at the realization of wishes], cooperation between professionals offering medical, nursing, and welfare care was shown to be particularly important in predicting the trajectory of the disease, preparing a care plan,<sup>32</sup> and ensuring a medical system for palliation.<sup>2,3,33</sup> This study's results demonstrated that CMs, visiting physicians, visiting nurses, and visiting pharmacists were also leading the way. In a previous study, it was reported that CMs who were care workers or social workers needed advice regarding medical aspects.<sup>34</sup> Medical professionals must be consciously involved in supporting CMs. Inadequate symptoms control may lead to unwanted hospitalization; therefore, it is extremely important for medical professionals to collaborate care management together. In the case of [Emotional support for acceptance of the EOL period], previous studies have reported that educating family members about preparation for death<sup>35</sup> and [Spiritual support], which includes support for positive meaning-making,<sup>34</sup> are effective strategies. In this study, multidisciplinary professionals reported involvement with older adults that included listening and continuing to monitor the patient's fluctuating feelings.

This study integrated the narratives of multidisciplinary professionals, including CMs, about the care management needed by older adults at home during the EOL period. In the EOL period, not only caregiving medical needs increase.<sup>19</sup> In the future, community care will be required to support a society that will experience the deaths of many older adults among the aging population. Multidisciplinary professionals sharing care management could be expected to enhance collaboration and coordination in community care. The sharing of care management during the EOL period among multidisciplinary professionals, and each professional's exercise of care management functions as an additional function of his/her own professional role will enable the smooth and continuous provision of integrated care and fulfillment of the wishes of older adults approaching death. In this study, there are several limitations. First, there may be a bias in the variation of participants. In the local community, there are also various professionals supporting home-dwelling older adults, such as welfare equipment providers and visiting bathing facilities. Second, the participants may have social desirability response bias. Future research, such as anonymous self-administered questionnaires, is necessary. Third, the results of this study cannot be applied in all contexts due to cultural and social differences among countries. However, as we know, this is the first study in the world's leading aging society that comprehensively describes the care management conducted by multidisciplinary professionals to support home-dwelling older adults in their home until the end of their lives. By sharing these results among multidisciplinary professionals, there is a potential for developing a strong, mutually complementary, layered care management approach.

## 5 | CONCLUSIONS

Multidisciplinary professionals, including CMs, collaborating in a mutually complementary manner by sharing a comprehensive

understanding of care management might prevent knowledge fragmentation, and efficient and effective care management can be provided to older adults that require home-based EOL care.

## ACKNOWLEDGMENTS

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICS APPROVAL STATEMENT

The study was approved by the Medical Research Ethics Committee of Yokohama City University (approval number: A200200001).

## PATIENT CONSENT STATEMENT

Study participants were provided written and oral explanations of the study; all participants gave their consent.

## ORCID

Akiko Kaneda  <https://orcid.org/0000-0001-8121-4219>

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