



## Original article

# Consideration points in the decision making in chronic respiratory diseases

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## Abstract

**Objective:** Even though dynamic multidisciplinary team discussions are crucial for end-of-life care management and decisions concerning chronic obstructive pulmonary disease (COPD), the details of the discussion contents remain poorly understood. This study aimed to identify essential considerations in decision-making for patients with chronic respiratory diseases to enhance a consensus-based approach.

**Materials and Methods:** A qualitative content analysis of focus group conversations on published clinical case reports in the Japanese community about end-of-life care for patients with chronic respiratory disorders was conducted. The cases were searched through Igaku Chuo Zasshi (ICHUSHI) and Google in February 2021, using the keywords: “COPD”, “chronic respiratory diseases”, and “end-of-life care”. A total of 41 healthcare professionals participated in the focus group discussions.

**Results:** Four major themes evolved from the qualitative content analysis: unpredictable disease prognosis and stages, low awareness of patients on disease severity, acute exacerbations, and home oxygen therapy (HOT). The participants perceived that assessment of severity and prognosis in chronic respiratory diseases such as COPD was a core discussion point to enhance patients’ decision-making. The study’s findings also indicated that healthcare providers evaluate the influence of acute aggravation of the condition on patients’ perceived health status and decision-making.

**Conclusion:** The study reaffirms the significance of informed consent in patients with chronic respiratory disease. It details how, after a thorough assessment of disease severity, patients are given personalized explanations of standardized HOT. This approach ensures they fully understand the unpredictable nature and various stages of their condition resulting from acute exacerbations.

**Key words:** decision-making, chronic respiratory diseases, qualitative content analysis

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## Introduction

Chronic respiratory diseases exert a profound and enduring impact on the airways and various anatomical structures within the lungs. Foremost among these maladies is

chronic obstructive pulmonary disease (COPD), an ailment distinguished by its status as a persistent, inflammatory lung condition that constricts the vital airflow originating from the lungs<sup>1</sup>. Those afflicted by COPD endure a gamut of distressing symptoms, encompassing but not limited to labored breathing, a persistent cough, and the generation of excessive mucus (sputum), conspicuous wheezing, unwarranted fatigue, and an unintentional loss of body weight<sup>2</sup>. The relentless progression of COPD poses a substantial threat, establishing it as the third leading cause of death globally. To put the staggering toll in perspective, the year 2019 alone bore witness to a chilling 3.23 million fatalities attributable to COPD<sup>2</sup>. The complex and extensive end-of-life needs of patients grappling with COPD arise from the relentless nature of this condition. Typically, the transition into the ter-

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terminal phase is characterized by a protracted decline in functional capacity, invariably accompanied by a burdensome array of symptoms, recurrent acute exacerbations, profound emotional distress, and a prevailing sense of social isolation<sup>3,4</sup>. It is also imperative to underscore that while COPD primarily stands as a terminal condition, its trajectory may be further complicated by the presence of concurrent medical conditions, such as cardiovascular disease<sup>1</sup>.

COPD poses intricate challenges, notably marked by the recurring episodes of respiratory failure, demanding nuanced considerations to guide decision-making throughout the disease, which ultimately culminates in an irreversible outcome<sup>5</sup>. In addressing the unique circumstances that unfold over this journey, it becomes imperative to consider the distinctive needs of the older adult population. These individuals often present with complex and highly specific biopsychosocial and functional disorders, necessitating a holistic, multidisciplinary approach to ensure comprehensive and tailored care<sup>6,7</sup>. This emphasis on comprehensive care calls for the convening of dynamic multidisciplinary team meetings and discussions, which hold a pivotal role in the management of end-of-life care and the facilitation of well-informed decisions<sup>5</sup>. To enhance the understanding of the crucial facets entailed in decision-making support for chronic respiratory diseases, it is essential to undertake a thorough review and synthesis of the available body of evidence. Such synthesis equips multidisciplinary professionals with a wealth of valuable references, enabling them to navigate the complexities of decision-making with enhanced confidence and to provide optimal care to individuals grappling with chronic respiratory diseases. Relying on these evidence-based insights empowers healthcare teams to address dilemmas and conflicts effectively, ensuring that individuals receive the highest standard of care.

Although there is an existing body of research that has delved into multidisciplinary case discussions and practical approaches pertaining to COPD<sup>8–10</sup>, a noticeable gap in the literature lies in the scarcity of studies that explicitly concentrate on the practices of multidisciplinary case discussions concerning decision-making support for daily activities, medical care, and prospective treatments for patients afflicted by chronic respiratory diseases, including COPD. Furthermore, the specific details and content of these discussions remain inadequately elucidated. Consequently, the primary objective of this study was to discern the pivotal factors warranting consideration in the context of decision-making support for patients grappling with chronic respiratory diseases. The study's core aim revolved around fostering a consensus-based approach among healthcare professionals who play a crucial role in the care of these patients. By thoroughly exploring and clarifying the various facets and nuances involved in these decision-making processes, this research endeavors to make a meaningful

contribution to the evolution of more effective strategies for decision-making support in individuals facing the challenges of chronic respiratory diseases, such as COPD.

## Materials and Methods

The methodology employed in this study hinged on qualitative content analysis<sup>11</sup>. The analysis was rooted in focus group discussions (FGDs) centered on published clinical case reports within the Japanese population. These case reports pertained specifically to end-of-life care for patients afflicted by COPD and other chronic respiratory diseases. Through this approach, the study sought to gain deeper insights and understanding regarding the nuanced aspects of end-of-life care within the context of these chronic respiratory conditions, as experienced by the Japanese population.

### Preparation for case scenarios

To acquire pertinent published case reports with a specific focus on end-of-life care for patients grappling with chronic respiratory diseases, the authors conducted a thorough search. This search encompassed the utilization of two primary sources: the widely recognized Japanese bibliographic database “Igaku Chuo Zasshi (ICHUSHI)” and the ubiquitous web search engine Google. This search was conducted in February 2021, and it involved the use of carefully selected keywords, including “COPD”, “chronic respiratory diseases”, and “end-of-life care”. Through these strategically chosen keywords and the two sources, the authors aimed to retrieve a comprehensive and representative collection of case reports that would serve as valuable source material for their study.

### Eligibility criteria and selection process

The process of selecting case reports for inclusion in the study began with the screening of titles and abstracts to determine their eligibility. Inclusion criteria encompassed any case report that demonstrated decision-making support in the context of chronic respiratory diseases. Reports focusing on decision-making in conditions other than chronic respiratory diseases, as well as articles concentrating on chronic respiratory diseases but not related to decision-making, were excluded from consideration. To ensure a focus on Japanese case reports, only those written in Japanese were considered.

Importantly, the search was not restricted to academic papers, but instead encompassed a wide range of clinical case reports, irrespective of their publication year. This decision to cast a wider net was motivated by the aim to amass a substantial body of publications, ensuring a diverse array of discussion points relevant to decision-making support for chronic respiratory diseases. After this selection process, a total of 13 cases were identified and extracted for further analysis and examination. The inclusion flow diagram has

been demonstrated in Figure 1. The characteristics and details of the cases are demonstrated in Table 1.

## Participant recruitment

The authors adopted a convenient recruitment approach to assemble a group of focus group participants for this study. Eligibility criteria were extended to healthcare professionals, including physicians, nurses, and care providers, who were actively engaged in community-based integrated care, irrespective of their level of clinical experience in caring for patients with chronic respiratory diseases. Between February 2016 and July 2017, the primary author (YH) took on the role of conducting and facilitating online focus group discussions focused on case reports related to chronic respiratory diseases. These discussions were carried out through the Zoom platform.

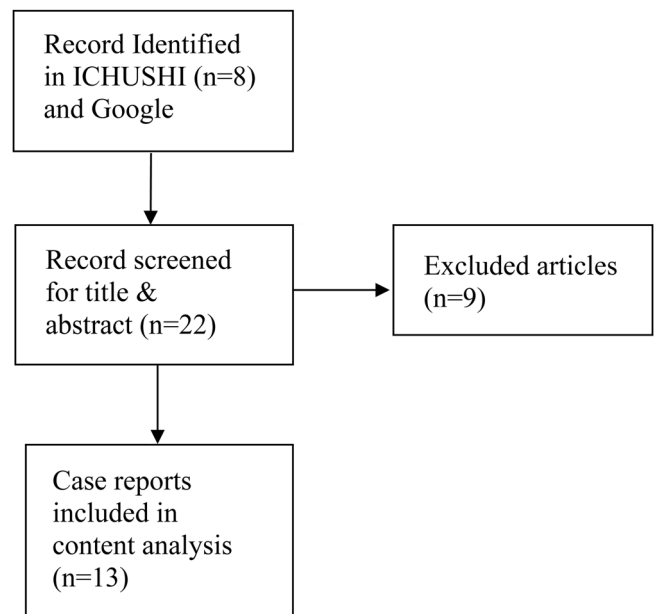
Each discussion session encompassed an examination of all 13 identified case reports, with a designated time allocation of 20 minutes for each case. To accommodate the extensive nature of the discussions, some participants opted to divide a single focus group discussion into multiple sessions. During the discussions, participants were individually prompted to identify and express their thoughts on the key considerations presented in each case report. The facilitator (YH) provided a succinct description of the case scenario, following which participants were encouraged to share their insights. To streamline the efficiency and effectiveness of the discussions, participants were instructed to respond with concise single-word utterances or short phrases in rapid succession, and these exchanges persisted until no new ideas or perspectives were forthcoming from the participants. The characteristics of the participants of FGDs have been provided in Table 2.

## Coding and analysis

To analyze the data, the voices of the participants were recorded and subsequently transcribed. The recorded utterances were then transformed into concise single-sentence labels, representing units of meaning. In a similar vein, the texts of the 13 case reports were also converted into single-sentence labels. These labels from the case reports were merged with the labels derived from the FGD data.

For qualitative content analysis, an inductive approach was adopted. Initially, the authors selected the most representative labels and organized them into groups through an inductive process. Labels that were unrelated to decision-making were excluded, while those sharing substantial qualitative similarities within a group were amalgamated into a single label. This process was then iterated multiple times until the number of created groups was reduced to ten or fewer categories.

Subsequently, a key phrase, capturing the fundamental essence of each group of labels, was coined by the authors.



**Figure 1** Flow diagram of the included case reports.

This key phrase served as a succinct summary of the core meaning embedded in that particular group. Finally, the groups of labels derived at the final stage were organized into several overarching themes, providing a structured framework for the analysis of the data.

## Ethical consideration

This study was approved by the Bioethics Review Committee of Nagoya University School of Medicine before the investigation (approval number: 2015-0444). Written informed consent was obtained from all the participants.

## Results

The focus group discussions in this study engaged a cohort of 41 healthcare professionals. This diverse group comprised one physician, one physical therapist, seven nurses, and 32 care providers. The age range within the participant pool was considerable, with a mean age of 47 years, spanning from 28 to 64 years. Their collective professional experience was equally extensive, with an average of 20 years of practice, ranging from 5 to 40 years.

The qualitative content analysis of the focus group discussions yielded four prominent themes that emerged from the data: Unpredictable disease prognosis and stages, Low awareness of patients on disease severity, Acute exacerbations, and Home oxygen therapy (HOT). These overarching themes revolve around the following key aspects, shedding light on the intricate dynamics influencing decision-making support for patients grappling with chronic respiratory diseases.

**Table 1** The characteristics of the included case reports

Author and year of publication	Age and sex of the participant	Disease of concern	Major theme
Case 1 Fujikawa <i>et al.</i> 2008	72-year-old woman	Pulmonary tuberculosis sequelae and bronchiectasis	Life review
Case 2 Wakabayashi <i>et al.</i> 2017	75-year-old man	Chronic obstructive pulmonary disease (COPD)	Labored breathing
Case 3 Yoshizawa <i>et al.</i> 2018	63-year-old man	Idiopathic interstitial pneumonia and chronic heart failure	Morphine
Case 4 Yoshizawa <i>et al.</i> 2018	84-year-old woman	Old cerebral infarction and multiple arthropathy	Incredible end-of-life wishes
Case 5 Kamide Kei <i>et al.</i> 2020	90-year-old man	COPD and postoperative colon cancer	Conflict in end-of-life wishes between patient and family
Case 6 Takegawa <i>et al.</i> 2011	70-year-old man	Type-2 diabetes and idiopathic interstitial pneumonia	Attitude toward home oxygen therapy (HOT)
Case 7 Japanese Nursing Association. Accessed on September 2, 2022	78-year-old man	COPD	Terminal sedation
Case 8 Accessed on September 10, 2022	78-year-old woman	Chronic sinusitis and bronchiectasis	Patient's deep trust in a hospital physician
Case 9 Watanabe <i>et al.</i> 2018.	76-year-old man	COPD	Living without HOT
Case 10 Accessed on September 10, 2022	82-year-old woman	Advanced dementia and COPD	Family satisfaction with home end-of-life care
Case 11 accessed on August 2, 2022	90-year-old woman	Cerebral infarction sequelae and COPD	Joyful respiratory rehabilitation
Case 12 Japan Geriatrics Society. Accessed on September 8, 2022	91-year-old man	COPD	Strong desire to die at home
Case 13 Takegawa <i>et al.</i> 2012	67-year-old man	Idiopathic interstitial pneumonia	Heart-to-heart conversation

## Unpredictable disease prognosis and stages

The focus group discussions shed light on the formidable challenges brought about by the capricious nature of disease prognosis and the diverse stages of chronic respiratory diseases. Healthcare professionals participating in the discussions conveyed their struggles in reliably foreseeing the progression and outcome of conditions like COPD. The inherent uncertainty surrounding the disease's trajectory emerged as a significant hurdle in the process of decision-making and in formulating comprehensive plans for the future care of patients. The erratic and unpredictable trajectory of these chronic respiratory conditions, often marked by acute exacerbations, poses a significant challenge for healthcare professionals. The uncertainty surrounding when to initiate discussions pertaining to decision-making causes legitimate concern among these healthcare providers.

*"I am afraid that his physician did not estimate prognosis accurately, nor has he known it"*

(Fifty-year-old man, Physician, Aichi, Case 7)

*"Appropriate timing to initiate advance care planning is difficult, especially for individuals living alone with*

*COPD. Such patients often experience acute exacerbation and death without discussing end-of-life care preferences"* (Fifty-five-year-old man, Physical Therapist, Akita, Case 8)

## Low awareness of patients on disease severity

Healthcare professionals participating in the discussions stressed the prevalent issue of patients having a restricted awareness of the severity of their chronic respiratory diseases. This lack of understanding frequently resulted in unrealistic expectations and posed a significant obstacle to effective decision-making. As a consequence, some patients remained so unaware of the severity of their condition that they were unable to endorse guideline-recommended therapies and medications.

*"If he can't imagine how distressed dyspnea must be for himself, the patient may express unrealistic end-of-life wishes"* (Fifty-seven-year-old-woman, Nurse, Aichi, Case 2)

## Acute exacerbations

Participants in the discussions highlighted that individuals, especially those with chronic respiratory diseases like

**Table 2** The characteristics of the participants of focus group discussions (FGDs)

Serial no	Age of the participants	Sex of the participant	Geographic location (Prefecture)	Profession	Years of experience
1	50	Male	Aichi	Physician	26
2	64	Female	Iwate	Nurse	32
3	56	Female	Iwate	Nurse	26
4	44	Female	Iwate	Nurse	22
5	57	Female	Aichi	Nurse	35
6	55	Female	Aichi	Nurse	34
7	63	Female	Gifu	Nurse	40
8	42	Female	Gifu	Nurse	20
9	48	Male	Akita	Care manager	18
10	44	Male	Akita	Care manager	14
11	36	Male	Akita	Care manager	16
12	55	Female	Akita	Care manager	30
13	52	Female	Akita	Care manager	22
14	52	Female	Akita	Care manager	20
15	52	Female	Akita	Care manager	20
16	46	Female	Akita	Care manager	18
17	46	Female	Akita	Care manager	16
18	44	Female	Akita	Care manager	15
19	41	Female	Akita	Care manager	12
20	34	Female	Akita	Care manager	12
21	32	Female	Akita	Care manager	8
22	30	Female	Akita	Care manager	7
23	49	Male	Iwate	Care manager	11
24	64	Female	Iwate	Care manager	30
25	54	Female	Iwate	Care manager	30
26	42	Female	Iwate	Care manager	8
27	41	Female	Iwate	Care manager	10
28	48	Male	Tokyo	Care manager	22
29	40	Male	Tokyo	Care manager	15
30	50	Female	Tokyo	Care manager	20
31	55	Female	Aichi	Care manager	32
32	50	Female	Aichi	Care manager	30
33	54	Female	Akita	Chief professional caregiver	24
34	45	Female	Akita	Chief professional caregiver	14
35	36	Female	Akita	Chief professional caregiver	16
36	33	Female	Akita	Chief professional caregiver	5
37	33	Female	Iwate	Chief professional caregiver	6
38	28	Female	Iwate	Chief professional caregiver	6
39	55	Male	Gifu	Professional caregiver	32
40	55	Female	Gifu	Professional caregiver	33
41	55	Male	Tokyo	Physical therapist	25

COPD, may encounter exacerbations as they approach the end of life. These exacerbations can trigger heightened anxiety, resulting in a deterioration of their overall condition and a progression of psychological distress. As a result, patients who have experienced exacerbations are more prone to altering their wishes and preferences compared to individuals dealing with chronic nonrespiratory diseases.

*“After they experience unendurable dyspnea or syncope once, patients with a chronic respiratory disease may*

*have a positive attitude on home oxygen therapy”*  
(Thirty-six-year-old-woman, Professional Caregiver, Akita, Case 13)

### Home oxygen therapy (HOT)

Long-term HOT enhances survival and reduces dyspnea in patients with hypoxic chronic respiratory insufficiency, and is covered by Japanese medical insurance. However, numerous studies suggest that the quality of life for patients commencing HOT can be significantly compromised due

to prevalent emotional disorders. Many patients feel embarrassed by their oxygen cylinders and tanks, believe that HOT restricts their daily activities, and view themselves as seriously ill, leading to self-discrimination. This perception has made some individuals with chronic respiratory diseases hesitant to adopt HOT.

*“Some patients with severe COPD hate to admit their deteriorating condition and refuse to increase oxygen flow rate”* (Fifty-year-old woman, Care Manager, Aichi, Case 9)

*“He seems to be so unaware of his condition that he tried to set the oxygen flow rate to the lowest level as long as possible”* (Fifty-five-year-old woman, Professional Caregiver, Gifu, Case 6)

## Discussion

The study highlights the critical importance of obtaining informed consent from patients with chronic respiratory diseases. It calls for healthcare professionals to conduct thorough discussions, focusing extensively on the assessment of disease severity, to ensure patients have a comprehensive and accurate understanding of their condition. Particularly, the discussions shed light on a significant issue: patients' awareness of the seriousness of their chronic respiratory conditions. Many patients might not fully understand the severity of their illness, which can affect their willingness to make informed decisions. By providing standardized HOT tailored to each individual's unique circumstances, patients can gain the necessary knowledge to make informed decisions about their healthcare.

The study's findings brought to light the concerns expressed by physicians regarding the timing of initiating decision-making discussions with patients affected by chronic respiratory diseases. The unpredictable nature of these illnesses created a sense of uncertainty regarding when it was most appropriate to engage in these crucial conversations. In contrast to diseases such as cancer or other non-cancer chronic conditions, where a patient's capacity to make decisions and effectively communicate about end-of-life care typically declines as the disease progresses<sup>12–14</sup>, the context of chronic respiratory diseases like COPD presents unique challenges. Sudden declines in capacity can occur due to acute respiratory failure and cognitive impairment triggered by hypoxia<sup>5</sup>. To address this challenge, prior studies and literature have recommended the early initiation of decision-making discussions for patients with chronic respiratory diseases, irrespective of the specific disease<sup>15, 16</sup>.

However, it's essential to recognize that patients who do not perceive death as imminent may not feel an urgent need for these discussions<sup>17</sup>. Striking the right balance between initiating discussions neither too late nor too early becomes crucial. Therefore, decision-making discussions for patients grappling with chronic respiratory diseases should com-

mence earlier than for other advanced illnesses. This approach should be characterized by a continuous process that adapts to the patient's changing health states<sup>5, 18</sup>. As necessary, these discussions can become more specific, addressing medical care and treatment preferences<sup>19</sup>.

Patients' lack of awareness regarding the stage of their disease hinders their ability to make informed decisions. Severity assessment algorithms for chronic respiratory diseases like COPD often incorporate respiratory symptoms such as shortness of breath during daily physical activities and persistent cough<sup>20</sup>. However, these symptoms may not manifest until significant lung damage has already occurred, partially due to reduced physical activity levels<sup>21</sup>. Spirometry is the most commonly used pulmonary function test to assess lung function, specifically measuring the amount and speed of airflow during inhalation and exhalation<sup>22, 23</sup>. Despite guidelines recommending the use of spirometry to assess disease severity in patients with chronic respiratory diseases, it is not consistently implemented in communities. This is primarily because primary care physicians may not fully recognize its utility in the diagnosis and management of these conditions<sup>24, 25</sup>.

Patients' end-of-life care preferences can evolve, regardless of the specific disease, as their health status changes<sup>26</sup>. Similarly, in line with previous studies focusing on decision-making among COPD patients<sup>5, 27</sup>, the findings of this study also indicated that acute exacerbations of chronic respiratory diseases can significantly impact the decision-making process and its content. Frequent exacerbations, particularly in patients with severe respiratory disease, not only accelerate disease progression but also contribute to increased mortality<sup>28</sup>. As a result, patients with frequent exacerbations face a dual burden of chronic respiratory disease: they experience distressing symptoms that suggest impending death, while also experiencing a more rapid decline in lung function, decreased quality of life, and reduced exercise performance. To address these challenges, healthcare professionals should initiate decision-making support before patients' health significantly deteriorates, without waiting until they are in the advanced stages of their illness or close to death. In cases where patients experience frequent exacerbations, the decision-making process should be continually revisited and revised to adapt to their evolving health status. By taking a proactive approach to decision-making support, healthcare professionals can better meet the needs of patients with chronic respiratory diseases, considering the impact of exacerbations and ensuring that decisions align with patients' preferences and goals of care throughout their disease trajectory.

Although HOT is frequently prescribed for individuals with chronic respiratory diseases to alleviate symptoms and enhance physical capacity, the study results indicate that some patients are often hesitant to follow physicians'

recommendations for HOT, largely due to stigmatization. A recent systematic review highlighted the ongoing challenges physicians face in prescribing oxygen and underlined the need for additional qualitative studies to explore the lived experiences of people with chronic respiratory diseases using HOT<sup>29</sup>). This study calls for a reassessment of the stigma associated with HOT, identifying the barriers it creates to optimizing oxygen therapy. This is essential for developing a systematic and theoretical framework to understand and modify patients' attitudes towards HOT.

There are some study limitations of this study. First, the discussion group facilitator was a physician (the last author, YH), and this might have prevented participants from speaking frankly and giving socially desirable responses. Second, since the FGDs touched upon legal and ethical issues, social workers facing several legal and ethical issues in social work practice throughout their careers were invited to take part in the discussions. However, very few accepted the invitation. In the study, numerous physicians and nurses with extensive experience in home respiratory care were invited to participate. However, the recruitment and selection process resulted in an insufficient number of physician or nurse participants, hindering the comparison of healthcare professionals' views in the FGDs. Third, the study's time constraints due to a pile of cases discussed might have prevented participants from brainstorming exhaustively. The lack of comprehensive qualitative data hindered the identification of differences in discussion content between COPD and other chronic respiratory diseases. Finally, to facilitate brainstorming, participants were asked to provide open-ended responses to a single open-ended abstract question: "What do you think of this case? or what makes you annoyed in this case?" Therefore, some participants who were not familiar with ethical considerations may have had difficulty identifying underlying ethical questions to discuss.

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## Conclusion

The present study identified essential consideration points in decision-making support for patients with chronic respiratory diseases through a content analysis of clinical case discussions. The results revealed that among patients with chronic respiratory disease, the unpredictability of the illness trajectory made their physicians worry about the timing of initiation of decision-making discussion. The results also revealed that some patients were so unaware of the disease severity that they could not agree to guideline-recommended therapies such as home oxygen therapy, and confirmed that patients' end-of-life care preferences can change over time because the change in health status may prompt change about their preferences. Unpredictable disease prognosis and stages caused by acute exacerbation should be also taken into consideration among healthcare professionals.

**Ethical approval:** This study was approved by the Bioethics Review Committee of Nagoya University School of Medicine before the investigation (approval number: 2015-0444). Written informed consent was obtained from all the participants.

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**Conflict of interest:** None declared.

**Author contribution:** Conceptualization: WM, KM-SUR, TM, YH conceptualization; Methods: KMSUR, YH; Analysis: WM, TM, YH; First draft: WM, KMSUR, TM, YH; Review and finalize: WM, KMSUR, TM, YH

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