



Original Article

# Nurses' Perceptions Regarding End-of-life Care for Individuals with Non-cancer Diseases on Non-invasive Positive Pressure Ventilation-dependent: A Qualitative and Descriptive Study

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## ABSTRACT

**Objectives:** Palliative care is essential for patients requiring respiratory assistance through non-invasive positive pressure ventilation (NPPV). This study aimed to describe nurses' perception of individuals with NPPV and non-cancer terminal diseases in various clinical settings.

**Material and Methods:** This qualitative and descriptive study was conducted using semi-structured interviews with audio recordings with advanced practice nurses from different clinical settings and obtained their perceptions of end-of-life care for patients with NPPV.

**Results:** Five categories of nurses' perceptions were extracted: Difficulty with an uncertain prognosis, differences in symptom management by type of disease, benefits and weaknesses of NPPV on palliative care, influence of physicians' attitude toward palliative care and the nature of the medical institutions and influence of patient's age in palliative care.

**Conclusion:** The nurses' perceptions showed differences and similarities across disease types. There is a need for skills improvement regardless of disease type to minimise the side effects of NPPV. Advanced care planning based on disease-specific characteristics and age-appropriate support and integration of palliative care into acute care is needed for terminal NPPV-dependent patients. Interdisciplinary efforts, as well as the pursuit of expertise in each field, are needed to provide good palliative and end-of-life care for NPPV users with non-cancer diseases.

**Keywords:** Non-cancer, Palliative care, Non-invasive positive pressure ventilation, Nurse, End-of-life

## INTRODUCTION

Palliative care services have focused on patients with advanced-stage cancer,<sup>[1,2]</sup> despite non-cancer patients accounting for two-thirds of those requiring palliative care services.<sup>[3]</sup> Although later than other developed countries, Japan has begun to focus on palliative care for non-cancer patients.<sup>[4]</sup>

Palliative care is more difficult for non-cancer patients because of an uncertain prognosis.<sup>[5]</sup> Since patients with respiratory and cardiovascular diseases deteriorate gradually with repeated remissions and exacerbations, it is more difficult to predict end-of-life for these patients compared with cancer patients.<sup>[2]</sup> The illness trajectory of these conditions has been modified by recent advances in symptom management, such as the use of ventilators for respiration and gastrostomy for nutritional management.

Respiratory failure in patients with chronic heart failure, chronic obstructive pulmonary disease and amyotrophic lateral sclerosis (ALS)/motor neuron disease is being managed with non-invasive positive pressure ventilation (NPPV).<sup>[6]</sup> NPPV is a nasal or face mask type ventilator shown to be beneficial in improving survival rates<sup>[7,8]</sup> and has been widely used in hospital and home care settings.<sup>[6]</sup>

There is a point where NPPV is no longer capable of providing palliation for respiratory difficulties as the disease progresses. There is a need to focus on the development of palliative care in situations where NPPV is no longer effective. A previous study showed that palliative care was not sufficiently provided for patients with neuromuscular diseases using NPPV at the end of life.<sup>[9,10]</sup> Therefore, it is necessary to understand the end-of-life care situation of NPPV users from an interdisciplinary perspective.

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## Objective

This study focused on nurses' perception because nurses are experts in medical care to support patients and their families. The purpose of this study was to describe how nurses perceived the end-of-life for patients with non-cancer diseases on NPPV, to consider good palliative and end-of-life care.

## MATERIALS AND METHODS

### Study design and participants

This was a qualitative and descriptive study. Since this study presumed to deal with complicated issues including ethical dilemma, the subjects were certified advanced practice nurses (either certified nurses or certified nurse specialists) who had experience in caring for patients on NPPV. We excluded those who only had experience caring for NPPV users with cancer. Convenient sampling was employed and nurses from four different clinical settings in the Kanto region participated in this study: Two certified nurse specialists in gerontological nursing, one certified nurse in chronic respiratory nursing and one certified nurse in intensive care nursing.

### Data collection

Face-to-face semi-structured interviews were conducted with participants by one researcher and one or two research assistants. The study participants were asked to describe their experience in providing support to two or three, currently deceased, then NPPV-dependent non-cancer individuals within the past 2 or 3 years. The question items included in the interview guide are shown in [Table 1]. All interviews were recorded with a voice recorder with consent from the participants.

### Data analysis for qualitative data

The qualitative inductive analysis was performed in reference to the analysis of multiple case studies<sup>[11]</sup> and based on the method proposed by Greg.<sup>[12]</sup> The interview data were transcribed verbatim. The verbatim transcripts were carefully read and abridged and careful to not lose semantic content. Those were first analysed individually and subcategories were extracted. The categories were extracted from these subcategories according to similarity, with cross-referencing among the participants. In the qualitative analysis process, this study employed constant comparative analysis to ensure trustworthiness. The analysis was also supervised by a nurse with a master's degree and a nurse with a doctorate degree who had substantial experience with qualitative inductive analysis.

### Ethical considerations

This study was approved by the ethical committee of the author's university (approval number: HS2016-061). All participants' signatures were obtained to signify their

**Table 1:** Question items included in interview guide.

Participants' characteristics
Age
Gender
Qualification
Years of nursing experience
Workplace
Characteristics of each patient the participants supported
Age
Gender
Disease
NPPV use
Living place
Patients' conditions nearing death
Participants' views based on their experience in caring for terminal non-cancer patients depend on NPPV
NPPV: Non-invasive positive pressure ventilation

informed consent after the researcher provided oral and written explanations. To ensure confidentiality, the participants were asked not to disclose the identity of the patients.

## RESULTS

### Demographic characteristics of participants and patients [Tables 2 and 3]

The participants were nurses in their late 30s or 40s, and their years of nursing experience ranged from 12 to 22 years. From these participants, we collected data on ten terminally ill non-cancer patients who were on NPPV until the moment of death.

Out of ten patients, two suffered from respiratory diseases, three suffered from heart diseases and five suffered from neuromuscular diseases. There were two patients in their 20s, two in their 60s, three in their 70s and three in their 80s or older at the time of their death. All patients died in the hospital. NPPV was initiated as a standard treatment for chronic respiratory failure for eight patients; the other two patients were initiated on NPPV during an acute exacerbation. There was no specialised palliative care available to any of the patients.

### Nurse's perception of end-of-life for individuals with NPPV and non-cancer [Table 4]

Five categories were identified regarding how nurses perceived the end-of-life for individuals with NPPV and non-cancer. The categories are described in the following sections. Categories are *Italic* and underlined and subcategories are denoted by <>.

#### *Difficulty with an uncertain prognosis*

This category consisted of two subcategories. <Unexpected death> was extracted from Nurses 1 and 3. Nurse 1

**Table 2:** Characteristics of participants.

Nurse ID	Age	Gender	Qualification (Speciality)	Years of Nursing experience	Workplaces
1	Late 40s	F	CNS (Gerontological nursing)	21 years	Mixed care hospital
2	Late 40s	F	CN (Intensive care nursing)	22 years	Acute care hospital
3	Late 30s	F	CNS (Gerontological nursing)	12 years	Home visiting nursing station
4	Late 40s	F	CN (Chronic respiratory nursing)	22 years	Long-term care hospital

CNS: Certified nurse specialist, CN: Certified nurse

**Table 3:** Demographic characteristics of patients.

Case ID	Age	Gender	Types of disease	Disease	NPPV use	NPPV use duration	Living place
					Before approaching death or admission		
Case A	60s	M	Neuromuscular	ALS	Intermittent	6 months	Home
Case B	70s	M	Ditto	ALS	Intermittent	3 months	Home
Case C	70s	M	Circulatory	HF	No use	0	Home
Case D	90s	F	Ditto	HF	No use	0	Home
Case E	70s	M	Ditto	dilated cardiomyopathy	Intermittent	1 year	Home
Case F	60s	F	Respiratory	atypical microbacteriosis	Intermittent	1 year	Home
Case G	80s	M	Ditto	COPD	Intermittent	3 years	Home
Case H	70s	F	Neuromuscular	Muscular dystrophy	Constant	over 20 years	Hospital
Case I	20s	M	Ditto	Muscular dystrophy	Night only	7–8 years	Home
Case J	20s	M	Ditto	Muscular dystrophy	Night only	10 years	Home

**Table 4:** Nurses' perceptions of end-of-life care for NPPV users with non-cancer diseases.

Categories	Ns. 1	Ns. 2	Ns. 3	Ns. 4
Subcategories	CNS	CN	CNS	CN
Difficulty with uncertain prognosis				
Unexpected death	✓		✓	
Difficulty in predicting whether patients recover or not		✓	✓	
Differences in symptom management by type of diseases				
Impression that opioids do not work well in ALS unlike cancer pain	✓			
Limited treatment choices for patients with pulmonary diseases			✓	
Difficulties in establishing a home care support system for patients with pulmonary diseases			✓	
Differences between muscle dystrophy and ALS				✓
Benefits and weaknesses of NPPV on palliative care				
NPPV weakness	✓	✓		
Benefits that allow patients to be at ease and live longer.		✓		✓
Difficulty in taking off NPPV masks to suction the sputum and saying something to their family for patients		✓		
Disadvantage of being restrained by mask fitting at the end of life, which increases suffering				✓
Influence of physician's attitude of palliative care and the nature of the medical institutions				
Less focusing on palliative care among the physicians in acute care hospital		✓		
Patient pain from continued NPPV influenced by physician knowledges				✓
Influence of patient's age in palliative care				
Difficulty for patients' parents to agree with the transition from active therapy to palliative care				✓

CNS: Certified nursing specialist, CN: Certified nurse

mentioned *Case B* who suffered from ALS, a male in his 70s. His respiratory condition suddenly worsened during his hospitalisation to receive respite care, and he died soon thereafter. She talked about his sudden death event stating, 'We regret that we could not do anything for him because he suddenly died a few days after the physician explained

that it was time for him to decide whether he wanted to be on tracheostomy positive pressure ventilation (TPPV)'. Nurse 3 mentioned *Case G* who suffered from COPD, a male in his 80s. His family member found him collapsed in the bathroom. He was transported by ambulance and pronounced dead at the hospital due to aortic dissection.

<Difficulty in predicting whether patients recover or not> was extracted from Nurses 2 and 3. Nurse 2 mentioned *Case C*, a male in his 70s diagnosed with heart failure Class IV. He was admitted to the hospital due to difficulty breathing as an emergency. Intra-aortic balloon pumping was performed but could not be removed due to hypotension. He was started on NPPV, and haemodialysis was initiated due to respiratory distress and oliguria, respectively. He was admitted to the intensive care unit (ICU) for approximately 2 months and died. Nurse 3 mentioned three patients. *Case E*, a male in his 70s was in the late stage of dilated cardiomyopathy and had a poor response to swelling and blood pressure medication. He was admitted to the hospital as scheduled for close monitoring while his medications were being revised. Yet, his physical functions declined rapidly and he died 2–3 weeks after admission. *Case F* who suffered from atypical microbacteriosis was a woman in her 60s and used NPPV to help her expectorate during the daytime. She had been repeatedly in and out of the hospital for 3–4 years. The situation eventually distressed her and decided to be hospitalised. She eventually died in the hospital, although she had wanted to die at home. Nurse 3 pointed out the uncertainty of mortality stating, 'I did not know if I should call the ambulance or not because it was uncertain whether the patients would recover or die. This would make it inevitable that they would die in the hospital'.

#### ***Differences in symptom management by type of diseases***

This category consisted of four subcategories. <Impression that opioids do not work well in ALS unlike cancer pain> was extracted from Nurse 1. She has provided support for ALS patients and mentioned: 'Unlike cancer pain, I have the impression that opioids do not work well in ALS and I believe, this was caused by the high level of anxiety'.

<Limited treatment choices for patients with pulmonary diseases> was extracted from Nurse 3. She has provided support as a home visiting nurse for patients with pulmonary diseases and mentioned the choice of treatment beyond NPPV as follows: 'For people with pulmonary diseases, the choices regarding treatment are limited and easier to agree on among the people involved'.

She also mentioned <difficulties in establishing a home care support system for patients with pulmonary diseases>: 'As the patient with the pulmonary disease has no visible physical disability such as paralysis, it is difficult to use home care support services under Japanese long-term care insurance system'. 'Few facilities provide short-stay services for patients with NPPV' and 'It is a big challenge to establish a home care support system for those with pulmonary diseases'.

<Differences between muscle dystrophy and ALS> were extracted from Nurse 4. She has provided support for patients with muscular dystrophy in a long-term care hospital mentioning, 'Muscular dystrophy and ALS are the

same neuromuscular diseases, although muscle dystrophy is different from ALS in which a tracheotomy or TPPV gives them a new life'.

#### ***Benefits and weaknesses of NPPV on palliative care***

This category consisted of four subcategories. <NPPV weakness> was extracted from Nurses 1, 2 and 3. Nurse 1 mentioned that many terminal ALS patients with NPPV suffered from thirst, trouble with mask fitting and face mask-related pressure ulcers. Nurse 2 who had worked in the ICU gave us information about two patients with heart failure who used NPPV, stating, 'Patients with heart failure expectorate a lot and removing the mask interface to suction tends to cause hypotension and arrhythmia' and 'NPPV may cause paralytic ileus by pumping air into the digestive organs. As medical device-related pressure ulcers are recognised as incidents in her hospital, she said, 'the nurses put a lot of effort into preventive care such as skin care by changing the type of mask interface'.

<Benefits that allow patients to be at ease and live longer> were extracted from Nurses 2 and 4. Nurse 2 mentioned, 'Patients with heart failure can be at ease by wearing NPPV masks. Thus, I do not think, the patient was aware that he was approaching death'. Nurse 4 had worked for long-term care hospitals and gave information on three patients with muscular dystrophy. She expressed positive opinions about the use of NPPV. 'I think NPPV is meaningful because I do not believe that patients could have lived this long if they had only received oxygen', and 'It would benefit the patient more if they used NPPV at an earlier stage rather than at the end of life'.

Nurse 2 stated <Difficulty in taking off NPPV masks to suction the sputum and saying something to their family for patient>: 'If we do not suction the sputum, the patient will suffocate, although if we do suction, the patient's blood pressure will drop'; 'When the mask is removed, the oxygen saturation level immediately drops; thus, the mask has to be reapplied, although I have been still wondering if he had something he wanted to say to his family in the end, even if it was painful for him to take off his mask'.

<Disadvantage of being restrained by mask fitting at the end of life which increases suffering> was extracted from Nurse 4. She said, 'If the patients use NPPV continuously for 24 h a day with the increased pressure, it becomes more difficult for them to adjust the mask. As a result, the patient is constricted by the mask fitting and suffers more'.

#### ***Influence of physicians' attitude toward palliative care and the nature of the medical institutions***

This category consisted of two subcategories. <Less focusing on palliative care among the physicians in acute care hospital> was extracted from Nurse 2. Regarding the choice of further treatment, she said, 'Our hospital is an acute care hospital where lifesaving is the top priority; thus, NPPV is

applied as the standard treatment for most patients'. She also pointed out that palliative care was excluded in her hospital, as 'few cardiologists in an acute care hospital think that it is better to use sedation', and/or 'many doctors end up not being able to use sedation due to patients' low blood pressure.'

<Patient pain from continued NPPV influenced by physician knowledge> was extracted from Nurse 4. She mentioned, 'I believe that whether or not further continuation of NPPV will cause more or less pain to the patients depends largely on whether the physician knows palliative care.'

### ***Influence of patients' age in palliative care***

This category consisted of one subcategory. <Difficulty for patients' parents to agree with the transition from active therapy to palliative care> was extracted from Nurse 4. She mentioned, 'When NPPV-dependent patients are in their teens or 20s, it is difficult for their parents to agree with the transition from active therapy to palliative care.'

## **DISCUSSION**

This study revealed five categories regarding the perceptions of certified advanced practice nurses. These findings showed differences and similarities across disease types. The author discussed the nurses' perceived challenges of palliative and end-of-life care for non-cancer patients dependent on NPPV to die without sufferings in the place of their choice.

### **Difficulty with uncertain prognosis**

One patient with ALS in this study died unexpectedly. Sudden death has been reported in ALS in multiple studies.<sup>[13-15]</sup> In addition, the participants commented that prognosis was difficult to predict in respiratory diseases due to repeated remissions and exacerbations; therefore, it was unclear when the terminal stage was. In addition, one patient with heart failure was admitted and treated as an emergency but died in the ICU. It has been reported that twice as many non-cancer patients were admitted to ICUs than cancer patients.<sup>[16]</sup> Another elderly patient with respiratory disease died suddenly, although the cause of death was due to another disease. The prognosis of patients with non-cancer diseases, who require long-term care, is considered to be more uncertain because of the issue of multi-disease comorbidity in elderly patients.<sup>[17]</sup> Therefore, it is necessary to promote advanced care planning (ACP) based on the disease-specific characteristics of non-cancer diseases and to conduct research to enable prognostication,<sup>[18,19]</sup> although predicting survival for terminal patients with non-cancer diseases is difficult.<sup>[20]</sup>

### **Differences in symptom management by type of diseases**

The nurses' perceptions revealed differences in palliative care for non-cancer patients according to the type of disease. Although ALS and muscular dystrophy are both neuromuscular diseases, the participants pointed out that

ALS is different from muscular dystrophy in that patients can be expected to survive if TPPV is attached. Moreover, neuromuscular diseases are different from other non-cancer diseases in that upper and lower limb function and swallowing function also decline. Patients are unable to put on and to take off the NPPV mask by themselves. ALS worsens at a faster rate than other diseases.<sup>[8]</sup> Comprehensive suffering relief, including anxiety reduction, is necessary to alleviate respiratory distress in patients with ALS.

### **Influence of patient age in palliative care**

The age of patients requiring NPPV varies. Two cases in this study were in their 20s or younger, and their parents were making the decisions instead of the patients. This may be because parents have been making decisions for their children since they were infants.<sup>[21]</sup> It is important to proceed with ACP in accordance with the growth of the patient and with family care and education.

### **Influence of physician's attitude to palliative care and the nature of the medical institutions**

It became clear that the concept of palliative care was not widely popular among cardiologists working in acute care hospitals because lifesaving was their first priority. In addition, cardiologists found the risk of hypotension due to sedation to be an obstacle in its use. It is necessary to educate cardiologists in acute care hospitals and to promote palliative care. Therefore, they need to collaborate with palliative care teams to integrate palliative care into acute care.<sup>[22,23]</sup>

### **Benefits and weaknesses of NPPV on palliative care**

When nurses provide care for patients dependent on NPPV regardless of the type of non-cancer disease, it is necessary to improve skills, such as quick suctioning of sputum and oral care, because removing the mask can cause cardiorespiratory compromise. Collaboration with clinical engineers and/or certified nurses specialised in wound care is also needed to improve the quality of care by minimising the side effects of NPPV.<sup>[5,24]</sup>

### **Strength and limitations**

Although the number of participants was small, the terminal status of patients and valuable opinions from certified advanced practice nurses were obtained. In addition, as the participants worked in four different workplaces, the findings showed differences and similarities across disease types. Future studies on palliative care in non-cancer patients receiving NPPV need to be conducted to increase the number of participants and to achieve better data collection on a larger scale for non-cancer diseases across different settings of care.

### **Implications and recommendations**

This study recommends the need for ACP based on disease-specific characteristics and age-appropriate support, to

integrate palliative care into acute care and to improve the quality of care to minimise the side effects of NPPV. Interdisciplinary efforts, as well as the pursuit of expertise in each field, are needed to develop good palliative and end-of-life care for NPPV-dependent individuals with terminal non-cancer.

## CONCLUSION

This study clarified advanced practice nurses' perceptions: Commonalities and differences across disease types in NPPV users receiving treatment in a variety of settings. Five nurses' perceptions were clarified: Difficulty with an uncertain prognosis, differences in symptom management by type of disease, benefits and weaknesses of NPPV on palliative care, influence of physicians' attitude of palliative care and the nature of the medical institutions and influence of patient's age in palliative care. The symptom management of palliative care during the terminal stage was insufficient. Interdisciplinary efforts are needed to provide good end-of-life care for NPPV users with non-cancer diseases.

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## Declaration of patient consent

Patient's consent not required as patients identity is not disclosed or compromised.

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## Conflicts of Interest

There are no conflicts of interest.

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