

# The palliative care needs for those advanced neurology patients on mechanical ventilator support

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**Abstract:** There are mainly two types of needs for the ventilator users with severe neurological diseases: respiratory related needs include mode of ventilation selection, mode of ventilator prescription, maintaining lung recruitment and good airway clearance; non-respiratory related needs include substantial nursing care, adequate nutrition, accessible communication and psychological support. All these are important to maintain the quality of life of these patients.

**Keywords:** Non-invasive positive pressure ventilation (NIPPV); nursing care; psychological needs

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## Introduction

Respiratory complications are the top morbidity and mortality of patients with advanced neurological conditions, especially for those with neuromuscular diseases. With the advanced respiratory care in recent decades, patients can be maintained ventilator-free for many years (1). However, in several circumstances, such as severe respiratory muscle weakness & central apnoea, ventilator has to be prescribed (2).

After these patients being put on ventilator support, their life will be totally different. It created mainly two types of needs: respiratory related needs & non-respiratory related needs.

## Respiratory related needs

### *Type and mode of ventilation support*

Non-invasive positive pressure ventilation (NIPPV) is the choices for these patients unless: (I) patient cannot handle the oral secretion or; (II) there is vocal cord palsy obstructing the airway or; (III) patient is unconscious and not able to breathe spontaneously. NIPPV has the benefit of less ventilator related chest infection as well as higher quality of life (3). However, choosing the suitable type of

interface for the patient is an art. Avoiding pressure injury to the face is the top priority in choosing the interface. Nasal mask suitable for those who are able to close the mouth. Oronasal mask is the commonest choice but frequently associated with nasal bridge pressure injury. Total face mask is as effective as oronasal mask but secretion encumbrance is problematic (4). For patients who are still able to control the head, mouthpiece connected to the ventilator is the best choice.

With the advancement of technology, nowadays, we can use Bi-level Positive Airway Pressure (BiPAP) machine to serve as the ventilator for NIPPV except for patients using mouthpiece (5,6). Furthermore, hybrid ventilators (which can be used as BiPAP machine and regular ventilator) are now available in the market which allow patients to switch the mode of ventilation when their lung condition changed.

Certain amount of tracheostomized ventilator users after gone through the acute events actually did not require the tracheostomy anymore (6). This frequently happened in neuromuscular diseases patients. We can switch these patients from invasive ventilation to NIPPV. Of course, we need special dressing to seal the tracheostomy site after switched to NIPPV initially.

When patients cannot be supported by NIPPV anymore

or patients have bulbar dysfunction to start with, invasive ventilation has to be prescribed. For patients using invasive ventilation with regular ventilator, pressure-limited mode usually preferred because patients feel more natural. However, studies revealed that volume-limited ventilation has same effectiveness, safety and patient satisfaction (7). One point that is commonly overlooked by physicians is that even when patients are on invasive ventilation, the setting of the ventilator may need to change from time to time because the respiratory muscle condition can fluctuate and the compliance of the lung will change.

### *Lung recruitment and airway management*

For NIPPV users, air stacking is very important with the help of resuscitation bag. It opens up the dead space of the lung, prevents losing vital capacity and prevents chest infection (3). Clear the airway with traditional suction usually not effective and assisted cough with air stacking helps to prevent chest infection. Mechanical insufflation-exsufflation allow patients to have good recruitment of lung at the same time having efficient airway clearance which is the best combination with NIPPV (3,8-10).

For patients with tracheostomy, air stacking can be performed by sighs breath from the ventilator (10,11). Although suctioning can clear the airway, it is traumatic and only large airway can be cleaned by this method. Chest physiotherapy can further improve the airway clearance (8). However, if you want one stone kills two birds, mechanical insufflation-exsufflation actually can be applied to tracheostomy and performs both lung recruitment and airway clearance at the same time except patients with Chronic Obstructive Airway Disease (3,8-10).

## **Non-respiratory related needs**

### *Nursing care*

Ventilator operation routine requires high demand of nursing care. Together with the high level of disability from the neurological diseases, not much family is able to handle a ventilator user at home. This is the reason why most of these patients end-up in intuitional care. However, if financial, manpower and space limitation can be overcome, ventilator operated at home is feasible. Thanks to the advanced ventilators nowadays can compensate the needs of the patients automatically. Also, due to advancement of information technology, data of the ventilators can be

remotely assessed and immediate helps from the venders or health care providers can be obtained easily.

Of course, carers stress is also another important issue. Modern technology such as electrical operated hospital bed, electric hoist and electric wheelchair are wonderful helpers for the carers. This can be further overcome by allowing patients admit to palliative facilities for short period of time when needed. Furthermore, rational use of community resources is also another important backup for the carers.

### *Communication needs*

Although NIPPV allows patients to talk, but the quality of the speech is poor. Fortunately, computer and smart phone nowadays are readily available. Communication with adapted switch or special apps can easily accommodate the needs of communication of ventilator users.

### *Nutrition needs*

NIPPV allows patients to eat. However, airway must be cleared after or during eating. Manual assisted cough or mechanical insufflation-exsufflation can effectively prevent aspiration pneumonia for these patients (12).

Percutaneous endoscopic gastrostomy (PEG) is the preferred choice if these patients required tube feeding. PEG does not affect the fitting of NIPPV interface and much less replacement required.

Avoid malnutrition is the primary goal of nutrition for these patients. On the other hand, avoiding too high carbon load for these patients effectively avoids carbon dioxide retention (10). However, the fluid and electrolytes requirement of these patients are usually higher and must not be overlooked (10).

### *Psychological needs*

It is extremely important for the attending physicians to understand the goal and value of the patients if they are conscious (10). This is especially true for those with neuromuscular diseases patients because some patients may prefer to terminate support when disability progress. For those unconscious patients, understand relatives' wishes is also important.

Adjustment problems and depression are not uncommon for these patients & relatives. Counseling, self-help group, clinical psychology services or even religion support can be employed for helping patients and families. Of course, for

severe cases, drug treatment may be needed.

## Summary

Ventilator users with severe neurological diseases need appropriate prescription of ventilator. NIPPV is preferred but if bulbar functions are poor, invasive ventilation required. Lung recruitment and airway clearance by assisted cough is very important to prevent chest infection and maintain lung compliance. Mechanical insufflation-exsufflation is a powerful tool for these proposes. High demand for nursing care and difficult to communicate with external world are real problems they are facing. Support to carers is the crucial factor for successful home ventilator use. Rational use of technology can also facilitate the care and communication. Fluid and electrolytes management of these patients are important. PEG should be the choice for tube feeding. Psychological support for patients and families is one of the important components of the whole care of these patients.

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## Footnote

*Conflicts of Interest:* The author has no conflicts of interest to declare.

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