Long term mechanical ventilation equipment for neuromuscular patients: meeting the

expectations of patients and prescribers

Online depository
Questionnaire for patients and prescribers

What are the important parameters while mechanically ventilated ?

Ventilator/patient synchronization : ensure that the ventilator follow the respiratory rhythm of patients at the closest even if cycles are less regular :

EVA: not important ┠┼┼┼┼┼┼┼┼┨ very important

Correcting alveolar hypoventilation (greater effectiveness): even at the expense of comfort

EVA: not important ┠┼┼┼┼┼┼┼┼┨ very important

Comfort : even at the expense of efficiency of ventilation

EVA: not important ┠┼┼┼┼┼┼┼┼┨ very important

Is it important to allow patient to change some ventilation settings by himself in accordance with their needs ?

EVA: not important ┠┼┼┼┼┼┼┼┼┨ very important

Would you think of a mode allowing assistance to cough could be added on the ventilator?

EVA : useless ┠┼┼┼┼┼┼┼┼┨ very useful

If there were such a mode on a ventilator, would you be interested in allowing the patient to start it when needed ?

EVA : not interested ┠┼┼┼┼┼┼┼┼┨ very interested

Would it be important for the patient to have a contactor for providing larger inspiratory volumes for coughing ?

EVA : not important ┠┼┼┼┼┼┼┼┼┨ very important

What do you expect from a circuit ? Rank by importance (1 = most importance)

	Compact
	Good length
	Easy to assemble
	Secure (difficult to disconnect)
	Single limb (only one tubing)
	Low weight

Getting a humidification system is:

EVA : not important ┠┼┼┼┼┼┼┼┼┨ very important

Heating the ventilator circuit is:

EVA: not important ┠┼┼┼┼┼┼┼┼┨ very important

Shall the humidifier be integrated to the ventilator?

a) ☐ yes   b) ☐ no   c) ☐ don't know

Do you think it is important for patients

to have a good tolerance of the interface?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

to get a satisfactory system to fix the interface ?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

to be able to fix the interface by patient himself?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

to be able to remove the interface by patient himself?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

to be able to remove the interface by patient himself?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

To use two different interfaces to alternate pressure points and prevent some complications? (Skin trouble…etc)?

EVA : useless ├┼┼┼┼┼┼┼┤ very useful

What kind of support do you prefer for ventilators on wheelchairs?

a) ☐ support at the back of the WC   b) ☐ appropriate bag

c) ☐ rigid and protective bag

                                            d) ☐ other, clarify :

What is the use of a humidifier (water chamber) when patients are in a wheelchair?

a) ☐ useful and not a problem   b) ☐ useful but problematic   c) ☐ useless but problematic

d) ☐ useless but not but not a problem   e) ☐ dangerous and therefore to prohibit   f) ☐ don't know

What do you think of allowing the patient using a mouthpiece to control insufflations through a contactor in order to trigger or stop insufflation for instance ?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

The ability to control ventilator through a contactor would also be a way to not deliver ventilation, on the face for instance, when patients are disconnected from the mouthpiece and extend battery life as well. What do you think?

EVA : not important ├┼┼┼┼┼┼┼┤ very important

Controlled insufflations could also be increased in order to allow inspiration of a bigger air volume at the time of cough test, or to replace Intermittent positive pressure ventilator **(Bird), or just before each sip of food. What's your opinion?**

EVA : not important ├┼┼┼┼┼┼┼┤ very important

Is it important to resort to a technical solution to improve speaking abilities with mechanical ventilation by tracheostomy?

EVA: not important (0) to very important (10)

Do you think one of these methods could help tracheostomized patients to speak in an easier way when ventilation is delivered? (several possible answers)

a) ☐ set a positive expiratory pressure on the ventilator   b) ☐ yes : a speaking valve

c) ☐ yes: a prolongation of insufflations

d) ☐ no   e) ☐ don't know

Would it be important for patients to be able to trigger an alarm in order to warn people around or caregivers?

EVA : not important ├┼┼┼┼┼┼┼┼┤ very important

Would it be important to get a remote control for the patient in order to change ventilator settings (in order to adapt to physiological conditions)?

EVA : not important ├┼┼┼┼┼┼┼┼┤ very important

What are the important parameters you would like to see displayed on the screen?

On/ Off icon

 EVA: not important ├┼┼┼┼┼┼┼┼┤ very important

Battery discharging / charging icon

EVA : not important ├┼┼┼┼┼┼┼┼┤ very important

2.24.1 What should be maximum time of charge for batteries?

a) From 4 to 12 hours

As a minimum, how long a ventilator should run on battery?

a) From 4 to more than 12 hours

What should be the maximum weight for a ventilator?

a) From 1 to 5 Kg

What do you expect from a future ventilator? *Rank by importance (1 = most important)*

Light
Compact
Quiet
Long battery life
Easy to adapt on a wheelchair

Would you like a ventilator with the following features?

a) ☐ phone   b) ☐ alarm clock   c) ☐ MP3

d) ☐ GPS   e) ☐ cinema   f) ☐ environment control

Questionnaire for prescribers

Among the following modes: volumetric (V mode), pressure (P mode) and pressure with minimum volume target (PV mode), which one of them do you usually recommend as a first preference for each following clinical situations :

Duchenne muscular dystrophy starting nocturnal NIV

Duchenne muscular dystrophy with both nocturnal and daytime NIV

Duchenne muscular dystrophy with tracheostomy ventilation

Steinert starting nocturnal NIV

Severe spinal muscular atrophy with tracheostomy ventilation

Among the following modes: controlled modes (C modes), assisted modes (A modes), assist control modes= backup rate (A/C modes), which one of them do you first recommend in the following clinical situations :
Duchenne muscular dystrophy starting nocturnal NIV

Duchenne muscular dystrophy with both nocturnal and daytime NIV

Duchenne muscular dystrophy with tracheostomy ventilation

Steinert starting nocturnal NIV

Severe spinal muscular atrophy with tracheostomy ventilation

In addition to the ventilator, do you prescribe any of the following for the same patient (several possible answers) ?

☐ a second ventilator

☐ percussive ventilator

☐ intermittent positive pressure ventilator

☐ a Cough Assist

Among the following interfaces: moulded nasal mask (MNM), industrial nasal mask (INM), nasal pillow (NP), full face mask (FFM), mouthpiece (MP) which one of them do you first recommend in the following clinical situations ? (several possible answers)

Duchenne muscular dystrophy starting nocturnal NIV

Steinert starting nocturnal NIV

Spinal muscular atrophy starting nocturnal NIV

Do you prescribe a humidification system for patients using NIV? If so, what kind?

Do you prescribe a humidification system for patients using tracheostomy ventilation? If so, what kind?

Questionnaire for neuromuscular patients

For patients under NIV only :

How are you connected to the ventilator ? (several possible answers)
With a :
-nasal masks
-facial masks
-nasal pillows,
-scuba
-mouthpiece

Can you fit your ventilator interface yourself without help ?
yes or no

Can you disconnect yourself from your ventilator interface without help ?
yes or no

For all patients :

Your ventilator delivers :
-an adjusted volume
-an adjusted pressure
-an adjusted pressure which can increase sometimes to allow a minimal volume

Your ventilator delivers :
-insufflations independently to your inspiratory effort
- insufflations which follow your inspiratory efforts
-insufflations at a minimal frequency, but it is possible for you to trigger insufflations by an inspiratory effort

How do you fell the mechanical ventilation :
-effective or not effective
-confortable or not comfortable

How do you fell the inspiratory effort necessary in order to be assisted by the ventilator ?
-too hard
-comfortable
-too tiny

When do you decide to increase the spontaneous respiratory frequency during mechanical ventilation ? (several possible answers)
-during effort or exercise
-when speaking
-when needing air

Do you use a humidification system during mechanical ventilation? If so, what kind? (several possible answers)
-an artificial filter
-a non-heated humidifier
-a heated humidifier

Did you experienced severe water inhalation in the airway when using a humidifier ?
yes or no

Did you experienced severe water condensation in the limbs when using a humidifier ?
yes or no

For patients using mechanical ventilation during daytime :

Are you able to disconnect from the ventilator more than 5 minutes ?
yes or no

If yes do you feel better when you used it ?
yes or no

And does diurnal ventilation improves:
-daytime dyspnea : yes or no
- speech: yes or no
- fatigue: yes or no
- meal: yes or no