Preliminary evaluation of end-of-life care for patients suffering from Motor Neuron Disease in Denmark

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**BACKGROUND**

In Denmark, 130 patients are diagnosed with NMD annually. Of these, 90-95% are referred to the National Danish Rehabilitation Centre for Neuromuscular Diseases (RCIM). RCIM is a highly specialized tertiary centre of excellence for neuromuscular disorders operating nationwide. RCIM functions as a key player in the coordination of a joint care effort among patients, hospitals, local professionals and caregivers. RCIM assists the affected patients and families with guidance and support throughout the entire course of the disease.

In spite of the highly specialized care, there is still very little knowledge about the terminal phase and end-of-life care for NMD patients in Denmark.

**OBJECTIVES**

To examine the following during the terminal phase with a view to quality enhancement:

- Where do NMD patients die, and is this their preferred place to die?
- Was the time of death expected by the family and relatives?
- How many patients use a feeding tube, non invasive ventilation (NIV) or invasive ventilation (IV) at the time of death?
- Is morphine prescribed in the terminal phase?
- How satisfied are the relatives with the support offered during the terminal phase?

**METHODS**

Information was gathered through telephone interviews with the closest relatives or the diseased person’s health professionals. The relatives had been invited to participate in the interview following the death of the NMD patient. The interview was based on a structured questionnaire with questions covering the death of the patient and the circumstances surrounding it.

**RESULTS**

During a period of one year starting February 2011, 120 MND patients died. Mean age was 68 years (range 43-97 years). In the results, we will only present responses from the relatives which made up 53% of the total responses.

**PLACES OF DEATH**

- 49% died in their own home
- 33% at a hospital
- 8% in a nursing home
- 10% at a hospice

60% of the relatives say that the patient died at the preferred place of death.

**DISCUSSION AND CONCLUSION**

It is difficult for patients and relatives to cope with the disease during the terminal phase without help and support from health professionals. A care plan for the terminal phase is essential to prevent anxiety and uncertainty, which can easily become dominant issues during that phase.

According to the relatives who participated in the study, 49% of the NMD patients died in their own home, and only 10% were in a hospice in the terminal phase. In general, not many Danish NMD patients spend their last days in a hospice.

It is noteworthy that in 39% of the cases, the relatives say death came unexpectedly and that only 60% of the patients died at the place he or she had preferred to die or the relatives had wanted for him/her to die.

Although care for NMD patients in Denmark is highly specialized and well-organized in NMD teams, respiratory centers and the National Danish Rehabilitation Centre for Neuromuscular Diseases, adequate care plans for the terminal phase are not successfully implemented at the moment.

In order to improve the situation, a closer collaboration with general practitioners and specialists in palliation can be recommended.

**FROM THE POINT OF VIEW OF THE RELATIVES, WAS THE DEATH EXPECTED?**

- 57% died at the expected time
- 37% at an unexpected time
- 5% of the deaths were planned termination of invasive ventilation. For 2% the answer is not available.

**AT THE TIME OF DEATH,**

- 65% of the patients were using a feeding tube (PEG)
- 16% were using NIV
- and 14% were on IV

During the terminal phase, morphine was prescribed as palliative treatment in 65% of the cases.

Level of support during the terminal phase

We asked the relatives how satisfied they were with the support they and the patient had received during the terminal phase from the various health care professionals. A total of 60% said they were satisfied on a scale ranging from ‘satisfied’ to ‘unsatisfied’.