**BACKGROUND**

- 8 out of 120 patients died at hospice
- In 27% of the cases, death was unexpected
- In 8% of the cases, the ALS patient did not die at the desired place of death
- Interview study 2011

**OBJECTIVES**

Need for establishing a formalized partnership between ALS and palliative specialists in Denmark and developing a set of evidence-based guidelines to improve the palliative effort in ALS rehabilitation.

**PROCESS**

- Contact to 12 specialized palliative units in East Denmark
- Data collection from 8 units
- Workshop about palliative services to ALS patients – attended by specialized palliative units

**RESULTS**

- All hospices had limited experience with ALS patients.
- 6 out of 8 hospices say ALS patients are more care and resource demanding due to the complexity of the disease.
- The EORTC QLQ C15-PAL is used by all palliative units on all patients – can

  - not stand alone. systematic highlight of QoL experiences and the effect of symptom relief.
  - 6 out of 7 hospices offer home-based care and symptom relief admission prior to the terminal phase.
  - All units collaborate closely with the home-health nurse whereas collaboration with the GP depends on his/her commitment.
  - Knowledge and experience with NIPPV and IMV very limited. 5 out of 8 want to collaborate with the national respiratory center on legal termination of the treatment – requires profound knowledge of the patient.

**DISCUSSION/CONCLUSION:**

- Visits to the eight units showed:
  - Very limited experience with ALS patients
  - Specific knowledge about ALS and disease progression is needed.

- Face-to-face meetings and regular contact between ALS and palliative specialists were imperative to the collaborative effort. The budding partnership provides the scope for adhering to the recommendations of the European guidelines for ALS that death be addressed as early in the disease course as possible and that clear agreements be made on terminal phase management.

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