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Collaboration between ALS and palliative specialists in Denmark

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BACKGROUND

- In 2011, 2/62 (3%) of ALS patients in Eastern Denmark died in a hospice. In 27 % of the cases, the nearest relative said that death came unexpected, and in 8 % of the cases, the patients did not die where they had wished to die [1]
- Until now, Danish ALS patients have not usually been referred to palliative units.
- In 2011, the Danish Health Authority changed the recommendations for palliative care in Denmark to include other life threatening disease than cancer such as ALS [2]

OBJECTIVES

To establish a formalized partnership between ALS and palliative specialists in Denmark to improve palliative care in ALS rehabilitation.

PROCESS

In January 2014, RCFM presented the project to nine palliative specialist units in Eastern Denmark and informed them about the disease and how ALS care and ALS treatment are organized in Denmark. At the same time, information about their knowledge and experience with ALS patients was gathered through interviews and questionnaires.

At the beginning of 2015 and 2016, meetings were held at each of the units where shared cases were discussed and the project evaluated.

A joint project meeting between the specialist units, four ALS teams, the respiratory department at Rigshospitalet, and RCFM was held in September 2015 where specific problems and the future of the project were discussed. Another meeting is scheduled for February 2017.

REFERENCES:

[1] RCFM interview study of relatives in 2011, not published

[2] The Danish Health Authority's recommendations for palliative care 2011

[3] NICE guideline: Motor neurone disease: assessment and management 2016

RESULTS

The project has resulted in closer collaboration on shared ALS patients between palliative and ALS specialists, for instance on telephone calls at the time of referral and joint home visits when needed.

Compared with 2011, the number of referrals to palliative units have increased.

Number of patients who died in palliative care:

- 2014: 5/56 (9%)
- 2015: 11/58 (19%)

DISCUSSION/CONCLUSION

As recommended in the NICE guidelines for MND, end of life care should be discussed regularly to identify:

- Patients' preferences about end of life care planning.
- The need for support to relatives in the terminal phase and after death [3].

International guidelines for palliative care such as the NICE guidelines for motor neuron disease (2016) will be adapted to Danish conditions in a care program for ALS.