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Background and Aim

Background:

Within neurology there is an increasing appreciation that palliative care is appropriate for patients with certain neurological disorders. The Ethics and Humanities Subcommittee of the American Academy of Neurology (AAN) has stated that 'neurologists understand and apply the principles of Palliative Care'. ALS is one of the progressive and incurable neuromuscular diseases for which this approach may be appropriate and 'optimal medical care depends on determining the most appropriate means of achieving those goals for each patient'.

A unique collaboration between a Tertiary Academic Neurology Center, 'Aeginition Hospital', with hospital based multidisciplinary care and a specialized department on neuromuscular diseases, and a sub-urban, community based Palliative Care Unit 'Galilee' was initiated (May 2016). The collaboration's main goal is to provide specialist Palliative Care Home Services to ALS patients and their caregivers, in the area of Mesogaia and Lavreotiki, in Athens, Greece.

Aim:

The purpose of this report is the exploratory analysis of three patients journey, following the integration of Home Palliative Care Services .



Patients and Methods

Patients and Methods:

Clinical data (sex, age and time from diagnosis) were obtained from their medical records and the Revised-Functional ALS Rating Scale was completed.

Patients and caregivers responded to qualitative interviews.

Questions included were:

- 1) Recently, you and your family had been introduced to Home Palliative Care. Would you please describe how you think we might help you?
- 2) What are your problems and needs?
- 3) We can help you in all domains: physical, social, psychological and spiritual. How do you feel about that?

The 'Problems and Needs questionnaires' (WOK) were completed bi-monthly, and home visits were performed from all the members of the interdisciplinary team, based on each patients' unique symptoms, problems and needs.

Results 1:

The 67 year-old-male patient had a R-ALSFRS score 6 and had been diagnosed 3 years ago. He had a gastrostomy feeding tube, as well as a mechanical ventilator via tracheostomy. The female patient (aged 62) and the young (aged 25) male patient had scores of 18 and 21. The diagnosis was achieved 7 years, and one year previously, respectively. The young male patient had recently stopped riluzole, due to hepatotoxicity.

A high problems and needs burden was recorded in all patients; pain, anxiety and depression, loss of independency and functionality, as well as unmet social and spiritual needs.

Results

76 home visits were performed for the palliation of the first patient; 36 by the physiotherapist. 2 emergency visits by the palliative care physician and nurse: one due to acute urinary and fecal retention, managed with a catheter and laxatives, and the other for neck stiffness, because of increased anxiety, managed with benzodiazepines. The female patient was visited weekly; 38 home visits took place, 50% from the physiotherapist. 2 emergency visits were needed, due to pain and a suicide attempt; managed pharmacologically and non. All team members were equally involved at the care of the younger patient.

Pain, spasticity, as well as insomnia were adequately controlled in all patients. Amitriptyline and alprazolam, along with baclofen, paracetamol and tramadol hydrochloride were mainly used. Psychosocial care was also essential. Caregivers felt relieved due to the team's active presence and the non-abandonment. No hospitalizations were required. The multidisciplinary team collaborated with the specialist palliative care interdisciplinary team, so that both patients with disturbed respiratory function used at home, with support and care, the Non-Invasive Positive-Pressure Ventilation (NIPPV).

Discussion

Our study suggests that the needs of patients with ALS can be met by specialist palliative care providers. Uncontrolled symptoms can benefit from the interdisciplinary assessment of the palliative care team. **The involvement of specialist palliative care services can be extremely important and in a more episodic way- in cases considered as emergencies.** Primary health-care providers might not have been able to adequately address such emergencies and hospitalizations might have been required. **The physiotherapist plays a very important role; the assessment of physical and respiratory symptoms and provision of advice, exercises, management strategies, and aids allow adjustment to altered demands of daily living.** Although the number of our ALS patients is low, patients' and caregivers' palliation and support is evident.

Conclusions

Home palliative care services for ALS patients and their caregivers could be provided and continued in sub-urban areas of Greece. The physiotherapist plays a key-role, while hospitalizations can be avoided and all symptoms adequately addressed.

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We all authors
have no
conflicts of
interest to
declare