

Background

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disorder in which motor neurons in brain and spinal cord are affected, causing muscle weakness. Respiratory failure, due to weakening of respiratory muscles, is the most common cause of death, limiting life expectancy to 2-5 years, rendering ALS a palliative disease. Therefore, multidisciplinary care with nutritional and respiratory support and a focus on comfort of patients remains the cornerstone of ALS management. To provide an optimal framework for palliative care in these patients, it is necessary to thoroughly understand their wishes regarding end-of-life.

Aim(s)

To identify and explore needs and perceptions regarding end-of-life and palliative care in ALS patients.

Methods

For this qualitative study, we contacted 25 adult patients for semi-structured interviews. Interviews were organized in the hospital or at patient's homes. Data were analyzed using Braun and Clarke's method of thematic analysis with a deductive approach supported by NVivo software V.14.

Results

Sixteen patients (response rate 64%) were interviewed about their perceptions and needs regarding end-of-life and palliative care. We included 11 men with an average age of 60y (range 30-73). Seven themes emerged from our data: (1) Feelings of fear, grief and powerlessness; (2) a strong need to live their lives to the fullest, yet with frustration with the inability to focus on this due to administrative hassles; (3) focus on practical arrangements concerning death itself, as well as financial arrangements for loved ones; (4) strong influence of and worries for loved ones; (5) needs around palliative follow-up; (6) difficulties with delineation of life and dying with dignity; and finally, (7) a lack of knowledge around disease course, palliative care options and who to address their questions to. Patients hesitate to initiate end-of-life conversations, yet want to grant permission when healthcare providers take the lead.

Discussion

This study is the first to explore needs towards end-of-life care in ALS. Our sample included a wide variation in disease duration, severity, age and disease characteristics, contributing to the validity of the results. Yet, selection bias may have been introduced since potential candidates were selected by healthcare workers and nine patients declined to participate, most due to fatigue or aversion of the end-of-life topic. Both may have led to overinclusion of patients with a tendency to openly express their opinions. Additionally, interviewer bias may have influenced the interviews and chosen themes. To minimize this bias, we used investigator triangulation, 3 different interviewers, as well as the use of a multidisciplinary analytical team.

Implications and future perspectives

Conversations around end-of-life care should be optimized and tailored to patients' needs. End-of-life conversations should feel empathetic, with inclusion of loved ones. Information should be provided early on, to improve understanding of the disease trajectory and options around palliative care and end-of-life counselling. As a next step in the process of optimizing palliative care, caregivers assessments can shed more light on their needs. The ultimate goal remains a palliative care model, where timely, transmutal palliative care is organized in line with patient's, caregivers' and healthcare professionals' needs.

References

N/A