Quality assurance in the rehabilitation of ALS patients and their relatives - tailoring and targeting group based seminars

**Background**

In Denmark, some 130 patients are diagnosed with ALS each year and 88% of them accept a referral to The Rehabilitation Centre for Neuromuscular Diseases (RCIM).

As a supplement to drawing up individual rehabilitation plans and various other interventions, RCIM has previously arranged free of charge group based introductory seminars for newly diagnosed patients. Participants have always reported a high degree of satisfaction with the form and contents of these seminars. However, only some 30 percent of the invited patients participated.

**Method**

In 2009, RCIM carried out a questionnaire survey among patients who had NOT wished to participate.

**Target group definition:**
- Patients diagnosed within the past eighteen months

**Main seminar topics:**
- Give ALS patients opportunity to meet each other and share experiences
- Inform about the disease and the newest in treatment and research
- Discuss coping strategies

**Results**

The survey did not give an unequivocal answer to the low rate of participation. It did, however, indicate that such seminars need to be tailored more specifically to the needs and wishes of the individual family.

**Objectives**

To study whether it is possible to obtain a higher rate of participation by
- Tightening the referral procedure,
- Customizing the seminars and
- Studying the patients’ motives for opting out.

**Conclusion / discussion**

The questionnaire survey showed that patients
- Did not opt out of the new seminars because they found them irrelevant
- Did not feel stigmatized because of their disability
- In large thought they could learn from other ALS patients’

In spite of that, only 21% of the invited patients accepted the invitation. Since all the patients had consented to home visits and to have an individual rehabilitation plan drawn up, we can conclude that regardless of the referral procedure, the majority of ALS patients prefer rehabilitation to take place at home and that the seminars should be seen as a supplement for a small group of patients.

A further development of this study might comprise questions about the ALS families’ participation in social networks prior to the ALS diagnosis.

**Results**

A total of 56 patients were referred and invited to two seminars and 12 (21%) accepted the invitation. All the invited patients had previously accepted a home visit from an ALS consultant and thereby gotten a chance to get to know the person in charge of the seminar beforehand.

A revised and more detailed questionnaire was sent to the patients who had decided not to participate in the seminars. 35 patients replied.

- Know enough about the disease and its consequences (81%)
- Intimidated by having to be away from home for two days (14%)
- Could learn from other ALS patients’ experience (59%)
- The topics of the new seminars were relevant (62%)
- Intimidated by having to meet other ALS patients (41%)
- Feel stigmatized because of disability (46%)

In 2010, the ALS consultants referred two well-defined target groups with comparable problems to two different free of charge seminars:

**Target group definitions:**
- Men with spinal symptoms and their spouses
- Young families with children and a personal assistant arrangement

**Main seminar topics:**
- Problems relating to nutrition and ventilation
- Personal assistant arrangements
- Children’s reaction to their parent’s disease
- How it affects the family to have personal assistants present around the clock

The patients who declined to participate in the seminars were asked to fill in questionnaires designed to identify the factors which had been decisive for opting out.

Both seminars were held at wheelchair-accessible conference centers located in scenic areas. Prior to the seminars, the ALS consultants had made informative material about the seminars which was sent to the patients to give them and their families a chance to immediately identify with the target group.