Improving quality of care for patients with Amyotrophic Lateral Sclerosis (ALS): Design and methods

INTRODUCTION

Setting:
- ALS is a rapidly progressive degenerative motor neuron disease (MND) with varying clinical presentation\(^1\,2\)
- Since no cure for ALS exists, management is focused on symptom control and preservation of quality of life (QoL)\(^3\,4\)

What is known out of (limited) evidence and practice:
- Management of ALS shows variation across healthcare institutions and countries\(^5\,6\)
- Degree of compliance to international guidelines is suboptimal\(^7\,8\)
- Multidisciplinary ALS care, may improve QoL and survival\(^9\)
- Lack of supranational, well-designed interventions to harmonize ALS care management\(^10\)

AIM

To take initial steps towards the development of a care pathway (CP) for the management of ALS care to improve quality of ALS care

Note: This project is part of the larger ALS-Care Programme (A Programme for ALS Care in Europe) which aims to improve quality of care for patients with ALS

METHODS

Methodological base:
- Medical Research Council Framework\(^11\)
- 7-phase method to design, implement and evaluate care pathways\(^12\)
- 8-step method to build the clinical content of an evidence-based care pathway\(^13\)

1. Defining quality of ALS care and development of a set of quality indicators (QI’s) to evaluate quality of ALS care

   - RAND modified Delphi’s in:
     (a) multidisciplinary European ALS experts
     (b) European patients with ALS and their caregivers

   - Operationalization of set of key interventions and outcomes into QI’s

   - Output: process indicators (PI’s) and outcome indicators (OI’s)

2. Mapping ALS care in terms of processes and outcomes

   - Design: Longitudinal prospective observational study (structured interviews)
   - Setting: 6 European ALS centers
   - Aim: extensive data collection in patients with ALS and their primary caregivers to describe ALS care within their health and social context
   - Focus: outcomes in ALS care

3. Initial steps in the CP development

   - Strategy: Compilation of data out of 1. & 2:
     - Target CP
       - Identify & tackle obstacles to quality of care
       - Inoculation of PI’s and OI’s on care process map (flowchart)
     - …