Etica della terminalità nella SLA

Andrea Calvo

UNIVERSITÀ DI TORINO
DIPARTIMENTO DI NEUROSCIENZE
UNIVERSITÀ DI TORINO
AZIENDA OSPEDALIERO - UNIVERSITARIA
Città della Salute e della Scienza di Torino
CentroSLA Torino

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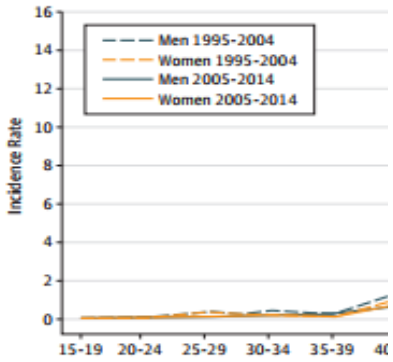
Secular Trends of A
The Piemonte and

Adriano Chiò, MD; Gabriele Mora, MD; Cristina
Stefania Cammarosano, MD, PhD; Antonio Ilar
Maurizio Grassano, MD; Fabrizio Pisano, MD;
Valle d'Aosta Register for ALS (PARALS)

Figure 2. Incidence Rates by Age Groups an

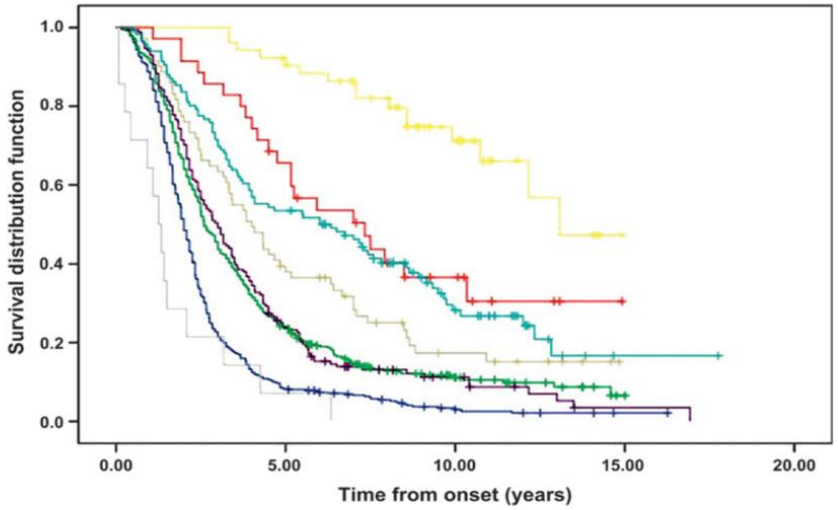


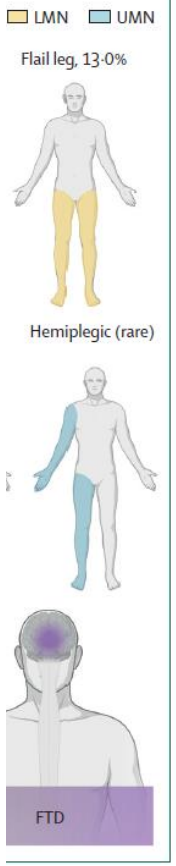
Phenotypic heterogeneity of amyotrophic lateral sclerosis: a population based study

Adriano Chiò,[1,2] Andrea Calvo,[1] Cristina Moglia,[1] Letizia Mazzini,[3] Gabriele Mora,[4]
PARALS study group*

J Neurol Neurosurg Psychiatry 2011;**82**:740–746.

Figure 3 Tracheostomy free survival, according to amyotrophic lateral sclerosis (ALS) phenotype. Yellow, PUMN; red, PLMN; light blue, pyramidal ALS; grey, flail arm; violet, classic ALS; green, flail leg; blue, bulbar; cyan, respiratory. Crosses are censored patients. PLMN, pure lower motor neuron phenotype; PUMN, pure upper motor neuron phenotype.





Prognosis for patients with amyotrophic lateral sclerosis: development and validation of a personalised prediction model

Henk-Jan Westeneng, Thomas P A Debray, Anne E Visser, Ruben P A van Eijk, James P K Rooney, Andrea Calvo, Sarah Martin, Christopher J McDermott, Alexander G Thompson, Susana Pinto, Xenia Kobeleva, Angela Rosenbohm, Beatrice Stubendorff, Helma Sommer, Bas M Middelkoop, Annelot M Dekker, Joke J F A van Vugt, Wouter van Rheenen, Alice Vajda, Mark Heverin, Mbombe Kazoka, Hannah Hollinger, Marta Gromicho, Sonja Körner, Thomas M Ringer, Annekathrin Rödiger, Anne Gunkel, Christopher E Shaw, Annelien L Bredenoord, Michael A van Es, Philippe Corcia, Philippe Couratier, Markus Weber, Julian Grosskreutz, Albert C Ludolph, Susanne Petri, Mamede de Carvalho, Philip Van Damme, Kevin Talbot, Martin R Turner, Pamela J Shaw, Ammar Al-Chalabi, Adriano Chiò, Orla Hardiman, Karel G M Moons, Jan H Veldink, Leonard H van den Berg

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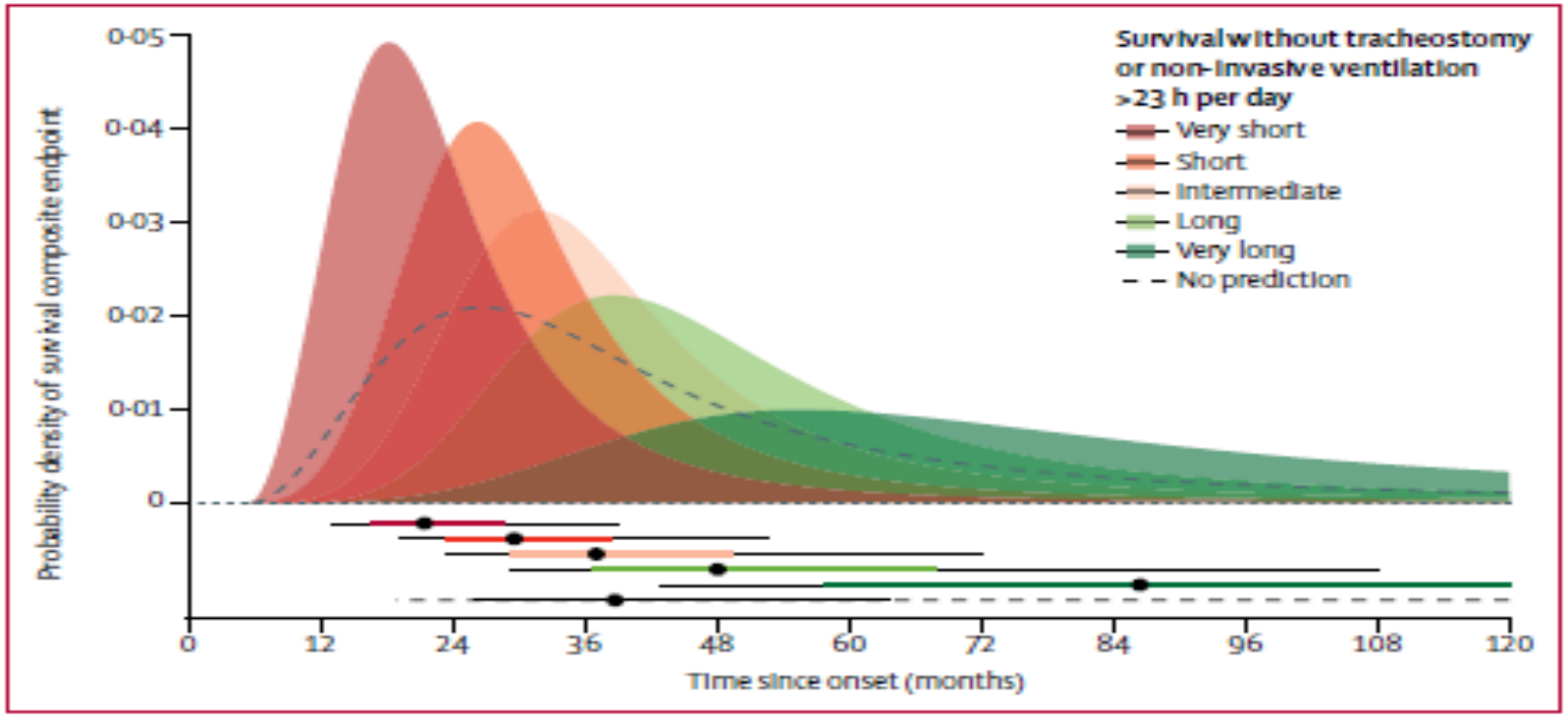
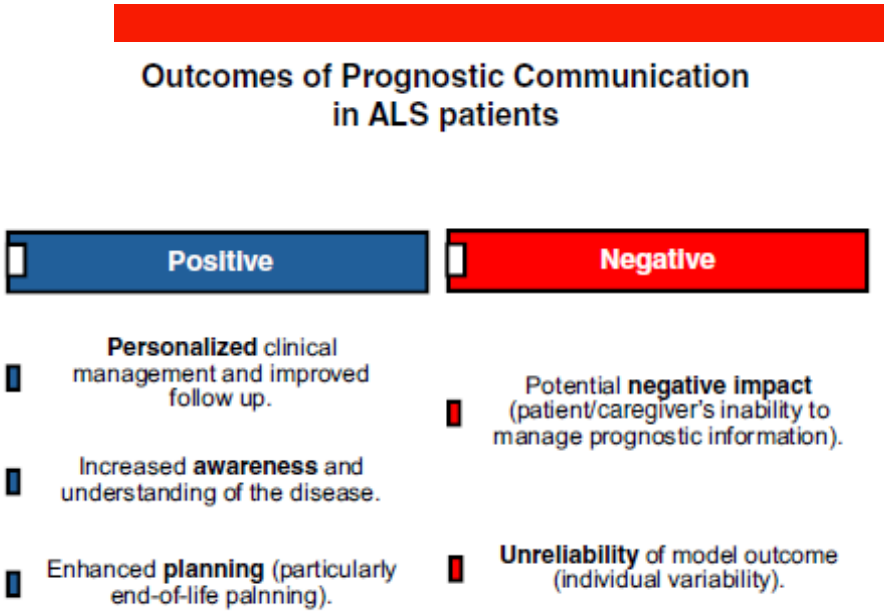


Neurological Sciences
https://doi.org/10.1007/s10072-024-07702-6

ORIGINAL ARTICLE

Prognostic communication in amyotrophic lateral sclerosis: findings from a Nationwide Italian survey

Cristina Moglia[1,2] · Francesca Palumbo[1] · Rossana Botto[1,3] · Barbara Iazzolino[1] · Nicola Ticozzi[4,5] · Andrea Calvo[1,2] · Paolo Leombruni[1,3] · MND Study Group of the Italian Society of Neurology



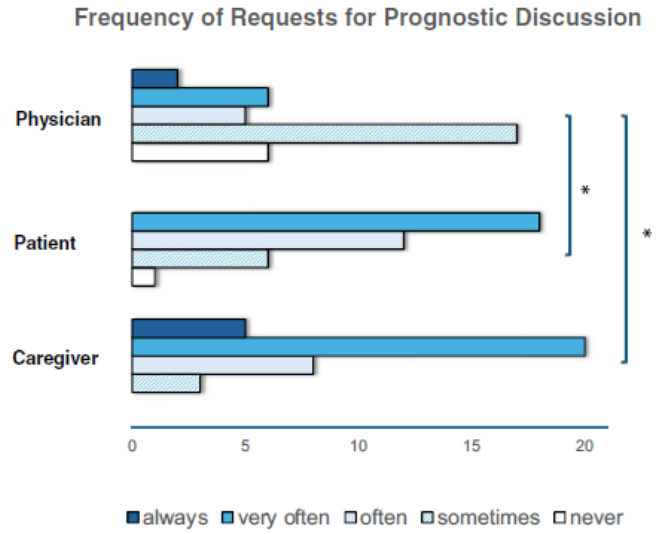


Fig. 1 Graph showing the frequency of requests for prognostic discussion of physicians, patients and caregivers. Patients and caregivers request prognostic discussion more frequenly than physicians (*): $p < 0.05$

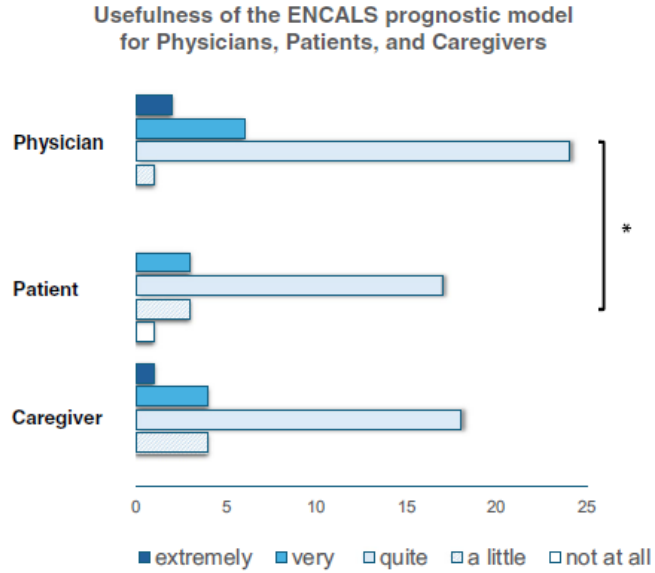
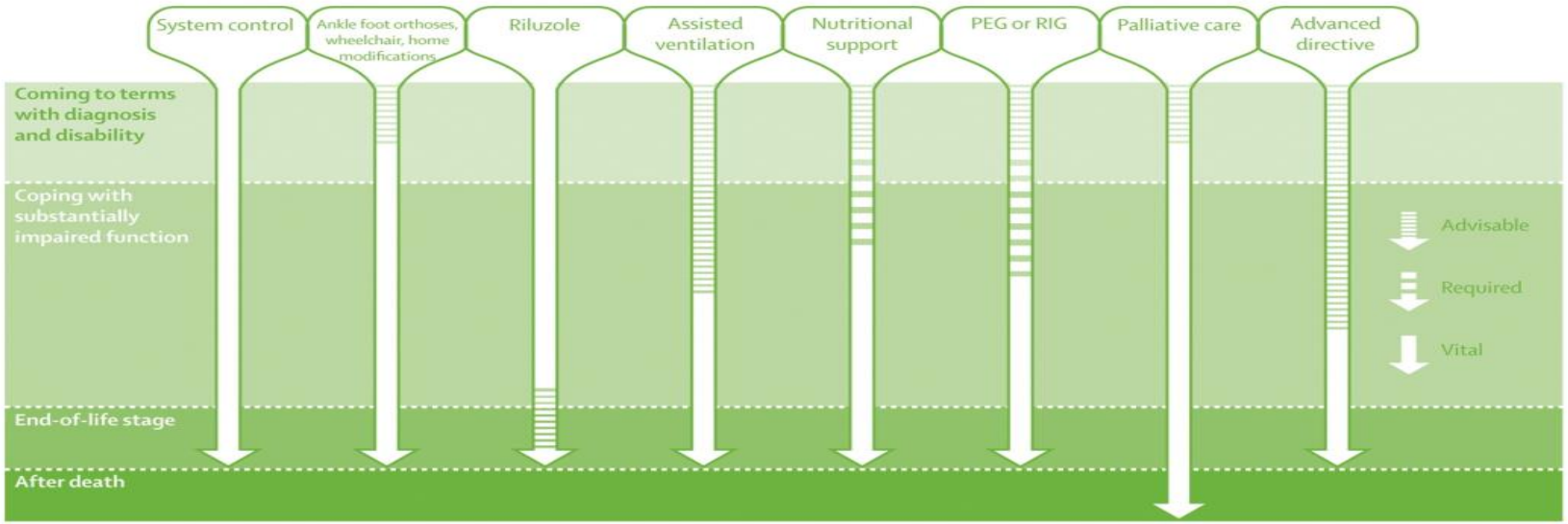


Fig. 2 Graph depicting the perceived usefullness of the ENCALS prognostic model for physicians, patients, and caregivers. The model was considered more useful for physicians compared to patients (significant, *: $p < 0.05$), and caregivers

Problematiche neurologiche di interesse palliativo nella SLA

- Dolore/disturbi sensitivi
- Nutrizione
- Comunicazione
- Motilità
- Problematiche associate alla motilità
- Correlati psicologici/psichiatrici
- Fine vita

La SLA come modello di cure simultanee



Radunovic et al, Lancet Neurology 2007

SLA: paradigma di scelte

- Comunicare la diagnosi e la prognosi
- Prescrivere terapie 'disease modifying' (riluzolo)
- La PEG/CVC
- La ventilazione non invasiva(NIV)/tracheostomia
- Controllo dei sintomi e qualità della vita
- Decisioni di fine vita, pianificazione condivisa delle cure (PCC)
- Il luogo di cura e di fine vita
- Le sperimentazioni cliniche
- Le terapie non convenzionali

REGIONE PIEMONTE

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C.R.E.SLA Torino
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UNIVERSITÀ DI TORINO

UNIVERSITÀ DI TORINO

AZIENDA OSPEDALIERO-UNIVERSITARIA Città della Salute e della Scienza di Torino

Grazie