

BIOPSYCHOSOCIAL NATURAL HISTORY OF AMYOTROPHIC LATERAL SCLEROSIS

Introduction to the Open Data, Access, and Use

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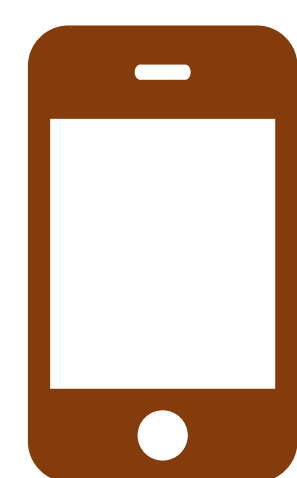


ALS has a median survival time of 3 years.

Patients and their social networks are faced with adapting to formidable physical challenges and shortened life expectancy. Quality of life can be affected by disease progression and treatments and in turn can predict ventilation-free survival.

METHODS

- **The Seattle Amyotrophic Lateral Sclerosis (ALS) Patient Profile Database is a rich longitudinal dataset of ALS patients (n = 143) and their partners (spouses, significant others, or caregivers; n = 123)** from clinics and ALS support groups in Seattle, WA; San Francisco, CA; and Philadelphia, PA.
- The purpose of the study was to characterize the psychosocial and physical natural histories of ALS and the interactions between them.
- Participants and partners (mostly spouses) were separately interviewed in their homes every 3 months for up to 18 months between March 1987 and August 1989, with survival data collected up to 2008.
- **Much of the data has never been analyzed or reported.**



Take a picture to go to the data or download the poster

More than 500 variables were collected in multiple substantive domains.



Psychological health and functions

- Anger
- Depression
- Purpose in life
- Stress
- Coping



Social cognition

- Attitudes
- Beliefs
- Personality (informant)



Family structure and medical history



Social role activities

- Time use
- Work and volunteer
- Religious attendance



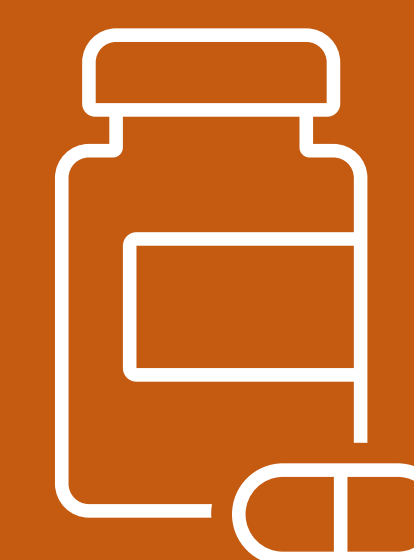
Perceived social support and use of support groups



Alcohol and tobacco use

Disease treatments and devices

- Feeding tube
- Respiratory therapy
- Dietary therapy
- Speech pathology
- Psychotherapy
- Psychotropic and other medications



Disease history, severity, and survival

- Symptom onset dates (by site)
- Respiratory function (FVC)
- ALS Severity Scale

Longitudinal, dyadic biopsychosocial data from ALS patients and study partners are now publicly available for use

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