

NEURO—KAYRÓS: two ACP contrasting experiences with neurodegenerative diseases, AD and ALS, common trades and differences in illness trajectories

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ADVANCE CARE PLANNING IN LIFE LIMITING ILLNESS

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In the Spanish advance care planning (ACP) Program 'KAYRÓS-Helping Conversations', inspired in Respecting Choices philosophy, we developed an innovative cluster research, NEURO-KAYRÓS, applied to two neurodegenerative diseases with contrasting trajectories: early Alzheimer's Disease (AD)-grant research project for clinical research ACP implementation in dyads (patient-surrogate)- and Amyotrophic Lateral Sclerosis (ALS)- stem cell non-commercial research grant clinical trial with clinical psychology follow-up. We monitor the ACP dyadic (patient-surrogate) interview with tools, combining quantitative with qualitative approaches, that allow us to gain insight in the process of living (and planning) with a threatening neurodegenerative illness/hoping for the best/preparing for the worst. Quantitative tools for: ACP knowledge; trends of preferences for goals of treatment in different potential (or experienced) losses during illness trajectory; congruence with surrogate; critical milestones marking transitions. Qualitative tools: discussion groups and in-depth interview. AD and ALS although share some common features, leaning towards dependency, vary significantly in some key notes regarding both with the perception of the illness trajectory (related to patient's own biography) and, along it, with the potential support received from the ACP process.

Initial lessons from the first 6 months of the ongoing 2 year project.

Illness trajectory (perception AD vs ALS): (slow) cognitive versus (fast) physical decline; advanced versus middle-age; slow versus fast adaptation (subject, carers & environment); role of substituted decision.

ACP Process: in clinical versus research (clinical trial) setting; from ignorance to gratitude if initial anxiety and/or threat are overcome by a system that shows that cares and stands, come what may.