

Conclusion A validated ACP_SEs in Spanish will allow measuring the impact of training programs designed to implement ACP in the Spanish-speaking context.

P74 ADVANCE CARE PLANNING AND END OF LIFE CARE FOR PATIENTS WITH HUNTINGTON'S DISEASE: A QUALITATIVE STUDY DESIGN

¹M Ekkel*, ²E Verschuur, ¹M Depla, ¹R Veenhuizen, ¹B Onwuteaka-Philipsen, ¹C Hertogh. ¹VU University Medical Center, Amsterdam, Netherlands; ²HAN University of Applied Sciences, Nijmegen, Netherlands

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Background Huntington's disease (HD) is an inherited neurodegenerative disease, characterized by movement disorders, psychiatric symptoms, and cognitive decline. In the later stages of the disease patients often are no longer able to express their wishes for care, because of problems with communication and cognitive decline. Little is known about advance care planning, advance directives, and end of life care for HD patients.

Aims: In this study we aim to explore HD patients' perceptions of their future, end of life, and end of life care, and whether these perceptions change over time. Furthermore, we aim to study the views of elderly care physicians on advance care planning and end of life care for HD patients.

Methods A qualitative approach is adopted using semi-structured interviews. Approximately 10–15 HD patients will be interviewed every 6 months for a period of 2 to 2.5 years. Topics are: quality of life, the future, end of life, death, advance directives and talking to others about these subjects. In addition, approximately 10 elderly care physicians will be interviewed once. The physicians will be encouraged to describe their experiences with advance care planning, end of life care, patients' decision making capacity, advance directives, and euthanasia in HD. All interviews will be audio recorded and transcribed verbatim. Atlas.ti will be used for analysis.

Results and conclusions Data collection started in 2017 and results are expected in 2020. The results of this study will provide valuable information on advance care planning and end of life care for HD patients.

P75 SHARED CARE PLANNING, THE TWIST THAT COULD SAVE THE UNFULFILLED POTENTIAL OF ADVANCE CARE PLANNING IN SPAIN

¹J Júdez*, ²C Lasmarias, ³I Saralegui, ⁴N Pérez de Lucas, ⁵H García-Llana, ⁶J Fernández-Bueno, ⁷N Granero-Moya, ⁸T Velasco, ⁹V Carrero. ¹Asociación de Bioética Fundamental y Clínica, Madrid, Spain; ²University of Vic-Central University of Catalonia, Vic, Barcelona, Spain; ³Organización Sanitaria Integrada Araba, Vitoria, Spain; ⁴Servicio Madrileño de Salud, Sermas, Madrid, Spain; ⁵Hospital Universitario La Paz, IdiPAZ, Sermas, Madrid, Spain; ⁶Hospital Universitario de La Princesa, Sermas, Madrid, Spain; ⁷Servicio Andaluz de Salud, Baeza, Jaén, Spain; ⁸Hospital Clínico Universitario San Carlos, Sermas, Madrid, Spain; ⁹Universidad Jaume I, Castellón, Spain

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Background The “right to grant and register an advance directive” has spread in Spain's health care legislation. Reality check: documents are completed by less than 1% of the population. Having ACP philosophy widespread elsewhere, this seems a rather meager approach that, additionally, does not sympathize with the way, we, human beings suffer, endure and face illness.

Method Intellectual journey, rationale and roadmap for a new twist in Spain's theoretical, ethical and policy development.

Results Few healthcare administrations and some individual experiences in Spain are promoting ACP implementation into public health care systems. In 2017, the “Spanish Working Group on Shared Care Planning” (GET-PCA in Spanish) was build up with the conviction that what could be done to take advantage of our strengths as a National Health System and a caring Mediterranean culture was midwifing shared-decision making (SDM) for current care together with the pursue of ACP for future care in what we named as “shared care planning” (SCP).

GET-PCA defines SCP as “a deliberative, relational and structured process that facilitates reflection and understanding of illness' and care's experiences, among all involved, focusing on each person facing a disease trajectory, to identify and express their preferences and expectations within their context of care. Its goal is to promote SDM in relation to current context and ACP to future care challenges, such as when the person might not be competent to decide for herself.”

Conclusion SMD matching ACP may save the day for Spain. Best of both worlds: welcome shared care planning!

P76 PREPAREDEM: HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS PREPARE FOR CARE IN ADVANCED ILLNESS AND END OF LIFE

J Dixon*. London School of Economics and Political Science, London, UK

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Background The number of people living with dementia is expected to double by 2050. Experiences in advanced illness and at end of life for people with dementia and their carers can be poor. Advance care planning (ACP) is especially challenging in dementia. In this study we will explore how people with dementia and their carers prepare for advanced illness and end of life. Using quantitative and qualitative data, we will look at what factors influence them. We will ask about their experiences, including of advance care planning or other support. We will especially consider how people with dementia and their carers interact and influence each other, and what expectations they have of each other. We will also examine whether preparing, through ACP or other means, makes a difference to end of life outcomes and experiences.

Methods Secondary analysis of data from the Improving the Experience of Dementia and Enhancing Active Life (IDEAL) study (gathered from a cohort of 1500 people with dementia and their carers).

- Qualitative interviews with 40–50 carers (and people with dementia where capacity allows) taking part in the DETERminants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their family carers (DETERMIND) study (a cohort of 900 people with dementia and their carers)
- Bereavement survey with carers from the DETERMIND study who are bereaved during the course of our study (2018–2023)

Results Findings will be reported over the course of the study in academic papers, blog-posts and at a range of conferences and meetings. We will also produce guidance for policy-makers and practitioners and a short film.