Validation by citizens of the Catalan model of advance care planning

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Introduction: Although in our cultural context death and end of life are still taboos, clinical approaches based on shared decision-making and person-centered care are emerging.

Advance care planning (ACP) is a core example of these new approaches that mainly rely on knowledge and respect for the autonomy of patients.

Respect for autonomy involves the active participation of the person in the caring process, being essential for professionals to apply the person-centered model to know in advance the values and preferences of patients and their families regarding their health problems and the way decisions will be taken, mainly in situations of advanced disease or when the patient can not decide for him or herself.

These arguments justify the need to develop an ACP model to suit individual needs and, at the same time, to integrate the social and health components of each clinical stage. The basis of ACP is the recognition and respect for the autonomy of the other, encouraging the participation of persons in the management of their own existence and the creation of their own life plan.

In this context, we still don’t have enough information about Catalan population’s experience and perspective on ACP.

Objectives: Identify the perspectives, values and experiences of citizens related to ACP.

Integrate the inputs from citizenship in order to validate both the conceptual framework as well as the practical guide of the Catalan model of ACP.

Provide practical recommendations for the implementation of the ACP model in real practice.
**Object population**: Persons older than 18 years living in Catalonia, of both genders, from rural and urban areas, with an appropriate distribution regarding levels of education and health status (healthy, non complex chronicity, complex chronicity, advanced disease and caregivers) that agreed to participate.

A theoretical sampling seeking the maximum discoursing variability was selected.

Recruitment of participants was from January to December 2015.

**Involved interested main ones**: Catalan Ministry of Health, citizenship, patients, caregivers, social and health professionals.

**Method**: Design: socio-constructivist qualitative study

Data collection: eight focus groups from eight to twelve participants.

Data analysis: successive readings of transcriptions (systematic, literal and anonymous), followed by a discourse analysis: formulation of pre-analytic intuitions, discoursing positions and fractions, textual overall interpretation (symbolic configurations), internalistic analysis searching the semantic attractors and the associative chains (semantic configurations).

**Aids to the research**: Formal research grant from the College of Nurses of Barcelona.

**Impact**: This qualitative approach is useful to provide:

- Generation of new knowledge about citizenship’s position.
- Integration of groups’ contributions on the conceptual framework.
- Practical recommendations for implementation, adapted to the continuum of chronicity.
- Encouragement of good practices in the clinical management of advanced disease and palliative needs, improving the experience of care for patients and their families.

**Conclusions**: Although the complete results of the qualitative analysis will be available in April 2015, preliminary information shows its feasibility to identify the perspectives, values and experiences of the citizenship regarding ACP process and use them in the validation of both the ACP Catalan model’s conceptual frame as well as its practical guide. As a consequence, we’ll be able to compile useful recommendations for ACP implementation as a paradigmatic example of integrated person-centered good practices and of the collaborative work between patients and professionals.

**Keywords**: advance care planning; person centred care; share decision making; end of life; integrated care