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OP.015 Informed consent in patients with dementia: A mixed-methods study on palliative care professionals' views

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Background: Cognitive impairment is frequently present among patients with dementia. This challenges the process of informed consent both for clinical interventions and for research. Evidence shows the potential for enhancing the informed consent process by using diverse measures, tools and aids. Nevertheless, very little is known on their applicability and usefulness to improve the informed consent process in palliative care research involving patients with dementia.

Aim: To assess and understand palliative care professional's views on the informed consent process in healthcare and research involving persons with dementia. **Methods:** Mixed-methods approach, combining and integrating the use of both qualitative (semi-structured interviews) and quantitative (questionnaire built de novo assessing 4 items on an 11-point Likert scale) research methods and techniques. Participants were professionals working in palliative care in Portugal. Purposive sampling combined with snowball sampling was conducted until reaching theoretical saturation. Thematic content analysis was performed to the transcript of interviews; descriptive analysis were done to quantitative data. A total of 24 professionals from diverse institutions and cities participated in the study.

Results, Outcomes and Implications: In this study, professionals working in palliative care perceived the informed consent an effective practice in: general healthcare provision (41%); specialist palliative care (63%); clinical dementia research (72%); and clinical trials (78%). Participants claimed that, in specialist palliative care, due to the cognitive vulnerability of patients with dementia, informed consent became an effective practice by obtaining proxy consent. In clinical dementia research and clinical trials, participants considered the informed consent to be effective mainly due to the legal requirements that prevent research without obtaining consent. Five main themes emerged in our qualitative analysis: (i) impossibility to apply the informed consent process in face of cognitive impairment; (ii) efforts to involve the patient in the decision-making process; (iii) proxy consent, via family caregiver, as the preferred way to meet patients' wishes; (iv) innovative measures (e.g., visual aids) perceived as potentially useful, but not used in clinical practice or research; and (v) respect for dignity as respect for autonomy, where cognitive and situational vulnerability play a relevant role in how patients understand and perform their autonomy.

Conclusions: This study highlights the need to further research about the use of strategies to improve the informed consent process in palliative care and research involving persons with dementia. It shows the potential of innovative measures, which need to be designed in a tailored manner and require more research on their applicability and usefulness. **Acknowledgments:** ERA-NET NEURON-II/0001/2015 and FCT Portugal. Project ENSURE: Enhancing the Informed Consent Process. Supported decision-making and capacity assessment in clinical dementia research.

Keywords: dementia; informed consent; clinical research; palliative care.