How to Optimize Informed Consent in Patients with Dementia? A Qualitative 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 (IC) both in clinical practice and palliative care (PC) research. International research suggests the use of diverse measures and tools to improve the IC process in such cases. Very little is known on the application of such tools in PC and research.
Aims: To understand PC professionals' views about the actual practice and measures to optimize IC in clinical practice and research.
Methods: Qualitative study, using in-depth interviews with professionals working in PC in Portugal. Purposive sampling combined with snowball sampling was conducted until reaching theoretical saturation. Thematic content analysis was performed to the transcript of interviews. QSR-N-VIVO11 was used for data analysis. A total of 24 professionals from diverse institutions and cities were interviewed (10 nurses, 9 physicians, 2 psychologists, 2 social care worker, and 1 physiotherapist).
Results: Four main themes emerged in our analysis: impossibility to apply the IC process in face of cognitive impairment; efforts to involve the patient in the decision-making process; proxy consent, via family carer, as the preferred way to meet patients' wishes; innovative measures (e.g., visual aids) perceived as potentially useful, but not used in clinical practice or research. For all the participants, proxy and supported decision-making were the most common strategies used to obtain IC. Innovative measures were perceived as potentially useful, but none of the participants ever applied them in practice.
Conclusions: This study highlights the need to further research the use of strategies to improve the informed consent process in palliative care and research. 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.

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