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OP.021 Research ethics in palliative care: A critical review

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Background: Research ethics refers to the analysis of ethical issues that may occur when people are involved as research participants. The main goal of research ethics in palliative care is: to protect human participants, particularly those who are more vulnerable; to ensure that research serves interests of individuals, groups and/or society; and to scrutinize research activities and projects for their ethical soundness, looking at issues such as the management of risk, protection of confidentiality and the process of informed consent. This is an area of expanding interest, reason why it is unsurprising that ethical frameworks, guidelines, and international legislation coexist to address the ethical features of research. Nevertheless, the mere existence of these documents is not enough to ensure that research is ethically sound. To be so, researchers need to acquire the knowledge expressed in their content, integrate their inherent principles, translate them into everyday research practices, and become critically competent to mobilize them when facing ethical issues and challenges directly relevant to their research. This is particularly relevant in palliative care research, a context where more evidence is needed, as only high quality and sound evidence provide the best guarantee for ethically robust practices.

Aim: To critically review the existing international literature on research ethics in palliative care research.

Methods: Critical review, which is a type of review that presents, analyses and synthesizes material from diverse sources, in order to provide a new interpretation of the main ethical issues, challenges and frameworks of research ethics in palliative care. Searches were performed in five international databases and complemented by the manual search of the most relevant journals and manuals in the fields of both palliative care and bioethics. Synthesis was narrative and conceptual.

Results, Outcomes and Implications: Palliative care research involves human beings as participants and therefore raises ethical, legal, social and political concerns. Vulnerability was as a key issue in palliative care research. Vulnerability is a touchstone in palliative care, bioethics and a common denominator to research ethics. Patients in palliative care often exhibit several categories of vulnerability, namely: cognitive, situational, medical, allocational, social, and deferential. This calls for protection, but should not prevent research participation. Excluding vulnerable patients from participating in relevant research could suggest that society is failing in its obligation to improve high-quality, evidence-based healthcare. Other ethical issues identified in our review were: respect for research participants; the need for independent review by ethics committees; issues related to autonomy and the informed consent process; challenges related to the scientific validity of some data and findings; favourable risk-benefit ration; and fair participant selection.

Conclusions: This critical review aimed to develop an overview of the main ethical issues, challenges and frameworks in palliative care research. Particular ethical requirements give rise to particular challenges in this field. Nevertheless, none of these challenges are impossible to overcome. Acknowledgments: FCT Portugal - Scientific Employment Stimulus.

Keywords: research ethics; palliative care; vulnerability; critical review.