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Abstracts

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Abstract number: FC06.3
Abstract type: Oral

How and Why Did Belgium Come to Allow Euthanasia for Minors? A Descriptive and Ethical Analysis

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Aims: In early 2014 Belgium controversially amended its euthanasia law, making it legal for minors to request euthanasia if they are judged to have 'capacity for discernment'. This raises various ethical questions, the answers to which are relevant worldwide. The aim of this presentation is

- (1) to briefly sketch how the law came about and
- (2) analyse the most important arguments raised both against and in favour of this amendment.

Methods: This study concerns an analysis of the various official written reports of the Belgian Senate and House of Representatives which give first hand insight into how the law came to pass and which issues were raised during this process. From these reports the history of the amendment is sketched and the most raised ethical arguments are identified and analysed using existing international research and literature.

Results: Documents show that whether minors should be allowed to request euthanasia has been debated in Belgium since the passing of the initial euthanasia law in 2002. Though controversial, the amendment that was passed is the result of significant compromise as more radical and far-reaching proposals were made. As regards the arguments, the most often voiced arguments in favour of the new amendment are that it would avoid discrimination and would give legal security. Critics most often point to the fact that the law may be unnecessary, contains significant uncertainties, and is inattentive to the fact that minors are often not fully competent to make such big decisions. These arguments will be analysed for their ethical validity.

Conclusion: Even within Belgium the 2014 amendment was far from uncontroversial. Debate was fierce and many arguments were voiced both for and against, though a significant number of these are, ethically speaking, invalid. In short, this presentation will give an insight into how Belgium came to pass such a controversial amendment.

Abstract number: FC06.4
Abstract type: Oral

Ethical Decisions in Palliative Care: A Burnout Risk Factor? Results from a Mixed-methods Multicentre Study in Portugal

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Background: Ethical decision-making in end-of-life care is perceived as stressful. Making ethical decisions is related to higher levels of burnout among health professionals.

Aims: To identify the most common ethical decisions made by Portuguese palliative care teams and understand how the making of such decisions relates to burnout.

Methods: Mixed methods study in 9 palliative care teams. Data was collected through: questionnaires of socio-demographic and profession-related variables, and work-related experiences; Maslach Burnout Inventory; interviews; observations. Quantitative data analyses included descriptive, uni and multivariate logistic regressions; qualitative data was analysed inductively with themes/categories emerging from data. Triangulation ensured reliability. A total of 88 professionals (66% response rate) were included, 11 nurses and 9 physicians were interviewed and 240 hours of observations were fulfilled.

Results: The most common ethical decisions were caused by communication issues, forgoing treatment and terminal sedation. Although perceived as a burnout risk factor in the speech of the participants, quantitative data showed that making ethical decisions was not significantly associated with burnout. These findings were explained through the analysis of the transcripts of interviews and field-notes: The decision-making process using an interdisciplinary team approach and consulting ethical committees were identified as protective factors against burnout.

Conclusions: Making ethical decisions is not associated with burnout among professionals working in Portuguese palliative care teams. This is explained by the ethical deliberation and decision-making process followed by these teams. Promoting palliative care skills among professionals providing end-of-life care in other settings might be useful to diminish burnout related to making ethical end-of-life decisions.

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Can Saving Money Be Unethical? Managing Conflict of Interest in Advance Care Planning

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Background: While advance care planning (ACP) primarily aims at realising patient autonomy during the last phase of life, it may also reduce the costs of care. Given the increasing economic pressure in most health care systems, the sensitive ACP-communication process might be unduly influenced by cost-considerations.

Aims: To analyse potential conflicts of interests resulting from the cost implications of ACP programs and discuss corresponding ethical safeguards.

Approach: We assessed

- (1) the cost-implications of ACP by a systematic review and
- (2) the resulting conflicts of interest by analytical ethical investigation.

Results: Six of seven studies included in the review demonstrated cost reductions through ACP ranging from \$1,041 to \$64,830 per patient, which lets ACP appear an attractive tool for payers and policy makers (despite open questions regarding the direct and also the indirect costs of ACP). This involves, however, a considerable potential for conflicts of interests: incentivised facilitators might undermine the openness of the planning process, or

individuals might feel obliged to opt "autonomously" for less costly care. As a consequence, safeguards for patient autonomy are required: first of all, research must reveal financial gains and losses caused by ACP programs so payers' and policy makers' potential goals become transparent. The primary goal must remain to realise patient autonomy (and high quality care) near the end of life, even if this increases costs of care. Most importantly, quality and thereby openness of the facilitation process must be assured. Furthermore, facilitators should be specifically trained to manage potential conflicts of interest.

Conclusion: The potentially conflicting goals of ACP, realising patient autonomy and containing costs, require safeguards to guarantee the openness of the facilitation process.

Abstract number: FC06.6
Abstract type: Oral

A Palliative Approach: A Concept in Need of Clarity

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Background: Much of what we understand about the design of healthcare systems to support care of the dying comes from our experiences with caring for dying cancer patients. It is increasingly recognised, however, that in addition to cancer, high quality end of life care should be an integral part of care that is provided for those with other advancing chronic life-limiting conditions. A palliative approach has been articulated as one way of conceptualising this care but there is a lack of conceptual clarity regarding its essential characteristics.

Aims: To delineate the key characteristics of a palliative approach found in the empiric literature in order to establish conceptual clarity.

Methods: We conducted a mixed-methods knowledge synthesis of empiric peer-reviewed literature. Established knowledge synthesis procedures were implemented. Search terms pertaining to "palliative care principles" and "chronic life-limiting conditions" were identified. A comprehensive database search yielded 73 studies. Narrative synthesis methods and thematic analysis were used to identify and conceptualise key characteristics of a palliative approach.

Results: Our review revealed a burgeoning body of knowledge. Three overarching themes were conceptualised that characterise a palliative approach:

- (1) Upstream orientation towards the needs of people who have life-limiting illness and their families.
- (2) Adaptation of palliative care knowledge and expertise.
- (3) Operationalisation of a palliative approach through integration into systems and models of care that do not specialise in palliative care.

Conclusion: Our findings provide much needed conceptual clarity regarding a palliative approach and its delineation from palliative care. Such clarity is of fundamental importance for the development of knowledge regarding the integration of a palliative approach in the care of people with chronic life-limiting illnesses.

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FC07 Palliative care in non-cancer

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Preferences for End of Life Care and Treatment for Advanced Chronic Obstructive Pulmonary Disease (COPD) Patients: Results from a Discrete Choice Experiment

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Background: COPD is a chronic progressive condition with high symptom burden accounting for 26,000 deaths annually in England alone. Little is known about patients' preferences for care and how they change in advanced disease.

Aims: To identify patients' preferences for care in advanced COPD, and explore how these preferences change with deterioration in condition.

Methods: A discrete choice experiment was developed and included in a postal questionnaire. 305 patients with advanced COPD, recruited from GP practices in Eastern England and South London, participated in a three-wave six-monthly postal survey. In the choice experiment, each respondent considered five different vignettes describing different health states, and for each indicated their preferences for source and place of care should they experience an exacerbation. Both the health states and the care options available were varied within the survey. Twelve different versions of the questionnaire were used, enabling coverage of sixty different care choice contexts.

Results: The discrete choice model estimated from this data provides insight into the weight that respondents put on different aspects of care: whether to receive care at home or at hospital; who leads the care decisions in each setting; the support available outside of routine appointments; and the time to access this support. Respondents' demographics, exacerbation history and quality of life are incorporated into the model, revealing that these factors have a statistically significant influence on patients' preferences for both who makes the care decisions and the location where the care is provided.

Conclusions: This research provides new evidence enabling appropriate end-of-life care and support of advanced COPD patients living in rural-urban and inner-city regions. It will help health service providers to identify possible service modifications to meet COPD patients' needs.

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