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Caring for people with end-stage dementia: Ethical dilemmas and moral conflicts

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Introduction: Caring for people with end stage dementia living in the community and restricted to their home is mainly done by Home-Care-Units (HCU). Another uncommon program, in Israel, is implemented by the Home-Hospice-Unit (HHU), specializing in palliative End-Of-Life-Care (EOLC). The aim of this study is to characterize ethical-aspects, conflicts and dilemmas raised by staff and family-caregivers, caring for people with end stage dementia.

Methods: Qualitative research, using Sixty-five semi-structured interviews (with 25 staff-members and 40 family-caregivers) analyzed through a thematic-content-analysis approach.

Outcome: Dilemmas regarding palliative-care was the main theme, including definition of the disease as terminal, choosing 'comfort' over 'life-prolonging', clarifying patients' wishes and deciding whether or not to use artificial-feeding. Substantial differences were found between those two settings of care., The main difference being the difficulties to predict life-expectancy, which create a gap in the expectations, approaches and goals for EOLC, for making choices and voicing preferences regarding 'comfort' and 'life-extension'.

Conclusions: This study shows the importance of developing ethical, felicitous cultural-codes for professional-staff caring for people with end stage dementia and their irreplaceable, significant family-caregivers. The findings can enable us to develop ethical-codes for conducting quality of care and practicing equality and mutual help for people with end stage dementia, living in their homes.

Biography

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