Tittel: Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study.

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Sammendrag:

Background
Caring for people with dementia living in their own homes is a challenging care issue that raises ethical dilemmas of how to balance autonomy with their safety and well-being. The theoretical framework for this study consisted of the concepts of autonomy, beneficence, non-maleficence, paternalism and from the ethics of care. The aim of this study was to explore ethical dilemmas concerning autonomy that were identified when persons with dementia wished to live at home.

Methods
This Norwegian study had a qualitative, hermeneutic design and was based on nine cases. Each case consisted of a triad: the person with dementia, the family carer and the professional caregiver. Inclusion criteria for the persons with dementia were: (1) 67 years or older (2) diagnosed with dementia (3) Clinical Dementia Rating score 2 i.e. dementia of moderate degree (4) able to communicate verbally and (5) expressed a wish to live at home. The family carers and professional caregivers registered in the patients’ records were included in the study.

An interview guide was used in interviews with family carers and professional caregivers. Field notes were written after participant observation of interactions between persons with dementia and professional caregivers during morning care or activities at a day care centre. By means of deductive analysis, autonomy-related ethical dilemmas were identified. The final interpretation was based on perspectives from the theoretical framework.

Results
The analysis revealed three main ethical dilemmas: When the autonomy of the person with dementia conflicted with (1) the family carer’s and professional caregiver’s need to prevent harm (non-maleficence) (2) the beneficence of family carers and professional caregivers (3) the autonomy of the family carer.

Conclusions
In order to remain living in their own homes, people with dementia accepted their dependence on others in order to uphold their actual autonomy and live in accordance with their identified values. Paternalism could be justified in light of beneficence and non-maleficence and within an ethics of care.

Keywords: Autonomy, Dementia, Ethical dilemmas
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