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Transitions experienced by carers on the living-dying journey of a relative with dementia.

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EAPC Abstract

Title:

Transitions experienced by carers on the 'living–dying' journey of a relative with dementia

Text:

Background

The experience of care transitions for family carers of a relative living with dementia do not necessarily lessen once their relative is admitted to a care home. Goals of care and end of life care decisions need to be made. The process of reaching these decisions can be significantly challenging.

Aim

To explore the experience of family carers responsible for decision-making on behalf of a relative living with advanced dementia through their transitions from the community into a care home.

Method

Carers of a resident living with dementia were offered an individual interview in a qualitative study within a randomised trial evaluating an Advanced Care Planning intervention in care homes in Northern Ireland, UK. Twenty participants completed a semi-structured audio recorded interview, from which transcripts were thematically analysed.

Results

Interviews highlighted that carers were at different stages of the decision-making process for their relative's care when they were admitted to the care home. Some had previously discussed end of life care wishes with their relative, whereas others had to make an informed choice for the care without prior discussions. The emotional impact of this transition varied from high levels of stress and extreme guilt, to a sense of relief that their relative was content and safe in their new setting. Some carers reported that this decision process left them feeling isolated due to family conflict, but support was also available for others from their new 'family': the care home staff. However, reports of poor communication with and amongst staff, and inconsistencies of health care provision were an additional source of distress.

Conclusions

Key findings which require further investigation include: holding goals of care decision-making earlier in the dementia disease trajectory; recognition of family dynamics; the need for improved knowledge to facilitate informed decision-making, and improving communication with and between staff.

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