Advance care planning for people with dementia

UK policy and guidance state that people should have their preferences and priorities for end of life care recorded in the form of an advance care plan. However, for people with dementia and their families, issues of reduced capacity, difficulties with discussing end of life preferences and staff understanding can make this process challenging. This research focus summarises two studies that explore these issues.

Challenges in implementing an advance care planning programme in long-term care

This study explores the effectiveness of an education programme, Let Me Decide, designed to support the development of advance care planning (ACP) for people with cognitive impairment and frailty.

The programme was implemented with 30 senior nurses from two nursing homes and one community hospital in Ireland, totalling 290 beds. Surveys were carried out with staff to assess knowledge of ACP and palliative care, learning needs and perceived barriers to implementation.

Workshops on palliative care, communication skills, bereavement, symptom assessment and management were subsequently delivered to nurses and healthcare assistants in the respective settings.

Senior nurses were provided with documentation to implement ACP in their settings. Implementation involved assessment of residents’ cognition and capacity to complete advance directives, education of willing residents and families about ACP, and drawing up end of life care (EoLC) plans for those with limited capacity.

After the programme had concluded more than 50% of residents across all settings had EoLC plans in place. Of residents who had died, 86% had plans, of which 76% had been completed by the medical team with each resident, where able, and his or her family.

Healthcare decision-making: past, present and future, in light of a diagnosis of dementia

This study explores experiences of and views of healthcare decision-making in the past, present and future among people with dementia and their family carers.

It draws on an earlier study published by the authors in 2016, which found that family carers’ understanding of a person with dementia’s end of life wishes may differ from that of the person him or herself.

The study adopts a qualitative approach with a sample of six couples, including one additional adult child, taken from the original study. During brief, semi-structured interviews, participants were asked about previous approaches to healthcare decision-making, and how a diagnosis of dementia influences their decisions and may influence their decisions in the future.

Findings indicate that, although joint decision-making was previously common among the couples, it had not usually involved decisions about healthcare.

A diagnosis of dementia usually changed decision making, especially among carers who have taken on increased responsibilities. However, the ability to make long-term plans and decisions was found to be limited due to the challenges of getting through each day, leaving families with little energy to address future wishes.

The original study notes that people with dementia may have difficulty in imagining their future selves. Participants expressed uncertainty about making future decisions, and said they need more information and support to make decisions about EoLC.

The study concludes that families need ongoing support and guidance when making decisions about future healthcare preferences that take into account changes as dementia progresses. It also highlights that carers and people with dementia may have differing views about end of life care, and that such differences should be considered carefully. To implement advance care planning, therefore, clinicians should explore families’ previous approaches to decision making.

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