



Patient choice is a cornerstone of UK health policy. In the context of End of Life Care, patient choice can include an individual's general wishes and preferences about how they are cared for and where they would wish to die. The ability to state their preferences for end-of-life care, enables patients to experience a 'good death'. Researchers at the Cambridgeshire and Peterborough CLAHRC, are undertaking a project which explores how people talk about, and operationalise, choice in the form of advance care planning (ACP). This research will increase understanding of how ACP planning tools are being used, and aims to enable the improvement of end of life care service provision.

Policy context

Advance care planning involving patient choice is key to good quality end-of-life care.¹ Healthcare (and some social care) services across the country have adopted various end of life care planning tools, such as the Liverpool Care Pathway, Preferred Priorities of Care, and Gold Standard Framework. These ACP tools enable staff to know how and when to open up a discussion with individuals, and their relatives, about what they wish for as they near the end of life; and enable co-ordinated care planning across services.

The research

This project aims to identify what advance care planning means from a policy and practice perspective; and how healthcare professionals, policy makers, patients and carers talk about, and enable, patient choice to happen.

The first part of the research project involved interviews with the above named groups. The second part of the project is a longitudinal study following ten patients for up to a year, and observing how planning for their future care unfolded in daily life. The research is informed by social science research methods and theory, focussing on language, interaction, and relationships.

Findings

At the time of writing, analysis of the data is still ongoing. Initial indications are that advance care planning seems to be more of a concern to policy makers and healthcare practitioners than to patients and carers, although, as health deteriorates, patients may wish to anticipate the future. Choice and advance care planning appear to be carried out in practice as discrete 'tasks', which may not adequately reflect levels or type of care, nor patients' or carers' concerns about the future.

ACP tools shape patients' preferences, particularly in how people choose to die at home. In discussing their

present concerns and the future, patients tend to focus more on how they, their care and health, are situated within a family and/or wider social context. Being able to stay at home is often dependent on the availability of family support; and patients often worry about the impact of staying at home on family dynamics.

Implications

These preliminary findings indicate possible implications for future service planning, and expectations around the role and capacity of informal carers within the family and kinship unit.

Advanced care planning has the ability to incorporate concerns about, and changes within, family relationships towards the end of life. However, this may be dependent on available time, professional ability, and the capacity to recognise and address concerns appropriately, as well as the availability of services that support informal care networks.

Key learning points

- **Social science research can inform how policy relates to healthcare practice and people's everyday life experiences.**
- **Advance care planning is often done as a procedural task. This may not adequately reflect levels of care or people's concerns about their future.**
- **As people plan for the future they are concerned about their relationships with others.**
- **Being cared for and dying at home can impact on family dynamics. This is not always addressed in advance care planning discussions.**

References

1. End of Life Care Strategy: Promoting high quality care for all adults at the end of life. Department of Health (2008)