



Planning for the end of life

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Introduction

Advance care planning (ACP) is promoted as a key component of 'the good death' enabling individuals to preserve autonomy through the exercise of choice and control about the place and circumstances of dying and death. However, little is known about the implementation of ACP in real world settings and how patients respond to the opportunity to plan their future care.

The Care and Communication Study

Investigated patient and carer responses to ACP in community health care settings in the East Midlands of England, and how closely expressed preferences influence outcomes of end of life care. This poster uses one case study to illustrate some key findings.

Method

Qualitative study involving:

- 21 longitudinal case studies triangulating patient, carer and health professional perspectives and experiences of advance care planning over six month follow up.
- 37 interviews with health professionals working in community settings.

'An interesting experience'

"Once I was told I was terminal, I got quite excited. Because, you're only ever going to get one shot at this kind of thing... There was a very strong feeling of excitement, yeah, like going on a journey. I found it very interesting in ways I observed myself and my reactions to things, and then the biggest one of all, one day, suddenly hit me: 'I'm free, I have never been so free in all my life.' But then, you know, very quickly, you realise, actually, you're not as free as you think you are. Because you have to take into account other people's thoughts, their feelings, their emotions, and to some extent, their needs while you can still give something back." Peter

Anticipating the future

"I would rather stay here [home] for as long as possible. If it gets to the point where I can't manage to go to the toilet by myself, I'll have to rethink that. And I think everyone's got their limits of what they're prepared to put up with, or dignity. There's all sorts of things that come into it, into play. But I'm not at that point at the moment." Peter

Case study: Peter

Peter was diagnosed with terminal cancer, aged 63, and given what proved to be an accurate prognosis of 9 months to live. He was unusual in his open awareness and willingness to discuss his reaction to his prognosis and preferences for future care. His initial sense of freedom quickly changed to awareness of his obligations and relationships to those around him. He wanted to die at home but was uncertain about what would happen as his illness progressed. Peter had a strong desire to maintain his personal dignity. He felt this would be undermined if he became a burden to his family, particularly if they had to provide personal care.

Peter was admitted to a hospice for symptom control of severe pain. He expressed a strong desire to return home to die. Hospice staff tried hard to realise this goal. However, Peter's condition continued to deteriorate, his pain was not controlled, and his capacity began to fluctuate. Peter's wife now felt she could not cope with care at home. The focus of decision making shifted from Peter's wishes towards his needs and who could best provide for them. His consultant decided that he could not be discharged. Peter remained in the hospice for a month and died there with his family at his side.

The future arrives

- Peter is admitted to hospice for pain control
- Prognosis 6 weeks
- Progressive deterioration
 - Uncontrolled pain
 - Fluctuating capacity
- Discharge planned 3 times
- Peter feels 'in limbo' : 'wants to get out of here quickly'
- Desire for euthanasia recorded
- Concerned about burdening his family
- Wife feels she cannot cope with Peter at home
- Consultant feels Peter cannot be discharged
- Preferred place of death is changed to 'hospice'.

Balancing conflicting interests

"At the end of the day, doesn't matter how much a patient wants to die at home, if the family are not going to cope, I don't necessarily think it's the right thing to do to send them, unless the family agree to try. Because I just think you're setting them up to fail and then everyone feels worse....I think that his wife was so relieved, in the end, when the decision was to keep him here [hospice]. ...If we took his best interests and ignored everything else that was going on around him that might actually not be in his best interests." Consultant

Conclusion

The study findings reveal the real world difficulties that patients, carers and professionals confront in establishing the best thing to do in challenging and difficult circumstances. Patient preferences are inclined to be uncertain, pragmatic, complex and shifting in response to unfolding uncertainty and the demands of contingency. Participants struggle to balance conflicting interests of obligation and imposition. The language of 'choice' 'empowerment' and 'autonomy' has little salience for patients' lived experience.

