

Care and communication between health professionals and patients affected by severe or chronic illness in community settings



The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Pollock, K, Wilson, E, Seymour, J, Cox, K, Avery, T, Crosby, V, Finn, G and Scott, H

Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care

School of Health Sciences, University of Nottingham kristian.pollock@nottingham.ac.uk

Background

Advance Care Planning (ACP) is a process whereby a competent patient, in consultation with health care providers, family members and important others, expresses preferences about their future care and/or makes an advance decision to refuse treatment in case of loss of capacity to make or communicate decisions. Care and treatment at the end of life are often inadequate and crisis driven. The National End of Life Care Strategy promotes the use of ACP as a means of addressing these issues. It aims to increase the number of people able to realise their preference to die at home and reduce the incidence and associated personal and economic costs of unnecessary and unplanned hospital admissions at the end of life. However, engaging with ACP can be difficult for all participants and little is known about how ACP discussions are initiated or how they are conducted between patients, family carers and professionals.

Aim

To investigate patient and professional perceptions and experiences of initiating and subsequently reviewing ACP discussions and decisions throughout the last six months of life.

Methodology

The study is situated within a theoretical framework in which, rather than constituting a 'one off' recording of instructions for future medical treatment, ACP is understood to involve a process of ongoing discussion, reflection and review involving a) input from several/diverse persons and perspectives (patient, family, professionals) and b) change over time. As such a qualitative study design was employed to gather data in two workstreams:

- Workstream one – professional perspectives interviews
- Workstream two - longitudinal patient-centred case studies

The data collection phase is complete and analysis is ongoing. The study is due to complete in July 2014

Professional Perspective Interviews

Cross sectional semi-structured interviews with health care professionals (n=37).

Professionals varied in experience, confidence and engagement with ACP. They tended to approach the topic cautiously, taking a stepped approach and often initiating discussion at a late stage of illness progression, and in a reactive rather than pre-emptive manner.

Professional	Number interviewed
GPs	12
Community nurses/district nurses	5
Community Matrons	6
Heart Failure specialist nurses	6
Specialist palliative care nurses	3
Specialist nurses (specific conditions)	3
Other	2
Total:	37

Case studies

Patients (n=21)		Family Carers (n=13)			HCP (n=16)	
Male 12	Age range 62-91	Male 3	Female 10	None 7	None	8
					GP	4
					Macmillan nurse	6
					Consultant	1
Female 9	Age range 38-92	Spouse		10	Community Matron	2
		Son/daughter		2	Other	3
		Sibling		1	Total	16

The processes and outcomes of ACP, or its absence, were explored through a) initial and follow up interviews with each patient, and each of their nominated family and professional carers and b) analysis of medical records and documentation of ACP (accessed with permission). Each patient recruited to the case study workstream was followed-up for a period of up to six months, or until their death if this occurred sooner.

Patients varied widely in their understanding of prognosis and in their willingness to anticipate and plan for death and dying. When it occurred, ACP tended to be focused largely on completion of DNACPR forms and recording of preferred place of death. Patients and professionals were mindful of the limitations of planning in the face of an unknown and uncertain future. Plans for end of life care were liable to rapid change, and likely to be overtaken by events. This was one reason for deferring discussion of ACP until it became evident that death was imminent.