

Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life

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Scientific summary

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Background

The Care and Communication study, presented in this report, investigated how seriously ill patients, their relatives and the health professionals caring for them understood and experienced discussions about end of life care (EOLC) involving advance care planning (ACP). ACP is a key component of current UK health policy to improve the experience of death and dying by enabling patients and their significant others to consider their options and preferences for EOLC. It is considered important that patients have the opportunity to do this while they retain capacity to make and communicate decisions. ACP aims to enable family and professional carers to take account of, and where possible to implement, patients' expressed wishes for care and treatment. Evidence of the nature, frequency and outcomes of ACP discussions remains limited and frequently conflicting. However, it is apparent that ACP remains uncommon in most areas of professional practice and that both professionals and patients tend to avoid discussions they find difficult. Patient and family responses to ACP and its effect on EOLC outcomes remain poorly understood.

Aim

The purpose of the study was to explore the implementation of ACP in community care settings through investigation of how patients, carers and professionals negotiate the initiation of ACP, and the outcomes of discussion and planning for EOLC in terms of how closely the preferences that patients express are subsequently realised.

Objectives

- To investigate patient and professional perceptions and experiences of initiating, and subsequently reviewing, ACP discussions and decisions throughout the last 6 months of life.
- To investigate patient and carer responses to the offer of an ACP discussion.
- To identify barriers to the implementation of ACP.
- To investigate outcomes for EOLC: how patient preferences for care, expressed and recorded during ACP, match care received in the last week of life.
- To investigate how professionals, patients and carers assess the quality of EOLC.
- To generate evidence for best practice in the implementation of ACP.
- To establish professional training and support needs for confident and skilful communication in ACP.

Design and methods

The study was based in generalist community health services providing EOLC to patients living with life-limiting and terminal conditions in their own or residential care homes and registered with GP (general practitioner) practices in the East Midlands of England.

This 2-year qualitative study was based on two workstreams.

Data collection

Workstream 1: professional perspectives interviews

Qualitative semistructured interviews were carried out with health professionals including GPs, community nurses, clinical nurse specialists (CNSs) and Allied Health Professionals (AHPs).

Workstream 2: longitudinal patient case studies

Patients were recruited through their GP or CNS to participate in longitudinal case studies involving a series of interviews over a 6-month period. Where appropriate and possible, patients nominated a family carer and a health professional to participate as part of their 'case'. In addition, permission was sought to view patients' medical records.

Most interviews were conducted in patients' homes and professionals' offices, with a few (mainly professional) being carried out by telephone.

Analysis

Interviews were audio recorded with permission. Anonymised transcripts were imported into the qualitative analysis software program NVivo 10 (QSR International, Warrington, UK) along with written field notes. Individual case profiles were compiled through detailed scrutiny of all relevant data sources and the restoring of each case into an integrated, sequential narrative. Data collected from serial follow-up interviews with case study participants go beyond cross-sectional and static accounts of specific stakeholders. This enables an understanding of ACP as a potentially ongoing process of communication between the multiple and changing perspectives of patients, family carers and professionals. The qualitative software program NVivo 10 was used to facilitate organisation of a complex data set and support a thematic analysis of the data, following principles of constant comparison within grounded theory. Each data set was subjected to both separate and integrated analysis to enable identification and comparison of themes occurring within and between professional interviews and patient cases. Coding and analysis were ongoing throughout the study.

Ethical approval

Approval for the study was sought through the National Research Ethics Service and granted in March 2012 (11/EM/0439). Subsequent research and development approvals and letters of access were issued by the NHS trusts participating in the study. The research involved a vulnerable patient population and investigation of a topic that participants could be expected to find challenging. The researchers remained acutely aware of the need to approach contacts with patients and family carers with the utmost care and sensitivity. In order to avoid causing distress to respondents who may not have been aware of, or did not wish to acknowledge, the terminal or life-limiting nature of their condition, the study was presented in general terms as research into the quality of care and communication about serious, chronic and life-limiting illness.

Patient and public involvement

Patient and public involvement was engaged throughout the project, from a variety of groups and individuals. Support included review and discussion of the study aims and objectives, salience of the topic, patient and carer contact documents, the ethics application, interview guides, study findings and the final report.

Research findings

Demographics

Most patient cases and professional respondents were recruited through 11 GP practices that were broadly comparable with national data in terms of practice size, deprivation scores and registered patients over the age of 65 years, including a spread of locations across rural and urban areas.

Workstream 1: professional perspectives interviews ($n = 37$)

Thirty-seven health professionals and AHPs were recruited to participate in workstream 1 (GPs $n = 12$, CNSs $n = 12$, community matrons $n = 6$, community/district nurses $n = 5$, AHPs $n = 2$). All interviews were undertaken on a one-to-one basis with the exception of one group interview, which included four heart failure nurse specialists. Most professional interviews were carried out face to face, with one being conducted by phone. They ranged in length between 12 and 59 minutes.

Workstream 2: patient case studies ($n = 21$)

A total of 21 patients (male $n = 12$, female $n = 9$, age range 38–91 years), 13 family carers and 14 health professionals took part in the case studies. Eight patients did not identify a family carer who was available, or whom they wished to participate in the study. Family carers were predominantly spouses ($n = 10$) and female ($n = 10$). Health professionals nominated were GPs ($n = 5$), palliative care nurses ($n = 3$), AHPs ($n = 3$), community matrons ($n = 2$) and a consultant in palliative medicine ($n = 1$). Seven patients did not have a nominated health professional.

A total of 59 interviews were undertaken with patients in the case studies: 33 were joint interviews with the patient and a family carer and 26 were with patients alone. In addition, seven interviews were with family carers alone, usually after the death of the patient. The 14 individual nominated health professionals took part in a total of 31 interviews as part of the case studies. All interviews took place over a period of approximately 6 months and were undertaken as and when was appropriate for each case. The minimum number of interviews per case was one and the maximum was 11. In total 97 interviews were undertaken for the patient case studies. Nine (43%) patients died during the study follow-up period.

Patients recruited for the case studies had a range of conditions, and often more than one. However, two-thirds (14 of 21) had been referred to the study because of a cancer diagnosis. Other primary conditions included chronic obstructive pulmonary disease, renal disease, liver disease, heart failure and spinal injury.

Just under half (9 of 21) of the patient cases had no evidence of ACP. Eleven patients had documented preferred place of death (PPOD) and the same number had a completed do not attempt cardiopulmonary resuscitation form. One had a (poorly worded) advance decision to refuse treatment document. Six of the nine patients who died during the period of follow-up did so in their preferred place, which was home.

Qualitative findings

The study supported previous research in finding ACP to be uncommon and focused primarily on specific documented tasks involving decisions about PPOD and cardiopulmonary resuscitation. A category of frail elderly patients was identified, often living alone with complex health problems, with no engagement in ACP. There was no clear allocation of responsibility for ACP, which could be initiated by a wide range of health professionals and also, sometimes, patients. In practice, this task was often undertaken by specialist nurses on the basis of a strong relationship and regular contact with patients and their families. The documents used to record decisions constrained the process and communication of ACP and the issues included for consideration. Some professionals thought that forms and templates had a positive impact in prompting and structuring discussion. Others felt they reduced ACP to a bureaucratic 'tick-box' exercise. Professionals expressed awareness of ACP being assessed in terms of financial and performance targets.

Advance care planning discussions intersected two parallel strands of planning. 'Professional planning' related to the organisation and co-ordination of care between staff and services. This was often managed through the Gold Standards Framework register for palliative care maintained in each practice and was carried out largely without patient knowledge and involvement. 'Personal planning' referred to the practical and emotional preparatory work, which patients and families undertook to prepare themselves for death. This type of planning included tasks such as making a will, planning their funeral and arranging family events, and happened largely independently of professional awareness or involvement. ACP involved the intersection of these two strands of forward planning, when patients, relatives and professionals engaged in discussion and decision-making about future care. However, this rarely extended beyond consideration of specific decisions about resuscitation and place of death. Reference to the role of ACP in extending personal autonomy in the event of lost capacity was rare.

Several barriers to ACP were identified. Current guidelines for ACP assume a degree of accuracy in prognostication that is rarely achievable in practice. Professionals found it difficult to identify patients entering the last year of their lives. ACP tended to be initiated in response to a significant event or marked deterioration in the patient's condition, which signalled they were approaching death. Patients also tended to expect that discussion about end of life would be prompted by a deterioration in their condition and concurred with professionals about the importance of 'timing' for these conversations. Consequently, ACP discussions were likely to be reactive, rather than pre-emptive, and to happen late, if at all. Professionals found discussions challenging. Although broadly positive about ACP in principle, they described practical difficulties and limitations in practice. They were wary of causing distress and harming patients by an untimely initiation of the topic, and expected that a substantial number would not welcome an invitation to discuss this. Consequently, ACP was approached with great care and caution, as professionals searched for cues and a 'moment of opportunity' to broach the topic. When talking about ACP, professionals described the use of vague and euphemistic language. This strategy allowed patients the option of whether or not to take up the topic for discussion. However, it also risked misunderstandings and uncertainty about what had been established.

A minority of patients were open in their awareness and willingness to discuss, and even initiate, ACP discussion. More commonly, respondents were cautious and pragmatic in their approach, and reluctant to commit to decisions about an uncertain future that they felt unable to control. Others had no wish to consider plans for death and dying before they had become gravely ill. Professionals sometimes described supporting patients to understand their situation and foresee how their illness would progress. This involved a focus on the present and immediately unfolding future, moving in a stepwise progression to help patients foresee what was likely to happen next and incrementally towards the end of life.

Much emphasis has been placed on home as the PPOD for the majority of patients. Most respondents who expressed a preference chose this, and six of the nine who died did so at home. However, expressed preferences to die at home tended to be tentative and conditional, rather than committed. A stronger focus was on concerns about limiting the burden of care for families, and being made 'comfortable' at the end of life. While strongly committed in principle to supporting patients to die at home, professionals also recognised the limitations of this option. They could not guarantee that resources would be available when needed, or that intractable symptoms would not develop and require a move to institutional care. Professionals were also sensitive to the difficulty that families could experience in trying to support their relatives in dying at home, in which case transfer to a hospice, care home or even hospital could be a better option.

Professionals talked of offering patients 'choice' in EOLC. However, the notions of 'choice' and 'autonomy' did not feature in patients' or relatives' accounts. Respondents were uncertain about how their preferences might change, and the future options that would be available to them. This was one reason for not planning too far in advance. It is likely that some patients, especially those with extended illness trajectories, will be more receptive to ACP than others. Within the study, it was the specialist nurses caring for patients with neurological conditions such as multiple sclerosis and motor neuron disease who had most knowledge and experience of ACP.

Strengths and limitations

Although a small-scale qualitative study, this research makes a significant contribution to the limited literature on how ACP is implemented in the complexity of real-world settings, rather than as research interventions. Although a considerable body of data was collected, the original aim of recruiting complete triads for each patient case was not achieved. Nevertheless, triangulation of case participant perspectives and different data sources within a longitudinal study design enabled an understanding of the complexity and difficulty of ACP discussion and the tentative, shifting nature of plans and decision-making in situations of intrinsic and enduring uncertainty. The study findings have highlighted the considerable divergence between the abstract policy formulation of ACP and its implementation in community care settings. They point to the need for greater conceptual clarification and further research into the value and acceptability of ACP in practice. We consider that further work is required before a formulation of best practice in implementing ACP or recommendations for professional training can be made. Consequently, the original objectives of the project to identify best practice and continuing professional development needs were not addressed.

Conclusions

Current policy regarding ACP has not translated easily to health-care practice in community settings. This study supports findings from previous research that ACP is not common, is often limited to documentation of a few key decisions about cardiopulmonary resuscitation and place of death, is reported to be challenging by many health professionals, is not welcomed by a substantial number of patients and tends to be postponed until death is clearly imminent. Professional respondents in the Care and Communication study expressed a low awareness of current policy and guidelines relating to ACP, particularly as this relates to issues of decision-making and capacity. This tended to be operationalised pragmatically in terms of specific, discrete and easily measurable tasks, rather than viewed as a means of exploring patient goals and values in relation to future care, as well as death and dying. These tasks were subsumed within the sphere of EOLC. ACP does not resonate with the concerns of many patients, whose responses to future planning are diverse, shifting and not infrequently ambivalent. Some patients wish to be, and to remain, informed about their prognosis and to make plans for future care. Others are less certain: wanting to know, but not too much; preferring to set the future aside for as long as possible. The current strategy of professional caution in initiating discussion of ACP corresponds with the preferences of many patients who do not wish to deal with death and dying before they have to. In consequence, however, those who do wish to engage in anticipatory planning may find it difficult to do so. The findings point to the potential value of establishing ACP as a structured intervention delivered by specialist facilitators, possibly targeted at specific groups of patients, rather than a task to be routinely undertaken by diverse professionals in community care settings. There is a considerable divergence between the abstract formulation of ACP and its practical implementation. In particular, there are tensions between the goals of ACP as a means of extending patient autonomy, reducing health-care costs and promoting 'patient choice'. The study makes a substantial contribution to the limited evidence base underlying the current policy and implementation of ACP. It highlights the need for much greater critical scrutiny of the concept of ACP, as well as greater understanding of its public salience and acceptability, as prerequisites for its future development and sensitively targeted application.

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