

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.



Final report

August 2014

University of Nottingham, School of Health Sciences

Authors:

Dr. Kristian Pollock¹ and Dr. Eleanor Wilson¹

Competing interests: None declared

¹ School of Health Sciences, University of Nottingham

Corresponding author:

Kristian.pollock@nottingham.ac.uk<http://www.nottingham.ac.uk/research/groups/srcc/projects/index.aspx>

[Word count 52,409](#)

© Queen's Printer and Controller of HMSO 2014. This work was produced by Pollock *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Important

A 'first look' scientific summary is created from the original author-supplied summary once the normal NIHR Journals Library peer and editorial review processes are complete. The summary has undergone full peer and editorial review as documented at NIHR Journals Library website and may undergo rewrite during the publication process. The order of authors was correct at editorial sign-off stage.

A final version (which has undergone a rigorous copy-edit and proofreading) will publish as part of a fuller account of the research in a forthcoming issue of the *Health Services and Delivery Research* journal.

Any queries about this 'first look' version of the scientific summary should be addressed to the NIHR Journals Library Editorial Office NIHRedit@soton.ac.uk.

The research reported in this 'first look' scientific summary was funded by the HS&DR programme or one of its predecessor programmes (NIHR Service Delivery and Organisation programme, or Health Services Research programme) as project number 10/2002/23. For more information visit <http://www.nets.nihr.ac.uk/projects/hsdr/10200223>

The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors have tried to ensure the accuracy of the authors' work and would like to thank the reviewers for their constructive comments however; they do not accept liability for damages or losses arising from material published in this scientific summary.

This 'first look' scientific summary presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

Plain English Summary

Advance Care Planning (ACP) is a process whereby patients, in discussion with healthcare providers and family members, make plans for their own future health care, based on what they would like to happen if they become unable to make decisions for themselves. Little is known about how Advance Care Planning is carried out, or how it affects patients' and families' experience of death and dying. This study investigated when and how patients, family carers and health professionals communicate with each other about ACP for patients who are anticipated to be approaching the end of their life.

Researchers interviewed thirty-seven health professionals including GPs, community and specialist nurses, about their experience of talking to patients about ACP. In addition, twenty-one case study patients were interviewed several times during a period of approximately six-months. Thirteen family carers and fourteen health professionals were also involved in the case studies, resulting in a total of ninety-seven interviews.

The study found evidence that just over half (12/21) of patients in the study had been involved in Advance Care Planning. The considerable uncertainty of prognosis made timing of ACP discussions difficult. Professionals often faced difficulties in raising the topic and recognising when patients were ready to talk about the future. Discussion was usually limited to decisions about specific issues, including where the patient wished to die, or if resuscitation should be attempted. The difficulty and complexity of decision making about preferences for future care, combined with the volatility of illness, frequently prompted a change of plan. Those who wished to consider ACP often preferred to leave discussion until they had become severely ill, rather than create plans in advance of a time when they may become unable to make decisions for themselves. The study findings highlight the complexity of decisions about end of life care, and the diversity of patient and family responses. In particular, they challenge the basic assumptions underlying current formulations of Advance Care Planning: that patients do (or should) wish for open awareness of death, that home is always the best and preferred place to die, and that place of death is a matter of overriding importance for the majority of patients.

Word count 286

First look draft

© Queen's Printer and Controller of HMSO 2014. This work was produced by Pollock *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Scientific Summary

Background

The Care and Communication study investigated how seriously ill patients, their relatives and the health professionals caring for them, understood and experienced discussions about end of life care 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 end of life care. 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 end of life care outcomes remains 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 end of life care in terms of how closely the preferences which 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 six 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 end of life care: 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 end of life care.
- To generate evidence for best practice in 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 end of life care to patients living with life limiting and terminal conditions in their own or residential care homes and registered with GP practices in the East Midlands of England.

A two-year qualitative study based on two workstreams.

Data collection

Workstream one – Professional perspectives interviews

Qualitative semi-structured interviews were carried out with health professionals including GPs, community nurses, clinical nurse specialists, and allied health professionals.

Workstream two – Longitudinal patient case studies

Patients were recruited through their GP or specialist nurse to participate in longitudinal case studies involving a series of interviews over a six-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 programme NVivo10 along with written field notes. Individual case profiles were compiled through detailed scrutiny of all relevant data sources and the restorying of each case into an integrated, sequential narrative. Data collected from serial follow-up interviews with case study participants goes beyond cross-sectional and static accounts of specific stakeholders. This enables an understanding ACP as a potentially ongoing *process* of communication between the multiple and changing perspectives of patients, family carers and professionals. The qualitative software programme NVivo10 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 was ongoing throughout the study.

Ethical approval

Approval for the study was sought through the National Research Ethics Service (NRES) and approved in March 2012 (11/EM/0439). Subsequent R&D 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 which 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

© Queen's Printer and Controller of HMSO 2014. This work was produced by Pollock *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This 'first look' scientific summary may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

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 eleven GP practices that were broadly comparable with national data in terms of practice size, deprivation scores and registered patients over the age of 65, including a spread of locations across rural and urban areas.

Workstream one – Professional perspectives interviews (n=37)

Thirty-seven health and allied professionals were recruited to participate in Workstream 1 (GPs n=12, clinical nurse specialists n=12, community matrons n=6, community/district nurses n=5, allied health professionals 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 from between 12 and 59 minutes.

Workstream two – Patient case studies (n=21)

A total of 21 patients (male n=12, female n=9, age range 38-91), 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 who 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), allied health professionals (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 was undertaken with patients in the cases studies. Thirty-three were joint interviews with the patient and a family carer, 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 cases studies. All interviews took place over a period of approximately six 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 cases 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) had been referred to the study because of a cancer diagnosis. Other primary conditions included COPD, renal disease, liver disease, heart failure and spinal injury.

Just under half (9/21) of patient cases had no evidence of ACP. Eleven patients had documented preferred place of death and the same number a completed Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form. One had a (poorly worded) Advance Decision to Refuse Treatment (ADRT) 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 Advance Care Planning to be uncommon and focused primarily on specific documented tasks involving decisions about preferred place of death and cardiopulmonary resuscitation (CPR). 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 from 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 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.

ACP discussions intersected two parallel strands of planning. 'Professional planning' related to the organisation and coordination of care between staff and services. This was often managed through the Gold Standards Framework (GSF) register for palliative care maintained in each practice and was carried out largely outwith 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 anticipatory 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 Advance Care Planning 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 anticipate 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, Advance Care Planning discussions were likely to be reactive, rather than pre-emptive, and to happen late, if at all. Professionals found discussions challenging. While broadly positive about Advance Care Planning 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 anticipated 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 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 anticipate how their illness would progress. This involved a focus on the present and immediately unfolding future, moving in a stepwise progression to help patients anticipate what was likely to happen next and incrementally towards the end of life.

Much emphasis has been placed on home as the preferred place of death 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, requiring a move to institutional care. Professionals were also sensitive to the difficulty that families could experience in trying to support their relative 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 end of life care. 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 will be more receptive to Advance Care Planning than others, especially those with extended illness trajectories. 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 Advance Care Planning 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 Advance Care Planning 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 Advance Care Planning has not translated easily to healthcare 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 CPR 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 Advance Care Planning, 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 end of life care. 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 bracket the future 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 Advance Care Planning 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 Advance Care Planning 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 Advance Care Planning, as well as greater understanding of its public salience and acceptability, as prerequisites for its future development and sensitively targeted application.

Funding: NIHR Health Services Research Programme (project number 10/2002/23)

Word count 2634