



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Advance care planning for cancer patients in primary care: a feasibility study

Citation for published version:

Boyd, K, Mason, B, Kendall, M, Barclay, S, Chinn, D, Thomas, K, Sheikh, A & Murray, SA 2010, 'Advance care planning for cancer patients in primary care: a feasibility study', *British Journal of General Practice*, vol. 60, no. 581, pp. 882-883. <https://doi.org/10.3399/bjgp10X544032>

Digital Object Identifier (DOI):

[10.3399/bjgp10X544032](https://doi.org/10.3399/bjgp10X544032)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

British Journal of General Practice

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Advance care planning for cancer patients in primary care: a feasibility study

Kirsty Boyd, Bruce Mason, Marilyn Kendall, Stephen Barclay, David Chinn, Keri Thomas, Aziz Sheikh and Scott A Murray

ABSTRACT

Background

Advance care planning is being promoted as a central component of end-of-life policies in many developed countries, but there is concern that professionals find its implementation challenging.

Aim

To assess the feasibility of implementing advance care planning in UK primary care.

Design of study

Mixed methods evaluation of a pilot educational intervention.

Setting

Four general practices in south-east Scotland.

Method

Interviews with 20 GPs and eight community nurses before and after a practice-based workshop; this was followed by telephone interviews with nine other GPs with a special interest in palliative care from across the UK.

Results

End-of-life care planning for patients typically starts as an urgent response to clear evidence of a short prognosis, and aims to achieve a 'good death'. Findings suggest that there were multiple barriers to earlier planning: prognostic uncertainty; limited collaboration with secondary care; a desire to maintain hope; and resistance to any kind of 'tick-box' approach. Following the workshop, participants' knowledge and skills were enhanced but there was little evidence of more proactive planning. GPs from other parts of the UK described confusion over terminology and were concerned about the difficulties of implementing inflexible, policy-driven care.

Conclusion

A clear divide was found between UK policy directives and delivery of end-of-life care in the community that educational interventions targeting primary care professionals are unlikely to address. Advance care planning has the potential to promote autonomy and shared decision making about end-of-life care, but this will require a significant shift in attitudes.

Keywords

advance care planning; cancer; palliative care; primary health care.

INTRODUCTION

Advance care planning is viewed as an intrinsic component of end-of-life care programmes in many developed countries. In the US, advance directives were originally intended to allow people to record an advance refusal of invasive, life-prolonging interventions.¹ The limitations of this approach resulted in a progressive move internationally towards a broader process of advance care planning that also includes discussion of personal goals, wishes, and preferences about future care.²⁻⁴ Programmes in the US and Australia that have adopted a regional strategy towards educating professionals, patients, and the general public about advance care planning have had some success.^{5,6}

Proactive care planning is central to recent UK policies, and the expectation is that it will now be offered to all patients approaching the end of life.^{4,7}

K Boyd, FRCP (Ed), honorary clinical senior lecturer; **B Mason**, PhD, research fellow; **M Kendall**, PhD, senior research fellow, Primary Palliative Care Research Group; **A Sheikh**, MD, MSc, MBBS, professor of primary care research and development; **SA Murray**, MD, FRCP(Ed), FRCGP, St Columba's Hospice chair of primary palliative care, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh. **S Barclay**, MD, MSc, FRCGP, Macmillan postdoctoral research fellow, General Practice and Primary Care Research Unit and CLAHRC End of Life Care Team, Institute of Public Health, University of Cambridge. **D Chinn**, MSc, PhD, research and development coordinator, NHS Fife, Lynebank Hospital, Dunfermline, Fife. **K Thomas**, MSc, MRCGP, national clinical lead for the Gold Standards Framework and honorary professor of end of life care, University of Birmingham.

Address for correspondence

Dr Kirsty Boyd, Primary Palliative Care Research Group, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh, EH8 9AG.
E-mail: kirsty.boyd@ed.ac.uk

Submitted: 7 June 2010; Editor's response: 13 July 2010; final acceptance: 30 July 2010.

©British Journal of General Practice.

This is the full-length article (published online 29 November 2010) of an abridged version published in print. Cite this article as: *Br J Gen Pract* 2010; DOI: 10.3399/bjgp10X544032.

Advance care planning is conceptualised as an ongoing process of discussion between an individual, who has the capacity to make healthcare decisions, and their care providers about future care when deterioration in the patient's condition can be anticipated. Thus it includes planning for loss of capacity to make decisions, and nomination of a healthcare proxy. Preferences and goals for treatment and future care (including place of care) are to be recorded and communicated to all professionals involved in care. The key underpinning values of this approach are patient choice and autonomy (Box 1).^{8,9} Although patient participation in advance care planning is voluntary, it is being strongly advocated by the UK royal colleges, with a recommendation that GP practices demonstrate that it was offered to all their patients whose death could be anticipated.^{10,11}

Communication between health professionals, patients, and families about end-of-life issues is often suboptimal, with health professionals tending to underestimate patient and carer information needs and overestimate their understanding and awareness.¹² The evidence suggests that most seriously ill patients want information about their diagnosis, but preferences about prognostic information are more variable, and family carers have different information needs as the patient deteriorates.¹³

When oncologists were able to discuss end-of-life issues with cancer outpatients and their families in a cohort study, those patients had less-intensive medical care near death, and family bereavement adjustment was also found to be better.¹⁴ Similarly, an advance care planning process in care homes that promoted discussions about future care reduced inappropriate hospital admissions and mortality.¹⁵ A nurse-led, advance care implementation process using a recommended advance care planning tool significantly increased home deaths for those patients in the intervention group who had cancer and a relatively short prognosis.^{9,16} Some, but not all, cancer patients and their families in another advance care planning interview study welcomed an opportunity to discuss end-of-life care if the discussions were timed carefully and took account of individual coping strategies.¹⁷ However, English GPs and community nurses often found it difficult to elicit patients' preferred place of death well in advance, and identified multiple constraints preventing them from discussing and eliciting patients' wishes.¹⁸

It seems that advanced care planning may prove helpful in managing some patients with cancer and people living in care homes. However, there has been little research assessing the impact of advance care planning with UK primary care professionals, even though they are to have a central role in offering it to larger numbers of people in the community.

How this fits in

Advance care planning is currently a key element of end-of-life care policies in many countries. These policies direct professionals to identify patients in the last year of life, then discuss and document their future care preferences, with the aim of facilitating a 'good death' in line with those wishes. An evidence-based intensive educational workshop about advance care planning delivered in primary care increased clinicians' knowledge and skills, but had limited perceived impact on patient care. Multiple structural and professional barriers hinder implementation of advance care planning by primary care teams, particularly the tension between intuitive, personalised care and highly structured approaches. These will need to be addressed if advance care planning policies are to achieve the desired improvements in end-of-life care.

Therefore, this study set out to explore the views of GPs and community nurses in four Scottish practices about advance care planning for cancer patients; to evaluate their learning objectives; and to see if a tailored educational intervention that could be delivered at practices during continuing education sessions would encourage greater involvement in advance care planning.

METHOD

Sampling and recruitment of practices

Four diverse GP practices in south-east Scotland were recruited sequentially between July 2008 and March 2009 to provide a purposive sample representing

Box 1. Advance care planning: policy definitions.⁸

Advance care planning is a voluntary process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included.

Suggested timing and context include:

- life-changing event (for example, a close bereavement)
- new diagnosis of a life-limiting illness
- indicators of a limited prognosis
- multiple hospital admissions
- admission to a care home

An advance care planning discussion might include:

- understanding of illness and prognosis
- the individual's concerns about his/her health and future care
- important values or personal goals for care
- preferences for types of care or treatment in the future
- preferred place of care
- advice on appointment of a proxy decision maker (health and/or financial)
- Documentation of a legally binding advance decision to refuse specific medical treatments
- Decisions about cardiopulmonary resuscitation

Table 1. Study participants.

	Initial interview	Workshop	3-month interview
Practice 1: four GPs, semi-rural, 3200 patients, 64% deprivation score ^a 2 or 3			
GP 1	✓	✓	✓
GP 2	✓	✓	✓
GP 3	✓	✓	✓
GP 4	✓	✓	✓
District nurse 1	✓	✓	✓
Practice nurse 1	✓	✓	✓
Practice nurse 2	✓	✓	✓
Practice 2: eight GPs, 8200 patients, urban, 71% deprivation score 1			
GP 5	✓	✓	✓
GP 6	✓	✓	✓
GP 7	✓	✓	✓
GP 8	✓	✓	✓
GP 9	✓	✓	✓
GP 10	✓	✓	✓
GP 11	✓	✓	✓
GP 12	✓	✓	✓
Practice nurse 3	✓	✓	✓
Practice 3: five GPs, 5000 patients, suburban, 40% deprivation score 5			
GP 13	✓	✓	✓
GP 14	✓	✓	✓
GP 15	✓	✓	✓
GP 16	✓	✓	✓
GP 17	✓	✓	✓
Practice nurse 4	✓	✓	✓
Practice nurse 5	✓	✓	✓
Practice 4: three GPs, 3000 patients, urban, older, 87% deprivation score 5			
GP 18	✓	✓	✓
GP 19	✓	✓	✓
GP 20	✓	✓	✓
District nurse 2	✓	✓	✓
Practice nurse 6	✓	✓	✓

^aDeprivation scores from Information Services Division Scotland: 1 = most deprived, 5 = least deprived.

different practice sizes, organisational structures, and populations served, in order to allow the intervention to be refined as the study progressed. The four practices were using the Gold Standards Framework Scotland 2005 tools, so already had registers of cancer patients and well-developed care-planning processes for those patients and families.¹⁹ Details of the practices and the community professionals who participated in the study are summarised in Table 1. The primary care clinicians consented to individual interviews before and after the intervention, and also gave signed consent to participate in the workshops.

Refining and delivering the intervention

One researcher visited each practice to discuss how an advance care planning process might fit with existing working practices. The researcher then conducted face-to-face, semi-structured interviews lasting around 30 minutes with individual GPs, practice nurses, and district nurses to explore their current understanding of advance care planning and possible barriers to its use. Specific learning objectives for those clinicians were

elicited for inclusion in a tailored educational workshop given at that practice.

The intervention consisted of an afternoon workshop at each practice, delivered jointly by a palliative medicine consultant with expertise in postgraduate communication education, and a senior GP researcher. The workshop included discussion about advance care planning and its role in end-of-life care, a toolkit of resources for professionals and patients, and a sample advance care planning document based on the tool from the Gold Standards Framework Scotland, developed mainly for use in care homes (Copies of this document are available from the author on request.)²⁰

Effective ways of discussing end-of-life issues with patients and families were explored through use of an interactive role-play interview using a participant-generated scenario. The scenario consisted of a series of key events that might trigger advance care planning. An internationally recognised, Australian consensus document on communicating prognosis and end-of-life decisions with patients was used as the theoretical basis for the communication education.²¹ During the workshop, participants discussed ways of trying an advance care planning process with their own cancer patients.

Assessing the impact of the workshop and the generalisability of the findings

The researcher interviewed the community professionals again 3-months after the workshop. The post-intervention interviews looked at whether the workshop was considered effective, and if the primary care clinicians had changed their approach or attitudes to advance care planning.

Once the intervention study in all four practices was completed, telephone interviews were conducted with a purposive sample of nine Macmillan GP facilitators (GPs with a special interest in palliative care education) from other parts of the UK, to establish whether the findings in south-east Scotland were likely to be generalisable.

Data handling and analysis

The interviews were recorded, transcribed, and entered into NVivo™ (version 7) for thematic analysis, along with field notes taken by the researcher at each workshop. Regular discussion of the emerging findings among the project steering group with an established cancer service users' reference group linked to the project team, and with the two workshop leaders strengthened interpretation and led to modification of the advance care planning intervention and document in successive practices (Appendix 1). Although the workshops were broadly similar, discussion of issues of particular interest to

each practice was encouraged, and topics that had emerged in previous workshops were introduced. The study took place when major end-of-life policy initiatives were being implemented across the UK, so these were raised for discussion with participants in the four practices and with the GPs from across the UK who were interviewed by telephone. The impact of the current policy directives was also considered in data analysis. These discussions allowed the researchers to gain a broad range of perspectives on advance care planning and to establish whether the emerging themes were representative of more generally held views.

RESULTS

Five practices were approached and all were keen to participate, but one could not do so in the time frame of the study. There was a high level of engagement in the interviews and workshops (Table 1). A total of 20 GPs and eight community nurses from four practices in south-east Scotland participated. It was clear from the first interviews and at the workshops that these primary care clinicians had limited understanding of advanced care planning as defined in UK policies and did not practise its main components in a structured way. Instead, they operated a very well-developed model of multidisciplinary care, which focused on ensuring that dying people with a short prognosis received optimal care in the community at the end of life.

GPs' understanding of advance care planning and their practice before the intervention

The GPs and community nurses described components of advance care planning, but did not articulate these in a cohesive or consistent way. They reviewed their palliative cancer patients regularly, concentrating on practical aspects, such as completion of financial benefits forms, documenting cardiopulmonary resuscitation status, and organising care at home:

'When I hear the words "advance care planning", I think that it puts a bit of pressure on that we're not doing things soon enough. It's normally quite obvious when somebody is now in the dying stages and we are trying to be more proactive, doing the DS1500 [benefits form] pretty early on ... and with our regular meetings we're all more aware what needs to be done and who is going to do it.' (GP 2, practice 1, interview 1)

The absence of structured advance care planning processes did not mean the participants were failing to initiate proactive end-of-life care discussions. Indeed, they prized palliative care as one of the few remaining 'old fashioned' aspects of primary care, as much an art

as science, based on relationships, and something that should not be at risk of reduction to a checklist or form. These professionals believed that they were already providing the kind of individualised, personal care that policy makers and patients wanted:

'I think what makes for really good successful palliative care is the relationship you develop between yourself, the patient, and their carers.' (GP 8, practice 2, interview 1)

'Yes, I suppose it's not very PC [politically correct] to say it's intuitive but I think it has to be because you're dealing with you know the very core sort of sentiments about life and death and that can't be too calculated or tick boxed.' (GP 9, practice 2, interview 1)

'Bringing up certain points like advanced care directives is very important but I don't think it should be done as part of a tick-box exercise ... almost like you're doing things for the sake of doing them. Whereas I think in good palliative care, you are trying to figure out the patient's wants and needs and their best interests.' (GP 17, practice 3, interview 1)

'Planning for dying' rather than 'planning for living and dying' in primary care

All the practices were operating a structured care model designed to ensure patients' last weeks of life and death were well managed. This consisted of a coordinated and often rapid response by the multidisciplinary team once it was clear that the patient would die soon. The most common trigger was discharge from hospital care once oncology treatment had ended. Before this, multiple factors hindered open discussion, particularly prognostic uncertainty, limited liaison with hospital services, and experiences of hospital staff focusing on the likely benefits of treatment even when the patient appeared to be deteriorating. Sometimes patients did provide a clear prompt to start end-of-life discussions. Persistent symptoms, including pain, were seen as 'opening the door' once they became impossible for the patient to ignore. Occasionally, a patient asked questions that indicated they were 'ready' to discuss their future care and end of life issues:

'There is still a grey area where treatment is not going to cure you, but you are not actually about to die. Patients look for their cues and their leads from their hospital specialist. And if they are getting what I would perhaps think of as inappropriately positive messages from the hospital, it is then very hard for us to introduce the

topic of, "But where would you like to die?".' (GP 16, practice 2, interview 1)

'If you're requiring more treatment and something to fix the pain that you're in it becomes almost easier to have that discussion as well.' (GP 7, practice 1, interview 1)

Barriers to change in end-of-life care planning

The biggest barrier to initiating earlier conversations was a strongly expressed fear of destroying positive coping strategies. When asked to describe the key components of a conversation about end-of-life planning, these professionals almost always started with the preferred place of care at the end of life and worked backwards from that point. Formal advance care planning was perceived as 'planning for dying' too soon and in a way that did not take account of professional-patient relationships and individual patient needs. Discussing the place of death before the illness was more advanced, conflicted directly with promoting hope, maintaining normality, and letting patients enjoy as much of their remaining lives as possible:

'He's got pancreatic carcinoma, inoperable, and he is palliative, but he's just been on a cruise and he's fine you know. It wouldn't be right to go in and constantly talk about death for him. I'm sure he will go downhill quite quickly, but at the moment he's enjoying life so that's great.' (GP 11, practice 2, interview 1)

Expertise in end-of-life care was mostly considered to be something that could not be taught easily but would be gained with experience in practice. In the GP practices in this study, involvement in end-of-life care tended to be restricted to a small number of senior doctors and community nurses. Many of the younger doctors had little or no experience of end-of-life care in the community and were keen to receive more training. When a GP did raise end-of-life issues sensitively, patients appreciated it and the doctor's confidence increased:

'I think it really just comes from experience and you know what you've learned through life and picked up.' (District nurse 1, practice 1, interview 1)

'One often gets a feeling of relief from the patient that somebody's prepared to open up that conversation and that if you do it in a sensitive way those patients who are not ready to have that conversation are able to say so.' (GP 19, practice 4, interview 1)

Implementing an advance care planning process in primary care

Integrating any paper-based advance care planning documentation into computerised practice record systems will prove difficult. The written care plan that practices were asked to evaluate was perceived to be static, likely to lead to 'ticking boxes', and a duplication of other systems for recording and communicating patient information. During the project, a new patient-held guide to forward planning was generated, which could be used as an aid to discussing a patient's thoughts and goals. During the workshops, the participants discussed a standardised cancer patient scenario. They always chose to work on the communication challenges associated with the point where cancer treatment was no longer an option and the patient's prognosis was limited. This was consistent with their model of 'planning for dying' which meant that they needed to explore strategies for delivering bad news about the end of treatment before being able to move on to shared decision making about end-of-life care.

In the follow-up interviews and visits to practice meetings, a variable response to the intervention was found. The workshops were considered relevant and of practical educational value. Understanding of advance care planning had clearly increased, but there was limited evidence of a change in practice. One experienced district nurse reported being able to initiate end-of-life care conversations with a patient after the workshop. Four senior GPs described using the initial form as an aide-mémoire when speaking with patients, but were ambivalent about its benefits. One GP had used the final patient-held final version of the form to aid advance care planning discussions with three people and thought it useful, but not for all patients:

'I think certainly from the workshop I found it easier to lead the conversation ... before I wouldn't have had the confidence to have gone into the depth that I did, so it was very helpful.' (District nurse 1, practice 1, interview 2)

'I haven't used the form because I felt very uncomfortable using a form in what to me feels like a very intimate sort of conversation ... it's almost something where you don't want forms.' (GP 12, practice 2, interview 2)

For the telephone survey of GPs with a special interest in palliative care education, nine Macmillan GP facilitators from England, Ireland, and other parts of Scotland were recruited. These doctors described how they were actively promoting regular review and care planning for palliative care patients in line with the Gold

Standards Framework Scotland, but were not practising or documenting an advance care planning process routinely in their own practices. Difficulties over terminology and confusion with related activities, like anticipatory care planning, were common. There were general concerns about formal processes being overly prescriptive and difficult to achieve in primary care:

'We are doing a lot of planning but not necessarily formally. We certainly aren't using a lot of documentation or any specific crib sheets or pro-formas. What we are doing is a part of normal care, needing to have the conversations about the issues that are important. If you formalise it then it starts to feel false or pressured or we have to do it at a particular time, which has the potential to affect the natural patient-doctor relationship, or introduces time pressures that we just don't want.'
(Macmillan GP 5: palliative care educator)

DISCUSSION

Summary of main findings

This feasibility study explored current practice in end-of-life care for cancer patients in the community and found a well-established working model that differed significantly from recent national policies. The formal advance care planning policy approach and the current management of end-of-life care by these primary care teams share the common goal of 'planning well for dying' so as to ensure that patients receive high-quality care that is consistent with their wishes and values.

Although the study participants supported the general principles of advance care planning, namely respect for patient autonomy and provision of individualised information about prognosis and future care, they were very concerned about the dangers of an externally imposed and monitored system as a driver for improved care. Less-experienced clinicians were keen to engage in training that improved their abilities to discuss end-of-life issues. More open communication with patients about end-of-life issues was hindered by lack of information or conflicting information from secondary care.

Professionals strived to balance their responsibility to share appropriate information about the future in a timely manner, with maintaining positive coping strategies. For some patients, living well with cancer was seen as incompatible with frank discussions about the practicalities of dying until the illness was far advanced. The primary care professionals in this study often associated advance care planning with having to discuss the preferred place of death, and this difficulty was compounded by pressure on them to increase home deaths when they had serious doubts about whether this was a realistic option. The present

findings in south-east Scotland were replicated in a broader survey of some of the GPs who might have been expected to have adopted advance care planning in their own practices, but had not done so, thus suggesting that the findings of the present study are likely to have wider generalisability.

Strengths and limitations of the study

This study provided a detailed analysis over time of how a diverse selection of primary care teams in Scotland manage their dying cancer patients, and generated a better understanding of the informal, but complex, interpersonal and organisational structures that underpin their current model of care. Repeated discussions with a series of practices allowed exploration of their views about how best to plan care in the last year of life, and identification of key barriers to changing practice in line with the new policies. The study sampled a diverse group of primary care professionals who evaluated the strengths and weaknesses of different approaches to planning for dying with the research team. Insights from the user group complemented professional perceptions in developing and evaluating the intervention. The telephone survey of GPs with a special interest in palliative care education clearly suggested that the study findings are not restricted to one part of the UK.

During the study, new policies in end-of-life care were being implemented across the UK and were not yet well established in south-east Scotland, so it is likely that understanding of advance care planning will continue to evolve. The study focused on one diagnostic group and setting: cancer patients were chosen for study as a readily identifiable group of dying patients in the community. Advance care planning may be more relevant to people at greater risk of losing capacity, such as those with early dementia or progressive neurological conditions; to people receiving life-prolonging treatments, such as renal dialysis; and to those living in care homes.^{22,23} Nurses were under-represented among the study participants due to staff changes at the time of the study, but a recent study with English community nurses found similar barriers, including concerns about the bureaucratisation of end-of-life care planning.²⁴

Comparison with existing literature

Advance care planning at any stage of an advanced progressive illness requires open discussions about future deterioration, death, and dying, between patients, professionals, and family members, and this may be a greater barrier than the content of any advance care plan itself.²⁵ Clinician factors leading to ineffective advance care planning and medical decision making near the end of life are complex, and

can include responses to adverse emotional experiences, strongly held beliefs or attitudes, and communication skills deficits, such as blocking behaviour and 'jolly' patients along.^{26,27} Physicians caring for cancer patients in the US have reported that they would not discuss end-of-life options with patients who are feeling well, but would wait for symptoms or the end of treatment.²⁸

Patients and families have engaged with advance care planning to a variable extent, and barriers have been identified at each stage of the process: thinking about the future, discussion with family and friends or with a doctor, and completing the documentation. Seeing advance care planning as irrelevant to current personal circumstances was common.²⁹ Difficulty contemplating serious illness and fears about premature treatment withdrawal are important concerns to address if wider public engagement in advance care planning is to be achieved.¹

The Association for Palliative Medicine of Great Britain and Ireland (APM) has supported the principles of advance care planning, but has expressed concern that the process might not remain voluntary if advance care planning were to become a health service outcome measure. APM has also emphasised that flexibility is important because patient and family views often evolve over time, for instance, regarding the place of death.³⁰

Changing professional and public attitudes about end-of-life care to greater openness about death and acceptance of the limitations of curative medicine have been identified as crucial to the success of UK end-of-life care programmes.^{4,7,31} Some cancer patients find that being open about their illness and a limited prognosis enhances communication in the family and a sense of control in end-of-life decisions; but other patients need to maintain a degree of ambiguity about their future to cope with the illness.³² Maintaining hope in the face of any life-limiting illness is challenging, but forward planning can contribute positively if patients and families are supported to cope with uncertainty and are helped to focus on achievable personal goals.^{23,33}

Advance care planning does not guarantee, however, that a patient's previously documented preferences will be realised, given the uncertainties of illness and medical care.² Nor does advance care planning lessen the responsibility of professionals to offer information, guidance, and leadership in taking decisions about what treatment will be of benefit to the patient, and when treatment goals should shift to best supportive care and planning for dying well.³⁴

Implications for future research and clinical practice

Planning for future care has the potential to promote

patient autonomy and can offer a valuable means to increase public and professional dialogue about end-of-life care. Given its complexity, it is important to understand more about how best to respect individual patient and family preferences for information about their illness and prognosis, and how to support them if they wish to make choices in different illnesses, circumstances, and settings. Thus, interviews with patients as well as professionals are indicated.

It is important to acknowledge the extensive professional experience, values, and current approaches towards good care of the dying in primary care. Fostering hope through discussing reasonable options for future care and treatment and ways of managing uncertainty, alongside personal and family goals, should be at the centre of any care-planning process. The patient-held advance care plan developed in this study needs to be evaluated further in primary and secondary care and with patients who have palliative care needs from any advanced illness. It may offer a means of encouraging patient autonomy while retaining best practice in the art of personalised primary care, as advocated in the recent General Medical Council guidelines.³⁵ However, even more basic research may first be needed to find out how best to identify patients in primary care routinely who could benefit from a palliative care approach, as the majority of such patients are not currently being identified.

Funding

Cancer Research UK funded the study (C18005/A9742).

Ethical approval

Lothian Research Ethics Committee and NHS Lothian management approvals were given for the study (07/S1104/44).

Competing interests

The authors have stated that there are none.

Acknowledgements

We thank all the participants and collaborating organisations for their contribution to the study.

Discuss this article

Contribute and read comments about this article on the Discussion Forum: <http://www.rcgp.org.uk/bjgp-discuss>

REFERENCES

1. Fried TR, Drickamer M. Garnering support for advance care planning. *JAMA* 2010; **303**(3): 269–270.
2. Perkins H. Controlling death: the false promise of advance directives. *Ann Intern Med* 2007; **147**(1): 51–57.
3. Kass-Bartelmes BL, Hughes R, Rutherford MK. *Advance care planning: preferences for care at the end of life. Research in action Issue 12. AHRQ Publication No 03-0018*. Rockville (MD): Agency for Healthcare Research and Quality, 2003. <http://www.ahrq.gov/research/endliferia/endria.pdf> (accessed 1 Sep 2010).
4. Department of Health. *NHS national end of life care programme*. <http://www.endoflifecareforadults.nhs.uk/eolc/> (accessed 1 Sep 2010).
5. Gundersen Lutheran Medical Foundation, Wisconsin. *Respecting Choices®: an advance care planning system that works*. <http://www.respectingchoices.org/> (accessed 1 Sep 2010).
6. Austin Health, Melbourne, Australia. *Respecting patient choices: advance care planning*. <http://www.respectingpatientchoices.org.au/> (accessed 1 Sep 2010).

7. The Scottish Government. *Living and dying well — a national action plan for palliative and end of life care*. Edinburgh: The Scottish Government Health Department, 2008. <http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell> (accessed 1 Sep 2010).
8. Department of Health. *Advance care planning: a guide for health and social care staff*. London: Department of Health, 2008. <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide> (accessed 29 Oct 2010).
9. PPC National Review Group. *Preferred priorities for care: version 2*. London: Department of Health, 2007. <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare> (accessed 29 Oct 2010).
10. Royal College of Physicians. *Advance care planning: concise evidence based guidelines*. London: Royal College of Physicians, 2008.
11. Royal College of General Practitioners. *End of life strategy document, 2009*. London: Royal College of General Practitioners, 2009. http://www.rcgp.org.uk/pdf/CIRC_RCGP%20End%20of%20Life%20Care%20Strategy%20Document.pdf (accessed 1 Sep 2010).
12. Hancock K, Clayton JM, Parker SM, *et al*. Discrepant perceptions about end of life communication: a systematic review. *J Pain Symptom Manage* 2006; **34**(20): 190–200.
13. Parker SM, Clayton JM, Hancock K, *et al*. A systematic review of prognostic/end of life communication with adults in the advanced stages of a life limiting illness: patient/caregiver preferences for the content, style and timing of information. *J Pain Symptom Manage* 2007; **34**(1): 81–93.
14. Wright AA, Zhang B, Ray A, *et al*. Associations between end of life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008; **300**(14): 1665–1673.
15. Caplan GA, Meller A, Squires B, *et al*. Advance care planning and hospital in the nursing home. *Age Ageing* 2006; **35**(6): 581–585.
16. Thompson-Hill J, Hookey C, Salt E, O'Neill T. The supportive care plan: a tool to improve communication in end of life care. *Int J Palliat Nurs* 2009; **15**(5): 250–255.
17. Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning interview schedule: a focus group study. *Palliat Med* 2007; **21**(1): 23–28.
18. Munday D, Petrova M, Dale J. Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England. *BMJ* 2009; **338**: b2391.
19. *Gold Standards Framework Scotland (GSFS)*. <http://www.gsfs.scot.nhs.uk> (accessed 1 September 2010).
20. National Gold Standards Framework Centre. *Advance care planning*. <http://www.goldstandardsframework.nhs.uk/AdvanceCarePlanning/> (accessed 1 Sep 2010).
21. Clayton JM, Hancock KM, Butow PN, *et al*. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007; **186**(12 Suppl): S77–108. http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html#0_i1092495 (accessed 1 Sep 2010).
22. The Scottish Government Health Improvement Team. *Long term conditions collaborative: improving complex care*. Edinburgh: The Scottish Government, 2009. <http://www.scotland.gov.uk/Publications/2009/03/06140257/0> (accessed 1 Sep 2010).
23. Davison S, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006; **333**(7574): 886–889.
24. Seymour J, Almack K, Kennedy S. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliat Care* 2010; **9**: 4. <http://www.biomedcentral.com/1472-684X/9/4> (accessed 1 Sep 2010).
25. Hancock K, Clayton M, Parker SM, *et al*. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007; **21**(6): 507–517.
26. Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ* 2002; **325**(7366): 697–700.
27. Weiner JS, Cole SA. Three principles to improve clinician communication for advance care planning: overcoming emotional, cognitive and skill barriers. *J Palliat Med* 2004; **7**(6): 817–829.
28. Keating NL, Landrum BM, Rogers SO, *et al*. Physician factors associated with discussions about end of life care. *Cancer* 2010; **116**(4): 998–1006.
29. Schickedanz AD, Schillinger D, Landefeld CS, *et al*. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* 2008; **57**(1): 31–39.
30. Association for Palliative Medicine. Position statement on advance care planning. *APM Newsletter June 2009*; **31**: 3.
31. Kennedy S, Seymour J, Almack K, Cox K. Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a national evaluation. *Palliat Med* 2009; **23**(4): 283–294.
32. Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 2009; **23**(1): 29–39.
33. Tulsy JA. Beyond advance directives: importance of communication skills at the end of life. *JAMA* 2005; **294**(3): 359–365.
34. Murphy B. What has happened to clinical leadership in futile care discussions? *Med J Aust* 2008; **188**(7): 418–419.
35. General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. GMC Guidelines in palliative care. London: General Medical Council, 2010.

Appendix 1. Future care plan.

Making plans for my future care

Helping you to take control and make your choices heard.

This Plan belongs to:

Some information for you

To be able to give the best care to people with a serious illness, we need to talk about what is important to each person and their family now and in the future. This 'Future Care Plan' can help you to think about what things are important so you can talk about them with your family and the people who are looking after you.

What is a Future Care Plan?

It is a Plan that some people like to use to write down important information about their plans and wishes for the future. It helps other people know what your wishes are.

What goes in the Plan?

You can use the Plan in any way you like. You can put in information about the kind of care and treatment you want to have, and where you would like to be cared for in the future as well as the things about your life that are important to you.

What doesn't need to go in the Plan?

The Plan is not a medical or legal document so you don't need to put medical or legal information in it unless you want to.

Do I have to have one?

No. It is up to you. Some people just use the Plan to help them talk about things with their family or professionals like their doctor or nurse.

When should I start one?

Many people like to start thinking about issues to do with their care a long time in advance while they are feeling well. Other people like to wait until later.

Any more questions?

We have put some more ideas about ways you might fill in this Plan at the end.

My Plans and Thoughts

Planning ahead

(eg. Important events coming up, things I want to do in the future, things that I enjoy now and want to carry on doing.)

Looking after me well

(Things about my treatment and care which are important to me.)

My concerns

(Things that worry me now and any worries about what might happen in the future.)

Other important things

Appendix 1 continued. Future care plan.

Things I want to know more about

Some people like to know about other things that can be important to someone with a serious illness and their family. Some of these are:

- Asking a person you can trust to speak for you and help make decisions about your health if in the future you are not able to do it yourself (a Welfare Attorney).
- A living will or advance decision to refuse a specific treatment
- Benefits advice
- Cardiopulmonary resuscitation decisions (DNA CPR): attempting to restart a person's heart

Things I want to ask about are:

Keeping track

(Each time you write in this Plan, you might like to write down the date and the name of anyone who helped you in this box.)

If you have added any extra pages please write down how many there are here:

Suggestions for filling in your Plan

How do I fill it in?

We have put boxes in to give you a few ideas about what some people want to write about. Some people fill in all the boxes. Other people just write in one or two. Sometimes people want to add a different page or box of their own. You can fill in your Plan all at once or bit by bit, and you can change it whenever you want.

Who can help me fill it in?

Anyone can help you fill this Plan in. Some people like to do it themselves, others like to fill it in with help from friends, family or professionals like your doctor or nurse. If someone does help you, please write down their name at the end.

Filling in the boxes

If you want to use the boxes then here are some suggestions for you.

Planning ahead: Write about the things that are important to you. Think about what you enjoy doing or want to do in future. Make a note of any important family events coming up. That way everyone can plan ahead and offer help if you need it.

Looking after me well: Write down any thoughts you have about where you might be cared for in the future and what kind of treatment and care you might want to have. This information can help the professionals looking after you try to make sure it happens.

My concerns: You can write about any worries you may have about yourself or your family, pets and so on. This way you can talk about them with someone you trust.

Other things: You can write anything in here that you think is important but does not fit anywhere else.

Things I want to know about: You can use this box to keep track of any questions you want to ask and the answers you got.

Where should I keep my plan?

You should keep your Plan with you. If you wish, your doctor can keep a copy at the practice.

Useful contacts:

My GP's name and telephone:

My district nurse's name and telephone:

Other important people: