Pilot Study

Advance care planning for patients with inoperable lung cancer

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Abstract

Aim To develop and pilot an advance care planning (ACP) intervention for lung cancer nurses to use in discussing end-of-life preferences and choices for care with patients diagnosed with inoperable lung cancer.

Design A prospective qualitative design with semistructured individual patient interviews. A grounded theory approach was used for the analysis.

Sample Fifteen patients took part in ACP discussions with their nurse and nine agreed to be interviewed by a researcher about their perceptions of the intervention.

Results Patients' reactions to the ACP process varied, but they welcomed the recording of their wishes and appreciated the courage of the nurses in bringing up the subject of future care.

Conclusion This study explored the role of ACP as a method of enabling patient choice for lung cancer patients in the UK. Further research is needed to determine the components of ACP and the training needs of staff.

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Enabling patient choice is currently a major priority for the UK government and national policy. The National Institute for Health and Clinical Excellence (NICE, 2004) recommends seeking ways of ensuring that patients' voices are heard and they are informed of the options available to them. Pressure groups, such as Help the Aged and Age Concern, have argued that older adults should be provided with opportunities to make choices about their end-of-life care (Seymour et al, 2005). Younger adults may also wish to express their autonomy through making known their choices for future care and treatment (Commission for Health Improvement (CHI), 2004).

However, there are difficulties in enabling choice in the context of end-of-life care, with a lack of research about how patients express individual preferences and wishes for the future. This context makes it essential to examine the role of health professionals in enabling patients' awareness of their options for care and treatment, and discussion of their preferences and choices for end-of-life care. Advance care planning (ACP) is one potential method of enabling patients' choice, which has not been developed as yet in the UK. *Box 1* provides a working definition of ACP and of advance statements which provide expressions of choice for people who may in the future become incapacitated.

While ACP may lead to the completion of an advance statement, the primary purpose is to facilitate discussions about end-of-life care preferences with a view to informing care. However, increasing interest in the potential of advance statements needs to be acknowledged. New legislation in the UK through the Mental Capacity Act 2005 will make it possible, by 2007, for people to appoint a proxy decision maker for healthcare decisions. The Act also provides provisions for people to make decisions in advance to refuse treatment if they should lose capacity in the future.

Issues involved in introducing ACP into clinical practice in the UK are unclear and lack supporting research evidence.

Background literature

In searching the literature, 618 articles were retrieved using the key words: 'advance care plan'; 'advance directives'; 'advance statements'; 'living wills'; 'palliative care'; 'terminal care'; 'patient choice'; 'patient experience'; 'patient satisfaction'; 'decision making'; 'patient participation'; and 'lung cancer'. The databases searched were: CINAHL, Medline, Embase, PsychInfo, BNI, Cancerlit, CareSearch, Cochrane Library, National Research Register, Zetoc and Web of Science from 1966–2004. From the articles retrieved, 129 articles were of relevance to the study. Of these, only 52 were original research studies.

The authors found three research studies about ACP originating from the UK. One of these was a survey of professional opinions within the NHS on advance directives (Diggory and Judd, 2000), one was a

qualitative study asking health professionals their views about a sample advance directive (Thompson et al, 2003) and one was a qualitative study describing the views of older people about advance statements (Seymour et al, 2004).

Seymour et al's (2004) study suggested that older people view advance statements as an aid to personal integrity and to relieving the burden of decision making for their families. This research also revealed that older people have worries and difficulties in talking about end-of-life care but want opportunities to have these conversations. Seymour et al (2004) concluded that the ACP process may be a possible way of addressing such concerns since it enables discussion and review of people's wishes for end-of-life care. However, no empirical evidence is available in the UK about patients who had a diagnosis of a terminal disease or their carers' experiences with ACP or advance statements.

Most research evidence comes from the USA and Canada and, more recently, Australia. The majority of studies consider advance statements (Blondeau et al, 1998; Curtis, 2000) and focus on the experiences of patients, healthcare professionals and care providers in their use.

ACP interventions have been used in the USA to promote discussions with patients and their carers about end-of-life preferences for care (Briggs, 2003). For example, a discussion guide for engaging and communicating with patients about ACP has been developed and tested and used to assist patients, their carers and the health professionals involved in their care to have a clearer understanding of the patient's disease, the affect and meaning the illness has on their daily life and expectations about future care (Curtis, 2000; Gundersen Lutheran Medical Foundation, 2003). ACP of this type may facilitate completion of an advance directive, but ultimately it is aimed at improving end-of-life care (Briggs, 2003).

There is some evidence from the USA that ACP protocols implemented in the community with patients who have life-limiting conditions and their families have been shown to be associated with improved palliative care outcomes (Hammes, 1996; Hammes and Rooney, 1998; Ratner et al, 2001; Tierney et al, 2001). There is no available evidence of this in the UK.

This study aimed to explore the feasibility of developing ACP as a possible intervention to enable patient choice. The objectives were to:

- Adapt and pilot an ACP interview guide for use by lung cancer nurse specialists (CNSs) with patients (and their carers)
- Observe and describe the CNSs' documented use of the ACP guide in the patient's notes/records
- Identify the use of a clinic letter to GPs and assess the acceptability of the protocol to patients, carers and CNSs
- To describe and compare patients', carers' and CNSs' perceptions and experiences of advance care planning.

Box 1. Definitions

Advance statements
Advance statements include 'oral and written decisions, advance refusals and advance authorizations of treatment and statements of future desires and intentions as well as firm decisions' (British Medical Association (BMA), 2000)

Advance care planning (ACP)
ACP is the process by which a dialogue is initiated with patients and carers about their understanding of the patient's medical history, condition and prognosis and their preferences for future care and treatment options. ACP may result in an advance statement but this is only one component (Hammes, 1996)

Methods

A small study was carried out using a prospective qualitative design to develop and pilot an ACP intervention. The intervention was for use by lung cancer nurses with patients who had a diagnosis of inoperable lung cancer. Descriptions were sought of the outcomes of lung cancer nurses' use of the intervention with their patients within one urban health community within South Yorkshire, UK.

The project was aided by a steering group which included users, health professionals and the participating lung cancer nurses who were recruited purposively for their varied expertise as clinicians, academics and personal experience. This article reports on qualitative interviews conducted with participating patients, in which they were asked about their views of the ACP discussions they had with their nurse. An exploratory design with employing interviews was chosen because of the limited research evidence on ACP in the UK. Interviews were also chosen because they allow flexibility in data collection from patients living with advanced disease who may be tired or lack concentration.

The intervention piloted consisted of the following three elements:

- An ACP interview guide was developed as an 'aide memoir' in collaboration with the lung cancer nurses by the researchers and expert project steering group. This guide was adapted from the following schedules which have been used extensively in North America: *Respecting Choices* (Gundersen Lutheran Medical Foundation, 2003); *Five wishes* (Ageing with Dignity, 2004); and *Caring Conversations* (Centre of Practical Bioethics, 2004). *Box 2* provides a subset of the ACP interview guide used by the lung cancer nurses.
- An ACP record using a GP clinic letter style was also developed by the researchers and steering group as a means of providing a written record of the ACP discussion. This letter included a brief note describing the patient's response to the ACP discussion and details about the patient's main concerns, stated preferences for the future and preferred place of care.
- An ACP checklist was developed by the lung cancer nurses and added to the intervention after the first two patients to clarify with the patients the content of the ACP record. The checklist was also used to gain patients' consent to sharing the record with other members of their healthcare team. The checklist also served to check that patients were happy to receive a written copy for themselves.

Sampling

Patient sample

A purposive sample of 15 patients were recruited by the lung cancer nurses with the inclusion criteria of a diagnosis of inoperable lung cancer and English speaking. Lung cancer patients were chosen for this study because of their predictable disease trajectory and to aid nursing practice development in the care of lung cancer patients.

Box 2. Advance care planning intervention guide used by lung cancer nurses (subset of full guide)

- Can you tell me about your current illness and how you are feeling?
- Could you tell me what the most important things are to you at the moment?
- Who is the most significant person in your life?
- What fears or worries, if any, do you have about the future?
- In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?
- What would give you the most comfort when your life draws to a close?

The patients who took part in an ACP discussion with their lung cancer nurse agreed to have their preferences and choices for care recorded on a GP clinic letter. With their agreement, this was then copied to other members of their healthcare team. Of these 15, nine patients participated in an interview with a researcher to gain their views on the ACP process. Patients were given a letter from the research team by their lung cancer nurse. This enclosed an information sheet giving details of the study. Where patients gave verbal consent to a researcher contacting them, they were then contacted by the research assistant (KS), who visited them to discuss possible consent. Interviews were arranged at the patient's convenience.

Six patients chose to have a family member present during the research interview. For this pilot study, extensive demographic data about participating patients was not collected. Of the nine patients who took part in an interview with the researcher, three were male and six female. They ranged in age from 52–87 years old. Four patients were married and the remaining five were widowed, divorced or separated. Four of the nine patients died within the 6-month data collection period.

Staff sample

Lung cancer nurses and GPs were also interviewed; however, for the purposes of this article, we will not be reporting on this here.

Data collection

Data were collected from October 2004 to March 2005. A semistructured interview schedule was developed to explore patients' views about the ACP discussion they had with their lung cancer nurse. The questions for the schedule were generated initially from the principal researcher's previous experience as a hospital Macmillan nurse and further developed in collaboration with the project steering group. Informed written consent was gained before the interview, including time to respond to any questions that patients and carers rose. Seven patients were interviewed in their own home and two patients in hospital.

Ethical issues

Interviewing patients with advanced disease requires detailed ethical consideration. Interviewing patients can cause emotional distress and they may not benefit from

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the suggestions resulting from this study. To minimize distress the questions were developed in liaison with the project steering group. Issues arising from the first two patient interviews were discussed and the aide memoir adjusted accordingly. Informed consent was obtained from all participants and local ethical approval was obtained.

Analysis

Interviews were transcribed verbatim and entered into an NViVo database to enable a modified grounded theory analysis (Glaser and Strauss, 1967). The text was read and words or segments of text which described an experience, perception or feeling were given a code. Codes then generated categories, which were grouped into themes. Themes did not reach theoretical saturation owing to the small numbers of patients who participated in this pilot. The principal researcher and research assistant coded patient data separately to check for concurrence on emerging categories and themes. Field notes were kept to contribute to the analysis. The patients' own words have been used to illustrate the emerging themes from the data.

Results

Seven main themes can be identified based on the experience and views expressed by patients and they are detailed below.

Nurse attributes facilitated ACP discussion

Patients described certain attributes of their lung cancer nurses that enabled them to talk about end-of-life issues. The nurse being knowledgeable about their condition helped them ask questions and initiate discussion about their disease. The nurse was perceived as 'down to earth', 'approachable', 'caring', and 'supportive' and this enabled discussion of end-of-life issues and preferences for care. Other attributes which were seen as helpful in opening up a discussion about end-of-life issues were being 'easy to talk too' and 'feeling at ease' with the nurse. One patient commented that:

> **'...there aren't many people you can talk to about things like that. There aren't.'** *(Female, aged 76 years)*

Patients talked about how the nurse picked up signals and built up sensitively to discussing difficult issues without 'going too far'. Patients also commented on the lung nurses' understanding of their condition and the fact that having met their lung nurse in clinic and then seen her again at home helped them feel more able to discuss options and choices:

> **'I think just to show an understanding. What is going to happen and offer the options that are open...you see I had no idea of any of this, because I've never been involved, you don't know what can happen and what is available.'** *(Female, aged 60 years)*

> **'We saw her [lung nurse] in hospital and then she visited afterwards and we had already discussed some of it in hospital, and then she come here and went into it a bit more depth I think. Like the stuff on the paper there [ACP record]. What my wishes were sort of thing.'** *(Male, aged 70 years)*

Content of the ACP discussion

Patients and their carers emphasized how their lung cancer nurse provided them with an explanation of their disease, what may happen in the future and possible options. They also reported how they had appreciated the information which their lung cancer nurse had given them. The following quote illustrates how a patient's daughter appreciated the nurse's explanation about the future:

> **'It's like [nurse] has explained to her, the pain she is getting, cos this is why she was really good, she said "do you want to know exactly where you have got your cancer and how its going to affect you?" And I think when people know, they can work themselves towards what to expect later on.'** *(Daughter of female, aged 68 years)*

Patients talked about the nurse assessing their needs and offering options through the ACP discussion as well as providing answers to their various questions about what to expect. Patients were able to express their fears and talk about what may happen at the end of life as the following patient describes:

> **'To be honest with you, I asked her [nurse] the questions, in some ways in that, I said to her like, is it**

'One participant was worried about his loss of memory and saw the recording of his wishes as protecting his autonomy.'

painful towards the end and that sort of thing, you know. And she said not today, she said that nobody should suffer today, towards the end since cancer sufferers used to do. There are different medications and morphine and whatever. Should be able to pass away nice, quiet and peacefully.' (*Male, aged 79 years*)

Reactions to ACP

Patients' and their carers' reactions varied. Some patients, when asked about how they felt discussing their preferences for future care with their lung cancer nurse, thought that it was quite a 'personal thing' to have to talk about with the nurse. Other patients were happy to discuss issues about their future with the lung nurse because she kept the discussion positive and they felt that enabled them to talk about everything. Carers' reactions also varied with some grateful for the nurse opening up the discussion about the future and others preferring not to think ahead and preferring to 'live one day at a time'.

Some patients and carers talked about the fact that the lung cancer nurse was the only person whom they could discuss things with:

> **'She [nurse] seems to be the only person who you can discuss things and get down to brass tacks.'** (*Wife of male, aged 79 years*)

Patients believed that discussing future care was a job that nobody wanted to do:

> **'My honest opinion is that it is perhaps one of them things where everybody wants to shove on one side. It is a job what nobody wants to do I would think. It would likely get shelved. I think it is a very brave thing erm, to face somebody and tell them what the future is, you know.'** (*Male, aged 70 years*)

Recording choices and preferences

Patients were happy generally to have the main content of the discussion with their lung cancer nurse recorded in writing and for the record to be shared with their healthcare team. Even those patients who thought future preferences were a personal thing agreed to have their preferences recorded:

> **'I think it is a lot better, it is a lot more clearer to everybody, everybody knows where they are if it is written down, and you do express your wishes like.'** (*Female, aged 52 years*)

One participant was worried about his loss of memory and saw the recording of his wishes as protecting his autonomy. Another participant viewed the ACP record as being useful to record her wishes about place of death and felt this record would prevent arguments between family members:

> **'I want it down...because I want no argument with my family. It is my wish. And I don't want my two saying "she is stopping at home."'** (*Female, aged 76 years*)

Wanting choices carried out

Some patients who had been asked by their lung cancer nurse about their wishes for future care and had an ACP record, held high expectations that these wishes would be carried out. Others were more pessimistic and held views that they may not necessarily get what they wanted even if it was recorded:

> **'Well as long as, how can I put it? So long as what my wife and I want are carried out, that's fair enough.'** (*Male, aged 79 years*)

> **'But at the time...I mean it is nice for them to know what you want, but you'll not always get what you want.'** (*Female, aged 71 years*)

Outcomes of ACP

Most patients were pleased to have had the time to discuss their preferences for their end-of-life care with their lung cancer nurse and felt better for it. For some patients, the ACP discussion had helped them decide on their preferred place of care:

> **'No, I don't think I had decided...I hadn't really thought about it. But, er, when we were talking about it, I thought, well, I have two daughters, they can't both be here. They have got families and you know, it's not fair on kids. So for last 2–3 weeks, whatever, I would rather go in a home, in a hospice.'** (*Female, aged 76 years*)

> **'Ah, I think our talks and discussions and that sort of thing, she has**

'Lung cancer nurses may have the appropriate knowledge but might require additional skills and confidence to begin advance care planning (ACP) discussions.'

done me the world of good. To be honest with you. You know, in different questions that I asked her and that she asked me and that sort of thing. And it lists a lot of things out into the open, in a sense.' (*Male, aged 79 years*)

Patients felt the future needed discussing and that they could now put it to the 'back of their head' and it was 'sorted'. Interestingly, three out of the four patients who died during the data collection period had expressed a preference to die at home and fulfilled their wish. The patient who did not realize his wish had fallen at home, was admitted to hospital in a confused state and did not recover.

Talking with family about end-of-life choices

Some patients had already initiated discussions with their family before seeing the lung cancer nurse, but were still glad to talk to a nurse who understood their condition. However, for others they found they either could not bring up the subject with their family or their family would not listen. The following patient describes her struggle in talking to her daughters about the future:

'Because [daughter's name] especially is very, I don't know, she takes a lot on does [daughter's name]. I don't know how she would take it. I don't really. I think [other daughter] would be alright because she is used to living away from home. But [daughter's name] I don't know.' (*Male, aged 76 years*)

Discussion

This small pilot study looked at developing and using an ACP intervention to facilitate discussion between lung cancer nurses and their patients about preferences and wishes for future care. The key findings were that: nurses' attributes aided the discussion about future care and treatment; patients appreciated the information and explanation offered to them; and patients accepted the recording of their preferences, which were shared with their healthcare team.

Patients reported on the skills and attributes of nurses which enabled them to talk openly about end-of-life issues. Curtis (2000) and Jezewski et al (2003) suggest that providing sensitive and effective communication requires training and preparation. Further research is needed to establish training needs and competencies of those conducting ACP discussions. The nurses were fearful of compromising their relationship with the patients by touching on a difficult subject. This sometimes became a barrier to initiating the discussion.

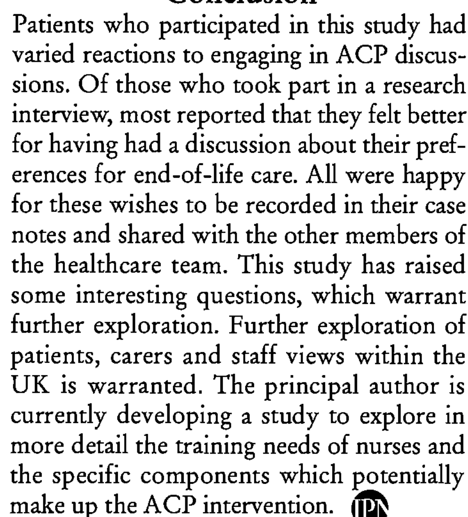
Most patients interviewed in this study welcomed the information and explanation given to them by the nurse including the options available to them. They appreciated the opportunity to communicate their wishes for future care using a written record. All 15 patients who took part in an ACP discussion agreed to have a written record of their expressed preferences and choices for the future in their medical records and to share this record with other members of their healthcare team, although they did not always want a copy for themselves or their families.

Several clinical implications have been raised through this study. Questions have been raised about who is the best person to initiate ACP discussions. Lung cancer nurses may have the appropriate knowledge but might require additional skills and confidence to begin ACP discussions. Patient, staff and public education is needed to enable understanding about ACP so that its use and any accompanying record is acted on and reviewed at key points.

Ethically and morally, there are issues about establishing sufficient resources to be available to enable patients' preferences and choices to be realized. While patients may realize that they may not have their future wishes fulfilled, it is reasonable for them to expect that every effort will be made to provide care in accordance with their preferences. To this extent 'real choice presupposes there is a range of safe, effective and accessible local services delivered by appropriately qualified healthcare professionals' (Curry, 2005).

Limitations of study

This study looked at a small sample of patients with inoperable lung cancer and three lung cancer nurses in one health community in South Yorkshire. Owing to the size of the sample and difficulty in recruiting patients because of their rapid decline in health, the emerging themes were unable to be theoretically saturated. Another limitation was the variation in the lung cancer nurses' previous experience and confidence in initiating discussion about end-of-life care, which led to differences in their use of their ACP intervention.



Conclusion

Patients who participated in this study had varied reactions to engaging in ACP discussions. Of those who took part in a research interview, most reported that they felt better for having had a discussion about their preferences for end-of-life care. All were happy for these wishes to be recorded in their case notes and shared with the other members of the healthcare team. This study has raised some interesting questions, which warrant further exploration. Further exploration of patients, carers and staff views within the UK is warranted. The principal author is currently developing a study to explore in more detail the training needs of nurses and the specific components which potentially make up the ACP intervention.

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Key words

- Advance care planning
- End-of-life care
- Patient experience
- Cancer
- Preferences
- Advance statements

Ageing with Dignity (2005) *Five Wishes*. (http://www.agingwithdignity.org/5wishes.html) (accessed 3 April 2006).

Blondeau D, Valois P, Keyserlingk E, Hebert M, Lavoie M (1998) Comparison of patients' and healthcare professionals' attitudes towards advance directives. *J Med Ethics* **24**(5): 328–35

Briggs L (2003) *Shifting the Focus of Advance Care Planning: Using an In-depth Interview to Build and Strengthen Relationships*. Innovations in End-of-Life Care (www2.edc.org/lastacts/archives/archives-march03/featureinn.asp) (accessed 3 April 2006)

BMA (2000) *End-of-life Decisions: Views of the BMA*. (www.bma.org.uk/ap.nsf/Content/Endof life~statements?OpenDocument&Highlight=) (accessed 3 April 2006)

Centre of Practical Bioethics (2004) *Caring Conversations: Making Your Wishes Known for End-of-life Care*. (http://www.practicalbioethics.org/cpb.aspx?pgID=886) (accessed 3 April 2006)

CHI (2004) *Children's Voices Project*. CHI, London

Curry T (2005) The real choice debate. In: Royal College of Nursing. *Real Choice in the Health Service. An RCN Discussion Document*. RCN, London: 2 (www.rcn.org.uk/publications/ pdf/Realchoiceinthehealthservice.pdf) (accessed 3 April 2006)

Curtis J (2000) Communicating with patients and their families about advance care planning and end-of-care. *Respir Care* **45**(11): 1385–98

Diggory P, Judd M (2000) Advance directives: questionnaire survey of NHS Trusts. *BMJ* 320: 24–5

Glaser BG, Strauss AL (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Sage, Newbury Park, California

Gundersen Lutheran Medical Foundation (2003) *Respecting Choices: The Representational Approach to Patient Education with Advanced Care Planning: The Patient-Centred ACP (PC-ACP) Interview*. (www2.edc.org/lastacts/archives/archivesmarch03/printPCACP.pdf) (accessed 12 April 2006)

Hammes B, ed (1996) *Respecting Your Choices. Training Manual*. Lutheran Hospital, La Crosse

Hammes B, Rooney B (1998) Death and end-of-life planning in one midwestern community. *Arch Intern Med* **158**: 383–90

Jezewski M, Meeker M, Schrader M (2003) Voices of oncology nurses: what is needed to assist patients with advanced directives. *Cancer Nurs* **26**(2): 105–12

NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. NICE, London

Ratner E, Norlander L, McSteen K (2001) Death at home following a targeted advance care planning process at home: the kitchen table discussion. *J Am Geriatr Soc* 49(6): 778–81

Seymour J, Witherspoon R, Gott M, Ross H, Payne S (2005) *End-of-life Care: Promoting Comfort, Choice and Wellbeing for Older People*. Help the Aged. Policy Press, Oxon

Seymour J, Gott M, Bellamy G, Ahmedzai S, Clark D (2004) Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med* **59**: 57–68

Thompson TDB, Barbour RS, Schwartz L (2003) Health professional's views on advance directives: a qualitative interdisciplinary study. *Palliat Med* **17**: 403–9

Tierney W, Dexter P, Gramelspacher G et al (2001) The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* **16**: 32–40