

**Evaluation of Preferred Place of Care (PPC):
Towards Quality Improvement**

Final Report to Dimbleby Cancer Care

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Table of Contents

Acknowledgements	2
Background	3
Overview of the study	5
Results	6
Discussion	15
Conclusions	18
References	20

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Background

End of life care in England

Each year about 500,000 people die in England, with the majority of deaths associated with chronic illness (Department of Health 2008). Over the years there has been increasing institutionalisation of death and dying, however most people identify home as the place they would like to die but only the minority do die at home (Brumley, Enguidanos et al. 2003; Munday, Dale et al. 2007). The quality of care and satisfaction of people's nominated choices for care people receive at the end of their life is variable (Lynn, Teno et al. 1997).

Good palliative and end of life care are essential components of high quality care for all those with a life-limiting illness (Field and Cassel 1997; Byock 2000; Council 2001). This has become increasingly recognised by governments worldwide and in the United Kingdom in 2003, the National Health Service (NHS) committed £12 million towards specific end of life care initiatives to improve the quality of palliative and end of life care for all people with terminal illness, regardless of diagnosis (Programme 2004; Storey, Wood et al. 2006). The goals were to offer patients greater informed choices about the manner and place of their care at the end of life and decrease emergency admissions to acute settings for people who wished to die at home. Three major initiatives were endorsed: the Gold Standards Framework, the Liverpool Care Pathway and the Preferred Place of Care document (PPC) (Gysels and Higginson 2004).

In 2008, building on these previous government initiatives, the UK End of Life Care Strategy was published by the Department of Health. Within this strategy, a care pathway approach for the delivery of integrated care is recommended. The initial step in this pathway is the identification of people approaching the end of life and the initiation of discussions about preferences for end of life care to enhance patient and family choices in this area (Health 2008).

Advance care planning

Honouring care preferences and priorities of patients who are dying requires knowledge and understanding of those preferences (Davies and Higginson 2004). This can be achieved through the process of advance care planning. Advance care planning can be described as a process of discussion between health care providers and patients and families and is often associated with the setting on record the views, values and treatment choices of those with a life-limiting, progressive illness, and the periodic review of these choices (Seymour and Ingleton 2008).

This process of shared discussions and decision-making provides an inclusive framework which places the patient and their family in a central position for their views and wishes about end of life care to be heard and accommodated. Research has shown that patients and families feel empowered through communication and shared decision-making in this way and regard it as a positive value at the end of life (Steinhauser, Clipp et al. 2000). The PPC was developed to facilitate these advance care planning discussions.

The PPC

The *Preferred Priorities for Care* document (PPC; formerly known as *Preferred Place of Care*) is a patient-held advance care planning tool that is intended to promote the consideration, discussion and documentation of wishes and preferences for care for people who are approaching the end of life. The document is primarily centred on three key questions aimed at eliciting patients':

- understanding of their condition;
- views about what they would and would not like to happen to them; and
- preferences for where they would like to be cared for at the end of their life (Turner 2008).

The PPC is used to initiate and record discussions with patients and carers about death, dying and choices about end-of-life care and the potential resources required to meet these needs. It is a dynamic document, taking into consideration changes in the patient's condition over time, and, as a patient-held document, it is intended to travel with the patient into different care settings. By having patients share the document with their family members and professional care providers across settings (such as home, hospital or hospice), it is hoped that PPC will promote communication and provision of appropriate care consistent with the patient's wishes and choices.

The original tool, the Preferred Place of Care document, was developed by the Lancashire and South Cumbria Cancer Services Network (LSCCSN) in 2003 (Turner 2008). Following published guidance on advance care planning (in part to clarify the impact of the 2005 Mental Capacity Act which has recently come into effect), it was revised in 2007 (Health 2005; Programme 2007). This tool has been recommended by the National Institute for Health and Clinical Excellence (Gysels and Higginson 2004) and also endorsed by the Department of Health.

The roll-out of the document was accompanied by a training and mentorship programme and a specific communication skills training course. A total of 441 health and social care staff from Lancashire and South Cumbria attended the 2.5 day experiential training course (Turner, 2008). Although the PPC is now used throughout the UK, its most concentrated implementation to date has been in the northwest of the country. While the document encompasses all life-limiting conditions, the method of the roll-out meant those with cancer and their families were primary recipients of PPC.

Evaluating PPC

Although the PPC is a nationally endorsed initiative, use of PPC lacks a sufficient evidence base. In order to understand and enhance the value of PPC for cancer patients, this advance care planning tool requires evaluation. Consistent with the Medical Research Council framework for evaluation of complex interventions, published recommendations for a PPC evaluation programme stated the need for initial retrospective stock-taking of PPC utilisation followed by primary data collection on the experiences of people who have used the document (Council 2000; Storey, Wood et al. 2006). Our multi-disciplinary research team's retrospective analysis of the first 100 PPC returns has been reported elsewhere (Wood J, Storey L et al. 2007), however, there had not been a study on the experiences of PPC users. Prior to this study a small pilot was conducted with both users and non-users of the document, involving patients, family members and health care professionals. This was primarily aimed at testing the acceptance of the methodology and refining the interview questions.

The examination of how people experience the process of completing the PPC, how people perceive its influence on communication around advance care planning, and its perceived value as an advance care planning tool is especially critical at a time when national policies are highlighting the importance of advance care planning and patient-centred decision making. It is important that systematic evaluation research on PPC be available to inform PPC use in the future in order to best serve the palliative and end of life care needs of patients and their families and to add to the evidence base for advance care planning tools in practice.

Overview of the study

Aims of the study

The primary aim of this study was to evaluate how PPC is perceived, utilised and experienced by patients with cancer, family members and professional health care providers who have used the document. Specific aims of the research were to:

- determine in what ways, if any, the use of PPC promotes and facilitates communication among patients, family members and care providers;
- identify advantages and shortcomings of specific content and format components of the PPC document; and
- elicit users' recommendations for the implementation, content, and format of PPC.

This paper reports on the experiences of community nurses who have used PPC in their clinical practice with patients with cancer. The original study design included interviews both with professionals and with patients/family members. Substantial difficulties with patient and family recruitment, due to the recruitment mechanism, mean that we will report solely on the nurses' results. The challenges with patient and family recruitment will be discussed in the Discussion portion of the report to enable discussion of implications and recommendations for future research.

Methods

Recruitment of nurse participants

The study aimed to include a purposive sample of 45 health care professionals who had used the PPC document. It was reasoned that nurses who had completed the communication skills training workshops were more likely to have used the PPC in their clinical practice and therefore this group was targeted for potential participation in the study. In order to gain varying perspectives on the use of PPC and to increase the potential number of participants, the research team also made contact with senior medical and/or nursing staff at six inpatient hospices in the North West area of England to inform them of the study and request their assistance with recruitment.

Local NHS research ethics committees gave authorisation for the study to proceed and the research adhered to the research governance requirements of the NHS.

Data collection

Qualitative research methods were used to inform this study. Therefore one-time, individual in-depth interviews were conducted face-to-face with nurses who had used PPC with patients with cancer. All interviews were conversational in style and semi-structured around a range of pre-defined themes aimed to elicit the following personal perspectives:

- how PPC is perceived, used and experienced;
- advantages and shortcoming of PPC; and
- recommendations for PPC.

Analysis

All interviews were audio taped, transcribed and then analysed by a panel of multidisciplinary researchers. Qualitative thematic data analysis methods were used to

determine interview themes related to the aims of the study. Atlas.ti software, specifically designed to assist in coding and managing data for qualitative analysis of audio-tape materials (Muhr 1997), was used to facilitate coding for content and topic themes.

A code book was developed that included code names and descriptions, inclusion and exclusion criteria for each code, and a quote from the interview data illustrating the example. Data was examined iteratively using standard thematic analysis techniques (Strauss and Corbin 1990; Miles and Huberman 1994; Ryan and Bernard 2000).

Results

Recruitment

Recruitment of participants utilised community nursing agencies and hospice staff. Twenty-seven nurses in all were recruited to the study. The cancer network provided the major source of participants through its database of course attendees. Initially the first 100 nurses on the database, chosen by job title and numerical attendance at workshops, were contacted by mail regarding the study. To maintain anonymity, the researchers posted study packs to the network and the mail out was undertaken by them. All packs were mailed to individual nurses at their workplaces. A second mail out was conducted 3 months later to the next 100 nurses on the database.

The sample

The majority of the sample comprised registered general nurses working in community settings. Of the nurses ($n = 27$), all were female except one, the majority ($n = 9$) were community staff nurses or team leaders (Table 1).

Table 1. Demographic characteristics of nurse participants

Nurse type	<i>n</i>	% of N
Community staff nurse	9	33
Community sister, team leader	9	33
Clinical nurse specialist (palliative care) home care	3	11
Community sister	2	7
Macmillan nurse	2	7
Specialist nurse practitioner	1	4
Clinical nurse specialist (palliative care) inpatient care	1	4
Total	27	100

Other characteristics of the nurse sample:

- Age range: 34 – 57 years, mean age 49.8 years. The median age was 51 years and the mode 25 years.
- Years of nursing experience: a range of 8 – 36 years post-registration experience, mean number of years 26.4 years. There was a median of 28 years post-registration experience and a mode of 25 years.

- Current patient mix: 76% currently nursing both acute and palliative patients with the remainder caring for palliative patients only
- Versions of PPC used: 72% have used versions 1 and 2 and were currently using version 2, 18% have only used version 1 and were still using version 1

Nurse interviews ranged from 15 – 45 minutes with a mean interview time of 33 minutes. Eighty percent of interviews were conducted in primary care agencies with community nursing centres.

Themes from nurses' interviews

Multidisciplinary qualitative analysis of the data has revealed a broad range of information regarding people's experiences with using PPC. Three overarching categories appear in the data to help explain the experience of using PPC:

- the environment within which the document is used;
- the process of initiation and completion of the document; and
- the outcomes of the information obtained by PPC.

Within these categories, eleven major sub-themes important to the use of PPC were identified (Table 2).

Table 2. Major themes and sub-themes identified through data analysis.

Themes about the experience of using PPC	Sub-themes
(1) The setting/environment in which PPC is used	Nurse characteristics
	Patient characteristics
	Health care service characteristics
	Nurse/patient relationship
(2) The initiation and completion of PPC	Experience with using PPC
	Factors involved in nurse decision-making around the use of PPC
	The PPC document
	Nursing approach to using PPC
(3) Outcomes of PPC information	Impact of PPC on patients and families
	Impact of PPC on health professionals
	Carer skills/bereavement

Theme 1: The setting/environment in which PPC is used

The PPC document is used within a particular therapeutic environment in a one-to-one patient situation and four themes emerged here that impact on using PPC: individual nurse characteristics; individual patient characteristics; the health care service in which the document is used, and the existing nurse-patient relationship that forms the setting for PPC use.

Nurse characteristics

The sample interviewed was primarily that of experienced community nurses who have varied clinical experience nursing both acute and palliative patients, but have no specific post-registration qualifications in palliative care. All nurses had completed a two-day communication skills training course aimed to improve knowledge and skills in using the PPC document. (Other demographic characteristics of the sample are recorded elsewhere in this report.) The number of years of nursing experience was seen as being helpful in judging the right time to initiate conversations around PPC.

'I mean if it's my patient and I know them then I think that I gauge it, but maybe I'm just being over confident. But I just gauge it that I kind of know when the right time is.' Participant S9

Years of clinical experience also appeared to play a role in nurses' feelings of comfort in discussing issues arising from the PPC information, e.g. conversations regarding the patients' future physical deterioration and death. Nurses stated they felt comfortable with discussing issues around death and dying with patients and their families as long as they received patient cues that the patient was ready to talk about these issues.

'I have no problems discussing death and dying with patients. I can quite easily discuss it. But I will only discuss it when I feel that they're ready to talk to me about it. And often you'll get... they'll say something to you that indicates that they want to talk about it.' Participant S21

When asked their preferences for place of care and death for patients, nurses thought home was the place where most patients should be cared for.

Patient characteristics

An issue raised by nurses that impacts on the use of PPC is patient comfort in discussing issues of advancing disease, death and dying. Nurses reported varying levels of comfort expressed by patients and carers, but think that there will always be people who are not comfortable with these issues and this will impact on their use of the document.

'I think once you've broached the subject...and talked to them about it, most of them are fine. I've had one or two that have been very 'I don't want to talk about that'. But that's patients who generally don't want to talk about the fact that they're going to die anyway, and who are in denial, and don't want to talk about it.' Participant S9

According to nurses, most patients seem to express a preference to die at home, although sometimes it is not made clear the difference between patients' preferences for place of death or place of care.

Health care service characteristics

Interviewees were primarily generalist community nurses whose patient population was a mix of acute and palliative clients. No comments were made about the role of the community health services in the completion of PPC documents or whether health services managements had expressed particular views about the importance of the document. Nurses did express views that one of the aims of community services is to maintain patients at home until death and this view was brought out when nurses were discussing the main purpose of the document.

Community nurses report that they seem to be the staff who are initiating and completing PPCs with patients and they feel this is appropriate due to the nature of relationships they have with families in the community.

'So we feel - and I think the GPs feel - that we're in a better position to do this. And our Macmillan nurse will do it as well. But even she feels that... because you know at the time, maybe when we're taking it in, we know the patient better.' Participant S12

Nurse-patient relationship

The PPC document is used in the context of an ongoing nurse-patient relationship, and interpersonal factors appear to be important to nurses in setting the scene with patients and families for discussion of PPC. Nurses do not appear to be comfortable in initiating the document unless they have an existing and ongoing relationship with patients.

Nurses offer PPC to patients with a variety of medical conditions, not just those with a diagnosis of cancer. There does not appear to be any ongoing criteria in use for the selection of patients, but decisions will be made in individual cases dependent on patient cues and the existing relationship between the nurse and the patient. Those patients who are not offered PPC are those who, in the nurses' opinions, are not ready to engage in conversations around end of life issues.

'We've offered it to most patients. We started off obviously with the cancer patients, because they were our predominant work. At the hospice and in palliative care, we're embracing now the non-malignant disease, so we do offer it to the non-malignant patients as well.'

Participant S19

Theme 2: The initiation and completion of PPC

A large proportion of the participant interviews was focused on information around the process of using PPC in clinical practice and the factors nurses found important for their decisions of when and where to use the document. Four sub-themes were identified that are important in the experience of using this advance care planning tool: experience with using PPC; factors involved in decision-making around PPC; the PPC document, and the nursing approach to using PPC.

Experience with using PPC

Nurses reported varying levels of personal usage of PPC with most nurses stating they had used it less than a dozen times. The exception was one nurse who stated she had initiated PPC 'hundreds of times' (S4, Community Nurse Sister, Team Leader). General comments indicated that PPC is not used greatly by the agencies in which nurses worked. Even though the updated version of the document (Preferred Priorities for Care) was developed at the end of 2007, both versions of the document are still in current usage.

'I think that's probably, of all the documents, I think the PPC is probably the least used of the documentation. And I think that's a lot to do with having the confidence to bring it about, you know.' Participant S29

The PPC is not regarded as a document for everyone, and nurses appear to make decisions for each individual patient as to whether the document is relevant for their particular situation.

Factors involved in nurse decision-making to use or not use PPC

Much of the interviews centred around how nurses integrated PPC into their daily clinical practice with patients with cancer, exploring their feelings about the document and gaining ideas about the process of implementation: nurse views of the concept of advance care

planning; individual comfort levels with initiating and discussing PPC; perceived purposes and benefits of PPC including patient ownership aspects, perceived disadvantages of PPC and other methods of recording care priorities. Nurses' views around discussing death and dying are also important here, and these have been mentioned previously when discussing individual nurse characteristics.

Nurses appear to agree with the concept of advance care planning, and can see advantages from both their and their patients' perspectives of taking a planned approach to future care. However, advance care planning is done in individual cases and when done, completion of the PPC is not seen as an integral part of the process. It appears to be one tool that nurses sometimes use. Other methods of recording care priorities were reported, such as documentation in the medical or nursing notes.

'It's no good relying on last minute decisions, because often they're the wrong decisions aren't they? And it's better to manage something than manage a crisis... So the more preplanning we can do then the better.' Participant S3

Nurses were asked their views on the level of their comfort with initiating and discussing PPC. Similarly to discussing death and dying, nurses' levels of comfort are often linked to those of the patient and/or family member and nurses take their cues from the patient that the discussions will be accepted. Not all situations were difficult.

While nurses interviewed felt comfortable initiating and discussing PPC with receptive patients and family in the context of a trust relationship, especially those with specialist training and experience such as Macmillan nurses, they reported concerns expressed by other, less-experienced staff in these situations.

'The younger ones, the more junior ones, are quite frightened if you say this is the document we use, take it in to so and so today, you're going to visit them, just take it in with you. And they look as if to say oh no.' Participant S2

Communication, control and choice were concepts often mentioned by nurses when asked about the main purpose of the document. Nurses discussed issues relating to both end of life, and care prior to end of life when talking about purposes and saw the document as encompassing both aspects of palliative care. They felt that patient control and choice were enhanced in the situations when patients had nominated home as their preferred place of care.

Not all nurses agreed that patient choices were enhanced through completion of the PPC and they reported different outcomes of conversations. The PPC is seen by some nurses as a document to actively encourage people to stay at home.

The PPC is seen as a useful tool to assist communication with all health professionals who are involved in the patient's care such as the nursing team and the patient's GP and also those who may become peripherally involved such as out-of-hours GPs and emergency staff.

'But I think... it's useful for the patient to have that. So if they go into hospital, or if the doctor visits them at home, they can produce that document and say these are my wishes. They don't have to tell them, they can just hand the document over to whichever professional it is visiting, so that they can read and take that into consideration when they're discussing treatment options.' Participant S3

Many benefits of completing PPC were identified and these were often closely linked with the purposes of the document, especially in relation to the communication aspects. The

benefit of the document as a prompt to aid communication in difficult areas was recognised. The PPC was seen as helping raise discussions between the patient and family members around end of life issues in situations when communication has not been optimal and also helpful for reinforcing patients' wishes as they became more ill. Patients were able to document both the type of care they wanted and did not want.

'It actually gets patients and relatives to talk about the issues. Very often relatives are talking to us, patients are talking to us, and it's just getting them both to talk to each other about the same issues that they're talking to us about. And this is a good way of doing it.' Participant S12

Nurses also saw PPC as beneficial as a tool for themselves to use when initiating conversations they found difficult. The questions on the document acted as a prompt to guide discussions, especially for those staff with limited experience in the area. PPC could also give nurses insights into patients' views that they might otherwise have been unaware due to the content of patient documentation and the fact it is often written by the patient.

'And it's good for us, because it gives us an insight. You thought gosh I didn't realise that really was the way they were looking at that. So it's helpful for the professionals as well.' Participant S13

Although PPC is a patient-held document and some nurses did report positively on this aspect of the document, this did not come out strongly either as a purpose or benefit of PPC. One participant could not see any advantages to the document.

'To be perfectly honest I don't see any advantages to it. That's my opinion, because in my experience, without using that document, I know where my patients want to be cared for. I know what they want. And we usually document it in our patient records, without the use of a document like that.' Participant S21

Even though many advantages and benefits of PPC were identified by respondents, they also reported disadvantages to completing PPC. The main disadvantage of the document seen by nurses is the fact that patient wishes documented on the form would not necessarily be followed. This could be due to a number of reasons, and was either as a result of a deliberate action or an unavoidable circumstance.

Nurses spoke about situations when patients had identified a place other than home as the place they would like to die. In most cases this was the hospice (with hospital nominated by few of their patients) and nurses were unable to guarantee hospice admission at the patient's choice. This reinforces the nurses' views of PPC working best in situations when home is the preferred place of care.

The other situation when PPC information is often not followed is in the case of a sudden change or deterioration in the patient's condition. Family members have required support during emergency situations and this need has potentially overridden home as the choice on the PPC.

Nurses identified some disadvantages from the patients' perspectives. According to the nurses, some patients expressed a fear that writing preferences down meant they would be unable to alter these at a later date, while some patients were unable to fill the document in unaided as they were unsure of its meaning.

The PPC document

Nurses interviewed appeared generally happy with the document itself. As has been reported, they had used both versions and did not show any strong preferences for either version. Only one nurse commented on the change of name from 'preferred place' to 'preferred priorities', feeling 'priorities' was a broader and more appropriate term.

'It's absolutely easy to use. It's fine. I mean it's dead easy to read, it's straight to the point.'
Participant S4

Most nurses interviewed were happy with the physical aspects of the document, but some offered suggestions for improvement, such as making the document smaller to allow greater ease of use for patients and increasing the size of the type to cater for a primarily elderly population who are using the document.

One nurse gave an interesting perspective on the availability of the document and thought it should be integrated much more into the mainstream to enhance personal ownership of PPC and help change societal views around death and dying.

'I think it should be there, out in the community, on the high street, there for people to access themselves and look at, and not just be something that's given by the community nursing service, or by the Macmillan nurse, or the hospice. Give them ownership of that document, to be able to access, fill in, and look at.' Participant S27

Nurses reported a wide variety in the amount and type of information recorded on the document. They did not have any expectations about what should be written, but left it to the patients' discretion as to what they wanted to write.

Nursing approach to using PPC

As has been reported, nurses spoke of using their professional judgement and taking cues from the patient or family members to initiate conversations around care preferences for end of life and the PPC. Apart from receiving patient or family cues, nurses often found it hard to verbalise when they considered the right time to introduce PPC, but would use generalist language to explain an intuitive feeling that the timing would be right for discussion of the document.

Some comments were made that often the document could be introduced at an earlier time, but respondents were often unable to state when this time should be for particular patients.

'Maybe at the time that they're given that news, that the treatment is now palliative, that document maybe should be introduced more formally. Sometimes when we get to meet the patients they're actually approaching the end. And I don't think that that's the best time to be introducing the PPC.' Participant S3

Nurses were asked how they usually approach patients to raise discussions around PPC and how they go about facilitating completion of the form, including the sorts of vocabulary they use. The most common method of completion mentioned by nurses was to introduce the form at one visit, leave it for the patient and family to complete, and then ask about the content at a later visit. However, not all nurses felt this was the best approach and some preferred to facilitate completion of the form with the patient present.

Nurses reported that some patients asked for assistance with filling in the PPC and further explanation as to what the questions were asking. Nurses would often present potential scenarios to the patient to assist their understanding and decision-making.

Nurses were asked about the specific words they would use when introducing the document and questioning patients about their future wishes. Most nurses stated they would not use the words 'death' or 'dying' when talking about the patient's future, but would only talk about becoming sicker or deteriorating.

'I would say I would use the word... you know as you get more poorly, or as you're not as well, or you know if your condition deteriorates. I probably wouldn't use the word dying or death. I would always use deteriorating or you become more poorly. I can't think I've ever used the word 'when you're dying', I think that's a bit stark really.' Participant S10

It appears that most of the time families are involved in these end-of-life discussions. Nurse stressed the importance of this as families often play a large role in end-of-life care when the patient chooses home as the preferred place of care.

'Frequently I find that the families often get involved in these discussions. Although I have had to talk to people on their own because they've not wanted to talk in front of families for fear of upsetting them, or not wanting to discuss death and dying with the people that they're closest to. But generally people talk quite openly.' Participant S1

Theme 3: Outcomes of PPC information

The information recorded on the PPC document stays with the patient and is read by family members and a number of different health professionals. Three sub-themes emerged from these outcomes that help explain the consequences of this information: impact of PPC on patients and families; impact of PPC on health professionals, and carer skills/bereavement.

Impact of PPC on patients and families

Nurses were questioned regarding the types of responses they obtained from patients and families following the initiation of discussions around PPC. Patients have responded in a number of ways:

- respond positively to the discussions and are happy to fill in the document;
- make it clear in some way that they do not wish to discuss issues around their future deterioration and needs, or
- accept the document but do not fill it in.

Most nurses could recall situations when patients and family members had become upset following the introduction of PPC and subsequent discussions and some appeared reluctant to put things in writing, but the most common responses reported were positive, from both patients and family members.

In situations when the PPC was not filled in, some nurses would bring up conversations again at later visits, but others would not raise the issues again as they felt that patients were not ready to deal with the discussions.

The information recorded on PPC impacts family members as there are implications for the amount and type of care they may have to provide for the patient. This is done in the knowledge of what the patient's wishes are, reported as usually wanting to be cared for at home, and most family members want to support these wishes.

The following quote illustrates a situation when family members were unable to provide the level of symptom control required by the patient but refused the offer by the community nurse of hospice admission as the patient had stated they wanted to stay at home.

Nurse reported that the information recorded on PPC positively impacted on both the future conversations they had with patients and families and also ongoing care planning and coordination with other services.

'If you were gearing towards this patient going to the hospice then you know that you need to be in touch with the hospice. You need to know that the clinical nurse specialist in palliative care from the hospice is involved in that patient's care and you can help make sure that that happens.' Participant S9

Some nurses would use the information to set up a dialogue around patient feelings and future care needs and found the document helpful for creating opportunities for those discussions. It was also helpful in having wider family discussions regarding concerns about care that people may have.

'And there are some people that say you know I'd like to be looked after at home, and the relatives say well you know I don't think I can. But that gives you a chance to address those issues.' Participant S6

Nurses reported on situations when the information recorded on PPC was and was not followed. The two most common scenarios reported refer to a lack of hospice beds available if this has been the nominated place of death and a lack of carer confidence to deal with specific emergencies around symptom management and patient deterioration. This can encompass both professional carers who may be called on in a once-off situation and also non-professional carers, usually spouses.

Impact of PPC on health professionals

Nurses expressed different opinions as to whether they thought the information recorded on the PPC is taken into account by other health professionals who may become involved in the patients' care. Some nurses expect that what is written on the PPC will be followed and have had positive experiences to back up this expectation. They saw it as helpful in getting all disciplines involved in thinking about the patient's wishes.

'So if they go into hospital, or if the doctor visits them at home, they can produce that document and say these are my wishes. They don't have to tell them, they can just hand the document over to whichever professional it is visiting, so that they can read and take that into consideration when they're discussing treatment options.' Participant S3

However, other nurses appear unsure as to whether the information would be followed in an emergency or out-of-hours situation.

Carer skills/bereavement

The choices that patients record on the PPC can impact family members in positive and negative ways, both during the caring process and also after the death of the patient. It is a written reminder of patients' wishes and because it is a patient-held document is something that will remain with the family after the patient's death. This has been reported as comforting for the family in situations when the patient's wishes have been able to be fulfilled.

Nurses reported times when family carers have been unable to cope with the physical changes associated with end stage deterioration and/or impending death and have called for professional assistance resulting in patient admission to hospital at the end of life. The carer in the study did the same thing, even though she knew hospital admission was against her husband's wishes.

'But I mean I have heard of a couple of cases where patients or relatives have panicked, and the ambulance has come and unfortunately not taken into consideration the PPC, and the patient has died in the hospital.' Participant S10

This has led to psychological distress for carers when patients had nominated home as the preferred place for care and carers were unable to provide effective symptom management in the home situation.

Discussion

This study has explored the use of an advance care planning tool, the PPC, evaluating how it is perceived, utilised and experienced by community nurses who have used it. The interview-based study is part of a programme of research to understand better the role and place of this document in the British health system, particularly because PPC is endorsed by the End of Life Care Strategy.

Breadth of PPC Use

There appears to be limited and adhoc use of the document by non-palliative care trained community nurses in this study. Whilst the document has been mandated for use by the Department of Health (Health 2008), nurses interviewed reported low usage, with most nurses stating they had used it less than a dozen times. Nine nurses from the sample (33%) stated they had initiated a PPC less than four times since the inception of the document.

There does not appear to be any specific directives by individual health services to use the PPC. It almost appears to be seen as an 'optional extra' by nurses, to be used at their discretion in individual cases. This view is held by both junior and senior members of community nursing teams in this study. Evaluation has reported that nurses often have discussed the issues around advance care planning such as preferred place of death, but do not document this, but rather communicate it verbally to other staff (Kennedy, Almack et al. 2007). This view was also expressed in this study.

It is unclear how these reports of low usage compare to the nationwide usage of PPC. In a national evaluation of the End of Life Care Strategy, the PPC was seen as the 'poor relation' to the other two initiatives as it was not developed by medical staff, did not have national organisational backing and did not have a wide support network of prominent individuals (Kennedy, Almack et al. 2007).

Using PPC

There appears to be a lack of accountability for the use of the document making it unclear who is responsible for the initiation and completion of the document. In this apparently non-regulatory environment an important factor influencing the use of PPC may be how individual nurses perceive the usefulness of the document, both for themselves as well as patients and families. Nurses are not likely to initiate advance care planning discussions or introduce PPC if they don't see benefits (Barnard 2002).

Nurses appear to make decisions to initiate the document based on an existing trust relationship they have with their patients, their professional judgement regarding the appropriateness of the document for a specific patient, and cues they obtain from patients or family members that discussions around end of life care will be accepted.

Usage figures would suggest that nurses may not think that the document is likely to be beneficial for every palliative patient, they may not feel comfortable discussing the issues raised, or they may have had negative experiences with PPC outcomes in the past. The issue of time to discuss the document was not raised as important when discussing implementation and yet this has been identified as a limiting factor in other studies (Kennedy, Almack et al. 2007).

Also, if nurses are introducing PPC to patients at a late stage in their disease it may not be appropriate to approach these patients due to complex symptom management issues which require priority or imminent death. It may also be the case that if patients and/or carers are the initiators of end of life conversations then these may occur in situations of well-advanced disease. It is known that patients often avoid these uncomfortable discussions (Larson and Tobin 2000) and have a preference for health professionals initiating end of life conversations (Clayton, Butow et al. 2005). This may account, in part, for the low usage of the document.

The PPC does not appear to be onerous to fill in and nurses are generally happy with the content and layout of the PPC document. Nurses seem to consider the concept of ACP important but don't seem as concerned as to whether the PPC is used in the process. It is not seen as a 'mandatory' piece of documentation.

Does PPC enhance advance care planning discussions?

The PPC document aims to facilitate discussions between care providers, patients and their families and our research has shown that nurses think it can be helpful in that respect. It can assist in communication between patients, their families and members of the health care team and can also be seen as 'living proof' that someone's wishes have been followed through. Conversations range from issues around place of care and supports required to physical deterioration and death.

Nurses tended to give non-quantifiable responses to the question of when they feel is the right time to have end of life discussions. Apart from patient cues, nurses stated their intuition and experience helped them decide, but patient cues were the strongest influencing factor. Whilst the document caters for changing plans, the question of how often the information was revisited by nurses or patients remains unclear.

Nurses' comfort in discussing death and dying

Comfort with discussing death and dying is an integral part of the process of advance care planning and therefore the use of the PPC document. Most nurses reported they were comfortable to discuss issues of death and dying with patients, and yet many didn't use those words in the interviews we conducted and stated they didn't use them with patients either. However, research has shown that patients want health professionals to use these words (Clayton, Butow et al. 2005; Parker, Clayton et al. 2007).

The use of alternative terms for words around death and dying may lead to confusion or misunderstandings and it may be unclear the exact messages patients are getting, and therefore how patients and families see the purpose of the document. Poor patient recruitment in this study means that this perspective was unable to be adequately explored.

While nurses stated they were happy with discussing issues around death and dying it is interesting to note that most wait until the patient or family member brings up the topic for discussion. Previous studies have shown that while patients may not voice their concerns regarding approaching death, they may still be ready to discuss the issue if broached sensitively by another (Clayton, Butow et al. 2005; Munday, Dale et al. 2007).

It has also shown that a differentiation must be made between initiating discussions around end of life issues and taking part in discussions that have been initiated by others, such as the patient or a family member. With or without the PPC, nurses will, in general, not initiate conversations but will feel comfortable in discussions once they have been raised.

This raises the question of how comfortable nurses actually are if they do not feel they can initiate conversations but have to wait for patient cues. This may impact on how many discussions are taking place, when discussions are taking place, the number of PPCs completed by patients and the usefulness of the information recorded. The PPC document has been in use since 2006 and yet the sample interviewed reported low levels of use of the document.

Advance care planning – what decisions are being made and who is making the decisions?

PPC is aimed to allow for discussions around preferences for care and place of death, and allowing for patient preferences in this area to give them some control and choice over this stage of their life. However, how much real choice do patients have? PPC is used in a policy and service environment that aims to reduce the number of inpatient admissions, has a limited number of hospice beds and is initiated by nurses who show a preference for patients to be cared for at home. In previous studies these factors have been shown to be predictors of home deaths (Thomas 2005). How much of this is communicated to patients and will influence their choices about place of care and death? Participants have mentioned that the purpose of the document is to keep people at home when they are dying. They don't feel it is really there to give patients the choice about how they want things to be, but to reinforce the message of home care and deaths.

And what are patients and families making decisions about – preferred place of care, preferred place of death, or both? This research has shown there may be some confusion as nurses are not often using the words death or dying and so it is unclear how patients may interpret such discussions. Agar et al. (2008) have shown that patients and caregivers may have different preferences for each and these may change over time.

Family members, the PPC and end of life

A number of instances were reported by nurses that the patient had made it clear they wished to die at home. However, when the patient deteriorated the carers 'panicked' and called for emergency assistance. At times the PPC was shown to these health care staff with varying results. The outcomes of such events were, at times, at odds with the preferred outcomes recorded on PPC.

These situations raise many questions regarding the perceived usefulness of the document. Why do these situations occur? Is it a sign that the dying process had not fully been explained? How does a carer recognise when death is happening? How do they know that the 'emergency' they are witnessing is a sign of impending death and not something else that can be treated? This also holds for health professionals who do not know the patient. E.g ambulance drivers, locum doctors.

It is known that one of the problems with end of life care, especially in a home setting or when non-specialist staff are involved, is the fact that dying may not be recognised or acknowledged (Health 2008; Pleschberger, C et al. 2009). It is unclear from this study how much discussion goes on between nurses and carers about the process of dying, and also what the skills of community nurse are in the recognition of the dying process.

And whose responsibility is it to make them aware – carers, nurses, the pt? And as it is not a legal document then where might they legally stand in relation to allowing the death of a patient for example? How much discussion goes on to see if a carer can cope? How much skills training of carers by nurses goes on?

Study limitations

The original design of the study included interviews with patients with cancer and family members who had used PPC, but the study is unable to report about the direct experiences of patients and family members. Recruitment of patients and carers for the study proved difficult. The sample obtained for this study was below that proposed, especially for patients and carers. There may be a number of reasons for this.

Low usage of the document means that individual nurses may not be caring for many patients who have a PPC and therefore potential participants are not available. Those patients who do have a PPC in place may have far advanced disease and be too unwell for an interview.

The study design meant that the researchers could not approach patients and carers directly about their participation, but had to rely on interviewed nurses or clinical hospice staff to make the initial approach. The gate keeping role played by staff is well-recognised (Barlow, Harrington et al. 2009) and may be a factor in the low recruitment rates obtained.

Areas for future research

Study designs for research around this advance care planning tool need to take into consideration different methods of patient recruitment, taking into consideration the gate-keeping role of health professional, especially in the area of end of life care. Using a more participatory approach with district nurses has been shown to be helpful with recruitment numbers for palliative patients (Hopkinson, Wright et al. 2005) and this should be considered for future studies.

This study has looked at the use of PPC with patients with a cancer diagnosis, and the nurses interviewed had the most experience using it in these situations. Even though it was developed by a cancer network, it is meant to be used across the population. However, it is unclear how it will be experienced with those who have other life-limiting conditions such as chronic heart or lung disease. Most cancers have a defined disease trajectory and end stage deterioration often follows a fairly predictable course in terms of functional decline. This is not the case with other conditions such as organ failure where the final terminal event may be unpredictable (Teno, Weitzen et al. 2001). This may have implications for when nurses feel it appropriate to be thinking of advance care planning and initiating end-of-life conversations. Patients may not have the (often) ongoing functional deterioration and signposts leading to impending death that may be the stimulus for them or their families to bring up end-of life conversations.

Conclusions

Advance care planning tools are becoming more common and this study adds insight into the use of one such tool by a primarily generalist group of nurses for a palliative population. The experiences of the nurses suggest a number of conclusions.

- PPC is not widely used by non-palliative care trained community nurses in this sample

- The decision to use PPC is made by individual nurses in the context of the existing nurse-patient relationship on a case-by-case basis
- Nurses are not happy initiating conversations around death and dying
- Patients often need to provide the impetus for nurses to use PPC and nurses are happy to use the document in this scenario
- PPC outcomes are more likely to occur if the patient has nominated home as the preferred place of care
- There are a number of situations when the information recorded on PPC is not followed, so the usefulness of the document is in question
- Nurses are not a good source of patient referral for research around PPC

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