

VIEW FROM THE OBSERVATORY

Developing an evaluation strategy for 'Preferred Place of Care'

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In addition to our programme of work on the global development of hospice and palliative care, the International Observatory on End of Life Care also retains a strong interest in matters of policy and evaluation relating to the UK context. We report here on work in progress relating to the Preferred Place of Care instrument, which forms a key element in the UK Department of Health End of Life Initiative.

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In recent years, the UK Government has exhibited a modest, but growing, sense of commitment to the development of palliative care. In 2003–2004, to assist palliative care improvement, it provided cancer networks with £50 million per year, for 3 years and, in December 2003, it committed a further £12 million for specific end-of-life care initiatives in England, to improve palliative care for all terminally ill patients, regardless of their diagnosis. In the same month and announcing an 'end-of-life initiative' for England, the then Secretary of State for Health, Dr John Reid, stated: 'People with incurable illnesses should be able to choose appropriate services that can offer them relief. They also want to make choices relating to the end

of their life, such as where to die. We are working towards an NHS where every patient has a choice of when, where and how they are treated.' In July 2004, more detailed guidance on the initiative was issued to Strategic Health Authorities (1). It indicated that whilst over 50% of patients wish to spend their final days at home, less than 20% in practice are actually able to do so and it emphasised that currently 95% of referrals to specialist palliative care teams are for cancer patients (2). The initiative, therefore, contains three elements to tackle these problems (3):

1. *The Gold Standards Framework (GSF), developed by Kerri Thomas and colleagues in association with Macmillan Cancer Relief, which focuses on the improved co-ordination of end-of life-care for patients in the primary care setting (4).*
2. *The Liverpool Care Pathway (LCP), originally developed by John Ellershaw and colleagues and supported by Marie Curie Cancer Care, which focuses on optimal care and support for patients in their last hours of life (5).*
3. *The Preferred Place of Care (PPC) instrument, developed in the Lancashire and South Cumbria Cancer Services Network by Les Storey and colleagues, which provides a patient-held record that makes patients' wishes about their treatment clear to all those involved in their care (6).*

The combined goals of these interventions are: (i) greater choice for patients in where they wish to live and die; (ii) decrease in number of emergency admissions of patients who wish to die at home; and (iii) decrease in the number of older people transferred from a care home to a hospital setting in the last week of life.

The PPC initiative seeks to offer patients informed choice about the manner and place of their care at the end of life. Yet, whilst it has found its way into the national initiative for England, it lacks a programme of rigorous evaluation (even more so than the other two measures involved) and evidence for its efficacy remains partial and fragmentary, mainly coming from anecdotal sources or small implementation initiatives at the local level. PPC clearly warrants a detailed systematic evaluation of its use to date and an assessment of its potential for further development. We, therefore, set out here some of the

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background to the development of PPC and report on progress in relation to an evaluation strategy. To date, no identified funds have been set aside for the evaluation of PPC, but it is hoped that appropriate funds might be obtainable if a robust evaluation strategy can be developed.

PPC is a patient-held document that enables nurses, doctors and others to discuss with patients and carers their preferences relating to end-of-life care in ways that are intended to promote informed choices. The PPC plan includes the opportunity to discuss and record: (i) a family profile and carers' needs; (ii) the patient's thoughts about care choices and preferences; and (iii) the services that are available within a locality.

PPC was first introduced into practice in December 2001 (7). In 2004, it formed a part of the guidance on Supportive and Palliative Care for Adults with Cancer produced by the National Institute for Clinical Excellence (8). The 12-page PPC document includes a section where patients and carers can comment on their experiences. In addition, it serves as a care planning and audit tool. The PPC provides a mechanism to audit patient experiences, monitor the patient's trajectory of care during the palliative stage of the disease, record patient and carer preferences and highlight deviations from the preferred care plan. PPC provides a mechanism for regular review and recording of patient wishes and needs and can be utilised in multidisciplinary team meetings to co-ordinate care delivery. It also offers a framework for provider organisations and cancer networks to audit services and promote discussion for the review of care provision and the promotion of new initiatives. There is anecdotal evidence that PPC has provided some families and carers with a tangible record of the final illness of the deceased person and some have requested permission to keep the document for this reason.

Developing an evaluation strategy for PPC

Over a period of time, Les Storey (University of Central Lancashire) and David Clark (Lancaster University) have had discussions about how an agenda for the evaluation of PPC can be taken forward. To this end, some initial work is being conducted by Justin Wood on the first 100 patients to make use of the PPC instrument (9). We were also eager to involve others (researchers and practitioners) in discussion about how the evaluation of PPC might be promoted. Therefore, in March 2006, we held a meeting at Lancaster University to invite discussion on the evaluation of PPC among other interested stakeholders. The goals of the meeting were:

1. *To hear updates from those involved in pilot projects involving PPC, especially where there is some evaluation component.*
2. *To present results from the analysis of the first 100 cases.*

3. *To consider how we could collaborate to develop a co-ordinated approach to the development of evaluation studies involving PPC.*
4. *To identify opportunities to develop an evidence base for PPC.*

Some 19 colleagues attended the meeting. In addition to the authors, these included Professors Sheila Payne (Sheffield) and Jane Seymour (Nottingham), Dr Gunn Grande (Manchester) and practitioners from Lancashire and Cumbria, Cheshire and Mersey Strategic Health Authorities. There were also colleagues from South Essex Primary Care Trust and Humberside Cancer Network – who had used PPC in practice and had undertaken small scale local evaluations. Also present was Claire Henry, National Lead for the End of Life Care Programme in England (10).

The discussions and presentations at the meeting began by highlighting a number of complex questions about the nature and purpose of the intervention. PPC was characterised as a specific example of an advanced care plan and seen as part of a much broader orientation to 'patient-centredness' that is becoming a part of NHS culture in the UK. In a sense, PPC formalises accepted good practice: it is patient-held, the patient is asked about preferences, the responses are recorded, and they are available for others in the care team to see. The need for PPC is that such approaches are not consistently embedded in practice and may well be absent in some settings. At the same time, PPC has the potential to raise certain ethical issues – Does it adopt an unrealistic view of 'autonomy'? Does it raise issues of confidentiality? Does it foster undeliverable expectations? Does it provide a mechanism for families to discuss and resolve differences? It also highlights issues about the quality of the communication skills that are needed to implement it effectively – and it was noted that, in the original pilot scheme and in a subsequent 'roll out' in Lancashire and Cumbria, a programme of advanced communication skills training had been made available alongside the introduction of the plan. It was also acknowledged that the name of the plan is somewhat misleading – with the suggestion that it might be better called: Preferred **Priorities** of Care. It was agreed that by recording and making information available, PPC has the potential to formalise good practice relating to communication at the end of life and offers a practical way forward, especially to nurses. It was also acknowledged that PPC is a complex intervention that needs a realistic, modular and sustained programme of evaluation, linked to a wider understanding of the end-of-life initiative for England. Research and evaluation relating to PPC should, therefore, proceed in a step-wise fashion, from the descriptive to the analytical and recognising the value of interim findings in shaping and influencing the refinement of the intervention.

Avenues for research into Preferred Place of Care

There is some merit in approaching the evaluation of PPC with reference to the MRC Framework for Complex Interventions, building up in-depth exploratory work before moving to more structured analyses and conceptual models and in due course developing and testing specific versions of PPC. Three phases or clusters of activity were identified.

Retrospective stock-take

A key building block in the evaluation of PPC is the retrospective analysis (from case notes and the completed plan itself) of the first 100 cases, implemented in Lancashire in the period January 2003 to March 2005. This work will describe the characteristics, experiences and views of the first 100 patients and address a series of questions:

- Which patients made use of PPC?*
- By which health professionals was PPC initiated and used?*
- When was PPC used?*
- How did its use develop across practices?*
- What was the preferred place of death of patients?*
- Where did patients actually die?*
- What concerns did patients express about their illness?*
- What concerns did patients express about their place and type of care?*
- What family support was available to patients?*
- What issues were faced by the carers of patients?*
- How long did patients survive after initial assessment with PPC?*

Complementary to such an analysis, but one requiring additional primary data collection, is a project to describe the characteristics, experiences and views of health professionals who have initiated the PPC, not only in Lancashire and South Cumbria but also in other areas. Here the indicative research questions would be:

- With how many patients has PPC been undertaken?*
- How was it initiated?*
- What issues and questions were raised in its use?*
- Did any ethical or other difficult issues arise?*
- How were patients selected?*
- What changes resulted from the use of PPC?*
- What had to happen to help a patient remain at home?*
- What extra work was created?*
- Did the use of PPC affect the relationship between patient and carer?*

It would also be useful to describe the characteristics, experiences and views of health professionals working in settings where PPC has been initiated, but who themselves have not made use of it. Here the following indicative research questions would apply:

- Is the health professional aware of PPC?*
- What training, if any, has been received in its implementation?*
- What do they understand of PPC?*
- Why have they not made use of it?*
- What might encourage use of PPC?*

Those at the Lancaster meeting took the view that such projects should form the first phase of the evaluation strategy and that this should be regarded as essentially a 'retrospective stock-take' of PPC, covering the first 3 years of its implementation. The authors agreed to take on the role of holding and maintaining a database and archive of PPC evaluation data, including copies of unpublished reports and audits. To these would be added further data on where PPC has been implemented, with how many patients, over what period of time. Such work might involve combining datasets assembled in different parts of the country as well as building up a series of case studies from different settings.

Action research projects

From here, the group considered the feasibility of evaluating PPC through action research projects that would: (i) add new knowledge about the impact of PPC; and (ii) contribute to its refinement and specificity. Studies in this mode would explore the risks and benefits of its use as perceived by professionals. They would also involve the use of reflective practice techniques and workshops to gain feedback and generate recommendations for improvement. Such work could involve more detailed scrutiny of the role of advanced communications skills training as a prerequisite for implementing PPC – something of particular interest within the cancer network in which PPC was developed. Studies of this kind could also involve 'critical incidence' scrutiny of cases where those enrolled on PPC did not die in the place of their choice. One suggestion was for a 'multiple embedded case study methodology' that would generate narrative accounts of the trajectories of dying through detailed scrutiny of a small number of patients and families.

Quasi-experimental studies

Building on an initial 'stock take' and a series of action research projects, it may well be possible to move over towards some more experimental form of evaluation leading to pragmatic trials of clinical issues with patient-focused

outcomes The results of such work could be used to formulate prospective studies designed to measure the outcomes of care generated by PPC. There was considerable hesitancy at the Lancaster meeting as to whether PPC would be suitable for evaluation by randomised control trial. Work might be done to assess how PPC works with cancer patients when compared to those with other diseases. Or comparisons could be made between outcomes in different regions and service settings. Certainly, there does seem to be scope to develop outcome measurements for PPC, but only once some of the more fundamental evaluative building blocks have been established.

CONCLUSIONS

It is clear that PPC provides several opportunities and challenges in relation to evaluation. The participants at the Lancaster meeting were enthusiastic about the potential offered by the PPC process for enhancing end-of-life care for individuals and their families – and the need to build an evidence base around this.

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