Education to achieve symptom control for patients with cancer

MANY patients who have cancer receive suboptimal symptom relief because of a lack of skills and knowledge in the health professionals providing care. The aim of this project was to improve symptom control for patients undergoing treatment for cancer.

Initially the intention was to consider the patient’s journey from a health professional’s view to determine deficits in care that could be remedied in manageable chunks within the resources and time available. It was also hoped to obtain a patient perspective by setting up a patient focus group. Unfortunately this proved impossible within the time allowed. However, it will be undertaken as a separate project in the near future.

The NHS Executive funded an evaluation of the project, which was organised and overseen by a core management group. It had to be completed within a six-month period, and had five main objectives:

- Investigating the impact of the project from the perspective of the patient and from that of the health care professional;
- Examining the process from the perspective of continuous quality improvement as a mechanism for change and assessing beneficial and hindering factors;
- Enabling the professionals involved to gain new knowledge;
- Investigating whether any change has been maintained 12 months after completion of the project;
- Examining the project from the perspective of the core project group, who received on-the-job training as facilitators from qualified supervisor facilitators from Bournemouth University.

These objectives were agreed after holding discussions between the core project group and the supervisor facilitators to ensure the overall aim of the evaluation could be achieved within the specified time frame. The aim was to enable the key stakeholders involved with the project to judge the value of continuous quality improvement initiatives and decide how to proceed in terms of future development.

Methods
Design
The focus of the evaluation was on both the process and the outcome of the project and consequently a descriptive design was used with a developmental perspective (Ovretveit, 1998). The main features of this method are:

- The focus is on one or a small number of services;
- An intervention is involved;
- Collaboration and feedback are characteristics of the design of the evaluation;
- Neither controls nor an experimental design are used.

The study was longitudinal in design incorporating a follow-up assessment six months after completion of the project. The criteria against which the outcome of the project was to be assessed were defined in terms of the five project objectives outlined above.

The project development group comprised two individuals who were trained as facilitators by experienced facilitators in a local university before the action learning sessions began.

Sample
An action learning group of professionals was recruited in two stages to participate in the project. The community area in which the research was to take place was selected on the basis that it was a pilot site for the first Macmillan cancer nurse specialist within primary care, and the fact that the associated primary care group had chosen cancer as a priority area. Sixteen health professionals working in Poole Cancer Centre, who were based in or near the targeted area and were willing to take part in the project, were selected to form the action learning group.

Members of the action learning group had varying levels of experience in working in the community, both in terms of the number of years experience and in the nature of the work they did. However, it was agreed by the core project group and the project development group that it was not appropriate to take account of such differences in the design of the evaluation.

Intervention and the quality tool
The change in the usual practice of the 16 health professionals in the action learning group is referred to in this context as the intervention. The intervention consisted of exposure to and the use of a continuous quality improvement tool which was utilised throughout the project (Briscoe and Arthur, 1998).

The first step in quality improvement involves identifying processes that need improvement, cost control, or both (Briscoe and Arthur, 1998). Continuous quality improvement requires constant attention and process-focused action for these goals to be achieved. Our continuous quality improvement team focused on clinical and operational processes.

Second, the continuous quality improvement process involves assembling a team of those directly involved in health care delivery, including managers and possibly patients. Among other factors for success, it is important to create an environment of trust and learning, gain everyone’s commitment, plan regular and well-structured meetings, as well as gain budgeting support (Briscoe and Arthur, 1998).

The continuous quality improvement delivery team is
constantly striving for simple, efficient processes for streamlining care delivery. The team sought to minimise process variation. One such process used to achieve this was the ‘Plan Do Check Act’ (PDCA) cycle – a continuous test to periodically examine variations in processes.

Several factors are essential for success, including flexibility to evaluate, adjust and re-evaluate as necessary to make continuous improvements (Porter O’Grady, 1996). The managers gave the team the power to make the necessary changes.

Among the problems the team identified were inefficient direct and indirect patient care processes, predominantly due to a lack of understanding of each others’ roles and working environment. Some of the key skills and knowledge acquired related to these problems and included:
- Learning to work with patients;
- New methods of problem-solving;
- Trusting the process;
- Not being intimidated by a ‘large job’;

Brainstorming focused on recognising and resolving flaws in the processes that affect patient care. Some actions enabled immediate, quick-fix results to be achieved while others needed more time. Overall, the continuous quality improvement teamwork facilitated positive consequences. This resulted in a more unified team, and thus improved care for patients with cancer across the primary-secondary health care interface.

Members of the action learning group would work directly with hospital, community groups and agencies over a six-month period from July to December 2000.

Data collection
Reflective diaries were selected to collect data on the process of the project. The diaries were designed to cover four key areas:
- Training;
- Community engagement;
- Liaison with community, acute and other agencies;
- Participants’ feelings about the process, be it as a facilitator or part of the action learning group.

For each area of the diary, participants were required to reflect upon the new knowledge they had gained, the skills they had acquired and the practices/activities they had undertaken. They were required to identify any negative factors or obstacles, which they perceived to be a barrier to progress. The participants were asked to complete the diaries retrospectively, on a weekly basis.

To evaluate the project six months after completion, a patient medication sheet and a district nursing information leaflet were designed for use in the Dorset-wide patient-held information record. An interprofessional education package was also developed for those in primary and secondary care. This incorporated seminars, case study work and workbooks underpinning competency-based training.

Final versions of these instruments were agreed with the project development team. These instruments were to focus more specifically on the impact they had on patient care, and the extent to which professionals’ practice and communication changed as a consequence of participating in the project.

Data analysis
In order to provide formative feedback during the project period, the reflective diaries were analysed in three batches. The feedback was provided to the health professionals and the project development team.

The first analysis was undertaken and feedback provided on the first six weeks of diary completion; the second on the following 12 weeks; and the third on the final 24 weeks. Data from the diaries was analysed and grouped to establish the main categories and themes that emerged. During feedback meetings, confidentiality was assured so that comments could not be traced back to individual action learning group members.

Results
The aim was to use the information collected to address the issues identified and defined at the outset of the project. Analysis of the diaries provided ample opportunity to offer important feedback on the process, and on the progress of the project. The issues that arose within the diaries were grouped within the key categories defined in the design of the reflective diaries listed above.

Training
Positive aspects of the training included the availability of structured help and expertise for:
- Collecting information;
- Drawing up plans;
- Meeting key individuals to discuss plans;
- Formalising and making changes to patient care within a limited time period.

As the project developed, the participants found that opportunities to share thoughts on progress with others in similar situations were of paramount importance. This was compounded by initially focusing on patients’ cancer journey from the health professional’s perspective, which developed an increasing feeling of ownership of the project. This created a sense of enthusiasm and empowerment, which in turn helped to drive the changes that occurred and which helped to bridge the gap between theory and practice.

Negative aspects of the training were also identified. Group members were initially uncertain about how it would help them develop the skills necessary to improve patients’ symptoms. This led to communication and other interpersonal difficulties between various individuals involved in the project in the early stages.

These difficulties were predominantly the result of a poor appreciation of the differences between primary and secondary care, despite both sectors existing within the NHS. Also, some members of the action learning group initially found it awkward to be in the group as they mistakenly believed that their lack of specific cancer knowledge and expertise would prevent them from making useful contributions to the process.
After the feedback sessions, the issues raised by this process were addressed in training sessions and were pursued with the group by the facilitators. By the end of the project all health professionals had produced the outcomes already noted and had resolved many of their initial difficulties.

Community engagement
At the outset, members of the action learning group identified particular needs in terms of developing mutual understanding and a willingness to work as part of a team with patients living in the community. Positive aspects of community engagement were as follows:

- Opportunities to network through consulting key players and organisations;
- Identifying health issues and other areas lacking support and being able to do something about them;
- Arranging meetings, which had successful outcomes;
- Observing how involving patients enabled a change of opinion from that of total satisfaction to one where patients could express opportunities for change, which they had been unaware of before.

Negative aspects of community engagement were centred on several aspects. There was initial confusion about prioritising objectives or even what objectives to adopt and how or whether to involve patients. Early difficulties in bringing community members together were experienced because of the disparate nature of different people’s agendas. There were problems explaining health care concepts to lay people and also in maintaining a high profile in various new initiatives. There was a definite lack of support and cover for the professionals who participated in the study developed skills in working with other health care settings, as well as more quantifiable skills such as experience of offering important feedback on the process and progress of the project.

The main issues raised by the project findings include the difficulties for the facilitators of having limited secretarial support and administrative assistance, which caused practical concerns such as difficulties in finding time to obtain and provide refreshments. Another problem at the beginning of the project was that the venues for meetings alternated between primary and secondary care, but the first meeting commenced within the hospital setting. On reflection it would have been better to have had this meeting on neutral ground so that all members of the group felt as safe as possible.

Community engagement
Individuals’ ability to trust fellow group members is fundamental to the success of such a project. Thankfully the facilitators received unsurpassed practical, skilful professionalism; determined support; time; and encouragement from the supervisor facilitators throughout. Without it, this project would have been impossible.

The professionals who participated in the study developed skills in working with other health care settings, as well as more quantifiable skills such as experience of using a continuous quality improvement tool, which assisted in focusing the project and evaluating it (Briscoe and Arthur, 1998). Despite this, it was recognised that the group was dynamic and that the use of a continuous quality improvement cycle would drive any changes and adaptations to the original project specifications. A number of projects were up and running in localities and the hospital by the end of the project.

Trainee facilitators
Positive aspects of being trained in this way were identified. It was seen as exhilarating, fun and exciting as the intentions of the project were clear from the beginning but the outcome was uncertain. There was little time allotted to gaining familiarity with the process for each group session before it occurred, but this ultimately increased members’ confidence in presenting and dealing with the unexpected. This presented a potential model of supervising trainee facilitators without qualified facilitators being present. The method enabled facilitators to function as such, so that ultimately the action learning group was directing the changes as a group and as a consequence it no longer felt chaotic. It was evaluated as a fascinating process in which to be involved.

Negative aspects were that while being exciting, much of the training and organisation of the sessions occurred in personal time. This was exhausting, coming on top of other work commitments. The structure of this method of learning at times felt chaotic and symbolic of patients’ cancer journeys, being very different to nursing or medical approaches to teaching. It initially caused conflict for all, as the expectation was that facilitators were to be experts in either a traditional teaching role or the process that was occurring, rather than facilitators.

Discussion
The action learning group members reported that they benefited from the project in several ways:

- It improved their ability to plan formally;
- They benefited from meeting people who were affiliated with different organisations;
- They gained better strategic vision.

Although the sample size was small, analysis of the content of the diaries provided ample opportunity to offer important feedback on the process and progress of the project.

The main issues raised by the project findings include the difficulties for the facilitators of having limited secretarial support and administrative assistance, which caused practical concerns such as difficulties in finding time to obtain and provide refreshments. Another problem at the beginning of the project was that the venues for meetings alternated between primary and secondary care, but the first meeting commenced within the hospital setting. On reflection it would have been better to have had this meeting on neutral ground so that all members of the group felt as safe as possible.

Trainee facilitators
Despite the perceived barriers participants all said that they had particularly enjoyed the ‘buzz’ they had from observing, and, being involved first hand in the changes that occurred. At eight months a further successful meeting was held to launch the patient-held information and the devised documentation, and to review this and the process of the project. This will be continued long term in Poole where the work has subsequently been taken up by phase 11 of the Cancer Collaborative Services Project. One of the authors has now moved back to Cornwall where there are hopes to utilise this exciting, liberating methodology in future ventures.