PATIENTS NEED MORE INFORMATION ON PALLIATIVE CHEMOTHERAPY

Research shows that people with advanced cancer should be better informed about treatment implications for survival and quality of life. Nerys Hairon reports

More than two-thirds of patients with cancer receive little or no information about the survival benefits of palliative chemotherapy before making treatment decisions, a study has found (Audrey et al, 2008). The research, published by the British Medical Journal, recommends that benefits and limitations of this treatment should be sensitively described, including survival gain, to help with decision-making and informed consent.

Palliative chemotherapy for patients with advanced cancer has modest survival benefits. There is an expectation in the UK that these patients should be given accurate information so they can give informed consent before starting the treatment. At the advanced stages of cancer, the survival benefit from such treatment tends to be months rather than years.

An accompanying editorial in the BMJ argues that patients need up-to-date, consistent information and comprehensive and expert communication from oncologists and supportive care teams (Munday and Maher, 2008). Cancer clinical nurse specialists and other practitioners are vital in ensuring patients are given enough information to make informed decisions and give informed consent to palliative chemotherapy, and to support them through this decision-making process.

BACKGROUND

The NHS Cancer Plan (Department of Health, 2000) emphasised the importance of good communication between patients and staff caring for them.

This was reinforced by the DH’s (2007) Cancer Reform Strategy, which featured staff training in communication as a key area (Hairon, 2007). The strategy said that all senior cancer professionals will, over time, be expected to demonstrate they have the necessary competencies in face-to-face communication after a training course. This means showing the level of competencies to communicate complex information, involve patients in clinical decisions and offer choice. The DH (2007) said it also needed to ensure that other healthcare staff who treat and support patients with cancer have had access to good communication skills training.

General skills that healthcare professionals should acquire to improve patient experience include the ability to:

- Deliver information to patients effectively;
- Work as part of an integrated multidisciplinary team;
- Engage in appropriate ‘what if’ conversations with patients.

The DH’s (2008) end-of-life strategy says patients need to be assessed in the time before their death so their needs and wishes can be established and set out in a care plan. Audrey et al (2008) outline the difficulties for healthcare professionals in discussing issues relating to survival benefits of treatment. They say there are concerns that the ‘intrusiveness of unfavourable numbers’ (in terms of months left to live) can undermine relationships with healthcare professionals and destroy hope. However, they stress that the challenge for oncologists and other members of the multidisciplinary team is to communicate enough information ‘to enable patients to make informed decisions based on realistic aspirations’. They add that part of this challenge is doing so in a sensitive manner and at patients’ own pace.

STUDY METHOD

Audrey et al’s (2008) research forms part of a larger study, known as ASPECTS. The study used qualitative research methods to
describe patients’ experiences of palliative chemotherapy and to explore how the decision-making process might be improved.

Audrey et al (2008) aimed to examine how much oncologists tell patients about the survival benefit of palliative chemotherapy during consultations at which treatment decisions are made. The study, funded by Cancer Research UK, was carried out at a large teaching hospital and a district general hospital in south-west England, where 37 patients’ cases were considered. All patients had advanced forms of cancer; three common types were chosen – colorectal, non-small cell lung and pancreatic cancer.

An experienced researcher interviewed patients before they saw the oncologist; then digitally recorded and observed the initial oncology consultation during which palliative chemotherapy was discussed. The researcher then interviewed patients again, at least once, in the following weeks. All recordings were transcribed fully, anonymised and electronically coded.

MAIN FINDINGS

The researchers found that towards the beginning of the consultation all patients were informed that their cancer could not be cured. They found that although there was consistency in informing patients that a cure was not being sought, the amount of information given about survival benefit varied considerably. This kind of information included: numerical data (‘about four months but very few people are “average” and so some people get quite a bit more than that, and sadly some people get no benefit at all’); or no mention at all. In total, during the recorded consultations, only six out of 37 patients were given numerical information about the survival benefit of treatment. In most consultations (26), the researchers say the discussion of survival benefit was either ‘vague or non-existent’.

The study also identified triggers and barriers to discussion of survival benefit. Triggers included patients or relatives specifically asking for details, and oncologists volunteering information to give a realistic expectation of what the treatment could achieve. Barriers to such discussion included patients making it clear they did not want treatment, patients or relatives (with patients’ agreement) blocking discussion, or oncologists emphasising other benefits of chemotherapy.

KEY MESSAGES FOR PRACTICE

Audrey et al (2008) argue that oncologists need to describe the benefits and limitations of palliative chemotherapy, including survival benefit, to help patients with advanced cancer make informed decisions. They warn that some of the barriers to the discussion of survival benefit might undermine informed consent. If healthcare professionals focus on other benefits of palliative chemotherapy but do not include information on survival gain, patients might assume it has much more potential to prolong life. On the other hand, if patients decline such treatment without knowing about its potential benefits, they may be making a decision based on incomplete information.

The researchers acknowledge that giving information on survival benefit is extremely difficult when patients or relatives indicate that they do not want any more bad news. The study includes an example of giving basic information on survival gain from treatment without giving ‘intrusive’ data on prognosis (see www.bmj.com).

The researchers recommend more support and training on how to communicate relevant information about survival benefit to patients. They explain that median survival is a difficult concept and can be open to misinterpretation. However, they suggest some simple reassuring messages that could be given (see box, left). In addition, they recommend that NICE considers whether – and how – it might include data about survival gain in the information for the public that accompanies its guidance.

CONCLUSION

Audrey et al (2008) conclude that most patients are not given clear information about the survival benefit of palliative chemotherapy, with implications for decision-making and informed consent. Training should include guidance on how to inform patients about the survival benefits of such treatment.

Munday and Maher (2008) say this study highlights the need for more research into how to transfer this information more effectively. This should include the development and evaluation of nationally agreed and updated information about the prognosis of advanced cancer and benefits of palliative chemotherapy. Decision aids should also be developed to help patients interpret information.

Nurses can provide vital support to patients in guiding them through the information and helping them to make difficult decisions, ensuring they have sufficient information to give informed consent.

SUGGESTED MESSAGES FOR PATIENTS

Simple reassuring messages that could be given to patients with advanced cancer might include:

- ‘We are going to do our best for you’
- ‘Our aim is to relieve your symptoms and improve your quality of life’
- ‘We also need to consider what you would gain from this treatment in terms of extra time’
- ‘The average gain may be a few months but very few people are “average” and so some people get quite a bit more than that, and sadly some people get no benefit at all’

Source: Audrey et al (2008)