

Informing, communicating and sharing decisions with people who have cancer

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There is widespread agreement that people should be informed about health care options and involved in decisions about their own care. In England and Wales the National Institute for Clinical Excellence (NICE) is intent on achieving a patient focus in its work and *The NHS plan* emphasises the need for patients to have more say in their own care and more influence over the way in which the NHS works.¹ Similarly, *The NHS cancer plan* for England and Wales emphasises the need for good communication between health professionals and patients, both for delivering high quality care and for empowering people to be involved in decisions about their own care.²

This paper summarises *Effective Health Care* bulletin 6(6) which focused on communication, information giving, and sharing of decisions between health professionals and people with cancer. Evidence from systematic reviews produced by the Cochrane Consumers and Communication Group, other good quality systematic reviews, and from guidance produced by the National Cancer Guidance Steering Group is also included.

Communicating with patients

The most common complaints made by patients with cancer are about poor communication and inadequate information.^{3,4} In 1993 the General Medical Council (GMC) recognised the need to teach communication skills as part of the British undergraduate medical education. However, in a survey of all consultant non-surgical oncologists working in the UK to which 83% of the 476 consultants responded, almost half considered that they had not received sufficient training in communication skills.⁵

Communication skills programmes vary in their content and training methods. A recent systematic review evaluated communication training programmes for nurses.⁶ Of the 14 studies included, eight were based in an oncology setting (two randomised controlled trials, one controlled trial, and five pre/post tests). Only one study measured the effects on patients; this randomised controlled trial found reduced levels of anxiety but no improvement in health professionals' empathy skills (the only professional outcome measured). The other randomised controlled trial and the controlled trial found improvements in health professionals' attitudes. The five pre/post test studies

reported mixed findings. However, it is unclear whether all relevant studies were identified and the quality of the included studies was not assessed, so the findings of this review should be treated with some caution.

An overview of five studies evaluating training programmes specifically for health professionals dealing with people with cancer found positive changes in communication skills in some participants.⁷ The programmes were based around the acquisition of specific skills and/or strategies for dealing with specific situations. Those who reported more negative attitudes at the beginning of the training programme appeared to benefit most. A systematic review assessing the effects of interventions to promote patient centred care within clinical consultations will be published later this year.⁸

Informing patients

A recent survey of over 2000 people currently receiving treatment for cancer in one of 34 hospital outpatient departments in the UK found that 87% preferred to be given as much information about their illness as possible (both good and bad).⁹ Information is required for different purposes—understanding the presenting symptoms and/or disease, learning about available services, and participating in decisions about treatment options.¹⁰ Patients cannot express informed preferences about their care, or about whether and how they want to participate in care decisions unless they are given sufficient and appropriate information. Findings from recent focus groups carried out with cancer patients suggest that people still experience a dearth of information although a great deal is theoretically available.¹¹

Information materials have been found to be lacking in several areas including omission of relevant data, failure to give a balanced view of the effectiveness of different treatments, ignoring uncertainties, and rarely promoting a participative approach to decision making.¹⁰ There are instruments available to help judge the quality of written information about treatment options¹² and guides to assist in the production of good quality information materials.^{13–15} The criteria for producing “good” quality patient information are shown in table 1.

Current sources of evidence based cancer information include: the Cancer Library which

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Table 1 Criteria for producing good quality information for patients

<i>Duman & Farrell</i> ¹³	<i>CHiQ</i> ¹⁶	<i>Entwistle & O'Donnell</i> ¹⁵
Informs about condition and available treatments and options	Accessibility: appropriate format	Clear statement of aims
Comprehensive, unbiased information about outcomes	Accuracy	Relevant
Outlines uncertainties and gaps in knowledge	Appropriateness	Accurate
Caters for people from a diverse range of backgrounds	Availability	Accessible, comprehensible, acceptable
Regularly reviewed and updated	Continuity: information is presented with other resources	Gives further sources of information
Integrated into a planned shared decision making programme	Currency: being up to date	Facilitates judgement about reliability of information
Simple and easily understood language and design	Legibility: clear presentation	
	Originality (not duplicating other sources)	
	Patient involvement	
	Readability	
	Reliability	

is available via the Cochrane Library; a cancer database being developed by Macmillan Cancer Relief and The Centre for Health Information Quality (CHiQ) which will be a source of reference to information materials about cancer and its management¹⁶; and the National Electronic Library for Health which also includes information for patients and the public.

TAILORED INFORMATION

The importance of tailoring information to suit patients' educational background, cultural orientation, and general level of comprehension has been emphasised.¹⁷ A recent Scottish randomised controlled trial has shown that patients with cancer prefer information based on their own medical records to general information.¹⁸

The Teamwork Project aims to help people with cancer work in partnership with health professionals with the aid of a personal information file.¹¹ The file contains general information about cancer, tests, diagnosis, treatment and care, together with a personal health diary where a record is kept of health and health care including personal test results and details of medication prescribed. The file is currently being evaluated by several NHS trusts.

Other personalised information includes recordings or summaries of consultations between people with cancer and their doctors. A recent systematic review of eight randomised controlled trials has evaluated the effects of giving recordings or summaries of consultations to people with cancer.¹⁹ The studies varied in terms of interventions, participants, and outcomes. Interventions ranged from giving audiotapes to people at the end of the consultation to making a written summary of the key points discussed during the consultation. Across the seven studies which provided data, 83–96% of participants receiving tapes or letters reported that they had found them useful. Four of the seven studies also reported better recall in the groups which received personalised recordings or summaries than in the control groups. Of the six studies that assessed anxiety and/or depression, none reported statistically significant differences between the intervention and control groups, although one study found mixed results among participants in the intervention group—psychological morbidity increased at follow up in those with a poor prognosis compared with those with a

better prognosis. Although the quality of the trials was poor, overall the evidence suggests that providing a record of the consultation can increase the amount of information recalled and satisfaction with the information given. There is some evidence to suggest that recordings might encourage participation in subsequent consultations and there is no clear evidence to show that they affect psychological health (either positively or negatively).

THE NEEDS OF HEALTH PROFESSIONALS

Health professionals are likely to need support if patients' information needs are to be met. The learning needs of clinicians in fulfilling the information needs of patients have been identified and include: placing a higher priority on patient information; understanding the patient's needs; understanding the emotional aspects of learning; helping patients to understand; learning from the patient; and knowing about information sources.²⁰ Ensuring that such needs are addressed in both undergraduate and continuing professional education will help in achieving the goals of current government policy.

ORGANISATIONAL CHALLENGES

As well as challenges to the health professional in meeting peoples' information needs, organisational challenges have also been recognised and recommendations made.²⁰ These include: treating patients' information needs as a core activity; ensuring adequate funding, space and time devoted to patient information; producing, implementing and reviewing guidelines on patient information and auditing methods of working.²⁰

Involving patients in decision making

The shared decision making model is increasingly being advocated as a way of promoting clinical effectiveness and more appropriate and efficient use of resources.²¹ A partnership between professionals and patients in which both contribute to decisions about treatment or care is encouraged. This differs from the informed choice model where the emphasis is on the patient to make the decision and from the more traditional model where the health professional makes the decision.^{22–25}

People are likely to vary in the extent to which they want to participate in decision making as well as in which decisions. Health professionals will need the necessary skills to elicit preferences for involvement along with other communication skills.²⁶

One way to support patient involvement in decision making about treatment is through the use of decision aids. Decision aids aim to help people make specific and deliberative choices by providing information on the options and outcomes relevant to their state of health.²⁷ The effectiveness of decision aids has been assessed in three reviews.^{28–30} The search strategy used in the most recent Cochrane review has been re-run and the same inclusion criteria adopted, with the addition that participants had to have a cancer diagnosis. Four randomised controlled trials which examined the use of decision aids in cancer patients were identified, three studies of women with breast cancer^{31–33} and one of men with prostate cancer.³⁴

Little evidence was found that video disk presentations were better than usual care,³³ that interactive multimedia were better than written information,³¹ or that a tape and workbook were better than a pamphlet³² in patients with breast cancer facing major treatment decisions. A very small (non-significant) difference was found toward a lower decisional conflict (agreement/disagreement about being certain, informed, clear about values and supported in decision making) in the tape and workbook group.³² The costs of developing and evaluating the tape and workbook were estimated to be more than \$250 000 (Canadian).³²

In contrast, there was some evidence that decision aids were helpful for men with prostate cancer in reducing anxiety and influencing decision making about treatment.³⁴ Men exposed to an “empowerment” intervention (an information and question pack based on their needs and wants) assumed a significantly more active role in decision making and had lower anxiety levels than men who were given just an information pack.³⁴ Support was also found for decision aids in a systematic review that included patients with a variety of different diagnoses.³⁰ Improved knowledge, increased participation, and decreased decisional conflict were reported.³⁰

Although questions around the use of decision aids remain, including the type of aid to use, the choice of appropriate outcomes to measure, and their effect on communication between patients and professionals,²⁴ they can provide a useful way of displaying and providing information about treatment options. However, barriers to implementing decision aids in practice have been found—for example, a recent US study found time pressures to be the main barrier.³⁵ It is likely that similar barriers would exist in the UK.

Conclusions and recommendations

If the goals of current NHS policy are to be achieved, then the information needs of patients must be addressed. Initiatives such as the Cancer Information Strategy³⁶ should take into account variations in peoples’ preferences for information and involvement in decisions about their treatment and care. This means that health professionals need to know how best to elicit patients’ need and readiness for information as well as their desire for involvement in decision making. Appropriate training

in communication skills addressing such issues should be considered and any programmes offered should be appropriately evaluated, with assessments of patient outcomes as well as professional skills.

Tailored information is an option for people with cancer; in particular, recordings or summaries of key consultations may benefit adults with cancer without causing additional anxiety. The effects of such interventions will, however, need to be carefully monitored because evidence for their effectiveness is currently limited. People should also be given the opportunity for involvement in decisions about their treatment and care, but individual preferences for different levels of involvement need to be respected. One option is the use of appropriate decision aids, although again evidence about the likely effects in people with cancer is limited and further evaluation is recommended.

The Health Services Research Unit receives core funding from the Chief Scientist’s Office, Scottish Executive.

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