Meeting patients' information needs beyond the year 2000

Abstract Advances in information technology, and changing patient expectation in regard to provision of information and participation in clinical decisions are already influencing the cancer consultation. In future, the oncologist's role will evolve further, and the cancer consultation beyond the year 2000 will be an opportunity for information relating to the particular patient's circumstances to be presented according to the patient's wishes. Patients' desired input into clinical decisions will be respected, and consultation audiotapes will be a widely used aid for patients after the consultation.

Key words Information needs • Information technology • Decision making

Introduction

Modern medical ethics emphasise the patient's right to be fully informed of his or her medical condition and to participate in decisions about treatment. Truth-telling, once regarded as cruel and insensitive, is now thought by many to be morally obligatory. Community attitudes have also shifted towards greater patient participation in and knowledge of medical matters. The rationale for this approach is that it will safeguard the autonomy and integrity of the individual and ensure that the patient plays an active role in decisions about his or her care.

In North America and in many western countries there was a major change in doctor behaviours with regard to disclosure of the diagnosis of cancer between 1960 and 1980 [3, 4, 21, 26]. During the past 15 years, patient information preferences have also changed, and now more than 80% of cancer patients in North America and Australia indicate that they wish to receive all information concerning their health status whether the news be good or bad [3, 7]. However, patients are frequently dissatisfied with the amount of information they receive at a medical consultation [23], and this poor outcome underpins recent efforts to improve information presentation before, during and after consultations. There has been a rapid development by voluntary cancer organisations, hospitals and the pharmaceutical industry of pamphlets, audiotapes and videotapes providing general and specific information about different cancers. Many voluntary cancer organisations provide a telephone cancer information service accessible to patients, their relatives and the general public. Some doctors not only provide pamphlets relevant to cancer but also offer audiotapes of cancer consultations [7, 19]. Some clinicians have also either provided patients with copies of correspondence with the referring doctor and/or have written patient-specific letters summarising the 'take-home messages' after a cancer consultation [6, 24].

Advances in information technology in recent time are already impacting on the provision of information to cancer patients and to health professionals [5]. Some cancer advocacy groups now communicate regularly on the Internet, while the development of the Cochrane Collaboration, with its goal of summarising evidence of the effectiveness or otherwise of health care interventions, provides an up-to-date summary via the Internet.
which is accessible to clinicians and patients [11]. The development of treatment guidelines based to varying extents on evidence of treatment effectiveness is in some cases matched by guidelines prepared for patients [13]. While the impact of these different guidelines on patient care has not been well documented, the possible medico-legal and other implications of guidelines are increasingly influencing medical practice.

Advances in molecular genetics are beginning to impact on community attitudes to individualised assessment of cancer risk. Familial cancer clinics have developed only recently, yet it is already clear that information and counselling support is an essential component of the effective and appropriate utilisation of this new technology [8].

In this paper we discuss the implications for the oncologist of recent research in doctor-patient communication and changing patient expectations in their desire for information and involvement in clinical decision making. We consider the likely use and the implications of the new information technology for the doctor's role. This paper does not discuss the roles of the cancer volunteer services and non-government organisations in the provision of information to cancer patients or members of the community.

### The cancer consultation

Research concerning the content of the cancer consultation is remarkably limited, even though many patients in the past have indicated that their doctor was the major source of information about their health status [10]. Computer-assisted interaction analysis systems are now being used to document and describe cancer consultations. In a recent study, for example, the time spent discussing content areas was described, as was the flow of questions, responses, and self-initiated statements between patient and doctor [1]. Research from the family medicine sphere potentially applicable in cancer medicine suggests that structuring the information presented in the consultation can significantly improve understanding and recall. These skills should be emphasised in medical curricula.

The manner in which information is presented in the cancer consultation has not been adequately researched, although several surveys report that how the cancer diagnosis was disclosed is an important determinant of patient satisfaction and psychological health thereafter [9, 22, 25]. The provision of hope in particular has been identified as an important factor [15].

It is increasingly recognised by clinicians and by patients that management options with similar outcomes frequently exist. The extent to which the doctor involves the patient in those treatment decisions varies greatly. Surveys of patients' involvement preferences, at least in Australia and the United States, indicate that about 60% of patients wish to be involved in treatment decisions, although many still prefer a doctor to make the final decision/recommendations [3, 25]. Preliminary evidence suggests that the opportunity to choose may have a larger impact on subsequent wellbeing than the actual treatment received [9, 22].

Methods of presenting information to patients clearly impact on their decisions about treatment. For example, outcomes expressed as percent survival are viewed more favourably than those expressed as percent mortality [20]. Nevertheless, evidence-based guidelines on how to present risk and treatment options have not been developed. Surveys clearly indicate that patients generally receive treatment based on the individual doctor's expertise rather than the alternative treatment option, which would be performed by a different specialist (e.g., surgery versus radiotherapy).

### Audiotaping the cancer consultation

Several groups have investigated the use of audiotapes of the cancer consultation as a means of enhancing the provision of individualised information to cancer patients and of enhancing their satisfaction and recall of the consultation [7, 9, 19, 22]. We studied, in a randomised trial, the impact of a cancer consultation audiotape versus a general information tape versus no information aid in a group of 100 cancer patients consulting the same oncologist [7]. The results indicated that the general audiotape reduced patient recall and satisfaction, though the specific audiotape did not significantly enhance patient recall of items of the consultation. Finding that general information provided after a cancer consultation may blur patient recollection of specific items relevant to their management is important and suggests that post-consultation pamphlets providing general rather than specific information may on occasion do more harm than good. The fact that the specific audiotape did not enhance recall suggests that poorly presented information heard twice does not improve information exchange. We believe that in the future a greater emphasis should be placed on improving communication within the cancer consultation.

### Providing information before the consultation

Few studies have investigated the effects of information provided to a cancer patient before the consultation [10, 18]. However, one study in Australia investigated the effects of a question prompt sheet prior to consultation with a medical oncologist [2]. This study found that patient question asking in general was not enhanced by the question prompt sheet. However, question asking