

CHAPTER 4 COMMUNICATION WITH THE PATIENT

4.1 The initial consultation

Patients and their carers often seek information about their cancer at the time of diagnosis, but studies have shown that only a proportion of the initial consultation is remembered.¹ Therefore, the provision of information should not end with the initial consultation. Patients and their families and carers should be given time to assimilate information and the opportunity to ask questions at a subsequent visit. It is not necessary to make treatment decisions at the initial consultation. Interpreter services should be provided for non-English-speaking patients. The interpreter should be a professional and not a family member.

4.2 Breaking bad news

Breaking bad news in language the patient understands should be the responsibility of the senior clinician. It should not be delayed unduly and, wherever possible, it should take place privately. A qualified and appropriate interpreter is essential if the patient does not understand English.

The NHMRC recommends the following approach, adapted from the New South Wales Cancer Council:²

- give bad news in a quiet, private place
- allow enough uninterrupted time in initial meeting
- assess the individual's understanding
- provide information simply and honestly
- encourage individuals to express feelings
- respond to individual's feelings with empathy
- give a broad time-frame for the prognosis
- avoid the notion that nothing can be done
- arrange a time to review the situation
- discuss treatment options
- offer assistance to tell others
- provide information about support services
- provide documented information
- Provision of patient-held records are beneficial for patients.³

4.3 How much should the patient be told

There is evidence to suggest that most cancer patients wish to be fully informed of all available information and they usually want a close relative or friend present at the initial interview.⁴ They report that the subsequent discussions about actions to be taken, and what the diagnosis means, are at least as, if not more important, than the disclosure of the initial diagnosis.⁵ Cancer patients appreciate and use communication aids such as audiotapes or personalised letters from the consultation when these are available.⁶ An assessment of a patient's previous experiences and expectations is needed so that information giving can be individualised. The terminology used in communicating about cancer affects patient anxiety. Vagueness and obscurity make a difficult situation worse.⁷

Most patients want to be given prognostic information because it helps in their decision making. This is regardless of stage of illness. When patients desire information, they want it presented honestly and clearly. They want specialists to explore and negotiate the amount, type and format of prognostic

information to be discussed. It is good practice to present prognostic information in a variety of ways to suit each individual.⁸⁻¹²

The NHMRC states that patients are entitled to make their own decisions about treatments or procedures and should be given adequate information on which to base those decisions:

- information should be provided in a form and manner which helps patients understand the problem and treatment options available, and that is appropriate to the patient's circumstances, personality, expectations, fears, beliefs, values and cultural background
- doctors should give advice, but should not coerce
- patients should be encouraged to make their own decisions
- patients should be frank and honest in giving information about their health, and doctors should encourage them to do so.¹³

Information for patients with Colorectal Cancer should include:

- causes of Colorectal Cancer, extent of disease
- proposed approach to investigation and treatment, including information on expected benefits, the process involved, common side effects, whether the intervention is standard or experimental, and who will undertake the intervention
- the likely consequence of choosing a particular treatment or no treatment
- the time involved
- the costs involved
- the effect of cancer and its therapy on interpersonal and sexual relationships
- typical emotional reactions
- appearance after surgery
- how to obtain special items such as colostomy devices
- entitlements to benefits and devices, such as subsidies for travel or prostheses
- access to cancer information services (also see Chapter 18).

4.4 Keeping the patient's other doctors informed

The main method of communication between consultants and general practitioners in Australia is the letter of referral to the consultant and the reply to the general practitioner. Surveys of referring doctors show that the letters to them from the consultant should cover diagnosis, clinical findings, future tests/test results, treatment recommendations, likely side effects and prognosis.¹⁴

4.5 Second opinion

Patients have the right to obtain a second opinion at any time. A second opinion may help patients to clarify questions and to decide which doctor they prefer to manage their condition, and which course of treatment to follow. It can also reinforce the accuracy of advice already given, and enhance their confidence. Doctors should cooperate fully in providing both a referral and all relevant information.¹⁵

4.6 Coordination of care

Treatment of Colorectal Cancer requires the contributions of multiple disciplines, including clinicians with specialist knowledge in surgery, radiation therapy, chemotherapy and general practice. Coordination and continuity of care ensure high-quality treatment for individuals with Colorectal Cancer. The choice of the person to coordinate this care should be made by the patient in conjunction with their general practitioner and specialists. The coordinator may not necessarily be a health professional but rather, a well-informed friend or relative where available an experienced oncology nurse can provide support for both patient and family.^{16,17}

It may be helpful to both patient and coordinators if the patient is introduced to a prompt list of structural questions to help facilitate acquisition of information during consultation. Such a template is described as having assisted patients in meeting their participation preferences and information needs.¹⁸

4.7 Clinical trials

Clinical trials are an essential component to finding better treatments for Colorectal Cancer. In Australia, clinical trials are conducted on a large scale through national and international collaborations. They are designed to define optimum management programs and test appropriate modifications to these programs. Doctors should encourage patients with Colorectal Cancer to consider participating in appropriate clinical trials for which they are eligible. Protocols should be approved by appropriate ethics committees. Patients must be provided with relevant and complete information about the trial protocol and must provide their written consent before taking part. The benefits of clinical trials are that trial patients with cancer have been observed to have a better outcome.¹⁹⁻²¹

Practice Recommendation

Should clinical trial participation be encouraged?

Clinical trial participation is recommended

- Patients who have cancer and who participated in clinical trials may have a better outcome than patients not included in such trials.
- Doctors should encourage patients with cancer to consider participating in appropriate clinical trials for which they are eligible.

4.8 Quality of life

Up to 50% of patients report psychological distress, depression or anxiety following a diagnosis of Colorectal Cancer.²² The prevalence of psychological dysfunction is greater for those with stomas compared to patients with intact sphincters. Anxiety and depression levels tend to decline, and overall quality of life improves in the months following treatment.²³ Psychological dysfunction associated with loneliness, stigma and low self esteem and disturbed body image are also reported and more prevalent in stoma patients than in non-stoma patients.^{24,25} In general, the psychological functioning of younger, female patients is more impaired than that of older male patients.²⁴ Patients reporting psychological distress function less well in their usual roles and activities than patients without distress.²³

Colorectal Cancer and its treatment can have adverse effects on social functioning, including work and productive life; relationships with friends, relatives and partners; and other social activities and interests.²⁶ Although both stoma patients and non-stoma patients report restrictions in their level of social functioning, such problems are more prevalent among stoma patients.

Bowel function usually improves and stabilises during the first year following surgery, although bowel problems may persist.²⁷ Both stoma and non-stoma patients report frequent bowel movements.^{25,28} Stoma patients report more problems with gas and urinary function, whereas patients with intact sphincters report more constipation.

The overall prevalence of sexual dysfunction is consistently higher in stoma patients than in patients with intact sphincters (66–100% compared with 30–75% respectively).^{28,29} The principal sexual problems in men pertain to erectile function and ejaculation.

Abdominoperineal resection appears to result in most severe reduction of sexual activity and functioning. Based on the few studies that have assessed female sexual functioning, sexual dysfunction (dyspareunia, cessation of sex) is also more prevalent among female stoma patients than among female nonstoma patients.^{28,30} It is estimated that one fifth of women who have stomas suffer from dyspareunia. Body image problems appear to be greater in women.

4.9 Counselling and support

The *Clinical practice guidelines for the psychosocial care of adults with cancer*¹⁷ provide a valuable resource for facilitating the practical psychosocial care of people with cancer.

There is accumulating evidence that psychological therapies improve emotional adjustment and social functioning, and reduce both treatment and disease-related distress in patients with cancer¹⁷.

A number of people involved in the patient's care may be involved in providing counselling and support in either a formal or informal manner. These can include family, friends, doctors, nurses, and other health care professionals or a cancer support service (a national telephone contact number for all such services is **13 11 20**, or **1300 361 366** in Queensland). These services provide peer and professional support to people with cancer. They may be specific, for example, an ostomy support group, or general, and are usually coordinated by volunteers.

Educational pamphlets are available from regional cancer councils and are particularly informative for individuals with stomas and their carers.

Stomal therapy nurses are usually hospital-based and are an important resource for patients who require a stoma. The services they provide include preoperative counselling and teaching, selection of stoma site, selection of skin care and pouching systems, postoperative patient teaching, and long-term follow up for rehabilitation. In studies of patients with other cancers discussions with a specialist nurse has been shown to reduce psychological morbidity, and increase understanding, recall of information and perceptions of support.^{17,31}

Sexual counselling may be appropriate for patients, and can be provided by stomal therapy nurses and/or referral to sexual and relationship counsellors. There is the potential for loss of fertility in both men and women. This may result from surgery or adjuvant therapies such as radiation and chemotherapy. Sperm storage should be considered for men undergoing rectal surgery or chemotherapy and for whom fertility is an important consideration. Referral for specialist advice with regard to ovarian and fertility preservation is recommended if loss of fertility is a possibility and women wish to retain the option of further childbearing.¹⁷ Referral for specialist advice in the setting of premature menopause caused by adjuvant therapies such as pelvic irradiation is also recommended.

Support needs for individuals with Colorectal Cancer and their families may include:

- counselling, including sexuality and fertility
- access to a cancer support service and/or stomal support group
- education and assistance with stomal therapy

- assistance with and care of children or other family members
- assistance with transport
- dietary advice.

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