

CHAPTER 22 COMMUNICATION WITH THE PATIENT

22.1 Introduction

Treating lymphoma patients is not just about treatment of the disease; it is also about helping the individuals deal with issues related to their illness. In these guidelines, we will present evidence to support the importance of good doctor–patient communication and of doctors being socially and culturally competent in dealing with patients. Communication with patients includes the ability to converse and provide best evidence-based and culturally appropriate information on issues that are important to their wellbeing. Frequently asked questions that relate to diet, exercise and psychological therapies are discussed in Chapter 23 and to complementary and alternative health practices in Chapter 24.

22.2 Communication with the patient

22.2.1 The initial consultation

Patients and their carers often seek information about their cancer at the time of diagnosis, but studies have shown that only part of the initial consultation is remembered.¹ Therefore, the provision of information should not end with the initial consultation.

It is not necessary to make all treatment decisions at the initial consultation.

A qualified and appropriate interpreter is important for patients who do not have English as their first language or whose understanding of English is limited in any way. The interpreter should be a professional and not a family member.

Breaking bad news in language the patient understands should be the responsibility of the clinician in charge and it should not be delayed unduly.

Figure 22.1 How much should the patient be told?

The NHMRC recommends the following approach², adapted from The Cancer Council NSW³:

- allow enough uninterrupted time in the initial meeting
- assess the individual's understanding
- provide information simply and honestly
- encourage individuals to express feelings, to be frank and honest in giving information about their health
- encourage patients to make their own decisions
- give advice but not coerce
- respond to individual's feelings with empathy
- give a broad time-frame for the prognosis
- discuss treatment options
- avoid the notion that nothing can be done
- give bad news in a quiet, private place
- provide information about support services
- arrange a time to review the situation
- document the information provided.
- that lymphoma is not a contagious disease.

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 Subsequent discussions about the meaning of the diagnosis, and what actions could be taken, are as important as the disclosure of the initial diagnosis, if not more important.⁵ Cancer patients' understanding, recall and/or satisfaction with the consultation increase when techniques such as audiotapes or personalised letters are used.⁶⁻⁸ Vagueness and obscurity make a difficult situation worse.⁹ Decision aids, including information on the disease, improves knowledge, reduces decisional conflict and stimulates patients to be more active in their decision making without increasing their anxiety or affecting overall levels of satisfaction with the decision making process.¹⁰ However, the effect of decision aids on patient outcomes (such as quality of life, persistence with choice) remains uncertain.¹⁰

Guideline — Patient information	Level of evidence	Refs
Patients and their carers often seek information about their cancer at the time of diagnosis, but studies have shown that only part of the initial consultation is remembered. Therefore, the provision of information should not end with the initial consultation.	II	1
Information for patients with lymphoma should include: <ul style="list-style-type: none"> • the meaning of lymphoma, suspected risk factors and the 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, physical and sexual relationships • typical emotional reactions • entitlements to benefits and services, such as subsidies for travel or prostheses • access to cancer information services. 	IV	3, 4

Providing an accurate and detailed record of the information given to the patient may facilitate continuity of care from within the treatment team and from the patient's 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.²

Patients have a right to obtain a second opinion at any time. Having a second opinion may help them clarify questions, decide which doctor they prefer to manage their condition, and decide which course of treatment to follow. It can also reinforce that advice already given was accurate, and increase their confidence.

22.2.2 Preparing patients for potentially threatening procedures and treatment

People diagnosed with lymphoma may undergo a number of potentially stressful medical procedures and interventions, such as surgery, biopsies, chemotherapy and radiotherapy. Providing patients with lymphoma with information on the procedure they are about to undergo significantly reduces their emotional distress and anticipatory side effects, and improves their psychological and physical recovery.¹¹⁻¹⁴

Various formats for providing information about procedures have been shown to decrease anxiety and psychological distress. They include discussions with a clinician or allied health professional¹⁵, booklets¹⁶, or videotape information.¹⁷

Sensory information describes what a person is likely to experience before, during and after a procedure, including their feelings in response to pre-operative medication and pain. Such information

has produced significant reductions in anxiety in patients undergoing medical procedures.¹² The best results appear to be achieved by providing both sensory and procedural information.¹³

Guidelines — Preparing patients for treatment	Level of evidence	Refs
Providing patients with lymphoma with information about the procedure they are about to undergo significantly reduces their emotional distress and anticipatory side effects, and improves their psychological and physical recovery.	I II	11–14
Various formats for providing information about procedures have been shown to decrease anxiety and psychological distress. They include discussions with a clinician or allied health professional, booklets, and videotape information.	II	15, 16 17
Sensory information significantly reduces anxiety in patients undergoing medical procedures. The best results appear to be achieved by providing both sensory and procedural information.	I	11, 12

22.2.3 Counselling and support

In a meta-analysis of 45 randomised controlled trials of adults with cancer, those receiving psychological therapies had, on average, a significant improvement of 12% in emotional adjustment, 10% in social functioning, 14% in treatment and disease-related symptoms, and 14% in overall improvement in their quality of life, compared to those not receiving psychological therapies.¹⁸

For some patients, access to volunteer peer support and self-help groups, including electronic online support groups¹⁹, may be helpful. Non-randomised research suggests that peer support and self-help groups decrease feelings of social isolation, depression and anxiety.²⁰

Younger people diagnosed with lymphoma may benefit from meeting others in a similar situation through specific support groups for their age groups. Educational pamphlets are available from regional cancer councils and are particularly informative for individuals with lymphoma and their carers.

A number of people may be involved in providing counselling and support in either a formal or informal manner. They can include family, friends, doctors, nurses, other health care professionals, and a cancer support service.

Guidelines — Patient support	Level of evidence	Refs
Support needs for individuals with lymphoma and their families may include:		
• counselling	I	12
• exploring feelings with a member of the treatment team	III	19
• access to a cancer support service and/or support group education	III	20, 21
• assistance with practical needs (e.g. child-minding, transport).	III	19

22.2.4 Recognition of cultural factors in patient management

Studies have shown the incidence of lymphomas and the approaches to dealing with cancers and treatment outcomes differ among different cultural groups. It is therefore important to apply this knowledge when managing patients with lymphomas.

Metabolic genetic polymorphisms may affect responses and tolerance to chemotherapy and radiotherapy, and increase susceptibility to drug-induced adverse reactions, for example, agranulocytosis.^{21,22} Orientals have reduced NAD(P)H:quinone oxidoreductase activity which catalyses two-electron reduction quinone compounds. This affects a patient's response to quinone-based cancer therapy because there is a decreased production of cytotoxic metabolites and a susceptibility to toxicities. There is a need to determine population frequencies polymorphisms. Genetic polymorphisms probably contribute to ethnic-specific effects on cancer susceptibility.

Cultural explanations for cause of cancer

Different ethnic groups may handle cancer in different ways. Some believe that the cause of lymphoma is related to actions they have taken. For example, Vietnamese believe breast/cervix cancer is caused by poor hygiene and that it could be contagious.²³

People's understanding of the symptoms of cancer can be influenced by their cultural upbringing, for example, somatisation among Asians with cancer versus 'psychologisation' among Caucasians.²⁴ The discovery of cancer may mean God's punishment. Some people may feel uncomfortable in touching someone with cancer, or would rather not know if they had incurable cancer. Vietnamese people, for example, believe that cancer cannot be prevented.²³

Quality of life; attitudes to treatment

In a study of outpatients affected by leukaemia, it was found that, compared with American patients, Portuguese patients reported better physical functioning, less bodily pain, more vitality, better social functioning and better general quality of life as measured by the Functional Living Index — Cancer (FLIC) total score.²⁵

Significant differences have been found between the attitudes and practices of Hispanic and Anglo families of children in both conventional and alternative treatment for cancer.^{26,27} The influence of culture on anxiety has also been examined in Hispanic and Anglo children with cancer undergoing invasive procedures. It was found that Hispanic parents reported significantly higher levels of anxiety than Anglo parents.²⁸ A recent study of first generation Greek migrants in Australia also found their attitudes to cancer management at variance with generally considered good clinical practice.²⁹

Key point

There is a need to develop culturally competent methods to assess the needs of patients with lymphoma. In the design of questionnaires and surveys, objective comparison of psychosocial adjustment to cancer in different cultures requires instruments that are valid and reliable in each culture.¹⁰ There is a place for qualitative methods, which allow the collection of greater depth information, identification of processes and relations among behaviours, and framing of variables and hypotheses for quantitative research.

Health professional issues

It is necessary to:

- conduct studies to evaluate the attitudes of medical, nursing and other staff in caring for patients of different cultural backgrounds

- provide training in the following to improve a health professional's cultural competence in dealing with patients with lymphoma:
 - 'breaking bad news', and to whom
 - whether patients should know certain information
 - how much a patient would like family members involved
 - care beyond medical management
 - after death
 - how to express grief and to remember the deceased
- provide culturally competent communication and counselling, telephone help line and community support
- assess cultural competence of printed cancer education materials, and other information
- mobilise religious groups, churches and other culturally specific groups
- collaborate with other non-cancer related and culturally competent health promotions.

22.3 References

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