Counseling Patients with Cancer

14

Laura Hope-Stone and Bertil Damato

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14.1 Introduction

All involved in cancer care need to understand their patients' needs and fears. They must also be able to recognise and respond to patients' psychological concerns appropriately. Every oncology service should have systems for providing appropriate psychological support to patients and their relatives.

14.2 Emotions and Fears

It is common for people with cancer to experience psychological distress, which is an understandable response to a traumatic and threatening life event (Box 14.1). On receiving a diagnosis of cancer, many patients experience a range of strong emotions, such as fear, anger, sadness and many others, which may be overwhelming in their intensity. For the majority, this distress will be a short-lived experience, not causing lasting problems [1]. In such cases, it can be understood as part of the patients' normal adjustment to their diagnosis. However, for some, the diagnosis and treatment of cancer increase the risk of developing depression, anxiety and other forms of psychological morbidity such as adjustment disorder.

Uncertainty is always unsettling so that it is only natural for patients to be afraid of 'the unknown' and to worry about what side effects might occur as a result of their treatment, whether their tumour will recur and how long they might

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Box 14.1: Patients' Emotions and Fears When Informed of Their Diagnosis and Treatment

- Uncertainty about local tumor control and survival
- Sense of 'unfairness'
- Concerns about possible loss of independence
- Fears about facial deformity

live. These valid concerns make many individuals feel 'like a walking time-bomb' or 'in limbo' as if their life is 'put on hold'.

Not surprisingly, the diagnosis of eye cancer comes as a shock to most patients. Many want to know why this has happened to them 'out of the blue'. They wonder whether they have done anything to deserve their illness and can feel angry, especially if they feel they have led a healthy life so that they perceive their situation as being 'unfair'. In addition to worries about their general health and mortality, patients with ocular malignancy are concerned about visual loss and all its implications. Some fear that they will lose their ability to work and their independence, becoming a burden to others. Their self-esteem and identity are therefore threatened.

Quite reasonably, patients are also afraid that they might lose their eye and that this may cause disfigurement, which might disrupt social relationships, work and other important aspects of life.

Many patients are concerned about the potential for tumour recurrence or metastatic disease. Indeed, feelings of uncertainty have fertile ground in which to develop, and the fear of recurrence is highly relevant in these patients. Other than their ocular symptoms, if any, they are most likely to be asymptomatic with regard to metastatic disease. Furthermore, fear of recurrence has been associated with psychological morbidity in patients with cancer [2]. Some aspects of uncertainty may diminish temporarily when the objective situation can be ameliorated, for example, following a clear scan, a normal blood result or a reassuring clinic review. However, there will be further follow-up, and uncertainty about recurrence often re-emerges before those episodes.

Giving information can help reduce uncertainty but needs to be sensitive to patients' changing needs and to take into account individuals' contextual factors such as stage of disease, prior life experience, age and degree of social support. Information alone may, however, not reduce uncertainty. It is important to recognise the critically important role of caring professionals whom patients can trust. It is not just the security of the relationship with the clinician that is important; it is the hope that if disease is found, there is the medical expertise and technology available to treat it [3]. Furthermore, while it may be a relief when an intensive course of treatment ends, patients may feel insecure because they receive less attention from the clinician [4].

Some individuals can learn to live with uncertainty. For many, however, this is not possible without help and support. Professionals therefore need to be alert to the distress that can develop as a result of uncertainty at different times during the cancer trajectory.

14.3 Coping Mechanisms

Patients develop their own individual coping mechanisms, with varying degrees of success depending on their personality, background, previous experiences of challenges, illness perceptions and support from family and friends. Crying and other manifestations of distress sometimes make patients feel that they are not coping, which is not the case. It is often helpful to remind people that their emotions are quite understandable given the circumstances. In the early stages, some people reduce their distress by retreating into a form of temporary denial or avoidance of their illness. Such responses represent normal psychological defences that can be adaptive in the short term. However, a complication for patients with ocular malignancy is that some common distraction strategies, such as watching TV or reading, might be difficult if vision is impaired.

14.4 Patients' Needs

Understandably, patients desperately want to survive and resume normal life as quickly and painlessly as possible (Box 14.2). They are anxious to do everything possible to achieve these ends. They therefore want to know that they are receiving the best possible treatment. Most want to be informed about their condition and its treatment and are usually keen to be involved in decisions about their treatment and care. However, it should be noted that patients vary in the amount of information they want and that this changes over time [5]. Furthermore, while patients wish to feel involved in decision-making, this does not necessarily mean they want to take responsibility for medical decisions [6]. Above all, patients want to be treated as individuals, with dignity and respect. They wish to have their say and need to feel understood. Different patients have different needs at different stages of their illness, and psychological management needs to be responsive to this variability [7].

Box 14.2: Patients' Emotional Needs

- Reassurance that they are receiving best possible treatment
- Involvement in decision-making
- To be treated with dignity, as individuals
- To feel they are understood

14.5 Eliciting and Addressing Patients' Emotional Needs

Although the potential for psychological distress among cancer patients is recognised, in many cases, it remains undetected and untreated [8]. Eliciting and addressing patients' emotional needs should not be considered as something separate from medical care. Instead it should be recognised as routine clinical practice [7].

Many barriers inhibit this process, some attributable to patients' attitudes, beliefs and behaviour and some to clinicians [9]. It is often the case that patients normalise or somatise their feelings, and this may reduce their chances of detection. Furthermore, many feel that their concerns are unreasonable or consider it inappropriate to raise them with the clinician [9]. Some clinicians also feel that it is not their role to address patients' psychological needs [9]. They may feel uncomfortable or may consider themselves inadequately trained to respond to patients' emotional distress. As a result, clinicians might employ techniques such as changing the subject, ignoring the cues, normalising distress and/or offering false or premature reassurance, which inhibit patients' disclosure [9]. Practitioners may also be concerned that by responding to patients' distress, they may lengthen the consultation, whereas research indicates the opposite is often the case [10].

Even when clinicians feel that it is their role to address patients' psychological concerns, they sometimes lack the necessary skills to elicit symptoms [9]. It is therefore important that clinicians are trained in techniques that increase their confidence and encourage rather than discourage emotional disclosure. Such techniques might include demonstrating empathy through active listening, the use of open questions, responding to emotional cues (verbal and nonverbal), acknowledging patients' distress and the use of a patient-centred consulting style [9].

14.6 Communication

Effective communication is key to eliciting and addressing patients' psychological needs (Box 14.3). It also fosters good relationships between the patients and their carers. Patients' psychological well-being is greatly influenced by the way in which they are informed about their diagnosis and treatment. The manner in which healthcare staff respond to patients' concerns is also important [11, 12]. If information is poorly communicated and patients concerns are left undisclosed and unresolved, patients can become confused and resentful and have a high risk of developing clinical anxiety or depression [11, 13]. If done well, communication can lessen distress and assist understanding and adaptation [12, 13].

Box 14.3: Requirements for Effective Communication

- Quiet surroundings, free of interruptions and distractions
- Compassion and empathy
- Close friend or relative accompanying patient
- Respect for how much they wish to know
- Opportunity to ask questions and express opinions
- Help remembering what was said
- Chance to speak to previously treated patients

Consequently, it is important to ensure that patients receive as much information as they want and that this information is provided honestly and compassionately in simple and unambiguous language [14]. When counseling patients about their condition, it is useful to describe the ocular anatomy and the tumor briefly, using a model eye and pictures of the tumor. Next, the patient is informed of how the tumor is likely to behave and what might happen to the eye and vision if it is not treated. This is a good lead-in to a short discussion on the objectives of treatment, explaining what is and what is not achievable. The preferred treatment is introduced, together with the logistics involved (i.e. anesthesia and days in hospital). Estimates of the chances of achieving the main objectives and of developing complications are given, in terms that the patient can understand. Alternative treatments are discussed, with reasons why they are less suitable than the preferred approach. The patient is then informed of plans for early aftercare and long-term follow-up. The scope of adjuvant therapy and screening for metastasis is discussed. The impact of the patient's condition on driving and other activities is considered. Finally, any family implications are discussed, whether or not the disease is hereditary.

The information given to the patient should be summarised in the charts. The senior author (BD) has prepared a list of outcomes and complications so that any estimates given to patients are recorded. It is preferable if these discussions are conducted by a senior clinician having special skills in counseling cancer patients. Ideally, these discussions should be held in surroundings that are quiet, private and comfortable. Enough time for proper discussion should be allowed, and precautions should be taken to prevent interruption by nonurgent phone calls and distractions. If possible, a close relative or friend should be present. The physician should try to find out how much the patient wishes to know about prognosis and other sensitive issues and should respect the patient's wishes. The patient and any accompanying persons should be given plenty of opportunity to ask questions and to express their views. The physician should confirm that the patient has understood what has been said. It is often difficult for patients to remember what they were told at times of high emotion [14]. Therefore, for several years, the senior author has given each new patient an audio recording of the actual consultation on cassette tape or CD-ROM. Feedback has been positive, although a few patients have preferred not to listen to the recording [15]. Other useful aids to communication are a dedicated website (e.g. www.looc.uk.com); a guidebook to the oncology service, which can be mailed to the patient before the first appointment; information leaflets specific to the selected treatment; and an information sheet regarding aftercare, which is given to the patient on discharge from hospital.

Immediately after the consultation, it is helpful if the patient and any accompanying persons can spend some time with a specialist nurse in a quiet room. There are usually many questions that patients consider too trivial to trouble a doctor with. It is often necessary for the nurse to provide consolation, reassurance and other psychological support. Some patients find it helpful to speak to someone who has been through a similar experience, and it is useful to have a 'bank' of volunteer patients who are available on the telephone. During their stay in hospital, patients find it reassuring when they are kept informed of how their treatment is progressing. It is well known that many patients feel particularly 'low' soon after their return home from hospital. It is therefore comforting for them to receive a telephone call from a specialist nurse at this difficult time.

Because of the rarity of ophthalmic tumors, patients find it difficult to get appropriate information and advice from their family doctor and from general ophthalmologists at their own hospital. It is therefore useful for them to be able to contact the ocular oncology service at any time if they ever have any questions or concerns. Appropriate contact information such as telephone number or e-mail is should be provided. Patients and their families should also be informed of any organisations and website that they might find helpful.

Increasingly in Britain, correspondence to the family doctor and general ophthalmologist is also sent to the patient. The senior author has followed this practice for several years, with positive feedback. However, if the results of pathological or genetic investigations might cause distress, they should be communicated in person, ideally at a hospital clinic or, if this is not possible, by means of a prearranged telephone call.

Follow-up assessments provide a good opportunity for psychological support, and the ocular oncologist can be particularly effective in this regard, for example reminding the patient of a good prognosis that was originally given or emphasising that the chances of local tumor recurrence become very small once the tumor has responded well to conservative therapy. In patients who were initially given a guarded prognosis, there might be scope for encouraging optimism once the 'danger period' has passed without incident.

At all times, the clinician should use every opportunity to encourage hope and optimism, albeit in an honest and realistic manner.

14.7 Decision-Making

In many countries, 'paternalistic' selection of treatment and other aspects of care has largely been replaced by a more 'consensual' approach. Although most patients want to have a say in their care, however, it is often difficult for them to decide what is best for them, especially if they are overwhelmed by the information provided to them and distraught as a result of their illness. Furthermore, many patients do not wish to take responsibility for major life-changing decisions.

The senior author approaches decision-making by first determining the patient's priorities, needs and fears then explaining how these are met by the various options and encouraging the patient to indicate the preferable course of action. Almost always, the patient spontaneously selects what the senior author considers to be the optimal treatment or action, whereupon the author immediately reassures the patient that the correct decision has been made. In this way, patients benefit by 'having a say' in the decision-making without being burdened by the responsibility for their decision [16]. When the patient selects what the author considers to be an inappropriate course of action, gentle probing usually reveals a misconception or misunderstanding so that the problem is resolved with further explanation. This combined 'paternalistic-consensual' approach is most successful when patients trust their clinician [17]. In an attempt to merit such trust, the senior author continuously performs a wide range of quality control studies evaluating not only objective outcomes, such as local tumor control, but also subjective measures such as the patients' long-term quality of life and satisfaction with the decision-making process.

14.8 Psychological Support

As they begin to adjust to their diagnosis and its implications, patients will each face a unique set of challenges shaped by their own personal circumstances, prior experience and beliefs [12]. Consequently, different patients are likely to require individualised psychological support, which may change at different stages of their illness [7]. Because of this variability, no single approach will meet the needs of all patients, and it is therefore best to view the patient as 'expert' in his or her own emotional adjustment [7].

The build-up of a patient's unresolved concerns has been shown to predict later distress

Table 14.1 Patients requiring additional psychological support

Failing to adjust over time
Experiencing an intense emotional reaction that compromises their mechanisms for family and social support
'Stuck' in a way that is likely to inhibit future adjustment
Experiencing emotional problems that are unlikely to resolve over time in a supportive environment

[11]. Careful assessment by interview is therefore recommended to identify and explore (1) the specific challenges faced by each patient, (2) the availability of emotional support and (3) the patient's ability to use different ways of coping. It may be helpful at this time to engage with patients in problem-solving including identifying and accessing sources of practical and emotional support and considering alternative coping responses that may reduce the emotional impact of their illness, also promoting adaptation. Eventually, in a supportive environment, most patients will adjust to their condition and its implications, in their own time [5]. However, some patients may require more specialised help (Table 14.1).

14.9 Patient-Reported Outcome Measures (PROMs)

It is not only the length of survival that is important to patients but also the quality of that survival. There are many ways in which the quality of life (QoL) and mood of patients with uveal melanoma might be impaired. Firstly, many of these patients must come to terms with a high chance of early death, even if their ocular tumor has been successfully eradicated. Secondly, most patients need to cope with some degree of visual loss, which may restrict their activities. Some may also be concerned about cosmetic deficit, caused by treatment such as iridectomy or enucleation. Assessment of patient-reported outcomes using self-report questionnaires to measure quality of life and mood can provide a better understanding of the effects on treatment over time. Clinicians can then advise patients about the functional difficulties they may experience and how they are likely to respond emotionally to their condition. Such insights can enable clinicians to anticipate problems and to adjust behavior and care accordingly. Additionally, by means of a simple tick box on the questionnaire, patients can be asked at regular intervals whether they would like any psychological support.

Unfortunately, studies investigating PROMs after treatment for uveal melanoma have produced conflicting results [18–23], possibly because of small sample sizes, and few have made comparisons with normative data. Therefore, units need to monitor these outcomes routinely so as to audit their own practice and to build up large data sets that would provide more definitive information about PROMs after uveal melanoma.

14.10 Self-Help

Every opportunity should be taken to encourage and facilitate self-help. There are many ways in which patients can improve their own well-being, and most are successful in discovering their individual ways of coping. Patients seem to do particularly well if they feel that some good has come out of their crisis, for example, discovering what is and what is not important in their life, helping others, fundraising and getting closer to their friends and family. Many patients find it helpful to write down their experiences, so that this idea should be given to new patients in case the thought of a diary does not occur to them. All patients should also be informed of any self-help groups that are available, both in their community and on the Internet. Considerations for organising effective psychological care to be available to patients with eye cancer are summarised in Table 14.2.

14.11 Family Support

Patients' well-being is greatly enhanced by any support they receive from relatives and friends. Such carers may themselves need support. It is therefore

Table 14.2 Considerations for providing effective psychological care

Appropriate training of all staff coming into contact with patients, so that distress can be recognised
Mechanisms to empower patients to recognise and manage their own psychological needs
Protocols for assessing all patients psychologically at key points in their care pathway
Protocols for providing psychological support that is appropriate to the severity of any distress, with mechanisms for organising specialist care if needed
Information on how to contact emergency psychiatric services, readily available wherever patients are at risk of self-harm
Systems enabling patients and caregivers to participate in their own care, in self-help activities and peer support
Mechanisms for ensuring that the psychological needs of staff caring for patients and caregivers are adequately met

helpful for the clinician to acknowledge carers that are present in any consultation and to provide them with recognition and encouragement.

Some patients faced with a diagnosis of cancer gain reassurance from still feeling physically well. That is, because their bodies feel normal, they can regard the cancer as less threatening. Their carers, however, do not have access to this way of coping [24]. Carers also often feel that they cannot share their concerns and fears with the patient for fear of upsetting the patient. Clinicians therefore often have a role of promoting open communication between patients and their carers and thereby circumventing the 'conspiracy of silence' that can add to the burden for each party [12].

Carers may benefit from speaking with a member of the clinical team when the patient is absent, for example, if the patient is admitted to hospital or in the operating room. It is therefore helpful to prepare for such an eventuality in advance by proactively obtaining and documenting the patient's consent for such communication.

Oncology services should also be ready to provide support to close friends and relatives at a time of bereavement. Carers will avail themselves of this support only if they know in advance that this service is provided.

14.12 Support from Patient Organisations

Patients should be informed of any organisations that can provide them with support. Examples of such organisations include Cure OM in the United States and Ocumel UK in the United Kingdom.

14.13 Children with Cancer: What Should They Be Told?

It is difficult to speak to a child about cancer and its implications. However, even very young children can sense fear and anxiety among family members [12]. If children are deprived of information about what is happening, they may generate their own ideas, causing them to fantasise or worry. Consequently, it is generally recommend that parents are as honest as possible with their child, allowing the patient to openly express fears and ask questions [26].

Parents know their children better than anyone else; therefore, their judgement of what is the right thing to do for their child and how much they should tell them should be supported and encouraged [12]. In a recent study of parents who had lost a child to cancer, it was observed that parents who talked to their dying child about death had no regrets about having done so [25]. Some parents who did not talk to their child about death subsequently wished they had done so. Clearly, the clinician's aim in such circumstances should be to help parents make the best decision for their family [26].

When providing any information to a child (as with adults), it is clearly important to use language that can be understood [7]. It should be noted that children are developing all the time, consequently information considered appropriate at one age may no longer be sufficient as the child gets older [12]. Therefore, it is important to establish the child's intellectual capacity as well as the level of understanding of the illness or treatment in question. Explanation and reassurance can then be provided in ways that make sense to the child [7].

Conclusions

Psychological support is an integral part of patient care, particularly with serious diseases such as cancer. Such support should be provided not only to the patients themselves but also to their close relatives. Any support should be tailored to each individual case.

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