Informational needs of patients with melanoma and their views on the utility of investigative tests

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Introduction

Many published studies suggest that the majority of cancer patients want to have detailed information about their disease, their prognosis and the treatment options (1,2). Not long ago, the most common complaint that patients made about their management was ‘not being told what is wrong with them’ (3). Cancer care professionals have now recognised the importance of communication in optimising cancer care and are increasingly more responsive to patients’ informational needs and preferences. The results of large psychosocial studies in cancer, over the last decade have influenced doctors’ training and practice and have led to a more open, patient-centred approach (4). As expected, patients with common tumour types such as breast, gastrointestinal and lung are more likely to be enrolled in these studies and it is difficult to appreciate whether their communication needs or perspectives are similar to those of patients with less common malignancies.

National statistics from the UK (5) and the United States (6) suggest that melanoma has a rising incidence worldwide, but remains a relatively rare malignancy (8900 new cases each year in the UK and 1800 deaths). Wherever applicable, it is primarily treated with surgery (7). Both radiotherapy and chemotherapy are used with palliative intent and benefit only a minority of patients (8). Over the last few years, new imaging tools such as positron emission tomography (PET scan) and procedures such as sentinel node biopsy (SNB) have been introduced in the management of melanoma. Although the prognostic value (9) of these procedures has already been recognised, their therapeutic role is yet to be defined.

Little is known about the amount of information melanoma patients want to receive and how they perceive prognostic information. Soon after the diagnosis, they realise that apart from surgery in the early stage disease, treatment options are limited. The psychological impact of this knowledge and the way it then goes on to affect future doctor–patient communication are unknown. Do patients want to receive prognostic information about the extent of their disease and their survival? Do they want to decide the timing of receiving this information? Or do they avoid seeking information about their disease when they realise the treatment limitations?
The role of PET scan in the management of melanoma is controversial. It has already been shown to have a high sensitivity and specificity in advanced melanoma (10,11) and it is superior to both clinical examination and conventional imaging in detecting distant metastases (12,13). However, PET might have no influence on the decision-making; for example, if patients are found to have widespread disease but remain asymptomatic, they might not require treatment as treatment is aimed primarily to improve symptoms. Therefore, the extent to which such patients would want to be scanned is of interest.

SNB is a relatively new method with good prognostic value; for SNB positive patients [AJCC stage III (14)], the 5-year survival is 65%, whereas for SNB negative patients it is 85%, but again no proven impact on further treatment (15). Many patients have a SNB as part of the initial work-up, but little is known of their understanding of the role and the outcome of this procedure.

The primary aim of this study was to identify the needs of patients with melanoma for information about their disease and their prognosis. The secondary aim was to obtain their views on the performance of PET scans and SNB. In particular, we attempted to investigate what patients understood to be the significance and the outcome of the procedures. To the investigators’ knowledge, no other study has assessed the informational needs of patients with melanoma.

Patients and methods

Patients with melanoma attending the weekly melanoma outpatients’ clinic at St Thomas’ Hospital London UK between February and August 2007 for their follow-up appointments were invited to participate in the study.

Inclusion/exclusion criteria

All patients with melanoma were invited to enter the study except for non-English speakers and those who had recently (< 4 months) been diagnosed with the disease. Non-English speakers were not included in the study, as accurate translation of some of the questions was not possible and it would have been difficult to provide emotional support via translation if any distress was caused. The actual number of non-English speakers in the clinic was extremely small.

Design and methodology

This was a cross-sectional survey using a face-to-face semi-structured questionnaire. The timing of enrolment into the study allowed participants to adjust to their diagnosis, understand the different aspects of their management and obtain some information about their prognosis. A member of the research team informed the patients about the study before, during or after their clinic consultation, and patients were given an information leaflet, which provided an overview of the purpose of the study. A clinical nurse specialist with a counselling background ensured that participants had all the necessary emotional support during and after the study. Written informed consent was obtained from all participating patients before they completed the semi-structured questionnaires with the melanoma clinical nurse specialist. The completed questionnaires were returned to the investigators the same day, and no additional visits were required.

Study questionnaire

This was based on questionnaires from other national and international studies on cancer patients’ preferences and information needs (1–3), most of which originated from Cassileth’s Information Styles Questionnaire (16). The modifications to the questions were made in relation with the fact that this study involved patients with melanoma only. Whenever appropriate, explanations were provided in the questionnaire to help the patients answer the questions, e.g. a short introduction reminded them that treatment for melanoma includes primarily surgery and that options for metastatic disease might be limited, and brief descriptions of the PET scan and SNB were provided.

Outcome measure

The principal research objective was to assess how much information patients with melanoma want to have about their disease and their prognosis. The study also examined the extent of supportive care patients require. In addition, they were asked to give their preferences on the timing and the way this information is given. The secondary research objectives were to ascertain patients’ views on PET imaging and SNB.

Statistical analysis

Summary statistics are presented for the patients’ responses to each questionnaire item. The median and range were used for continuous variables and the proportions (%) of patients in each response category for categorical variables.

Results

Participants

One hundred and twenty patients were approached to participate in the study. Of 110 patients who
agreed to participate, two were ineligible and two did not complete the questionnaire. The questionnaires from the remaining 106 patients were analysed. Demographical data are summarised in Table 1. The majority of patients were under regular follow-up and were free of disease (83%).

**Information about diagnosis**

The information needs of patients with regard to diagnosis and prognosis are shown in Table 2. The vast majority (88%) reported that they wanted to know everything about their disease and over 90% would like to be informed about the spread of their disease and their chances of cure. Around 85% wished to know the length of time to live (with and without symptoms), and 97% wanted to know about the palliative care input available.

Most patients wanted to discuss prognosis and palliative care support as soon as their disease became metastatic, and over 50% expected the doctor to impart the information without negotiation (Table 3).

**Information about investigations**

Sixty two percentage (55/89) of the patients had undergone PET scans previously as part of their assessment and 38% (34/89) had not. They were asked how often, if at all, they were willing to have a PET scan and their responses are shown in Figure 1. Those who had undergone previous PET scans expressed more willingness to be scanned regularly compared with those with no previous scan, who more likely leave it up to the doctor to decide. The most common reasons given for the willingness to have a PET scan were for reassurance and awareness of early detection.

Sixty one percentage of responders had undergone a SNB (Table 4) as part of their management and 98% was happy that the purpose of the procedure was explained to them. Over half (53%) of them chose to have SNB because the doctor suggested it, and 32% to get as much information as possible about their disease. Fifteen percentage of patients had believed that it would cure them. Only a small proportion did not understand the results (4%) or were never given the results (4%).

**Discussion**

Patients with melanoma are well aware that treatment options for metastatic disease are fairly limited.
The mainstay of treatment in early stage or small volume disease is surgery, while response to systemic treatment is poor. The aim of this study was to assess these patients’ informational preferences and to explore their needs for information on diagnosis, prognosis and investigations.

The participants in this study expressed their wish to know everything about their disease at diagnosis and be informed about the extent of the metastatic disease early on. With regards to prognostic information, there is no evidence that patients with melanoma behave differently to any other cancer group (1,17–19). In this survey, they expressed their desire for detailed prognostic information including chances of cure and the longest time they might live. Interestingly, half of them preferred the doctor to impart the information without negotiation. Doctors involved in the management of cancer are often unsure about patients’ expectations on survival details and prognosis, mainly in the advanced setting (20,21). They might be sceptical and even reluctant to provide patients with disappointing survival figures (22–24). The results of this study show that patients with melanoma are not afraid to ask difficult questions.

**Table 3** Timing and initiation of the discussion about diagnosis

| Type of information                      | Chances of cure | Longest time to live without symptoms | Longest time to live | Available palliative care input |
|-----------------------------------------|----------------|--------------------------------------|----------------------|---------------------------------|
| When would you want to discuss this issue? |                |                                      |                      |                                 |
| When first told the cancer has spread   | 85% 101        | 85% 93                               | 83% 82               | 71% 98                          |
| Next few consultations                  | 10% 12%        |                                      | 13% 23%              |                                 |
| Later, upon my request                  | 5% 3%          |                                      | 4% 6%                |                                 |
| Who and how would you want to initiate the discussion? |            |                                      |                      |                                 |
| Doctor just to tell you                 | 53% 102        | 59% 99                               | 57% 86               | 65% 97                          |
| Doctor to check first if you wanted to know | 40% 36%    |                                      | 40% 34%              |                                 |
| Doctor to tell you only if you asked    | 7% 5%          |                                      | 4% 1%                |                                 |

**Figure 1** Information about investigations: positron emission tomography (PET)

**Table 4** Information about investigations: sentinel node biopsy (SNB)

| Type of information                      | % of patients N |%
|-----------------------------------------|-----------------|
| Have you had a sentinel node biopsy (SNB)? |               |%
| Yes                                     | 61% 103        |
| No                                      | 39%            |
| If yes:                                 |                |%
| Has the purpose of the biopsy been explained to you? |               |%
| Yes                                     | 98% 61         |
| No                                      | 2%             |
| Why did you choose to have SNB?         |                |%
| To get as much information as possible about my disease |               |%
| To be cured                             | 32% 53         |
| Because the doctors suggested it        | 15%            |
| Who asked you to give consent?          |                |%
| Surgeon                                 | 57% 46         |
| Skin specialist (dermatologist)         | 35%            |
| Cancer specialist (oncologist)          | 9%             |
| How did you feel when you were given the results of the SNB? |               |%
| Never given the results                 | 4% 49          |
| Did not understand the result           | 4%             |
| Disappointed had spread to the lymph glands | 37%            |
| Happy had not spread to the lymph glands | 55%            |
| If no:                                  |                |%
| Would you want to undergo a SNB, if it was appropriate to your case? |               |%
| Yes                                     | 91% 35         |
| No                                      | 9%             |
They expect honest answers without delay, despite knowing that treatment options are limited.

A need for information on the longest time without symptoms and palliative care input was expressed in this survey. When their disease approaches the symptom control only phase, patients want to consider the available supportive care options. Hence, integration of palliative care services into the management of melanoma is of paramount importance. Patients with incurable disease should feel encouraged to discuss end-of-life issues, and oncologists should feel comfortable to disclose information and should be equipped to offer support (24).

A need for information about investigative tests was noted in this survey. Other studies reported similar results in patients with different types of cancer (25,26). PET is an exciting new imaging tool, but its role is not clear in the follow-up of early melanoma. Nevertheless, approximately half of the responders in this study wanted regular PET scans emphasising their need for awareness. Not surprisingly, this was cited as the most popular reason amongst patients with metastatic disease. For patients free of disease ‘reassurance’ that the disease had not recurred was equally important. Overall, patients appeared interested in expanding and updating their information level with regular scans.

Often, patients enquire whether scans are indicated as part of their follow-up, as they believe that several aspects of their management rely on the results of investigations. The main concern is that in a medical world of largely available and easily accessible imaging tools, doctors feel uneasy to deny patients regular scans, even if the indications are minimal. Acquiring patients’ perspective on this issue gives physicians the opportunity to develop strategies on educating patients on the role of investigations in their management.

SNB is widely accepted as one of the most significant prognostic factors in melanoma (9,27). What is not clear is how patients perceive its role and whether they understand its significance. The results of this study suggested that one in two patients proceeded with the procedure only because their doctors suggested it, and not more than one in three appreciated its prognostic role. It is disappointing that some (15%) of the participants thought this procedure would cure their disease, and smaller groups thought they were never given or did not understand the results.

These findings highlight the need for detailed, unhurried pre-SNB counselling and consent. One should bear in mind that despite how explanatory the first discussion might be, there is only a certain amount of information that patients can take in at that time. Offering a second consultation after the patients had the opportunity to go through the relevant written information might be a useful approach, especially for patients over 60 who appear significantly more likely to be doctor led in making decisions.

Several limitations to this study should be considered. Firstly, the sample was derived from one area in London with certain demographics and may not be entirely representative of the UK as a whole. Also, this consecutive sample of patients undergoing regular follow-up at a hospital outpatient’s clinic may not have the profile of an average melanoma patient. The majority of patients (83%) were disease free at the time of enrolment, which may affect their views on information needs. The participants appeared confident that they wanted to be fully informed about prognosis and palliative support if and when their disease progressed, but it could be the case that once they actually reach the metastatic stage their views might change.

Conclusion

To our knowledge, this is the first study to investigate the informational needs of patients with melanoma. These patients want to be informed of their diagnosis and openly discuss their prognosis as any other patient with cancer. The fact that therapeutic options are limited in melanoma has no impact on their needs for information. They also wish to receive information on investigative procedures, but do not always appreciate their role and appropriateness. More action should be taken towards educating patients about the role of these investigations, but perhaps first towards ensuring doctors (surgeons, dermatologists, radiologists and oncologists) are competent in providing patients with the information required. Patients’ views are essential in developing strategies and planning services in melanoma.

Acknowledgements

We are grateful to Ms Yvonne Camp, personal assistant to Dr M. Harries, for her invaluable help in realising this study.

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Paper received March 2009, accepted March 2009