The experiences of cancer patients

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Received 27 April 2011 and in revised form 23 June 2011

Summary

Objectives: To assess the needs of cancer patients for information about their condition and to understand the psychological impact of their illness.

Background: The discussion of prognosis and treatment options in the palliative setting is an important and difficult part of oncology practice. To evaluate this, we examined the experiences of cancer patients of the physical and psychological impact of their disease on their life, and their opinions on the communication of end-of-life decisions and treatment options.

Methods: A patient questionnaire was designed that encompassed communication regarding treatment and prognosis, quality-of-life attitudes subsequent to cancer diagnosis, end-of-life care and cancer drug funding. One hundred and twenty-five patients with a diagnosis of cancer were asked to participate and 96 questionnaires were completed and available for analysis. The questionnaire consisted of 63 questions and was completed in both an inpatient and outpatient setting.

Results: This survey brought to light a number of controversial issues in cancer service provision, highlighting the emotional and psychological changes brought about by a cancer diagnosis. Major concerns of our patients include fear of death and pain, changes in interpersonal relationships and financial constraints. Only 66% of the patients wanted to be given a prognosis by their clinicians and just 70% of the patients recalled being given a detailed prognosis. 11% of the patients were not prepared to undergo palliative treatment. In all, 7% were not prepared to accept treatment for 1 year and 2% for 5 years of life in exchange for the potential side effects of cytotoxic chemotherapy. 12% of the patients would not want to be in possession of the information that they were in the terminal phase of the illness with a short time to live and 16% would not want this discussed with their next of kin.

Conclusions: This study informs medical professionals about the importance of tailoring information to the needs of the individual patient, and we feel it provides insights into the successes and failures of our communication with cancer patients. It is important that difficult discussions are personalized to the individual patients’ wishes. These can vary dramatically both in the area of disclosure of bad news in prognosis and in end-of-life decision making. This study provides compelling evidence for good advanced care planning at an early stage in the management of patients with terminal cancers.

Introduction

Communication between patients and physicians following a diagnosis of cancer requires an understanding of patients’ emotions and sensitivities, needs to be individualized and cannot be formulaic.
It is clear that the evaluation of communication with patients must be an iterative process. But it is unclear what it is that patients need from their communication with medical staff. The information base on which doctors rely for their conversations with patients about prognoses has traditionally been limited, with individual doctors relying on their own experiences and that of their clinical teachers to inform their own method of ‘talking’ to their patients about matters of life and death. But do we really understand what patients feel about having cancer? The National Cancer Survey in the UK of 67,710 patients reported recently has provided insights into patients’ views on how well supported they feel and described their opinions on key issues such as the role of clinical nurse specialists, the significance of pain management and the quality of cancer services provided by the NHS. However, the survey did not examine how healthcare professionals communicate prognosis to patients nor identify what patients want to learn about their cancer. One study in Japan has looked specifically at the wishes of cancer patients regarding the disclosure of prognosis and found that ~86% of the patients wanted a full and realistic picture of their disease and outlook.

The discussion of treatment options in the palliative setting is clearly an important area. Keating et al. examined the significance of the role that patients take in the decision making process related to their management. Shared decision making between the patient and the physician were found to be more common when there was a good evidence base for an intervention, and when the evidence was uncertain for an intervention, patient control was greatest. However, we know very little of how oncologists communicate risk benefits in terms of potential treatment options in the palliative setting, and what actually constitutes a meaningful gain in life expectancy for patients taking part in these difficult discussions. Some recent studies have addressed some of the central themes in these discussions. Our objective was to find out cancer patients’ views in a UK cancer centre on a range of issues surrounding communication of prognosis and end-of-life decisions.

In this study, we sought to ascertain what potential gains in lifespan would be acceptable to patients in exchange for the side-effects associated with cytotoxic chemotherapy. We aimed to better understand patients’ views and experiences of communication of prognosis and treatment options, with the aim of informing future clinical practice. We also sought to elicit frank opinions regarding changes in patients’ attitudes and lifestyle with a diagnosis of cancer, patients’ views as to the exchange of information surrounding cancer and to understand what the most significant issues were in confronting and dealing with a cancer diagnosis.

Finally, we saw this as a forum for a freeform exchange of ideas between patients and ourselves. As an anonymous survey, it enabled patients to give their honest impressions of their journey through an NHS cancer centre and an opportunity at a local level to inform us as to what we could do to improve the doctor–patient relationship.

Methods
A questionnaire was designed that encompassed patient demographics, communication regarding treatment options and prognosis, changes in quality of life and attitude subsequent to a cancer diagnosis, and quality of treatment in the NHS, including the role of NICE and the funding of cancer drugs. The questionnaire was designed as an audit of patient experiences, and was compiled following consultation with medical and paramedical staff within the Department of Oncology. The questionnaire was completed in both an inpatient and outpatient setting at the Hammersmith Hospital between January and July 2010. The questionnaire contained areas where freeform responses were encouraged. A copy of the questionnaire is shown in Figure 1.

Results
Demographics
All ranges of ages were represented, 59 patients (61%) were of the age group 61–80 years (Figure 1). Of the patients, 65% had gone on to secondary or university education and 78% had English as their first language. There was a 1:1 ratio of men to women and 96% had undergone treatment (Figure 2).

<table>
<thead>
<tr>
<th>Characteristic</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td>0-20</td>
<td>0</td>
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<tr>
<td>21-40</td>
<td>13</td>
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<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>50</td>
</tr>
<tr>
<td>F</td>
<td>46</td>
</tr>
<tr>
<td><strong>Age at which completed education</strong></td>
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</tr>
<tr>
<td>Less than 16</td>
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<tr>
<td>16+</td>
<td>63</td>
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<td><strong>First Language</strong></td>
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<td>English</td>
<td>75</td>
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<tr>
<td>Not English</td>
<td>21</td>
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Figure 1. Demographics of patients completing the survey.
Communication of issues surrounding cancer and prognosis

Of the patients, 66% recalled being given a prognosis related to their malignancy, while only 61% had asked to discuss prognosis (Figure 3). Eight percent of the patients felt that physicians should not communicate bad news to patients, and 14% that clinicians should only communicate good news to patients. Information was sourced from the Internet by 31% of the patients and 7% of the patients sought information from other patients (Figure 5). Ninety percent of the patients felt that they received the clearest information about their cancer from their physicians (Figure 6). It is of interest that patients gained support in dealing with their illness from a variety of people that ranged from family and friends, nurses and doctors (Figure 7), but family for the majority of patients was the most important support (Figure 8).

Changes in lifestyle and attitudes following a diagnosis of cancer

Patients were asked about their relationships following a cancer diagnosis, and approximately one-third of patients acknowledged a change in their relationship to a close family member (Figure 9). One third of the patients noticed a change in their attitude to financial matters. We asked the patients how cancer had affected their lives. Amongst the worst aspects of their illness was the time spent in hospital and time lost in travelling to and from hospital. Our patients expressed concerns about pain

<table>
<thead>
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<th>Treatment Intervention</th>
<th>Number of patients</th>
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<tbody>
<tr>
<td>Radiotherapy</td>
<td>25</td>
</tr>
<tr>
<td>Surgery</td>
<td>38</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>74</td>
</tr>
<tr>
<td>Monitoring</td>
<td>37</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
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</table>

Figure 2. Treatments experienced by patients who undertook survey.

Would you like to know everything, both good and bad about your condition?

Do you think that you should only be given good news about your condition?

Do you think doctors should give patients bad news about their condition?

Do you think that it is a good idea that doctors give you accurate information about your …

Are you pleased that you were given a prognosis?

Did you ask to be given a prognosis?

Were you told your prognosis?

Figure 3. Patients’ views regarding communication of prognosis.

Figure 4. Why do you think you are being treated?

Figure 5. How have you informed yourself about your condition?
Treatment Decisions in Palliative care

We were interested in understanding how patients valued the costs to them of a notional extension of their lives. It is no surprise that 98% of the patients were willing to accept the considerable toxicities of chemotherapy for a 5-year extension to their lives, but it is possibly surprising that 89% would accept chemotherapy for a 3-month extension to life. Only a minority of the patients would not be prepared to accept a gain of lifespan alone when balanced with the side effects of chemotherapy (Figure 11). Patients understanding of why they were being treated varied (Figure 4) from symptom relief to cure.

We wanted clarity whether or not patients wanted to know if they had just a short period of life left in the terminal phases of their illness. The clear majority of patients wanted to be informed that time was short but 12% of the patients would not want to be told if they had a very short time left to live, and 16% of the patients would not want their family to be told (Figure 12).

Comments from patients

This study welcomed comments from patients and we reproduce some of their remarks because of their informative value.
Patient comments on the issue of prognosis
“I trust my caregivers to provide me with information as and when I need to know and I would never necessarily think that anything was being withheld deliberately... as information relating to my condition is in a constant state of flux and change”

“I sense that patients may be confused by not being given a detailed prognosis which may lead to a breakdown in communication between the doctor and patients of a certain disposition”

“Being provided with a full picture can undermine the very positive approach which is required to face up to such a serious health situation”

Patient comments on changes in attitudes since their diagnosis.
“I have developed a more positive attitude to those around me”

“I try not to think about the illness so it can’t affect my life”

“Getting to hospital so regularly is too expensive”

“‘It showed me who my real friends were’”

“‘I Listen more to my partner’”

“‘I appreciate my friends more because of the support they give me’”

“‘Money seems a bit more trivial’”

“‘I have had to cut down on what I can do and had to learn to cope with that’”

Discussion
This survey sought to highlight patients’ views on the difficult decisions that are discussed regularly in oncology. One hundred and twenty-five patients were issued questionnaires and 96 questionnaires were completed and available for analysis. This response rate of 76.8% compares favourably to the 2010 National Cancer survey response rate of 67%. The cohort of 96 patients were drawn from all age groups and were receiving a wide selection of oncology interventions including chemotherapy and radiotherapy.

The subject of prognosis disclosure in the palliative setting has been the focus of much research in recent years. The paternalistic practice of withholding information, previously justified as being in the patient’s ‘best interest’ has been shown to be confusing and even harmful to patients psychological well-being. Our questionnaire revealed that most patients do want to be given accurate information with regard to prognosis, even if this is bad news, and the large majority do not support withholding of information. However, this view is not universal and a small minority of patients do not want to know if the prognosis is poor. It is clear, therefore, that the dissemination of information needs to be tailored to the patient.

Patients obtain information about their cancer from a variety of sources and if we as cancer physicians are not taking the lead in finding out what the individual wants to know of their prognosis early on in their management process, they are likely to use one of these other sources to fill in the gaps in their understanding in order to come to terms with their malignancy. Our study has shown how wide the range of information is that patients use, and with this breadth of range come problems as this may lead to the patient being misled. We have observed that patients have used other patients and the internet as sources of information. What they learn may be accurate and relevant, but equally it may not be appropriate. This may lead to a divergence in management expectations between the patient and medical team, and ultimately an erosion in trust.
Patients have a diverse social support network and rely on friends, family and healthcare providers to cope with their diagnosis. A third of the patients felt that their illness had changed their relationship with their family. It is not surprising, therefore, that one of the greatest concerns after a diagnosis of cancer was a breakdown in family relationships as well as a change in attitudes of friends. Other expected concerns included the fear of death, pain, loss of income and a loss of dignity. Organizations including Macmillan Cancer Care in the UK have resources allocated specifically to address these difficult psychological sequelae, and it is clear from this survey that these resources are important and in demand. A surprising feature of our survey was the high proportion of patients who expressed that time in hospital, and more specifically difficulties getting to hospital for appointments was their major concern in importance. We recommend that this aspect of care be the focus of providers of healthcare.

When offering palliative radiotherapy or chemotherapy with the aim of improving symptoms and prolonging life oncologists often have to use time frames to describe to patients what the potential benefit could be. It is alarming that a recent study showed that approximately two-thirds of the patients undergoing palliative chemotherapy had not had a clear indication of the intended duration of benefit of the treatment in terms of life expectancy. Similarly another study in the Phase 1 setting highlighted failings in this discussion between oncologists and patients. When doctors give a prognosis to patients, their estimates are currently just ‘estimates’. Despite this limitation, the patient needs to understand risks and benefits of treatment in the context of life expectancy. Our study has shown that not all patients are willing to accept the ill defined or abstract concept of a general prolongation of life in exchange for a life burdened by the side effects of treatment. Furthermore, a defined subset of patients are consistently not willing to accept 3 months, 1 year or even 5 years more in life expectancy gained as a result of treatment. In many situations, the gain from palliative chemotherapy will be modest and measured in weeks. In our view, the observation that a significant minority of patients do not want the treatment that we offer them is relevant and practice changing. Accordingly, we need to discuss treatment goals that may be of limited efficacy with more precision with patients who may then elect to not undergo therapy.

Should we be telling patients that they are dying? A recent study has shown that patients who were informed of their terminal state had significantly less emotional distress, and interestingly, fewer symptoms than those who had to guess at their condition. It may, therefore, be beneficial for patients to know that they are in the terminal phase of their illness, but how many patients would want that information to be shared with them? Twelve percent of the patients in this study have indicated that they would not want to be informed if they were seriously ill with a short time to live, and 16% would not want their families to be informed. This fact clearly demonstrates the need for advance planning in cancer management and that as physicians we need to obtain a clear picture of what level of information the individual would like to possess. However, views do change as treatment progresses, and so clinicians do need to be aware that patients’ opinions on their information needs may alter with the course of their cancer. To this end, the UK General Medical Council document ‘End-of-Life Care’ gives clear guidance to clinicians regarding advance planning in the palliative setting.

Conclusions

This study aimed to give oncologists in the UK an impression of our patients’ opinions about areas of communication and management that have been controversial. Prognosis and end-of-life care are difficult areas and there are often conflicting opinions about what the patient should know, and what part they play in the decision-making process. Patients’ opinions vary as to what they wish to know about their prognosis and end-of-life care, and also as to what benefit is acceptable when undertaking life prolonging but not curative treatment. Significantly, there appears to be a minority of patients who do not want to know if their prognosis is poor or when they are approaching the end of their life. In the same way, a minority of patients do not wish for life-prolonging treatment at the cost of potential side effects, no matter how great the gain may be. The results presented here weigh strongly against any attempt to make generalized assumptions about cancer patients’ views. In one way to do so betrays the fundamental principle of individuality and autonomy that must guide oncologists when discussing these issues with their patients. We suggest that this study shows that we must focus on advance care planning. Furthermore, we advocate clear documentation of ‘what if’ discussions early on in a palliative patients’ management.

Conflict of interest: None declared.
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