The information needs and satisfaction with communication of cancer patients receiving palliative chemotherapy

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Introduction

Chemotherapy is used widely in the management of patients with advanced cancer. However, the decision to use chemotherapy is often complex and difficult. Palliative chemotherapy aims at the alleviation of symptoms or postponing future symptoms of disease and thus maintaining or enhancing quality of life. However survival gains are modest. Furthermore, the chemotherapy itself may be associated with adverse effects such as nausea, hair loss and fatigue.

The available evidence indicates that almost all patients want to be fully informed by their physician about the various aspects of their disease and their treatment. Although the expressed desire for information is uniformly high, patients vary widely in the type and amount of information-seeking behavior they actually exhibit during medical visits. Clinicians commonly underestimate patients’ desire for information and discussion. Doctors do not always communicate well with their patients and patients may have difficulties in expressing their needs. Patients and doctors must depend on each other if they want to achieve their common goals; effective communication is the necessary foundation of this alliance.

In the decision-making process, giving information as well as patients’ values and preferences become important issues. An insight into the patient’s decision making process can support clinicians having to inform their patients. Ensuring that patients receive appropriate information about the prognosis of their cancer and the likely outcomes of treatment and involving them in the clinical decision making process related to the management of their cancer may facilitate the process of informed decision making regarding their care. Two issues are important when discussing treatment options with patients. Firstly, the information given should match the patients’ preferences for the amount and type they need and want. Secondly, the extent to which patients are involved in the decision-making process should be congruent with their actual desire for participation.

Although these findings have led to an ever-growing interest in identifying the specific needs and preferences for information and communication of cancer patients in western countries, these issues have not been examined in our locality. Therefore, we have designed this study to examine the information needs, satisfaction with communication and perceptions on the decision making process of our patients.

Patients and Methods

The study was performed at the Department of Clinical Oncology, Queen Elizabeth Hospital from 1st May to 30th June 2009. Patients who are due to start a course of palliative chemotherapy will be approached by our research assistant and invited to participate in a questionnaire. These patients would have discussed their disease and management with a clinical oncologist from our department. Patients were explained about the aim of the study and informed consent to participate in the study was obtained. The questionnaire was developed from a literature review and through discussion with relevant experts including clinical oncologists and palliative care experts. The questionnaire was designed in Chinese and includes questions regarding 4 areas: patient’s demographic detail, information needs, perceptions on information disclosure and perceptions on the clinical decision making process. The investigator also reviewed the records of patients who participated in the study and collected relevant clinical data.

Results

A total of 97 patients were recruited in the study with median age of 62 years. Male to female ratio was 2:1 and the most common primary was lung cancer. (Table 1)
Patients were asked about their information needs including items shown in table 2. Almost all of these information were considered to be very important by more than 90% of the patients.

The average score for information needs was calculated for each patient. There was a significant association between gender (p=0.013) and occupation (p=0.045) with information needs using the one-way ANOVA test. Females patients were found to have more information needs than males. Housewives and retired patients have greater information needs than blue and white collar workers. Analysis revealed no significant effects for age, education, marital status, performance status, primary site, stage of cancer or line of treatment.

Patients were then asked whether their doctors had explained to them the information listed in the previous question and whether they understood the information provided. It was found that around one-third of patients were not given explanation or information about the prognosis and stage of the cancer. (Table 3)
Sixty percent of patients reported that they would like to have further information and thirty percent of them needed no more information. The categories of extra information most frequently required included the disease condition, follow up after completion of chemotherapy, efficacy and side effects of chemotherapy.

The next section included questions regarding patients’ perceptions on the process of information disclosure. Seventy-seven percent of patients reported that the doctors appeared concerned during the consultation whereas only one percent reported their doctors appeared unconcerned. Ninety-three percent of patients reported that the pace of information provision was optimal for them. Regarding the amount of information provided, 83 percent of patients considered it to be appropriate. Fifteen percent of patients considered the information to be a bit inadequate and only two percent considered the information too excessive. On analysis, the more educated patients were found to be more likely to consider the amount of information insufficient \((p=0.034)\).

Ninety-two percent of patients reported that they were given adequate time to ask questions and 93 percent of patients had asked their doctors questions. Seventy-eight percent of patients perceived that they understood what the doctors told them. For those who failed to understand, a lack of medical knowledge was the most common reason given for the inability to comprehend. Eighty percent of patients were satisfied with the consultation in general and only one percent of patients were dissatisfied. The reason for dissatisfaction was that the consultation was too brief.

Those who are retired and housewives were more likely to be satisfied than blue collar and white collar workers. Less educated patients and those married and living with their families were more likely to be satisfied.

The last section of the questionnaire sought the patients' perceptions regarding the decision making process. They were asked about much they depended on their doctors during the process of deciding whether to receive chemotherapy. Fifty-eight percent reported that the doctors’ influence was big and they depended on them for making the decision. Twelve percent of patients reported that doctors’ influence was little and they decided mostly for themselves. We found that older patients, those more than 75 years of age, were less likely to be influenced by doctors. Patients of poorer performance status and receiving more lines of chemotherapy were also less likely to be influenced by doctors.

**Discussion**

Results of this study support previous research that most patients want as much information as possible about treatment and illness.\(^6\) Traditionally, it was assumed that younger patients and patients who were professionals would have higher information needs.

However, our study however showed no significant differences in the age and education of the patients with their requirements for information. Housewives and retired patients were actually found to have higher information needs.

We found that the stage and prognosis of cancer were not explained to patients by their doctors in around one-third of cases. Anecdotal reasons of the doctors for not disclosing diagnosis and prognosis to their patients especially in an Asian country like Hong Kong include the following: (1) patient does not wish to know, preferring doctors to decide management, (2) family is influential, and family will be given information first and they shall decide whether to disclose to patient, (3) patients (especially elders) may be less well educated or less able to understand medicine\(^7\) (4) 'never destroy hope'.

However from this study we found that more than 95% of patients actually wish to know about the diagnosis, stage and prognosis of their cancer including elderly patients. Withholding the truth may lead to a lack of co-operation with the doctor, prohibit patients from sorting out practical issues and result in state of confusion in long run.\(^8\) It is more important to assess how to give what individual patients needs and what he or she can take instead of holding false assumptions.

In our study, 16% of patients considered the amount of information provided to be too little compared with 2% considering information to be excessive. Research has suggested that not being told enough is a more usual complaint than being told too much.\(^8\) No patients in the study consider the pace of information provision to be too slow, whereas 7% of patients

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considered the pace too fast. This emphasised the importance of providing as much information as possible at a pace comfortable for patients. It could be difficult for doctors to strike a balance in practice where time is always limited in these busy clinics.

More educated patients were more likely to consider the amount of information provided insufficient and they had lower levels of satisfaction with the consultation. This may be accounted by their higher ability to comprehend information and more access to other information sources. On the other hand, twenty-two percent of patients do not understand the information given due to a lack of medical knowledge, poor comprehension and poor memory. This highlighted the importance of using simple appropriate language when communicating with patients and avoiding medical jargons. We need to tailor to the individuals needs of patients, providing the right types of information given in ways optimal to their own level of understanding. Other resources may be invaluable for consolidating and supplementing information, including information booklets, DVD and websites which could be distributed to patients after the clinic.

Patients’ desire to participate in decision making varies. The role of doctors in the decision making process remain important despite the shift to a more egalitarian doctor-patient relationship nowadays. In the study, 58% of patients reported a big influence by doctors in their decision making process. The ability of doctors to predict the preference of patients in adopting an active, shared or passive role in decision making is very poor in palliative care. Studies showed that desire for information is not the same as desire to participate in decision making. In this study, older patients, those of poorer performance status and receiving more lines of chemotherapy were associated with lesser influence by doctors during decision making which is in contrary to what we commonly believe in.

Conclusion

Instead of questioning the need for giving more information, we need to develop ways to provide adequate information in a flexible and sensitive manner. Doctors should detect specific needs of the individual patient, and know how best to structure and present the information so that it is understood and remembered. Patients cannot participate in decision making to their desired extent unless they have the right types of information, given in ways optimal for their own levels of understanding. Desire for level of participation in decision making should be gauged for individual patients in the process of deciding treatment.

References