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The Impact of Cytotoxic Chemotherapy - Perspectives from Patients, Specialists and Nurses

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This study, carried out in three European countries, elicited the views and impact of three medical groups involved in patient care. Their views were compared with patients' perspectives of their condition. The main stage of the study was carried out by self-completion questionnaires by 300 patients across Italy, France and the U.K. The views of the medical profession were quantified via 150 hospital specialists, 75 cancer care nurses and 30 general practitioner interviews. Patients' symptoms most frequently seen by the medical profession were nausea, tiredness, loss of hair, vomiting, worrying and lack of appetite. On a scale of 1-4 (1 = not at all; 4 = very much) the frequency of these side effects were rated at 2.8 or over. Intensity of concern was highest for nausea and vomiting. These two symptoms was most frequently highlighted as one of the three highest concerns respectively for 74% and 54% of specialists, 64% and 60% of nurses and 50% of general practitioners. Patients on average reported a lower frequency of major symptoms. Most frequent were loss of hair, tiredness, lack of energy, nausea and decreased sexual interest. In terms of the impact of these problems, tiredness, nausea and loss of hair were the most frequently mentioned. Vomiting bothered them more than the frequency would suggest. 1 in 10 patients claim to have delayed their treatment because of previous experiences of side effects. The main impact on patient's quality of life related to the aspects of worrying and the effects on the family. In terms of communication, both the medical profession and the patients felt that patients were well informed about the disease and treatment. However, differences emerged between what patients claim to have been told about the disease and its treatment and what nurses and doctors claim to have said.

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INTRODUCTION

A TOTAL care approach for cancer patients receiving aggressive treatment regimes clearly involves not just the management of the condition itself, but also requires management of all the problems associated with the disease and its treatment. This requires a true recognition of the frequency and impact of the range of problems; involvement and recognition of the roles of specialists, family doctors, relatives, nurses and patients, and application of a range of therapeutic and supportive measures to deal with these problems.

This study was carried out in three European countries, France, Italy and the U.K., in order to elicit the views and impact of three of the medical groups involved in total patient care but who were (1) not considered to be "experts" in the field of oncology, and (2) considered to be "closer" to the cancer patient. These included hospital doctors who treat cancer within their own field of expertise (e.g. gynaecologists, surgeons, chest physicians) cancer ward/clinic nurses and general practitioners. Their views were compared with patients' perspectives of their condition and its management. These views could then be compared with those of the medical oncologists in the audience by means of a keypad question and answer system.

METHODOLOGY

The developmental stage to the project was carried out through 75 in-depth interviews with 30 nurses (10 per country) and 45 hospital specialists (15 per country) in order to elicit all the issues, obtain deeper views on motivations and reasons for behaviour and attitudes, and as an input to the main stage questionnaire design. Hospital doctors included gynaecologists, general surgeons, chest physicians, urologists and haematologists.

The main stage of the study was carried out with hospital specialists, nurses, general practitioners and patients. The patient research was via 300 self-completion questionnaires across 30 centres in Italy, France and the U.K. All patients were receiving cytotoxic chemotherapy. In addition to open-ended questions on what they had been told about their condition and its treatment, pre-coded symptom and quality of life scales were employed, utilising internationally acceptable scales. The medical professions' views were quantified via 150 hospital specialists, 75 cancer-care nurses and 30 general practitioner telephone interviews using a similar question format.

MAIN FINDINGS

Symptoms

The patients' symptoms most frequently seen by the medical professions interviewed were (in priority order) nausea, tiredness, loss of hair, vomiting, worrying and lack of appetite (Table 1). In answer to a question on the frequency of 22 potential symptoms experienced by their patients (using a 4-point scale scored from 1-4 with 1 = not at all and 4 = very much), all of the six concerns specifically mentioned above received a score of 2.8 or over with the majority being scored between 3.1 and 3.4. However, the intensity of concern was

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Table 1. Major concerns: medical profession
(22 side effects rated: scale 1 = not at all, 4 = very much)

Medical professions' view	:	Overwhelmingly vomiting and nausea (56% and 40% of profession)
Patients' view	:	Claimed to be a spread of reasons e.g. sore mouth/pain swallowing, nausea, tiredness, diarrhoea, lack of energy, vomiting

Table 2. Major concerns: patients
(22 side effects rated: scale 1 = not at all, 4 = very much)

I worry about the effect the illness has on my family	2.5
I find the treatment stops me working	2.3
I worry whether the treatment is working	2.2
I worry about the effect the treatment has on my family	2.1
I become nervous every time I come to hospital	2.1
I feel nervous	2.1

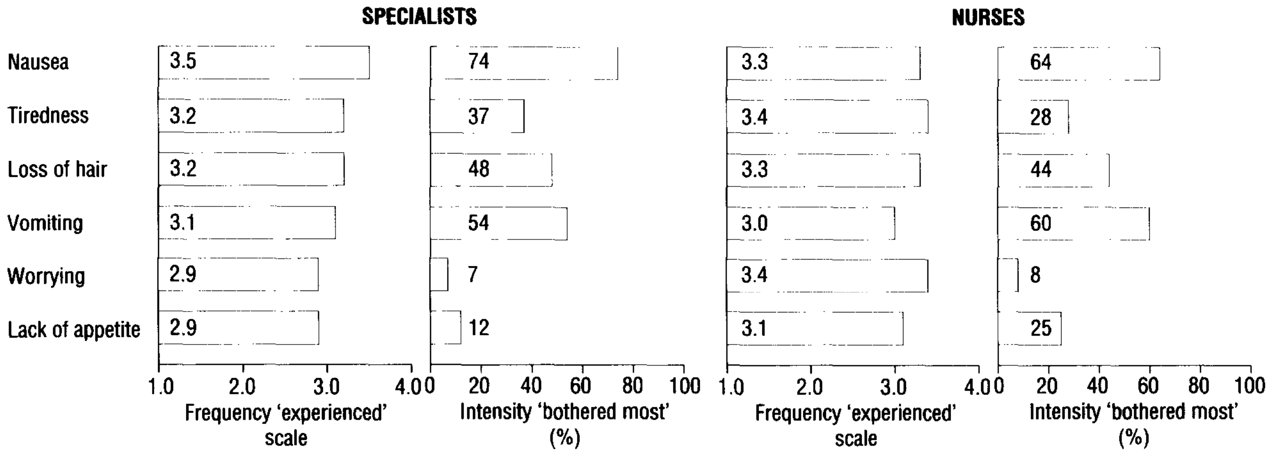
- Family worries are the major concerns.
  3 of the top 6 quality-of-life issues relate directly to worrying (accounts for 4 out of 16 scales).
- 2 of the top 4 worries are concerns about the impact of the illness and its treatment on their family.

clearly highest for nausea and vomiting, as these two symptoms were most frequently highlighted as one of the three (out of 22) symptoms which bothered patients most; nausea and vomiting was one of the three highest concerns, respectively for 74% and 54% of specialists, 64% and 60% of nurses, and 50% and 50% of general practitioners. Doctors rated nausea to be more distressing and experienced more frequently than vomiting, whilst nurses rated vomiting to be as equally disturbing as nausea. This difference is possibly owing to the fact that nurses have a closer contact with patients and therefore have greater awareness of the physical problems and their effect on the patient and family. Nausea and vomiting in the opinion of doctors and nurses was seen as far more important than the other major side effects of tiredness and hair loss.

Nurses' sensitivity to the occurrence of patient side effects, was greater than that for either specialists or general practitioners. The nurses scored a higher number of side effects at 3.0 or more than the doctors (eight side effects compared with four), and in particular identified "worrying" as of much higher concern. This concern was also identified when patients were scoring the quality-of-life measures. Worrying about the effects of therapy on their family were uppermost in the patients' minds. This is a another indication of the closer awareness of the nurses to the full range of patient concerns and problems. Family doctors' perceptions of the frequency of symptoms and the degree by which the patients were bothered by them were very similar to hospital doctors' and nurses' views.

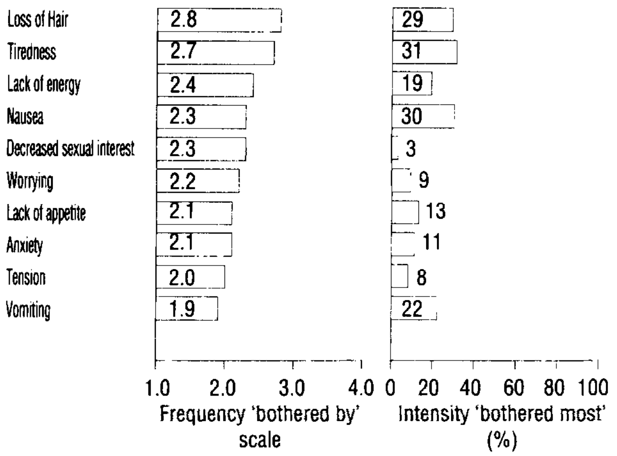
The patients surveyed, on average, reported a lower level of frequency of the major symptoms, and a slightly different range of problems (Table 2). Most frequently encountered problems were loss of hair, tiredness, lack of energy, nausea and decreased sexual interest. However, in terms of the impact of these problems, tiredness, nausea and loss of hair were most frequently mentioned. Vomiting also bothered them more than the frequency would suggest. Interestingly, decreased sexual interest is a frequent occurrence which the medical profession appear unaware of. The patients surveyed were generally unwilling to highlight or complain about how they felt and the side effects they were suffering from. This contrasted with the doctors and nurses who did identify the side effects more readily. This suggests that either patients do not generally complain very much about side effects of chemotherapy because they do not wish to be a burden to the people who are treating them, or that these problems are less of a concern than the medical profession perceive. However, we recognised that the patients interviewed suffered from a wide range of cancers and mean scores were difficult to interpret.

Despite this, 1 in 10 patients claim to have delayed their courses of therapy because of previous experience(s) of side effects (Fig. 1). It is important to bear in mind when comparing with other studies that these were patients already accepting the decision to take chemotherapy. The reasons were manifold but



Nausea, vomiting and loss of hair were specialists'/nurses' major concerns, although actual frequency of vomiting was lower than some other problems e.g. tiredness.

Fig. 1. Symptoms which may cause patients to delay (or stop) their therapy.



Tiredness, nausea and loss of hair were patients' major concerns although frequency of occurrence differed.

Fig. 2. Patients' concerns and impact on quality of life (16 quality-of-life measures rated: scale 1 = not at all, 4 = very much).

the most frequently mentioned were sore mouth/pain when swallowing, nausea, vomiting, diarrhoea, and tiredness. Half the doctors and nurses have experience of one or more patients delaying therapy for the same reasons. The specific side effects cited by specialists and nurses were vomiting and nausea.

Impact on quality of life

Sixteen quality-of-life statements, adapted from clinical quality-of-life studies were rated on a scale 1-4 (1 = not at all, 4 = very much) by patients. The main impact on patients of their disease and its management relates strongly to the aspects of worrying, more so than the day-to-day lifestyle limitations (Fig. 2). 'I worry about the effect the illness has on my family' and 'I worry whether the treatment is working' are the first and third rated concerns highlighted by patients. Another important area of concern was the impact of the whole process on their family. In this respect it seems the nurses were more sensitive to some of the patients' major problems than specialists and general practitioners.

Communication between the medical profession and patients

Similar scales used for measuring quality of life were employed to examine the relationship between patients and the medical staff. Both the profession and patients felt well informed by both doctors and nurses. This is demonstrated by very positive scores from 'I feel I have been well informed about my treatment by the doctors' (3.2 out of a possible maximum of 4.0) and negative responses to 'I find that nurses don't explain what they are doing to me' (1.2). However, it was interesting to note that the scores in the U.K. were higher than the average demonstrating that patients in the U.K. felt themselves to be better informed than patients in Italy and France. The U.K. nurses also seemed to have a more pro-active support role than the Italian nurses. This was evident from the qualitative interviews with both physicians and nurses in these two countries. In addition the level of agreement by nurses and hospital doctors with the statement "Talking about terminal disease distresses the patient and nothing is gained" was much higher in France and Italy (52% and 44% agreeing respectively) compared with the U.K. (only 12% agreeing). This country difference was also supported by the qualitative interviews, where doctors in these two countries were more often keen to protect the patients from the real situation.

Patients clearly feel well supported and informed by their care team. However, when comparing what patients claim they have been told about their disease and its treatment, and what nurses and doctors claim to say, quite different messages emerge. This is primarily because of fear of death by both the patient and the medical profession. Typical statements from physicians and nurses claimed the word "cancer" itself to be highly emotive, and associated with misery and death. Many doctors in our study avoided using the word cancer and explanations given to patients could be ambiguous or so technical that the patients misunderstand what they were being told. A small proportion of patients (31%) spontaneously claimed they had been told that they were suffering from cancer. Twenty per cent of explanations - or the way patients hear these could be classified as ambiguous, e.g. "A stomach ulcer bunch needs operation", or "Told by doctor I had a lung infection".

Similarly different messages emerged about the treatment. Over 80% of patients claimed to have been told much more about their curative drug treatment e.g. "Chemotherapy to prevent cancer spreading" or "Taking drugs to cure this dysfunction". Most patients recalled that they would receive drug therapy but only half spontaneously mentioned the word chemotherapy, although very few could actually name the drugs they were receiving. Only 1 patient in 10 heard and replayed the problems they were likely to experience with chemotherapy and fewer still were aware that the side effects would make them ill. In contrast, a higher proportion of (24% compared with 10% of patients) doctors and nurses claimed to have explained more about the potential problems of treatment e.g. "Chemotherapy is tough and hard work, with probable nausea and loss of appetite and hair". Clearly whatever the real conversation is between the care team and patient, different messages were heard or prioritised in patients' minds.

Finally, in terms of extra information to help the patient, the single thing most frequently mentioned from specialists and nurses was for psychologist back-up (19% and 27%, respectively). Nurses and general practioners also requested more information on drug side effects (20% and 30%, respectively). Again, differences existed between countries with the greatest responsibility being placed on the family in Italy. In addition, Italian family doctors expressed little faith in the nurse as a provider of psychological support.

In conclusion, both patients and the medical profession recognised nausea and vomiting as major problems, frequently encountered by patients receiving chemotherapy, along with tiredness, loss of hair, worrying and lack of appetite. In terms of communication, patients clearly felt well informed by their care team. However, differences emerged when compared with what patients claimed to have been told about their treatment and disease and what doctors claimed to have said.