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On the Receiving End—Patient Perception of the Side-effects of Cancer Chemotherapy

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Abstract—*We conducted a survey to identify and rank side-effects perceived by 99 patients receiving cancer chemotherapy. Non-physical side-effects constituted 54% of the 15 most severe symptoms, and included the thought of coming for treatment, the length of time taken by treatment and having to have a needle. Major physical side-effects were vomiting, nausea and hair loss. Differences in ranking of severity of side-effects were evident when patient groups were divided by sex, age, marital status and domestic situation, as well as by diagnosis, treatment and response. Evaluation of patient perception of the severity of side-effects is an aid to striking the cost benefit balance when deciding whether to use cancer chemotherapy.*

INTRODUCTION

CURRENTLY, most cancer chemotherapy is given with palliative rather than curative intent [1]. A rational decision to use cancer chemotherapy therefore involves weighing the benefits (anti-tumour effects) which it may confer and the costs (side-effects) which it may inflict. Although the biological significance of tumour response has been questioned [2], there is no doubt that accurate evaluation of the benefits of cancer chemotherapy has improved markedly in recent years. In contrast, evaluation of the side-effects of chemotherapy, particularly the psychosocial side-effects, has attracted less attention. As a first step toward the development of quantitative measures, we have surveyed what patients consider to be the side-effects of chemotherapy, both physical and non-physical, their perception of the relative importance of these side-effects and the effect on this ranking of factors such as age, sex, marital and domestic status, diagnosis and type of treatment.

MATERIALS AND METHODS

Ninety-nine patients who could read English and were attending medical oncology outpatient clinics at a major urban teaching hospital consented to participate in this study. They included 39 males and 60 females, with a median age of 52 yr (range 18–78 yr). All patients had advanced cancer and had received cytotoxic chemotherapy within the four-week period before study entry. The regimens employed are listed in Table 1. Patients had received 1–26 (median 3) courses of their current therapy. Forty-one of the patients had received prior chemotherapy with different regimens. Patients covered all socio-economic groups and had a wide variety of educational backgrounds. Seventy-nine of the patients were born in Australia, 8 in England and 12 elsewhere, of whom 8 spoke English as a second language. Seventeen of the patients had some form of medical or paramedical training.

Two sets of white cards were prepared. On each card was the name of one potential side-effect of chemotherapy. Group A (45 cards) listed physical side-effects and Group B (28 cards) non-physical side-effects (Tables 2 and 3). Each set of cards was shuffled and Group A cards were presented first, one at a time. The patients were asked by an interviewer, who had no prior knowledge of their diagnosis or treatment, to select any cards which described a side-effect they attributed to their current chemotherapy. They were then asked to rank the selected cards. The procedure was repeated for the group B cards, then the top five ranked cards in each group were combined and the patient was asked to select the five most severe symptoms regardless of group and put them in order from most to least severe. In order to obtain a ranking of the relative severity of symptoms to

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Table 1. *Chemotherapy at time of study*

Regimen	No. of patients
Cyclophosphamide, doxorubicin and vincristine	15
Cisplatin and chlorambucil	8
Vincristine, methotrexate and 5-fluorouracil	7
Cyclophosphamide, methotrexate and 5-fluorouracil	6
Methotrexate and 5-fluorouracil	6
Methotrexate	5
Cisplatin, vinblastine and bleomycin	4
Other	48
	99
Groupings used in analysis:	
all regimens containing cisplatin	22
regimens containing doxorubicin but not cisplatin	33
regimens containing neither cisplatin nor doxorubicin	44
	99

patients, a scale was defined by which five points were allocated to that symptom ranked as most severe, decreasing to 1 point for that symptom ranked as 5th. The points allocated to each symptom were then added and expressed as a percentage of the number of patients in the group to give an overall score. Patients were then asked several questions about their general physical status and details of their personal history, and to name any additional side-effects of chemotherapy which had not been mentioned on the cards. No single additional symptom was cited by more than two patients. Patients were also asked about the symptoms present prior to starting chemotherapy and their opinion of the efficacy of treatment. Patients were asked to complete an Eysenck personality questionnaire (EPQ).

Current treatment regimens were grouped into: (i) those containing cisplatin, (ii) those containing doxorubicin but not cisplatin, and (iii) those containing neither cisplatin nor doxorubicin. Patient responses were analysed according to age, sex, diagnosis, treament, patients' opinions of their progress and marital and domestic status.

RESULTS

The median number of non-physical symptom cards selected was 7 (range 0–21) and the median number of physical symptom cards selected was 12 (range 1–26), giving a median total number of symptoms selected of 19 (range 3–45). All but 2 patients selected and sorted at least 5 cards.

The ranks calculated for each symptom are summarized in Table 4 for the group as a whole.

Although the methodology limits the quantitative analysis of this ranking data, certain subgroups displayed noticeable deviation from the overall rank order (Tables 5 and 6). Thus the length of time taken by treatment ranked as the third most serious side-effect among males but 14th amongst females, while having to have a needle ranked 5th among females but 16th among

Table 2. *Group A—physical symptoms*

1. Feeling sick (nausea)
2. Being sick (vomiting)
3. Itching at injection site
4. Shaking all over
5. Change in the way things taste
6. Changes in how things smell
7. Not having regular bowel action (constipation)
8. Loss of liquid or frequent bowel action (diarrhoea)
9. Pins and needles in fingers or toes
10. Numbness in fingers or toes
11. Loss of weight
12. Weight gain
13. Increased hair growth on legs
14. Constantly tired
15. Giddiness on standing up
16. Loss of appetite
17. Sore mouth
18. Sore throats
19. Shortness of breath
20. Skin rash
21. Bruise easily
22. Difficulty sleeping
23. Pain passing water (painful urination)
24. Coloured urine
25. Ringing in ears
26. Deafness
27. General aches and pains
28. Tummy ache (abdominal pain)
29. Swollen tummy (abdominal fullness)
30. Periods stop
31. Periods become irregular
32. Changes in skin colour
33. Hot flushes
34. Heart beating fast (palpitations)
35. Headache/migraine
36. Loss of hair
37. Increased thirst
38. Passing more water than usual (increased urination)
39. Dry skin
40. Acne (pimples)
41. Increased appetite
42. Trouble with swallowing
43. Nose-bleeds
44. Cannot taste things
45. Fingernails go brown

Table 3. Group B—non-physical symptoms

1. Loss of sexual feeling
2. Loss of sexual ability (not getting aroused)
3. Feeling low, miserable (depression)
4. Thought of coming for treatment
5. Length of time treatment takes at the clinic
6. Feeling bad tempered (irritability)
7. Having to have a needle
8. Having to come to clinic rather than private doctor
9. Affects my family or partner
10. Feeling of not coping generally with treatment
11. Feeling of having to have treatment which I don't think will do any good
12. Feeling of having to have treatment which I don't want
13. Crying more often
14. Feeling angry
15. Cannot concentrate
16. Affects my work/home duties
17. Affects my social activities
18. Infertility (cannot have children)
19. Trouble finding somewhere to park near the clinic
20. Trouble getting to the clinic
21. Not having the chance to ask the doctor questions
22. Forget things
23. Not seeing the same doctor each time
24. Cannot get clothes to fit
25. Not understanding what is happening
26. Feeling anxious or tense
27. Having to wait for treatment with other patients
28. Feeling that the treatment is damaging my body

males. Females considered effects on work or home duties and anxiety as more important than males. Patients aged under 45 ranked anxiety as important, but were less concerned by sleeping difficulties and tiredness. The 45–60-year-old group placed higher importance on sleeping difficulties, but were less worried by having to have a needle and the length of time taken by treatment. Patients aged over 60 complained less of effects on family and sleep, but included a sore throat among their symptoms. Comparison of groups according to social circumstance was done in two ways: firstly by dividing the patients with a spouse from those without, and secondly by dividing those living alone from those living in some other situation (Table 5). As expected, the ranking of effects on the family was much lower in patients without a spouse, and none of the patients who lived alone selected this symptom. Patients without a spouse or living alone did not consider sleeping difficulties a problem. This may reflect a concern for the effect of sleep disturbance on a partner.

Sub-groups by diagnosis were somewhat smaller and thus susceptible to wider variability (Table 6). However, patients with lymphoma gave low ranking to tiredness and length of time taken by treatment, while patients with small cell lung cancer rated weight loss and decreased appetite highly. Patients with ovarian cancer, not surprisingly, ranked abdominal pain higher than average. Patients with breast cancer considered finding somewhere to park near the clinic a major problem.

Few major deviations from the overall pattern were noted when the patients were divided by treatment group (Table 6).

Patients were divided according to objective tumour response status [3], determined by the attending physician at the time of interview into those with objective response, stable disease or increasing disease (Table 6). Responding patients showed no major deviation from the overall rank order: those with stable disease gave higher ranking to sleeping difficulties and anxiety. The small group with increasing disease had a noticeably different pattern of symptoms, presumably reflecting to a greater degree the effects of disease as well as of treatment. They ranked constant tiredness, difficulty in swallowing, loss of appetite and a sore throat as important.

When the group was divided according to the patient's own opinion as to whether the treatment was working, there was little difference in ranking of side-effects between those who thought they were getting better and those who thought they were the same or worse.

Despite the smaller number of non-physical side-effects included on the cards (38%), 37 of the 99 patients included more non-physical than physical side-effects among the most serious 5.

Multiple step-wise regression of EPQ scores against the total number of physical and non-physical symptoms was performed, allowing for age. Patients scoring highly on 'neuroticism' selected more non-physical symptoms ($P = 0.02$), while those scoring highly on 'extroversion' selected fewer physical ($P = 0.04$) and non-physical ($P = 0.03$) symptoms. Older patients selected fewer non-physical symptoms ($P = 0.001$).

Table 4. Relative severity of side-effects for the entire group

Symptom (as on card)	Rank (score)*
Being sick (vomiting)	1 (168)
Feeling sick (nausea)	2 (156)
Loss of hair	3 (108)
Thought of coming for treatment	4 (96)
Length of time treatment takes at clinic	5 (54)
Having to have a needle	6 (53)
Shortness of breath	7 (49)
Constantly tired	8 (47)
Difficulty sleeping	9 (40)
Affects family or partner	10 (39)
Affects work/home duties	11 (34)
Trouble finding somewhere to park	12 (32)
Feeling anxious or tense	13 (29)
Feeling low, miserable (depression)	14 (26)
Loss of weight	14 (26)

*See text.

Table 5. *Relative severity of side-effects by patient characteristics*

Group (No. of patients)	Vomiting	Nausea	Hair loss	Thought of treatment	Length of treatment	Having to have needle	Short of breath	Constantly tired	Difficulty sleeping	Affects family	Other side-effects ranked highly by group (rank)
Entire group (99)	1	2	3	4	5	6	7	8	9	10	
Sex:											
Male (39)	1	2	5	4	3	16	7	6	9	8	Loss of weight (10)
Female (60)	2	1	3	4	14	5	6	9	10	13	Affects work (6) Anxiousness (8)
Age:											
Younger than 45 yr (32)	1	2	5	3	4	5	9	22	19	8	Anxiousness (7) Not coping with treatment (9) Don't want this treatment (10)
45–60 yr (37)	1	3	2	5	24	12	8	6	4	7	Difficulty parking (8) General aches and pains (10)
Older than 60 yr (30)	2	1	3	4	6	8	5	6	21	18	Sore throat (9) Loss of weight (10)
Marital status:											
Spouse (63)	1	2	4	2	5	12	18	7	5	8	Difficult parking (9) General aches and pains (10)
No spouse (36)	1	2	3	4	8	6	5	9	46	16	Affects work (7) Loss of appetite (10)
Domestic situation:											
Alone (13)	3	1	5	9	8	4	2	5	*	*	Increased thirst (7) Loss of appetite (10)
Other (86)	1	2	3	4	5	6	15	9	6	8	Difficulty parking (10)

*Not ranked among top 5 symptoms by any patients in group.

DISCUSSION

Evaluation of the quality of life of patients undergoing cancer treatment is one of the most difficult and important tasks facing the oncologist [4–6]. One recent study has determined the preferences for longevity and voice preservation among a group of healthy volunteers presented with hypothetical options for management of locally advanced laryngeal cancer [7]. It is apparent from this report that to maintain their voices 20% of volunteers would choose radiation treatment, even though the three-year survival probability was substantially lower than results of surgical treatment. In the present study the patients themselves have been asked to identify and rank the side-effects they attribute to their cancer chemotherapy. The incidence of non-physical side-effects cited as severe by patients (54% of the 15 most serious overall) suggests further consideration of these factors. The relative importance of fear of coming for treatment and having to have a needle has prompted us to use amnesic agents; we have found lorazepam useful in this context [8]. The fact that difficulty parking the car was a problem in some groups of patients underlines the frustration which many patients receiving regular treatments may feel at the frequent shortage of parking space close to large hospital clinics. Our findings highlight the importance of considering factors such as age and sex and the marital and domestic status of the patient when assessing the impact of chemotherapy. The importance of loss of sexual feeling or ability suggests the need for helping patients cope with age-related problems which may be exacerbated by disease or treatment [9].

Compilation of the pool of symptoms from which they were invited to choose was necessarily

Table 6. Relative severity of side-effects by diagnosis, treatment, response, objective and subjective

Group (No. of patients)	Vomiting	Nausea	Hair loss	Thought of treatment	Length of treatment	Having to have needle	Short of breath	Constantly tired	Difficulty sleeping	Affects family	Other side-effects ranked highly by group (rank)
Entire group (99)	1	2	3	4	5	6	7	8	9	10	
Diagnosis:											
Lymphoma (14)	1	2	5	3	11	8	5	16	4	5	Shaking all over (9) Loss of sexual feeling (9)
Small cell lung cancer (16)	3	2	1	6	5	12	6	10	27	11	Loss of weight (4) Loss of appetite (8) Loss of sexual ability (9)
Ovarian cancer (18)	1	2	5	3	27	4	15	15	9	6	Tummy ache (7) Increased thirst (7) Depression (9)
Breast cancer (23)	2	3	1	4	7	6	10	10	8	28	Difficulty parking (5) Affects work (8)
Other (28)	2	1	6	3	5	13	8	4	20	17	Sore mouth (7) Constipation (9) Sore throat (9)
Treatment:											
Includes cisplatin (22)	1	2	5	2	14	4	16	8	10	6	Anxiety (7) Depression (9)
Includes doxorubicin (33)	1	2	3	4	5	13	5	11	19	9	Loss of weight (7) Loss of appetite (8) Anxiety (10)
Other (44)	2	1	3	4	6	6	10	6	5	23	Affects work (9)
Objective response:											
Response (CR or PR) (55)	2	1	3	4	5	7	9	6	13	8	Affects work (10)
Stable disease (33)	1	2	3	4	11	7	8	17	5	14	Anxiousness (5) Affects work (9) Difficulty parking (9)
Progressive disease (11)	1	2	14	3	9	14	5	4	14	14	Trouble swallowing (5) Loss of appetite (7) Sore throat (7) Numbness (9) Skin rash (9) General aches and pains (9) Don't understand (9)
Patient opinion of effects of treatment:											
Better	1	2	3	4	5	7	10	12	6	9	Affects work (7)
Same or worse	2	1	3	4	8	5	6	6	12	10	Loss of appetite (9)

arbitrary but was designed to be comprehensive (Tables 2 and 3), and this was confirmed by the lack of importance of other symptoms suggested by patients. Although we have at present scored each symptom separately, groups of two or more may represent aspects of a single problem. We will publish elsewhere a quantitative analysis of these data together with the psychological variables measured. This will allow extraction of major factors and the construction of scales to measure them. Progress in this direction will provide tools necessary to inform patients of the difficulties that they may encounter as well as the potential benefits of cancer chemotherapy. The identification of patient subgroups and their particular potential problems with treatment contributes to the more accurate evaluation of the balance between morbidity and therapeutic benefit inherent in every decision to use cancer chemotherapy.

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