

## Original Article

### The problems faced by outpatients after gastrointestinal cancer chemotherapy and the methods they use to cope with these problems

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#### ABSTRACT

**Background & Aim:** Gastrointestinal cancer is one of the most common malignancies worldwide. Patients who undergo chemotherapy due to gastrointestinal cancer need to cope with the problems they face, as it will increase their quality of life and ability to take care of themselves. Therefore, it is important to determine patients' coping methods and their effects on nursing care. This study aims to explore the problems faced by outpatients after receiving chemotherapy due to gastrointestinal cancer and the methods they use to cope with such problems .

**Methods & Materials:** This cross-sectional study was conducted in outpatient chemotherapy units of the Divisions of Medical Oncology at two medical school hospitals of a state university in Ankara, Turkey, between February and September 2011. A questionnaire developed by the authors in line with the literature to determine the patients' demographic characteristics, the problems they face, and their methods to cope with the adverse effects of chemotherapy and the Nightingale Symptom Assessment Scale were administered to 88 patients with gastrointestinal cancer admitted to the outpatient chemotherapy units to receive their third course of chemotherapy who met the inclusion criteria.

**Results:** The patients mostly experienced nausea–vomiting (73.9%), malaise–fatigue (88.6%), loss of appetite (69.3%), and changes in taste and/or smell (54.5%) after chemotherapy. The methods most frequently used by the patients to cope with these problems were taking antiemetic drugs (46.6%), resting frequently/spending the day lying or sleeping (87.5%), and taking care of oral hygiene (27.3%). The general well-being was very good for 13.6%, good for 67%, fair for 15.9%, and poor for 3.4% of the patients. Of them, 40.9% received and 59.1% did not receive education on the adverse effects of chemotherapy.

**Conclusion:** Individualized education programs on the adverse effects of therapy and the ways to cope with these effects should be provided to the patients before and during the therapy at the outpatient centers.

## Introduction

Cancer, which is defined as uncontrolled proliferation of cells, is currently one of the most serious health concerns (1,2). It is one of the leading causes of morbidity and mortality worldwide, with approximately 14 million new cases in 2012. Globally, it is the second leading cause of death, and was responsible for 8.8 million deaths in 2015. It

causes about one out of six deaths around the world (3). In Turkey, neoplasms are the second leading cause of death in 49.946 men and 27.022 women (4). According to the GLOBOCAN, the most frequent types of cancers in the world were lung cancer (13.0%), breast cancer (11.9%), and colorectal cancer (9.7%) in 2012. Lung cancer is the leading cause of death with 1.69 million deaths, followed by liver cancer (788,000 deaths) and colorectal cancer (774,000 deaths) (3). The most frequent types of cancers in Turkey are lung cancer (21%), prostate cancer (13%), and colorectal

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cancer (9%) among men; and breast cancer (25%), thyroid cancer (12%), and colorectal cancer (8%) among women (4). Gastrointestinal cancers are also frequently observed causes of death.

Chemotherapy is a type of treatment in which some drugs are used to stop the progression of cancer and/or eliminate it. However, they might have many adverse effects because they also affect healthy cells (1, 2, 5). Chemotherapy is generally administered at outpatient chemotherapy units, and then, patients are left alone with the problems caused by chemotherapy. The education provided to the patients on the adverse effects of chemotherapy can be insufficient to cope with the problems they experience at home, and/or they may use certain methods to overcome such problems. Studies on this subject reported that the methods used by the patients were taking antiemetic drugs, taking care of mouth hygiene, eating in small amounts and frequently, resting or sleeping, limiting physical activity, using scarves, wigs or hats, eating vegetables, and drinking fruit juice and herbal tea (5-8). Richardson and Ream indicated that these methods include sufficient, partially sufficient, and insufficient approaches to cope with such problems (7).

Coping with these problems will increase patients' quality of life and ability to take care of themselves. It is important to determine patients' coping methods and the effects of these methods on nursing care, as it may help provide individualized nursing care and make the education provided to the patients more effective.

This study aims to explore the problems faced by outpatients after receiving gastrointestinal cancer chemotherapy, and the methods they use to cope with these problems.

## **Methods**

This cross-sectional study was conducted in outpatient chemotherapy units of the Divisions of Medical Oncology at two medical school hospitals of a state university in Ankara, Turkey, between February and September 2011. The study universe consisted of 90 patients in these units during this period of time. Except for the two patients who did not agree to participate, 88 of the patients met the inclusion criteria and were included in the study. During chemotherapy, the nurses informed the patients about the effects and adverse effects of chemotherapy and gave them educational leaflets that contained general information about chemotherapy, its effects and adverse effects, and the methods that can be used by patients to cope with these adverse effects. Only the patients who applied for the first course before treatment were provided with education. The inclusion criteria were being older than 18 years of age, being able to communicate, being diagnosed with gastrointestinal cancer and receiving outpatient chemotherapy, having completed the second course of chemotherapy and being admitted to the third course.

The study protocol was approved by the Ethics Committee of Ankara University Medical School in Ankara, Turkey with the number 22-438; and written informed consent was obtained from each patient before the interviews. A pilot study was carried out on 10 patients excluded from the study and the questionnaire was modified based on the pilot study.

The data were collected using the Nightingale Symptom Assessment Scale (N-SAS) and a questionnaire developed by the authors to determine the patients' demographic characteristics, the problems they faced and their coping methods.

The Nightingale Symptom Assessment Scale was developed by Can and Aydiner

and obtained from the authors with their permission to use the scale (9). The Cronbach's  $\alpha$  value of the scale was 0.93 for Turkish population and 0.906 for the present study. It is a 5-point Likert-type scale that consists of 38 items and shows the level of patients' general well-being related to treatment. Higher scores indicate poorer levels of well-being. The items are scored between 0 and 4; where 0 means not at all, 1 means a little, 2 means not much, 3 means a lot, and 4 means too much. The highest score was 4.00 on the scale. The well-being scores range between 0 and 0.50 indicating "very good", 0.51–1.50 indicating "good", 1.51–2.50 indicating "fair", 2.51–3.50 indicating "poor", and 3.51–4.00 indicating "very poor" (9).

The questionnaire developed by the author consisted of two sections (6-8, 10-12). The first section addressed the demographic characteristics of the patients and their knowledge about the diagnosis and treatment. In the second section, the patients were asked 40 structured questions to determine the problems they faced after chemotherapy, the methods they used to cope with these problems, whether they received education and educational material, and from whom they received education. The patients indicated more than one method for each problem. The data were collected by the author during face-to-face structured interviews in a private room in the hospital. Each interview took approximately 30 minutes. Before the interviews, the study aims and objectives were explained in detail, and the patients' verbal and written informed consents were obtained upon assuring them of the fact that their information would be kept confidential and that they had the right to withdraw from the study and are free to ask questions whenever they want.

Statistical Package for Social Sciences for Windows version 17.0 was used for data

analysis. Since the data complied with the parametric test hypotheses, One-Way Analysis of Variance (ANOVA) (F test) was used to assess the quality of the data, and the Student's t test was used to compare the differences between the groups.

## **Results**

Of the 90 patients who met the inclusion criteria, 88 agreed to participate in the study between February and September 2011. Table 1 and Table 2 show the participants' demographic, disease and treatment-related characteristics.

The general well-being was very good for 13.6%, good for 67%, fair for 15.9%, and poor for 3.4% of the patients. Female patients had higher general well-being scores ( $t=4.808$ ;  $p=0.000$ ). A statistically significant was found between the well-being scores of the occupational groups ( $F=3.443$ ;  $p=0.007$ ). The families with a lower income level obtained higher well-being scores than the families with a higher income level ( $t=2.165$ ;  $p=0.033$ ). Statistically significant differences were found between the general well-being scores of the patients depending on the disease stages ( $F=4.975$ ;  $p=0.009$ ) (Table 3).

The adverse effects faced by the patients include nausea–vomiting, malaise–fatigue, fever, hair loss, mouth sores, constipation, diarrhoea, loss of appetite, and change in taste and/or smell. Table 4 shows the frequency of these problems and the methods used by the patients to cope with them. The methods most frequently used by the patients were taking antiemetic drugs (46.6%), resting frequently/spending the day lying or sleeping (87.5%), taking care of oral hygiene (27.3%), eating dried apricots or plums, drinking apricot juice (28.4%) and eating fat-free, low-fibre, protein food (25.0%).

**Table 1.** Patients' demographic characteristics (N=88)

Variable	N (%)
<b>Gender</b>	
Females	41 (46.6)
Males	47 (53.4)
<b>Age group</b>	
35-49	14(15.9)
50-64	45(51.1)
65-79	29(33.0)
<b>Age (Mean±SD)</b>	59.7±(8.8)
<b>Education level</b>	
Primary school	53(60.2)
Secondary school	18(20.5)
High school	11(12.5)
Illiterate	6(6.8)
<b>Marital status</b>	
Married	77(87.5)
Single	11(12.5)
<b>Occupation</b>	
Housewife	37 (42.0)
Civil servant	14 (15.9)
Retired	11 (12.5)
Labourer	6 (6.8)
Farmer	7 (8.0)
Self-employed	13 (14.8)
<b>Social security</b>	
Yes	87(98.9)
No	1(1.1)
<b>Monthly income</b>	
<US\$1135	78 (88.6)
>US\$1136	10 (11.3)

Of the patients, 40.9% received and 59.1% did not receive education on the adverse

effects of chemotherapy. Of those who received education, 27.9% were educated by a doctor, and 72.1% were educated by a nurse. In addition, 69.3% of the patients were given educational material, while 30.7% were not.

**Table 2.** Patients' disease and treatment-related characteristics (N=88)

Characteristics	N (%)
<b>Diagnosis</b>	
Oesophageal cancer	1(1.1)
Stomach cancer	13(14.8)
Colon cancer	43(48.9)
Rectal cancer	14(15.9)
Pancreatic cancer	15(17.0)
Gall bladder cancer	2(2.3)
<b>Duration of diagnosis</b>	
6 months and before	69(78.4)
6 months to 1 year	11(12.5)
1 year to 2 years	8(9.1)
<b>Stage</b>	
Stage 2	25(28.4)
Stage 3	33(37.5)
Stage 4	30(34.1)
<b>Chemotherapy</b>	
Folfox	3 (3.5)
Folfox-4	37(42.0)
Folfox-6	1(1.1)
Gemcitabine	6 (6.8)
Gemcitabine +cisplatin	10 (11.4)
5-FU+folinic acid	30 (34.1)
Cisplatin+ etoposide	1 (1.1)

**Table 3.** General well-being scores according to gender, occupational Status, monthly income and stage (N=88)

Variable	N (%)	N-SAS score (Mean±SD)	
<b>Gender</b>	Female	41 (46.6)	1.17±0.56
	Male	47 (53.4)	0.69±0.34
<b>t / p</b>		<b>4.808 / 0.000</b>	
<b>Occupational status</b>	Housewife	37 (42.0)	1.15±0.53
	Civil servant	14 (15.9)	0.78±0.59
	Retired	11 (12.5)	0.90±0.35
	Labourer	6 (6.8)	0.71±0.25
	Farmer	7 (8.0)	0.70±0.39
	Self-employed	13 (14.8)	0.62±0.34
<b>F / p</b>		<b>3.443 / 0.007</b>	
<b>Monthly income</b>	<US\$1135*	78 (88.6)	0.96±0.52
	>US\$1136*	10 (11.3)	0.59±0.22
<b>t / p</b>		<b>2.165 / 0.033</b>	
<b>Stage</b>	Stage 2	25 (28.4)	0.83±0.49
	Stage 3	33 (37.5)	0.77±0.44
	Stage 4	30 (34.1)	1.14±0.54
<b>F / p</b>		<b>4.975 / 0.009</b>	

\*While performing statistical analysis, the groups with the income level ≤US\$567 and between US\$568 and 1135 were gathered as “<US\$1135” and those with the income level between US\$1136 and 1700, 1701 and 2267, and 2268 and 2886, and ≥US\$2287 as “>US\$1136

**Table 4.** Frequency and percent of side effect and its coping methods (N=88)

Side effects	N (%)	Methods	N* (%)
<b>Nausea-vomiting</b>	65 (73.9)	Taking antiemetic drugs	41 (46.6)
		Taking care of mouth hygiene	33 (34.1)
		Keeping home from unpleasant odours	22 (25.0)
		Eating salted crackers	20 (22.8)
		Eating cold food	11 (12.5)
		Washing mouth with lemon juice	5 (5.7)
		Distraction via music and TV	5 (5.7)
		Nothing	10 (11.4)
<b>Malaise-fatigue</b>	78 (88.6)	Resting frequently/spending the day lying or sleeping	77 (87.5)
		Having adequate (7-8 hours per day) sleep	39 (44.2)
		Performing their activities when they felt good	31 (35.2)
		Having 8-10 glasses water a day	24 (27.3)
		Early to bed	19 (21.6)
<b>Fever</b>	13 (14.8)	Attending a health-care facility	10 (11.3)
		Self-monitoring of fever	3 (3.4)
		Taking warm shower	1 (1.1)
		Taking antipyretic drug	1 (1.1)
		Nothing	2 (2.2)
<b>Hair loss</b>	41 (46.6)	Using hat or similar materials	14 (15.9)
		Having short haircut before chemotherapy	9 (10.3)
		Nothing	20 (22.7)
<b>Mouth sore</b>	35 (39.8)	Taking care of oral hygiene	24 (27.3)
		Gargling with medications	22 (25.0)
		Avoiding hot, spicy, acidic food and drinks	14 (15.9)
		Gargling with bicarbonate solution	12 (13.6)
		Nothing	1 (1.1)
<b>Constipation</b>	38 (43.2)	Eating dried apricots or plums, drinking apricot juice	25 (28.4)
		Eating food rich in fibre, such as vegetables, fruits, and cereals	21 (23.9)
		Taking laxative drugs	
		Taking adequate liquid (8-10 glasses per day)	18 (20.4)
		Walking and exercising	13 (14.8)
		Nothing	7 (8.0)
<b>Diarrhoea</b>	44 (50.0)	Eating fat-free, low-fibre, protein food	22 (25.0)
		Avoiding hot, spicy, fatty food	19 (21.6)
		Taking antidiarrheal medications	15 (17.1)
		Taking adequate liquid (8-10 glasses per day)	13 (14.8)
		Nothing	13 (14.8)
<b>Loss of appetite</b>	61 (69.3)	Eating meal in small amounts and frequently	14 (15.9)
		Taking adequate amount of fluids (8-10 glasses per day)	12 (13.6)
		Eating in a relaxing, cool setting free from food smell	10 (11.4)
		Walking and exercising between meals	2 (2.3)
		Nothing	34 (38.6)
<b>Changes in taste and/or smell</b>	48 (54.5)	Taking care of oral hygiene	32 (36.4)
		Staying away from disturbing smells	21 (23.8)
		Taking adequate amount of fluids (8-10 glasses per day)	15 (17.0)
		Nothing	11 (12.5)

\* Patients expressed more than one choice

## **Discussion**

Being able to cope with the problems of chemotherapy is important for patients because it increases their quality of life and ability to take care of themselves. All patients should be provided with education and educational material. Some patients do nothing to address the problems they experienced; therefore, the education content should be individualized based on the identified problems and the patients' needs.

In this study, male patients were found to have higher levels of general well-being than female patients, which may be because most of the female patients were housewives and had more responsibilities arising from their traditional roles. The gender-based difference between the groups was statistically significant. Can and Aydiner also found the general well-being of females to be poorer (9). In the present study, housewives had the poorest general well-being, followed by retired patients. This might be because the female patients had more responsibilities and less time for self-care due to their traditional roles, and the vital functions of retired patients decrease due to old age. The present study found that the patients with lower income levels had poorer general well-being. The reason for this may be a decrease in self-care due to a lack of financial resources for treatment. The difference between the general well-being scores depending on income level was statistically significant. A statistically significant difference was found between the general well-being scores of the patients depending on the stage of the disease. The patients at the stage 4 had the poorest general well-being. Can and Aydiner also found the general well-being of patients with metastasis to be poorer (9).

The present study showed that the majority of the patients (73.9%) experienced the problem of nausea–vomiting after

chemotherapy. Previous studies reported the rate of the patients experiencing nausea–vomiting to be from 40% to 70% (6, 8, 13). In this study, the most frequent methods the patients used to cope with nausea–vomiting were taking antiemetic drugs (46.6%), taking care of mouth hygiene (34.1%), and eating salted crackers (22.8%). Previous studies also reported that the patients tried to control nausea–vomiting using antiemetics (5, 14, 15, 16). Taking antiemetic drugs was the most frequently used method in this study, in line with the other findings, because healthcare professionals were not sufficiently informed about non-pharmacological methods against nausea–vomiting. Also other studies reported that the patients used the methods of modifying diet, eating light food, taking deep breath, smelling the flavour of orange or lemon when nauseous, watching TV or listening to music to reduce nausea–vomiting (14-17).

The present study indicated that 88.6% of the patients experienced malaise–fatigue due to chemotherapy. Similarly, some other studies reported that 90%, 85%, and 70–100% of the patients experienced fatigue after chemotherapy (7, 8, 18). To cope with malaise–fatigue, the patients used the methods of resting frequently/spending the day lying or sleeping (87.5%) and having adequate (7–8 h per day) sleep (44.2%). In parallel to this finding, other studies reported that the patients used the methods of resting or sleeping, limiting physical activity, diet regulation, exercise, saving energy, and reducing stress to reduce fatigue (5, 7, 11, 18-20).

Of the patients, 14.8% experienced fever after chemotherapy. These patients most frequently used the methods of attending a healthcare centre (11.3%) because the healthcare professionals in the hospital where this study was conducted generally advised the patients with fever to visit a healthcare centre. This method was followed

by the method of self-monitoring of fever (3.4%).

The rate of the patients experiencing hair loss was 46.6%. The most frequent methods used by the patients to cope with hair loss were detected as “using hat or similar materials” (15.9%) and “having short haircut before chemotherapy” (10.3%). In other studies, the patients used scarves, wigs, and hats, had short haircut, combed the hair gently, and used baby shampoo and herbal products (6, 8, 14).

Of the patients, 39.8% had mouth sore after chemotherapy. The patients were found to most frequently use the methods of taking care of oral hygiene (27.3%), gargling with medications (25.0%), avoiding hot, spicy, and acidic food and drinks (15.9%), washing mouth with water having sodium bicarbonate (13.6%), and eating soft food (10.2%) to cope with mouth sores. Some other studies reported the methods used for mouth problems as taking fluids, taking care of oral hygiene, eating soft food, drinking cold beverages or drinking water along with meals, dietary modification, and using topical mucosal protectants, anaesthetics, and analgesics (5, 8, 14-17), which were consistent with the findings of the present study.

After chemotherapy, 43.2% of the patients experienced constipation. To cope with constipation, the patients most frequently used the methods of eating dried apricots or plums and drinking apricot juice (28.4%), eating food rich in fibre such as vegetables, fruits, and cereals (23.9%), taking laxative drugs (20.4%), and taking adequate amounts of fluids (8–10 glasses per day) and food (14.8%). Piamjariyakul et al. found that 52% of the patients experienced constipation and the common methods used to treat constipation were taking laxative drugs, eating vegetables, and drinking fruit juice and herbal tea (6, 14).

Half of the patients had diarrhoea after chemotherapy. To treat diarrhoea, they most frequently used the methods of eating fat-free, low-fibre, protein food (25%), avoiding hot, spicy, fatty food (21.6%), and taking antidiarrheal medications (17.1%). In other studies, diarrhoea was observed in 50%–80% of the patients receiving chemotherapy (21, 22). Other studies conducted on this subject identified the methods frequently used against diarrhoea to be diet regulation and using prescribed medicines (6, 23).

Of the patients, 69.3% were observed to have loss of appetite, and they most frequently used the methods of eating meal in small amounts and frequently (15.9%), taking adequate amount of fluids (13.6%), and eating in a relaxing, cool setting free from food smell (11.4%) to cope with this problem. However, 38.6% of the patients stated that they did nothing against loss of appetite. Piamjariyakul et al. determined that 73% of the patients experienced loss of appetite and they commonly used the methods of forcing oneself to eat, eating in small amounts and frequently, taking supportive food such as milk and eggs, adding flavour to food to make it appetizing, providing adequate time resting before each meal and taking care of mouth hygiene to cope with loss of appetite (6, 16).

The present study showed that 54.5% of the patients experienced changes in taste and/or smell. These patients most frequently used the methods of taking care of oral hygiene (36.4%), staying away from disturbing smells (23.8%), and taking adequate amounts of fluids (17.0%). Other studies reported that the common methods used against change in taste were making dietary alterations, taking care of oral hygiene, eating aromatized food, eating candy or drinking sweet beverages before meals, avoiding sight and smell of food causing unpleasant sensation, using lemon

drops and using an antibacterial mouthwash (6, 12, 14, 16).

Finally, 40.9% of the patients received education on the adverse effects of chemotherapy, while 59.1% did not. Contrary to this finding, 69.3% of the patients were given educational material. However, they stated that these educational materials were not the source of their behaviours. This might be because the patients were reluctant to read these leaflets.

The limitations of the study were the low number of the participants due to the low number of patients referred to the units, and the fact that patients with different stages who were receiving different chemotherapy regimens were evaluated in the study.

According to the finding of the present study, the patients mostly experienced nausea–vomiting, malaise–fatigue, loss of appetite, changes in taste and/or smell and diarrhoea after chemotherapy. The methods most frequently used by the patients to cope with these problems were taking antiemetic drugs, resting frequently/spending the day lying or sleeping, taking care of oral hygiene and eating fat-free, low-fibre, protein food. Also the general well-being was good for 67% of the patients and 40.9% of the patients received education on the adverse effects of chemotherapy. Ability to cope with the problems of chemotherapy increases patients' quality of life and ability to take care of themselves. The patients with low general well-being scores, and particularly the patients who are unable to perform self-care properly (housewife, retired, patients with low income level etc.) should be supported to help them cope with adverse effects. Individualized education programs should be initiated on the effects and adverse effects of the therapy and the methods to cope with these adverse effects for the patients before and during the therapy at the outpatient centres. All patients should be provided with educational

materials and verbal education. Further studies should be conducted to analyse the use and effectiveness of methods to cope with chemotherapy-related problems.

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### **Conflict of Interest**

The authors of this study declare no conflicts of interest.

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