

Treatment-related symptom severity and occurrences among oncology adults in Australia

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ABSTRACT

Objective: Cancer treatments cause a range of distressing symptoms that can be well managed with pharmacological and nonpharmacological interventions. Treatment-related symptom screening and management by health care professionals is required to provide appropriate guidance to help patients to complete successfully their treatment regimen and achieve the best possible outcomes for patients. The aims of this study were to explore treatment-related symptom severity and occurrences among oncology adults in Australia and compare the results with the Chinese and Filipino studies. **Methods:** A cross-sectional descriptive survey of 84 adult patients over 18 years of age undergoing chemotherapy (CT) and/or radiotherapy (RT) in the Radiation Oncology and Medical Oncology Departments in one public teaching hospital in Canberra, Australia using the 25-item treatment-related symptom checklist (TRSC) was used in this study. **Results:** Six

symptom clusters emerged from combining the 25 symptoms. Patients receiving CT experienced highest fatigue symptom occurrences (95.8%) and greater symptom severity (mean = 2.59) for fatigue symptom cluster for patients receiving a combination of CT-RT. Australians treatment-related symptom severity and occurrences were higher compared with the Filipino and Chinese adult cancer patients. **Conclusions:** Nurses in oncology settings are uniquely placed to assess patients' therapy-related symptoms that will assist them to target education to cancer patients' individual needs. For all types of cancer, it is important to assess treatment-related symptoms and to provide the most appropriate interventions in consideration to the patients' preferences.

Key words: Australian, cancer, chemotherapy, radiotherapy, survey, symptom occurrence, symptom severity

Introduction

In Australia, 120,710 new cases of cancer were diagnosed in 2012 which have more than doubled between 1982 and 2012. Among these new cases, 67,260 were males and 53,460 were females. The five

most common cancers were prostate, bowel, breast, melanoma of the skin and lung.^[1] The incidence of cancer is expected to increase with age and is estimated that 75% of new cancer cases will be diagnosed in males and 65% in females aged 60 years and over. The risk of being diagnosed with cancer before the age of 85 years is 1 in 2 for males and 1 in 3 for females.^[2] When compared to cancer incidence internationally using data from GLOBACAN, the estimated age-standardized incident rate for Australia was 314 per 100,000 which is significantly higher than all regions in the world. This may be due to the high incidence of melanoma of the skin in Australia.^[3]

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Australia is a multicultural country with more than one in five Australians born overseas at the 2006 census. The top five countries of birth other than Australia were: England, New Zealand, China, Italy and Vietnam.^[4] The Capital Region Cancer Service provides cancer services for a population of about 600,000 within the Australian Capital Territory and South Eastern Region of New South Wales.^[5] More than one in five residents of Canberra and Queanbeyan were born overseas at the 2006 Census. Of people born overseas, the top five places of birth were: United Kingdom and Ireland, South-east Asia, North-east Asia, Europe and New Zealand. Overall, 35.8% of the overseas-born population in Canberra/Queanbeyan was born in Asia.^[6]

When patients learn that they have cancer, they are concerned about the symptoms they will experience especially those related to active treatment. About 70% of patients undergoing treatment experience pain that disturbs their sleep and ability to get things done.^[7] It is well known that cancer treatments, particularly chemotherapy and radiotherapy (CT-RT), cause patients a range of distressing side effects.^[8-10] An analysis of 25 symptoms from 922 patients with advanced cancer identified fatigue, neurological, gastrointestinal, nausea and vomiting, aerodigestive, debility and pain as common.^[11] Gastrointestinal symptoms including nausea and vomiting was found to be severe symptom in patients treated with CT^[12] while fatigue, weakness, lack of energy was also found to be a common treatment-related symptom.^[7,13]

Some of these symptoms, for example, pain, nausea and vomiting, can be well managed with pharmacological^[7] and nonpharmacological^[14] intervention. However, other side effects such as fatigue, eating difficulties, and skin changes are left to the patient to cope with and manage. Cancer symptom management is a priority for oncology nurses providing treatments, supportive care and education to patients, families and caregivers. Untreated or poorly managed symptoms are associated with psychological distress, loss of physical functioning and a decreased quality of life.^[8] Health-related quality of life is gaining increasing importance in health care. It is a multi-faceted concept, which includes effects and burden of disease, side effects of treatment, and physical and psychosocial functioning.^[15,16] In order to achieve the best possible outcomes for patients, treatment-related symptom screening and management by health care professionals is required.^[17,18]

Comprehensive symptom assessment is crucial for symptom control.^[19] Symptoms appear to vary with the assessment tool, disease stage, and in different populations.^[20] Tools

exists to assist the health professional identify treatment-related symptoms and patient methods of self-care for these symptoms, however, lengthy symptom assessment tools have less utility due to time limitations and mental or physical inability to complete them especially in sicker cancer patients.^[20] The therapy-related symptom checklist (TRSC) is an example of a short symptom assessment tool that has been tested and validated in a number of countries^[16,18,21] and has proven reliability and validity. Gathering information from patients on treatment-related symptoms leads to appropriate guidance in self-care that can help patients to successfully complete treatment regimens.^[20,21] Effective control of symptoms enhances therapeutic outcomes, improves quality of life and increases adherence to treatment.^[7] Thus, oncology nurses have a vital role in early assessment and management of treatment-related symptoms as well as patient education to prioritize interventions.

Project aims

The main aim of this study was to explore the symptoms severities and occurrences of treatment-related symptoms among adult oncology patients in Australia. A secondary aim was to compare these results with those of published studies of Chinese^[18] and Filipino^[21] cancer patients to determine any cultural differences in symptoms experiences. This study was compared to Chinese and Filipino patients with cancer as these studies used the same treatment-related symptom checklist (TRSC) used in our study.

Materials and Methods

This cross-sectional descriptive study was undertaken within the Radiation Oncology and Medical Oncology Outpatients Departments at one public teaching hospital in Canberra, Australia. Approval to conduct the study was granted by the Hospital's Ethics Committee. All adult patients undergoing CT and/or RT who met the inclusion criteria were invited to participate. The inclusion criteria were:

1. Must have completed at least 2 weeks of treatment,
2. Be at least 18 years of age,
3. Are able to complete the questionnaire in English, and
4. Sign the consent form.

Eighty-three ($n = 83$) patients consented to participate in the study. The participants completed the self-report 25-item therapy-related symptoms checklist (TRSC)^[22,23] and a demographics form while waiting for their treatment. The TRSC also has blank spaces for patients to add any other symptoms of concern not listed in the checklist. Patients were asked to rate the severity of the symptoms they were experiencing on a 5-point Likert scale from 0 = None

to 4 = Very severe and the number of occurrences they experienced these symptoms. Higher scores on the scale indicate higher severity of the symptom. The data collection period was conducted between February and June 2013. In our study, the Cronbach alpha for the entire scale was 0.88. Data analysis was performed using SPSS (version 20). Descriptive statistics were used to obtain the mean scores for the 14 symptom subscales of the TRSC.

For the purpose of comparison of the results with the Chinese and Filipino patients with cancer, a mean severity score >1 was considered symptom severity as reported in these two studies undertaken by the co-authors.^[18,21] The study among 222 (66% female) Chinese patients with either breast, gastrointestinal, lung, cervical or head and neck cancers was conducted in Xi'an China and Hong Kong. Their mean age was 55 years (standard deviation [SD] = 11 years).^[18] The study among 100 (65% female) Filipino patients with breast, cervical, ovarian, lung, colorectal or nasopharyngeal cancer was conducted in Manila, Philippines. Their mean age was 47 years (SD = 13 years).^[21]

Results

Patient characteristics

A total of 110 of eligible participants were recruited. However, only 83 Australian cancer patients consented to participate in this study with 42 female and 41 male patients, a response rate of 91%. Table 1 shows the demographic characteristics of the patients. The mean age was 59.3 years (SD ± 11.8, range 25-87). The participants were predominantly Caucasian but also included a small number of Asian participants. Almost three-quarters of the participants were married and most were living with their spouse/partner and/or children. More than half the participants identified their spouse/partner as their primary caregiver. A third of the patients were already retired.

Disease-related characteristics

Table 2 shows the disease-related characteristics. The sample includes a variety of cancer diagnoses, with breast cancer being the most frequent diagnosis (35%). Twenty-four patients had received CT only, 24 RT only while 35 patients had received both CT-RT. Twelve patients had metastatic disease. Eight patients also reported receiving adjuvant therapies such as elastin or trastuzumab.

Symptoms' severity and occurrences

Table 3 shows the mean severity of symptoms and the occurrence reported by patients by treatment type.

Table 1: Demographic characteristics of sample (n = 83)

Characteristics	n (%)
Mean age-years (range)	25-87 (59.3)
Ethnic background	
Caucasian	74 (88)
Asian	9 (12)
Marital status	
Single	6 (7)
Married	66 (79)
Divorced	8 (10)
Widowed	3 (4)
Living status	
With spouse/partner	54 (64)
With children	5 (6)
With spouse/partner and children	12 (14)
Sharing house	2 (4)
Living alone	10 (12)
Working status	
Not employed	11 (13)
Casual	2 (3)
Part time	11 (13)
Full time	26 (31)
Retired	32 (39)
Student	1 (1)
Primary caregiver	
Spouse/partner	60 (72)
Parent	12 (15)
Relative	8 (9)
Friend	3 (4)

Table 2: Disease-related characteristics (n = 83)

Cancer diagnosis	n (%)
Breast	29 (35)
Prostate	11 (13)
Head and neck	10 (12)
Gastrointestinal	10 (12)
Lung	9 (11)
Lymphoma	8 (10)
Genitourinary and gynaecological	6 (7)
Metastatic disease	12 (14)
Treatments	
CT	24 (29)
RT	24 (29)
CT-RT	35 (42)
Adjuvant therapy*	8 (10)

*These patients were also receiving either CT or RT. CT = Chemotherapy, RT = Radiotherapy, CT-RT = Chemotherapy and radiotherapy

Among the TRSC symptom list, the CT group reported experiencing symptom severity (mean >1) on 15 symptoms. Patients treated with RT reported a greater severity on 5 symptoms while patients receiving a combination of CT-RT reported severity on 17 symptoms. The three groups reported experiencing these symptoms 50% or more. Overall, patients receiving both CT-RT reported the greatest symptom severity in 11 of the 14 subscales.

Table 3: Comparison between treatment type and symptom severity on TRSC

TRSC subscale/symptoms	Australian						Kruskal-Wallis test
	CT (n = 24)		RT (n = 24)		CT + RT (n = 35)		Between group severity
	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence	P ≤ 0.05
Fatigue							
Feeling sluggish	2.29	95.8	1.54	75.0	2.59	94.3	0.007
Depression	1.29	66.7	0.25	25.0	1.09	54.3	0.002
Difficulty concentrating	1.54	79.2	0.54	37.5	1.47	65.7	0.040
Difficulty sleeping	1.29	66.7	1.17	62.5	1.97	71.4	0.061
Eating							
Taste change	2.00	95.8	0.24	20.8	2.31	80.0	0.000
Loss of appetite	1.88	79.2	0.75	33.3	1.89	82.9	0.001
Weight loss	1.42	83.3	0.58	29.2	1.15	54.3	0.009
Difficulty swallowing	0.70	41.7	0.33	12.5	0.94	51.4	0.012
Oropharynx							
Sore mouth	1.04	58.3	0.22	12.5	1.15	57.1	0.005
Sore throat	0.30	25.0	0.58	20.8	0.94	37.1	0.255
Jaw pain	0.25	16.7	0.13	4.2	0.44	20.0	0.164
Nausea							
Nausea	1.71	87.5	0.42	37.5	1.91	71.4	0.000
Vomiting	0.63	37.5	0.13	8.3	0.57	34.3	0.046
Fever							
Fever	0.96	50.0	0.25	12.5	0.88	40.0	0.021
Bruising	0.63	33.3	0.04	4.2	0.59	34.3	0.012
Respiratory							
Cough	0.33	25.0	0.29	20.8	0.79	45.7	0.037
Shortness of breath	1.08	58.3	0.46	25.0	1.53	65.7	0.004
Pain	1.0	45.8	1.08	62.5	1.79	60.0	0.113
Numbness in fingers±toes	1.33	58.3	0.17	12.5	1.09	51.4	0.001
Bleeding	0.04	4.2	0.17	12.5	0.71	28.6	0.015
Hair loss	1.79	62.5	0.17	8.3	2.56	77.1	0.001
Skin changes	1.63	79.2	1.13	45.8	1.91	77.1	0.093
Constipation	2.04	79.2	0.83	41.7	1.32	54.3	0.006
Soreness in vein	0.67	29.2	0.0	0.0	1.21	45.7	0.003
Decreased interest in sexual activity	1.83	75.0	1.38	54.2	2.12	68.6	0.196

Means severities of symptoms are calculated across all patients including those who report lack of presence or "0." This will provide a lower level of severity than a calculation only across patients who reported having the symptom, since the scores reported would equal or exceed "1" for each patient. % occurrence: Number of patients within that treatment group reporting the symptom, 14 subscales (principal component or clusters) on the TRSC are numbered; beneath 6 subscales are the TRSC items weighted on that subscale based on the study done in the United States (these symptom clusters are used in the current data because the sample size was too small to allow PCA in the Australian, Filipino and Chinese data). CT = Chemotherapy, RT = Radiotherapy, CT-RT = Chemotherapy and radiotherapy, PCA = Prostate cancer

Patients receiving CT alone reported a greater severity of fever, numbness in fingers and/or toes, and constipation.

In terms of percentages of patients reporting the occurrence of each of the 25 symptoms on the checklist, patients receiving CT alone reported a higher rate of occurrence of 13 of the symptoms. This was slightly higher than patients receiving both CT-RT, who reported a higher rate of occurrence in 11 of the 25 symptoms. The RT alone treatment group had the highest occurrence rate for only one of the symptoms: Pain. This is likely to be related to the cumulative burning effect of RT on the skin or mucous membranes of the oropharynx.

When three treatment groups among the Australian cancer patients were compared using Kruskal–Wallis test [Table 3],

there were no significant differences between severity of symptoms in constipation, jaw pain, sore throat, difficulty of sleeping and decreased interest in sexual activity. However, across all three treatment groups, the fatigue subscale had the highest mean severity and percentage of occurrence. The eating, oropharynx, hair loss and skin changes subscales ranked highly in severity and occurrence for patients in the CT-RT group.

Comparison between the Chinese and Filipino cancer patients

Compared with the Chinese and Filipino cancer patients receiving CT, the Filipino cancer patients exhibited severity in five TRSC subscales: Eating, fatigue, nausea, pain and hair loss while in the CT-RT group, severe symptoms were

reported on eight subscales: Fatigue, eating, oropharynx, nausea, pain, decreased sex interest, and constipation. The CT-RT group reported more severe symptoms, that is., mean severity score >1 was reported on 12 symptoms and 9 symptoms were reported by more than 50% of patients. Taste change was the most commonly reported symptoms among the Filipino cancer patients [Table 4].

Among the Chinese cancer patients, 7 symptoms were reported as severe by 50% or more by the CT group, 5 symptoms by 50% or more by the RT group and 8 symptoms by 50% or more by the CT-RT group. Other symptoms reported include diarrhea, hiccough, feeling dizzy, numb feeling of tongue and weight gain. Overall, as shown in the mean severity scores >1, the CT-RT group reported more severe symptoms.

Discussion

This study explored treatment-related symptoms of cancer patients in one regional state in Australia. The symptoms reported by this sample concurred with the symptoms identified by cancer patients in other studies.^[15,21,22,24] Compared with the patients who received either CT or RT alone, patients with combined CT-RT generally reported more severe symptoms. This quite likely reflects increased toxicity and symptom experience of combined RT and CT.

The RT scores reflect a greater tolerance of treatment or less severity of side effects among the Australian, Chinese and Filipino cancer patients. Owing to the fact that side effects of RT are cumulative even in the first few weeks after treatment commences, patients may not be experiencing therapy-related symptoms or be experiencing a low severity in the early stages. Short-term effects of RT occur within a few weeks into therapy whereas the late effects of treatment become apparent toward the end of and following completion of treatment.^[25,26] The cumulative and later effects of RT, therefore, possibly explain the lower severity and occurrence of symptoms in the RT group of this study. In addition, the patients participating in the study will have been at various stages of therapy, which will affect the mean severity scores and may also be culture-related.^[16,18,21,27] It would be helpful to capture the trajectories of symptoms and symptom clusters of such patients longitudinally over the course of treatment.

The most severe symptoms on the TRSC were the fatigue subscale with the highest mean severity and the highest percentage of occurrence across all three treatment groups. The subscales eating and oropharynx and the symptoms hair loss and skin changes in the combined CT/RT group

were the next most severe and frequently encountered symptoms. This is similar to results of studies conducted in the Midwestern hospital in the US,^[22] Thailand, China, and the Philippines.^[16,18,21]

Fatigue has been identified in this and other studies to have the highest severity and occurrence across the three treatment groups as well those reported by the Chinese and Filipino cancer patients. Fatigue has emerged as the most common, distressing complaint reported by cancer patients, due to advances in the management of disabling side effects such as nausea and vomiting.^[28-30] Cancer-related fatigue is multidimensional with multiple etiological factors such as the disease burden, its treatment, and related co-morbidities like depression or anemia.^[31] When these factors are compounded, the severity of fatigue experienced by patients increases.

In addition to the symptoms on the TRSC, participants were asked to nominate any other symptoms they experienced and to rate the severity of the nominated symptoms. Of high occurrence across all three treatment groups were diarrhea, reflux, esophagitis and dry mouth, or xerostomia. The severity of these symptoms was mixed with some more severe in the CT only group and others more severe in patients receiving both CT-RT. Comparison of these finding against previous studies^[16-18] cannot be made as, with the exception of the pilot study, no results have been presented for symptoms other than those listed on the TRSC. In the pilot study, only two “other” symptoms were identified: Diarrhea and facial hair growth. As diarrhea, reflux, esophagitis and xerostomia are common symptoms experienced in cancer treatment,^[9,10,26,32-35] their inclusion in the TRSC may be warranted. The symptoms on the TRSC now account for more than 80% of symptoms identified by patients as present and of concern to them during treatment.

The limitations of this study are the cross-sectional, descriptive study with a small sample size and its over-representation of Caucasians in the sample. In order to determine whether self-care methods used alleviate and control symptom occurrence and severity over time, a longitudinal study is needed that includes increased patient numbers that are a representative cross-section of the population. A longitudinal study would also better capture the symptom experiences of patients undergoing RT, owing to the delayed onset and severity of RT side-effects, as outlined earlier.

Conclusion

In the context of person-centered care, nurses in all oncology settings, particularly outpatient CT or radiation oncology

Table 4: Treatment type and symptom severity on TRSC among Australians, Filipinos and Chinese patients with cancer

TRSC subscale/symptoms	Australian				Filipino				Chinese					
	CT (n = 24)		RT (n = 24)		CT + RT (n = 35)		CT (n = 63)		CT + RT (n = 37)		CT (n = 63)		CT + RT (n = 73)	
	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence	Mean severity	% Occurrence
Fatigue	2.29	95.8	1.54	75.0	2.59	94.3	1.57	82.5	2.08	91.9	1.43	73.0	1.51	74.0
Feeling sluggish	1.29	66.7	0.25	25.0	1.09	54.3	1.29	63.5	1.19	59.5	0.52	34.9	0.52	32.9
Depression	1.54	79.2	0.54	37.5	1.47	65.7	0.97	50.8	0.59	35.1	0.49	30.2	0.71	43.8
Difficulty concentrating	1.29	66.7	1.17	62.5	1.97	71.4	1.48	69.8	1.54	59.5	0.87	47.0	1.21	61.6
Difficulty sleeping														
Eating														
Taste change	2.00	95.8	0.24	20.8	2.31	80.0	1.81	85.7	2.54	100	1.11	58.7	1.01	47.9
Loss of appetite	1.88	79.2	0.75	33.3	1.89	82.9	1.76	79.4	2.59	94.6	1.32	69.8	1.52	74.0
Weight loss	1.42	83.3	0.58	29.2	1.15	54.3	1.10	55.6	1.68	81.1	1.11	58.7	1.30	65.8
Difficulty swallowing	0.70	41.7	0.33	12.5	0.94	51.4	0.65	30.2	0.95	37.8	0.37	23.8	0.64	31.5
Oropharynx														
Sore mouth	1.04	58.3	0.22	12.5	1.15	57.1	0.73	44.4	1.05	45.9	0.40	17.5	0.40	21.9
Sore throat	0.30	25.0	0.58	20.8	0.94	37.1	0.67	33.3	0.70	29.7	0.40	28.6	0.66	35.6
Jaw pain	0.25	16.7	0.13	4.2	0.44	20.0	0.22	11.1	0.38	18.9	0.05	4.8	0.08	4.5
Nausea														
Nausea	1.71	87.5	0.42	37.5	1.91	71.4	0.54	36.5	0.30	27.0	1.17	60.3	1.14	57.5
Vomiting	0.63	37.5	0.13	8.3	0.57	34.3	0.32	20.6	0.05	5.4	1.02	49.2	0.88	47.9
Fever														
Fever	0.96	50.0	0.25	12.5	0.88	40.0	1.57	73.0	1.84	86.5	0.24	15.9	0.45	31.5
Bruising	0.63	33.3	0.04	4.2	0.59	34.3	1.24	52.4	1.38	67.6	0.17	9.5	0.0	0.0
Respiratory														
Cough	0.33	25.0	0.29	20.8	0.79	45.7	0.67	47.6	0.59	35.1	0.41	28.6	0.60	37.0
Shortness of breath	1.08	58.3	0.46	25.0	1.53	65.7	0.57	30.2	0.43	29.7	0.40	27.0	0.44	27.4
Pain	1.0	45.8	1.08	62.5	1.79	60.0	1.03	54.0	1.24	59.5	0.70	41.3	0.90	42.5
Numbness in fingers±toes	1.33	58.3	0.17	12.5	1.09	51.4	0.97	57.1	0.70	37.8	0.81	44.4	0.47	27.4
Bleeding	0.04	4.2	0.17	12.5	0.71	28.6	0.22	14.3	0.35	16.2	0.16	9.5	0.19	27.4
Hair loss	1.79	62.5	0.17	8.3	2.56	77.1	0.92	76.2	0.78	43.2	1.48	57.1	1.45	63.0
Skin changes	1.63	79.2	1.13	45.8	1.91	77.1	1.86	52.4	0.95	43.2	0.84	38.1	0.93	53.4
Constipation	2.04	79.2	0.83	41.7	1.32	54.3	0.98	58.7	1.27	48.6	0.83	47.6	0.96	47.9
Soreness in vein	0.67	29.2	0.0	0.0	1.21	45.7	0.89	57.1	0.54	45.9	0.67	42.9	0.55	30.1
Decreased interest in sexual activity	1.83	75.0	1.38	54.2	2.12	68.6	0.97	38.1	1.35	45.9	0.76	25.6	1.52	54.8

Means severities of symptoms are calculated across all patients including those who report lack of presence or "0." This will provide a lower level of severity than a calculation only across patients who reported having the symptom, since the scores reported would equal or exceed "1" for each patient. % occurrence. Number of patients within that treatment group reporting the symptom. 14 subscales (principal component or clusters) on the TRSC are numbered; beneath 6 subscales are the TRSC items weighted on that subscale based on the study done in the United States (these symptom clusters are used in the current data because the sample size was too small to allow PCA in the Australian, Filipino and Chinese data). CT = Chemotherapy, RT = Radiotherapy, CT-RT = Chemotherapy and radiotherapy, PCA = Prostate cancer

centers are uniquely placed to assess patients' therapy-related symptoms. Assessment of the problems patients are experiencing enables nurses to target education to the patients' individual needs. Information provided in studies such as this one will provide nurses with a range of options to present to their patients. These studies also improve awareness of the multiplicity of symptoms of concern to patients that occur in combination or in clusters.^[36]

The TRSC was found to be an effective tool that can be used in combination to gather information about symptom severity that could be used to guide translational approaches to treatment-related symptoms and thereby increase cancer patients' adherence and tolerance to curative treatments, enhance therapeutic outcomes and greater quality of life.

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