

PERSPECTIVE OF LEBANESE ONCOLOGISTS ON THE SYMPTOM BURDEN AMONG ADULT CANCER PATIENTS

<http://www.lebanesemedicaljournal.org/articles/64-4/original3.pdf>

Hind RAFEI¹, Maya KHALIL^{1,2}, Yasmin HASSOUN^{1,3}, Alain MINA¹, Zeina NASSER^{1,4}, Arafat TFAYLI^{1*}

Rafei H, Khalil M, Hassoun Y, Mina A, Nasser Z, Tfayli A. Perspective of Lebanese oncologists on the symptom burden among adult cancer patients. *J Med Liban* 2016; 64 (4) : 200-204.

ABSTRACT • Background : Proper approach to symptom control in cancer patients requires a good understanding of the prevalence of the various symptoms these patients have. **Aim :** This study aims at assessing the Lebanese oncologists' point of view concerning the symptom burden among cancer patients of Lebanon and comparing their opinions to the real complaints of patients themselves. **Methods :** A cross-sectional study was conducted among a representative sample of the Lebanese medical oncologists. Thirty-six physicians filled out a questionnaire regarding their demographics as well as the symptom profile of their patients. Those results were compared to the ones obtained from our previous study about symptom profile as reported by patients. **Results :** Fatigue was the symptom most our patients suffered from according to their physicians (64.167%). Also, a good percentage of physicians agreed that patients suffer from appetite loss, pain, weight loss, and nausea. When compared to the patients' reports of their own symptoms, a statistically significant difference existed between the two profiles for the majority of symptoms (14 out of 19). Also, for the majority of symptoms, physicians were found to underestimate the percentage of patients suffering from each symptom. **Conclusion :** This study shows that there is a statistically significant difference between the physicians' and the patients' perspectives on most of the common distressing symptoms. This entails more detailed questioning of the cancer patients about their distressing symptoms.

Keywords : palliative care, physicians' perspective, symptom burden

Rafei H, Khalil M, Hassoun Y, Mina A, Nasser Z, Tfayli A. La perspective des oncologues libanais sur le profil des symptômes de patients atteints de cancer. *J Med Liban* 2016; 64 (4) : 200-204.

RÉSUMÉ • Introduction : Il est indispensable de comprendre la prévalence des symptômes des patients atteints de cancer afin de les bien adresser. **But de l'étude :** Évaluer les opinions d'oncologues libanais sur le fardeau de symptômes dont souffrent les patients libanais atteints de cancer et les comparer aux plaintes actuelles des patients. **Méthodes :** Analyse transversale d'un échantillon représentatif d'oncologues libanais. Trente-six médecins ont rempli un questionnaire concernant leurs données démographiques ainsi que le profil des symptômes de leurs patients. Les résultats sont comparés à ceux déjà obtenus par notre étude précédente ayant établi le profil des symptômes rapportés par les patients eux-mêmes. **Résultats :** La fatigue était le symptôme le plus prévalent parmi nos patients selon leurs médecins (64,167%). De plus, nombre de médecins ont rapporté que leurs patients souffrent de perte d'appétit, de douleurs, de perte de poids et de nausées. La comparaison de ces résultats aux plaintes actuelles des patients révèle une différence statistiquement significative entre les deux perspectives pour la majorité des symptômes (14/19). Les médecins ont également tendance à sous-estimer pour chacun de ces symptômes le pourcentage de patients qui en souffrent. **Conclusion :** Cette étude montre qu'il y a une différence statistiquement significative entre les perspectives des médecins et celles de leurs patients concernant les symptômes les plus pénibles. Elle démontre la nécessité d'un questionnement mieux détaillé des patients à propos de leurs symptômes.

INTRODUCTION

Palliative oncology is a continuously growing multidisciplinary approach to symptom control among cancer patients. It had made immense strides over the last decade as it was able to optimize the quality of life of cancer patients by integrating symptom control, effective communication and quality care [1].

Departments of Internal Medicine

¹American University of Beirut Medical Center (AUBMC), Beirut, Lebanon.

²University of Miami Miller School of Medicine, West Palm Beach Regional Campus, Miami, USA.

³University of Cincinnati, Ohio, USA.

⁴Université Libre de Bruxelles, Belgium.

*Correspondence: Arafat Tfayli, MD.
e-mail: at35@aub.edu.lb

An essential component of palliative care remains the appropriate assessment of symptom burden in cancer patients, which was addressed extensively in the literature. A recent study published by our group under the title of "Physical Symptom Profile for Adult Cancer Inpatients at a Lebanese Cancer Unit" assessed the prevalence of symptoms among cancer patients in a Lebanese center and found that fatigue, nausea and pain remain to be the most distressing [2]. On the other hand, better delivery of palliative care services entails the awareness of oncologists about the epidemiology of patients' symptoms especially in our area where the trend is more toward unification of oncology and palliative care. In that concern, what is the Lebanese oncologists' point of view concerning the symptom burden among cancer patients and to what extent their opinions are concordant with those of patients themselves? In other words, what

is the level of awareness among Lebanese oncologists regarding cancer symptoms burden?

Assessing physicians' knowledge about a pivotal aspect of palliative care such as the symptom burden is the first step in making effective palliative care systems. In fact, answering the previously proposed questions will help direct education programs that aim at integrating palliative care into oncology. It will unveil one of the most important barriers to symptom management leading to better addressing the nontechnical aspects of patient care and thus to greater patient and family satisfaction.

The Eastern Cooperative Oncology Group (ECOG) conducted in 1993 a survey to determine the amount of knowledge about cancer pain and its treatment among physicians practicing in ECOG-affiliated institutions. The study showed that the inadequate assessment of patients' pain by physicians is the single most important barrier against a proper cancer pain management [3]. Similar thoughts were raised in a correspondence by Haris Charalambous whereby he attributed the lack of expertise in managing pain of cancer patients partly to the fact that oncologists are focusing more on disease directed therapy than on the physical, psychological, social and spiritual aspects of the disease and their treatments [4]. This compelled a recent ASCO statement to promote for integration into the care of cancer patients an individualized assessment of patients' needs, goals, and preferences and for paying attention to symptom management as well as quality of life [5]. In addition, ASCO started investigating the optimal timing for integrating oncology and palliative care in a recent randomized controlled trial [6]. Interestingly, Abrahm introduced the concept of "compassion fatigue" as being a barrier into integrating oncology with palliative care. "Compassion fatigue" is the burnout that oncologists reach after cumulative grief experiences so that they progressively dissociate from understanding patients' symptoms [7].

Concerning the classification of symptoms suffered by cancer patients as viewed by oncologists, the European Society of Medical Oncology surveyed its membership regarding their attitudes toward palliative care. Respondents were more commonly involved in treating physical symptoms such as pain (93%), fatigue (84%) and nausea/vomiting (84%) than in caring for psychological symptoms and end-of-life issues (depression and anxiety (65%), existential distress (29%) and delirium (12%)) [8]. Uncontrolled pain is also reported by physicians to be the cause that accounts for the major requests they receive for physician-assisted suicide and euthanasia [9]. In contrast, one study focused on the perspective of oncologists on pain specifically and uncovered the presence of substantial under-diagnosis of pain in cancer patients by their primary physicians. This leads to a late referral to palliative care and of course worse quality of life [10].

While many studies appealed for an urgent awareness-raising among oncologists about symptom management and a number of publications evaluated the diagnosis of pain by oncologists, there is no single comprehensive study

that assessed the opinion of oncologists about the profile of distressing symptoms among cancer patients. Our study aimed at assessing the Lebanese oncologists' point of view regarding the symptom burden among cancer patients and comparing their assessments to the actual complaints of the patients. Indeed, the question remains whether oncologists of Lebanon are aware of the hierarchy of symptoms that bother cancer patients.

METHODS

A cross-sectional study was conducted among a representative sample of the Lebanese oncologists. Local IRB approval was obtained. Among the 70 practicing medical oncologists in Lebanon, a total of 55 physicians were approached to be part of the study. Thirty-six physicians responded in total. This sample size (N = 36) represents roughly 50% of the total number of medical oncologists in Lebanon. After giving oral consent to participate in the study, all study participants were asked to fill out a questionnaire regarding their demographics (Table I) as well as the symptom profile of their patients. Specifically, they were asked to fill in the percentage of patients suffering from each one of the physical symptoms listed in table II among the patients who they were actively seeing. Also, each physician was asked to mention the symptom that is most distressing to the majority of his patients. The symptoms that they were asked about in the questionnaire included fatigue, pain, appetite loss, weight loss, dry mouth, constipation, dyspnea, edema, taste changes, urinary symptoms, dysphagia, hoarseness, skin symptoms, diarrhea, nausea, vomiting, cough, early satiety and sore mouth. Physicians were given the option to either answer from memory or do chart review if they would like to. The majority of answers were based on the physician overall impression of his patient population rather than exact chart review.

The average percentage of patients suffering from each symptom as reported by oncologists was calculated and accordingly symptoms were ranked from the one suffered by the highest percentage to the one suffered by

TABLE I
DEMOGRAPHICS and CHARACTERISTICS of ONCOLOGISTS

	Variables	N	%
Age	< 40	6	16.7
	40 < Age < 50	14	38.9
	> 50	15	41.6
	Not available	1	2.8
Gender	Male	28	77.8
	Female	8	22.2
Years of Practice	< 10	7	19.4
	10 < Years < 20	16	44.5
	> 20	13	36.1

the lowest percentage of patients. Also, the one symptom that was mentioned by most physicians to be most distressing to the majority of their patients was reported. Oncologists' assessment was compared to that of the 100 cancer patients who were interrogated in our previous study that reported physical symptom profile in Lebanese adult cancer inpatients. Though the data analyzed is derived from two different studies, the gap in time frame between the two was unremarkable since they were almost sequential.

Using the T test, a *p*-value for the difference between the percentages reported by physicians and the actual percentages (as reported by patients) was calculated for each of the symptoms.

The discrepancy between the oncologists' perspectives and the actual profile was evaluated.

RESULTS

A total of 36 physicians among the Lebanese medical oncologists were surveyed. Their characteristics are summarized in Table I. Essentially, 22.2% were females and 77.8% were males. The majority of the responding physicians were either older than 50 (41.6%) or between 40 and 50 (38.9%). Only 16.7% were younger than 40; 44.5% of the physicians have been in the practice anywhere between 10 to 20 years; 36.1% have been practicing oncology for more than 20 years while the remaining 19.4% reported less than 10 years of practice. This reflects a population with relatively long careers in the oncology field.

According to oncologists, fatigue was the symptom that is distressing to the highest number of patients (64.17%).

TABLE II
ASSOCIATION BETWEEN the MEAN of EACH SYMPTOM as SEEN by the ONCOLOGISTS and the MEAN of EACH SYMPTOM DESCRIBED by the PATIENTS

Symptom	Mean (Oncologists)	Mean (Patients)	<i>p</i> Value
Fatigue	64.167	77	0.003
Pain	41.25	62	< 0.001
Appetite loss	51.94	69	< 0.001
Weight loss	41.38	57	< 0.001
Dry mouth	26.52	59	< 0.001
Constipation	29.58	44	< 0.001
Dyspnea	25.69	33	0.009
Edema	22.42	27	0.042
Taste change	33.19	44	0.009
Urinary symptom	18.33	22	0.118
Dysphagia	14.34	15	0.714
Hoarseness	11.91	20	< 0.001
Skin symptom	25.63	40	< 0.001
Diarrhea	28.38	29	0.799
Nausea	53.88	65	0.012
Cough	24.30	29	0.019
Early satiety	20.88	60	< 0.001
Sore mouth	22.35	22	0.904
Vomiting	35.28	33	0.407

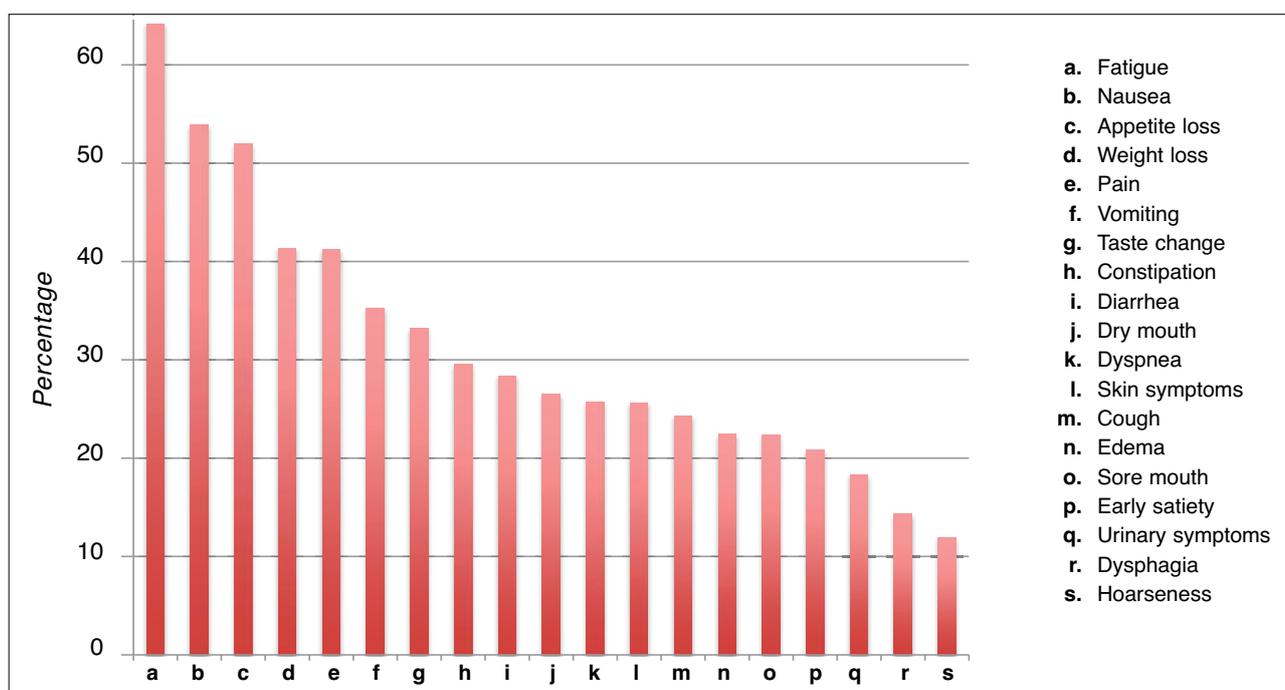


FIGURE 1. The mean percentages of patients with specific physical symptoms according to oncologists.

Also, oncologists consider that more than half of the patients suffer from appetite loss (51.94%) and nausea (53.88%). Among the symptoms that were regarded by oncologists to be distressing to a considerable number of patients are pain (41.25%) and weight loss (41.38%). Other symptoms like dry mouth, constipation, dyspnea, edema, taste changes, skin manifestations, diarrhea, vomiting, cough, early satiety and sore mouth were considered by oncologists to be suffered by one fifth to one third of the patients.

On the other hand, the symptoms that were thought to be least reported by patients included urinary symptoms, dysphagia, and hoarseness with the latter being the one that was regarded as distressing to the minimal number of patients. These results are illustrated in Figure 1.

Those results were compared to the actual percentages of patients suffering from each symptom. The statistical significance of the agreement between the two is shown in Table II. Symptoms were divided into two categories: those with statistically significant disagreement between the physicians' reports and the actual percentages and those with no statistically significant disagreement. Most symptoms fall into the first category. The difference between the mean described by the patients and that reported by physicians for each symptom where p -value is significant ($p < 0.05$) is illustrated in Figure 2 while that for each symptom where p -value is not significant is shown in Figure 3. For all the symptoms where there is no agreement between the opinions of physicians and patients, the oncologists perceived percentages were always lower than the actual percentage.

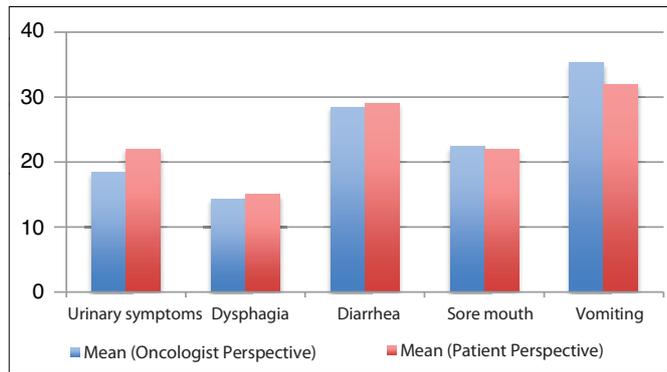


FIGURE 3. The difference between the mean of each symptom as seen by the oncologists and the mean described by the patients where p -value is NOT significant (p -value $>$ 0.05)

DISCUSSION

This cross-sectional study investigated the Lebanese oncologists' perspectives regarding the symptom burden among their patients. The primary aim is to evaluate the level of awareness among these physicians with regards to the distressing symptoms their patients are suffering from, mainly by comparing the results to the actual symptom burden profile of the Lebanese patients. This leads to the need to implement new strategies in the domain of palliative care essentially by focusing more on the communication between oncologists and cancer patients regarding their symptoms.

In this study, grossly, there is a concordance between both patients and physicians in terms of the most com-

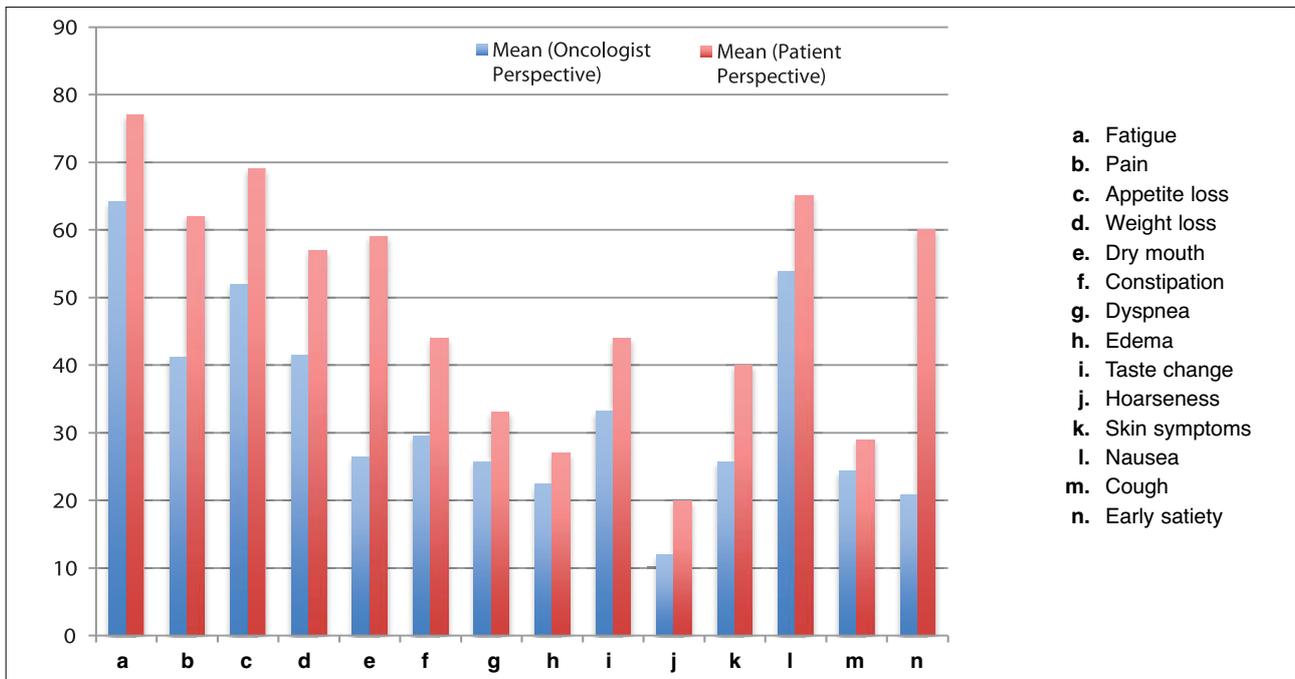


FIGURE 2. The difference between the mean of each symptom as seen by the oncologists and the mean described by the patients where p -value is significant (p -value $<$ 0.05)

mon symptoms. Fatigue, appetite loss, nausea and pain were found to be the most common among patients when surveying both patients at a Lebanese hospital and Lebanese oncologists [2]. However, in terms of percentages, there is a statistically significant disagreement between those reported by physicians and those reported by patients for the majority of symptoms. In a study by Oechsle *et al.* regarding the symptom burden in palliative care patients, physicians scored discordance in 67% of all the symptoms [11]. In our study, the discordance was scored in a similar number of symptoms (14 out of 19 or 73.68%). These symptoms include those that are actually most common among cancer patients (fatigue, appetite loss, nausea and pain) and the ones that are most distressing as well (nausea, pain and fatigue) [2]. This constitutes an additional threat to the unawareness among the physicians as the most important of the symptoms are not being well regarded, both in terms of frequency and magnitude of distress.

Our assessment of the agreement between patients and physicians showed that oncologists tend to underestimate all symptoms where there is a statistical significant disagreement (100% of the symptoms). Underestimation ranges from 4.58% to 39.12%. The highest rates of underestimation corresponded to early satiety (39.12%) and dry mouth (32.48%). Those findings go hand in hand with those concluded in a study by Laugsand *et al.* who found that health care providers tend to underestimate all symptoms among cancer patients in a multicenter European study [12]. However, the findings are in contrast to those in primary care where general practitioners as well as nurses tend to overestimate the symptoms among cancer patients [13].

The symptoms where disagreement was not statistically significant include sore throat, urinary symptoms, dysphagia, diarrhea and vomiting. Many of these symptoms are cancer type specific, cancer stage specific or therapy related. Sore mouth and dysphagia are common side effects of chemotherapy. Head and neck cancers also increase the risk of complaining from them. Mucositis is more prominent in patients with head and neck tumors who require large radiotherapy doses and in those with malignancies which treatment leads to neutropenia [14]. Also, dysuria and hematuria were found to be both common and significantly associated with bladder cancer among primary care patients [15]. This also alludes to some factors related to the absence of statistically significant disagreement. While our study was not segregated by cancer type, cancer stage nor the presence of therapy, it is always important to start by assessing the level of awareness of physicians regarding symptoms among the general cancer population.

CONCLUSION

This study shows that there is a statistically significant difference between the physicians' and the patients' perspectives on most of the common distressing symptoms. Thus, we can confidently conclude that the physicians

who are treating cancer patients are undermining a very important aspect of their care, which is symptom-related care. Addressing this issue constitutes the first step towards better palliative care.

CONFLICTS OF INTERESTS

No organization has sponsored the research. Authors have full control of all primary data and agree to allow the journal to review their data if requested. The authors declare that they have no conflict of interest to disclose.

REFERENCES

1. Epstein A, Morrison R. Palliative oncology: Identity, progress and the path ahead. *Ann Oncol* 2012; 23 Suppl 3: 43-8.
2. Halawi R, Aldin E, Baydoun A et al. Physical symptom profile for adult cancer inpatients at a Lebanese cancer unit. *Eur J Intern Med* 2012; 23: e185-e189.
3. Von Roenn J, Cleeland C, Gonin R, Hatfield AK, Pandya KJ. Physician attitudes and practices in cancer pain management: A survey from the Eastern Cooperative Oncology. *Ann Intern Med* 1993; 119: 121-6.
4. Charalambous H, Silbermann M. Clinically based palliative care training is needed urgently for all oncologists. *J Clin Oncol* 2012; 30: 4042-3.
5. Peppercorn J, Smith T, Helft P et al. American Society of Clinical Oncology statement: toward individualized care for patients with advanced cancer. *J Clin Oncol* 2011; 29: 755-60.
6. Bakitas M, Tosteson T, Li Z et al. Early versus delayed initiation of concurrent palliative oncology care: Patient outcomes in the ENABLE III Randomized Controlled Trial. *J Clin Oncol* published online on March 23, 2015.
7. Abrahm J. Integrating palliative care into comprehensive cancer care. *J Natl Compr Canc Netw* 2012; 10: 1192-8.
8. Cherney N, Catane R. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer. *Cancer* 2003; 98: 2502-10.
9. Breitbart W. Suicide risk and pain in cancer and AIDS patients. In: Chapman C, editor. *Current and Emerging Issues in Cancer Pain: Research and Practice*. New York City, United States of America: Raven Press, 1993: 49-65.
10. Akashi M, Yano E, Aruga E. Underdiagnosis of pain by primary physicians and late referral to a palliative care team. *BMC Palliat Care* 2012; 11: 1.
11. Oechsle K, Goerth KB, Mehnert A. Symptom burden in palliative care patients: Perspectives of patients, their family caregivers, and their attending physicians. *Support Care Cancer* 2013; 21: 1955-62.
12. Laugsand E, Sprangers M, Bjordal K, Skorpen F, Kaasa S, Klepstad P. Health care providers underestimate symptom intensities of cancer patients: A multicenter European study. *Health Qual Life Outcomes* 2010; 8: 1.
13. Ewing G, Rogers M, Barclay S et al. Palliative care in primary care: A study to determine whether patients and professionals agree on symptoms. *Br J Gen Pract* 2006; 56: 27-34.
14. Epstein J, Thariat J, Bersadoum R et al. Oral complications of cancer and cancer therapy: From cancer treatment to survivorship. *CA Cancer J Clin* 2012; 62: 400-22.
15. Shephard E, Stapley S, Neal R, Rose P, Walter F, Hamilton W. Clinical features of bladder cancer in primary care. *Br J Gen Pract* 2012; 62: e598-e604.