Unmet supportive care needs of lung cancer patients during the chemotherapy phase: A descriptive study

Andrea Serena[1,2,4], Anne-Claude Griesser[2], Patricia Débarge[2], Nadia Fucina[3], Solange Peters[3], Manuela Eicher[1,4]

[1] Haute école de santé Fribourg – HES SO
[2] Centre Hospitalier Universitaire Vaudois – CHUV
[3] Centre Pluridisciplinaire d'Oncologie – CePO
[4] Institut Universitaire de Formation et de Recherche en Soins, Université de Lausanne – HES SO

Introduction

In Switzerland, around 2500 males and 1200 females are newly diagnosed with lung cancer each year. Lung cancer is considered as the second most frequent cancer for male (13%) and the third for female (8%). Prevalence is increasing with age, and is highest between 50 and 75 years[1]. Federal Statistical Office[2] estimates that in term of mortality lung cancer will become the most frequent oncological cause of death for male and female. Compared to other major cancers, lung cancer has a low survival rate with 14% at five years. In spite of considerable advancement in multimodal cancer treatment, no significant decline in this cancer-specific mortality has been observed so far. Many tumours are discovered at a late stage partially due to the current status with no routine screening recommended for lung cancer[3,4].

Lung cancer patients suffer from more physical and psychological symptoms caused by the disease and the sides effects of the oncological treatment (chemotherapy, radiotherapy and surgery) than patients with other major cancers. Highest symptom prevalence has been observed for dyspnoea, cough, fatigue, anorexia, pain, insomnia, anxiety and depression[5-7].

Recently, studies investigated links between smoking behaviour and experience of lung cancer patients' showing that smoking patients recognized lung cancer as a self-inflicted disease, and experienced discrimination and stigmatisation by society[8,9].

Due to severe symptoms and unfavorable prognosis, lung cancer patients have specific supportive care needs that should be assessed and met by a multidisciplinary cancer team. The Multinational Association of Supportive Care in Cancer defines supportive care as «the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to Supportive Care»[10].

A growing body of research focuses on psychosocial needs aspect of cancer since needs assessments directly assess and identify specific issues of need for patients taking into account the hole perceived cancer experience[11,12]. In fact, patient-centred care is unlikely to occur without a good understanding of patient needs and influencing factors. An assessment of patients' perceived supportive care needs allows identifying the intensity of need including prioritization of service needs. Such an approach allows the individualised allocation of resources to prevent or at least to reduce problems through appropriate early interventions[13,14].

During the past decade, several studies focused on assessment of unmet supportive care needs reflecting the multidimensional impact of cancer. Cancer patients have reported high levels of unmet need related to issues such as

Tab. 1. Demographic and medical characteristics of participants

Variable		M (SD)	n	(%)
Genre	Male		19	(51.3)
	Female		18	(48.7)
Age		61.4 (8.7)		
Age (years)	<55		7	(18.9)
	55-64		19	(51.3)
	65-74		8	(21.6)
	75-84		2	(5.5)
	>85		1	(2.7)
Area of residence	City		25	(67.6)
	Countryside		12	(32.4)
Level of education	Obligatory educational		13	(35.2)
	Apprenticeship		17	(45.9)
	University, graduate school		7	(18.9)
Diagnosis	NSCLC		29	(78,4)
	SCLC		8	(21,6)
Stage of disease	I/II		9	(24,3)
	III/IV		20	(54,1)
	Limited		5	(13,5)
	Extensive		3	(8,1)
Smoking before diagnosis	Yes		31	(83.8)
	No		6	(16.2)
Smoking cessation after diagnosis	Yes		15	(48.4)
	No		16	(51.6)

provision of information, psychosocial support, practical assistance and sexual issues[15]. However, lung cancer seems an underexplored population. A search in CINAHL and PUBMED resulted in three studies assessing the supportive care needs of this specific population[16-18]. Many assessments of supportive care needs focused on cancer patients in general at different stages of the disease or specifically on breast cancers patients[15,19]. The few studies focussing on the needs of lung cancer patients suggest that lung cancer patients have significantly more unmet supportive care needs than other patients groups[16]. Results showed also that patients living with lung cancer reported especially high unmet supportive care needs in the psychological and physical and daily living domains[16-18]. To our knowledge, no needs assessment of lung cancer patients in the Swiss health care system has been conducted. To improve high quality care including patient self-determination needs assessments are among the prioritized goals of the national cancer programme[20].

The goals of this study are (a) to describe the unmet supportive care needs among patients suffering from lung cancer during the chemotherapy phase at a University Hospital in Switzerland and (b) to explore a potential relation between the unmet supportive care needs and the patient's age, gender and smoking cessation after diagnosis.

Method

Sample and Setting

We conducted a descriptive study by means of a cross-sectional survey in a Swiss University Hospital. Patients were recruited in the outpatients' and inpatients oncological departments following a non-probability consecutive sampling method. Adult lung cancer patients that were undergoing chemotherapy treatment between January 2011 until February 2012 with 5 months break (April-August 2011) were invited to participate in the study. Patient eligibility criteria included being registered in the hospital as lung cancer patients (NSCLC or SCLC), at least eighteen years of age, being diagnosed 16 weeks ago, being under chemotherapy treatment, being capable of speaking and writing in French and being physically and mentally able to complete the questionnaire. This study was approved by cantonal ethics committee (174/10).

Procedure

The oncologist of each patient met patients during post chemotherapy consultation and explained study objectives and methods, handed out two questionnaires with a stamped return envelope to patients. An accompanying cover letter was used to remind patients of the main study goal. Participants who did not return the questionnaires after 3 weeks received a follow-up telephone call by the investigator.

Measures

We used the Support Care Needs Survey, short form comprising 34 items (Supportive Care Needs Survey-SF34)[14]. The purpose of the SCNS SF 34 instrument is to provide a direct and comprehensive assessment of the multidimensional impact of cancer on the needs of cancer patients. The development and assessment of the survey's psychometric properties, including a list of survey items, are fully described in the user's guide[21]. The SCNS SF 34 asks patients to indicate their level of supportive care needs with issues grouped into 5 main domains: psychological (PS), health system and information (HIS), physical and daily living (DL), patient care and support (PC) and sexuality needs

Tab. 2. 11 needs that were not met by at least 50% of the patients (n= 37)

Rank	Need (Item of SCNS SF 34)	Domain	Unmet needs* n (%)
1	Uncertainty about the future	PS	26 (70.3)
2	Being informed about things you can do to help yourself to get well	HIS	24 (64.8)
3	Anxiety	PS	23 (62.2)
3	Worry that the results of treatment are beyond your control	PS	23 (62.2)
4	Not being able to do the things you used	DL	22 (59.5)
4	Feeling of sadness	PS	22 (59.5)
4	Learning to feel in control of your situation	PS	22 (59.5)
4	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	HIS	22 (59.5)
5	Fears about the cancer spreading	PS	21 (56.8)
5	Concerns about the worries of those close to you	PS	21 (56.8)
6	Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it.	HIS	19 (51.4)

Note. DL: Physical and daily living / PS: Psychological / HIS: Health system and information (HIS)
* dichotomized each item of SCNS SF 34 on Likert scale (1- 2 = no need) and (3-4-5 = unmet needs).

(S). Each item is preceded with the stem question, «In the last month, what was your level of need for help with …?» Importance of needs is rated on a 5-point Likert scale (not applicable=1; satisfied=2; low need=3; moderate need=4; high need=5). Translation from the English version of SCNS SF 34 to a French version assessed reliability of the SCNS-SF34 questionnaire for the five domains with a 0.7 Cronbach's alpha scores that is considered as the minimum score for the questionnaire to be considered as reliable[22]. Socio-demographic variables were measured by an additional survey exploring family situation, country of origin, education and other related socio-demographic factors. Medical data were based on medical records.

Statistical analyses
Descriptive statistics used STATA ® version 11. To identify level of dissatisfaction of patients for each domain of SCNS SF 34, we calculated a mean, median score (*Md*), standard deviation (*Sd*) and minimum and maximum (Min and Max) for each domain of the survey and standardised final scores on a scale from 0 to 100. The maximum possible score was 100 (high needs) and the lowest score 0 (no needs)[21]. To identify more specifically which supportive care need is unmet, we dichotomized each item of SCNS SF 34 to create two variables for each item (1-2 points on Likert scale=no need) and (3-4-5 points on Lickert scale=unmet needs) [21]. We used frequency distributions to show needs that were not met by at least 50% the patients. Ranksum Wilcoxon test was used to test if gender, smoking cessation after diagnosis and age (Spearman test) would be associated with level of supportive care need. Significant predictors were identified as those with a *p*-value < 0.05 in the final model.

Results

Participant
Of 220 eligible patients, 106 were approached by doctors and 37 agreed to participate in the study. In total, 37 patients sent back the questionnaire. Patients who refused to participate in the study were fatigued or not interested in the study.

Socio-demographic and medical data
Table 1 provides details on the main characteristics of patients. We found that 91.8% of patients were less than 75 years old and gender was equally divided. Thirty-five per cent had obligatory educational level and 45% had apprenticeship educational level. Based on the Tumour Node Metastasis classification system and The Veterans Administration Lung Group classification, 78.4% were identified as having a NSCLC and 21.6% SCLC. Sixteen per cent of patients did not smoke and among smokers, 48.4% stopped smoking after diagnosis.

Hierarchy of unmet needs
Table 2 describes the hierarchy of patients' needs. The results showed that 11 items were not met by at least 50% the patients. The two most prevalent unmet supportive care needs were: «Uncertainty about the future» (70.3%) followed by «Being informed about things you can do to help yourself to get well» (64.8%). Among 11 items that were not met by at least 50%, we didn't found items linked of sexual (S) and patient care and support (PC), but we found one item linked of physical and daily living: «Not being able to do the things you used» (59.5%).

Domains of supportive care needs
Across the five domains in the SCNS SF 34, participants reported the highest level of need for help with psychological needs (*Md*= 47.5), followed by physical and daily living needs (*Md*= 40), health system and informational needs (*Md*= 36.4), patient care support needs (*Md*= 30) and sexuality needs (*Md*= 16.7) [Table 3].

Relation between the unmet supportive care needs and the patient's age, gender and smoking cessation after diagnosis
Age, gender, and smoking cessation did not show to be significantly associated with total supportive care needs or any of the five subscales of the SCNS SF 34.

Discussion

This study highlights the high level of psychological (*Md*= 47.5), physical (*Md*= 40) and informational (*Md*= 36.4) unmet supportive care needs among lung cancer patients undergoing chemotherapy treatment. These findings suggest that unmet supportive care needs are common across individuals with lung cancer. Age, gender and smoking cessation did not show to be associated to unmet supportive care needs.

Tab. 3. Level of dissatisfaction about supportive care needs for each standardized domain of SCNS SF 34 (n. 37)

Domain	Md	M	Sd	Min-Max*
Psychological (PS)	47.5	46.3	20.9	7.5 - 82.5
Physical and daily living (DL)	40	41.2	19.8	10 - 90
Health system and information (HIS)	36.4	39.12	18.2	6.8 - 97.8
Patient care and support (PC)	30	33.2	21.6	0 - 100
Sexuality (S)	16.7	22.8	30.5	0 - 100

*Possible values ranging from zero to 100.

More than half of all patients expressed an interest in services related to information linked to self-care management at home. In fact, 64.8% (rank 2) patients expressed dissatisfaction concerning «Being informed about things you can do to help yourself to get well» and 59.5% (rank 4) concerning «Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home». One possible reason is that the level of educational background in the sample was low (35.2%) or medium (45.9%) which has been described as a factor predicting unmet needs linked to informational domain[23]. Nevertheless, our results differ substantially from other international studies in the field[16,17] and might therefore underline the importance of providing personalised information and education to patients. Another interesting finding was that the level of sexual needs was not expressed as unmet by the majority of patients. Indeed, several studies showed that high level of sexual needs was associated with high level of symptoms (nausea, vomit, dyspnoea, pain)[24-26]. Potentially, patients had unmet needs in the sexuality domain but those kind of needs weren't a priority in this phase of their illness trajectory.

High level of physical and daily living needs could be linked to side effects of chemotherapy and symptoms of disease such as fatigue, pain, sleep disturbance and dyspnoea[5,6,27,28]. High level of psychological needs could be explained by the influence of unfavourable prognostic which could cause more psychological distress than other cancers and the negative effect of high level of physical needs on psychological domain[28-30]. As our medical data show, a high proportion of patients had advanced stage of disease (54.1% III/IV) so that the additional burden caused by symptoms and unfavourable prognoses may have influenced the results. Our results regarding high level of psychological and physical needs are in accordance with the three similar studies focussing on assessment of supportive care needs on lung cancer patients. In contrast though, in our study patients expressed high levels of unmet informational needs that had not been observed elsewhere[16-18].

This study did not show any evidence of a relation between unmet supportive care needs and the patient's age, gender or smoking cessation after diagnosis. Concerning age and gender, our results are in accordance with a previous study of 109 lung cancer patients[17]. In contrast, previous studies observed an association of distress and quality of live with gender and age[29,30]. To date, few studies focused on a possible association between needs and to smoking habits in lung cancer patients. Further research is needed since perceived cancer-related stigma in lung cancer patients is higher than prostate and breast cancer[8]. This might impact the willingness or ability to express needs towards health professionals. Our study has several limitations. First, our sample size was limited to generalize results or to use parametric statistics tests. The recruiting showed to be particularly difficult in this patient population. The sample therefore is small (37 patients). Secondly, non-probability consecutive sampling method has several limitations in terms of representativeness of the target population. Finally as the study was performed in a single university hospital, our study findings may lack generalizability to other settings. In terms of practical implications of our findings, we point out the importance to improve supportive care for lung cancer through chemotherapy phase in targeting on physical, psychological and informational needs of patients. We suggest to integrate the Supportive Care Needs Survey Screening Tool 9 with existing care as to identify and address unmet supportive care needs[31]. Concerning the importance of providing personalised information and education to patients, our results showed the need to get educated on management of symptoms that could be provided in a prechemotherapy education intervention on patient distress, symptom burden, and treatment[32]. Furthermore, the promotion of coping strategies offered by health professionals could also improve the patient's self-efficacy to cope with symptomatology and their physical well-being[33]. More research examining longitudinal changes of supportive care needs integrating interventions to meet lung cancer patients' needs is strongly recommended. Additionally studies would enable us to investigate with a larger sample the relationship between smoking and supportive care needs.

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Correspondence:

Andrea Serena
Assistant de recherche
Haute école de santé Fribourg
Route des Cliniques 15, CH-1700 Fribourg
andrea.serena@hefr.ch
www.heds-fr.ch