

## Original Article

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**Author for correspondence:**

Michèle Aubin, Université Laval, Pavillon Ferdinand-Vandry, 1050 Ave de la Médecine, Room 4617, Québec, QC G1 V 0A6, Canada.  
E-mail: [michele.aubin@mfa.ulaval.ca](mailto:michele.aubin@mfa.ulaval.ca)

# Distress experienced by lung cancer patients and their family caregivers in the first year of their cancer journey

Michèle Aubin, M.D., PH.D., C.C.F.P., F.C.F.P.<sup>1,2,3</sup> , Lucie Vézina, M.A.<sup>1</sup>, René Verreault, M.D., PH.D., C.C.F.P., F.C.F.P.<sup>3</sup>, Sébastien Simard, PH.D.<sup>2,4</sup>, Éveline Hudon, M.D., M.A.<sup>5</sup>, Jean-François Desbiens, R.N., PH.D.<sup>3,6</sup>, Lise Fillion, R.N., PH.D.<sup>6,7</sup>, Serge Dumont, PH.D.<sup>3,8</sup>, André Tourigny, M.D., M.B.A., F.R.C.P.C.<sup>3,9</sup> and Serge Daneault, M.D., PH.D., F.R.C.P.C.<sup>5,10</sup>

<sup>1</sup>Department of Family Medicine and Emergency Medicine, Université Laval, Québec, QC, Canada; <sup>2</sup>Research Centre of the Institut de cardiologie et de pneumologie de Québec (IUCPQ), Québec, QC, Canada; <sup>3</sup>VITAM-Centre de recherche en santé durable, Québec, QC, Canada; <sup>4</sup>Department of Health Sciences, UQAC, Québec, QC, Canada; <sup>5</sup>Department of Family Medicine and Emergency Medicine, Université de Montréal, Montreal, QC, Canada; <sup>6</sup>Faculty of Nursing, Université Laval, Québec, QC, Canada; <sup>7</sup>Research Center of the CHU de Québec, Québec, QC, Canada; <sup>8</sup>Faculty of Social Sciences, Université Laval, Québec, QC, Canada; <sup>9</sup>Centre of Excellence on Aging, CHU de Québec, Québec, QC, Canada and <sup>10</sup>Research Center of the CHU de Montreal, Montreal, QC, Canada

**Abstract**

**Objectives.** Diagnosis of cancer is emotionally threatening not only for patients but also for their family caregivers (FC) who witness and share much of the illness experience. This study compares distress experienced by lung cancer patients and their FC during the year following the diagnosis.

**Methods.** A prospective cohort study of 206 patients recently diagnosed with inoperable lung cancer (participation rate 79.5%) and 131 FC (participation rate 63.6%) was conducted in an ambulatory oncology clinic in Quebec City (Canada). They completed validated questionnaires regarding their personal and psychological characteristics (Hospital and Anxiety Depression Scale—HADS), in the first months after the diagnosis of lung cancer and after 6 and 12 months. Univariate, bivariate, and linear mixed models were conducted to compare patient and FC distress.

**Results.** At baseline, 7.8% of patients reported distress (HADS total score >15) and their mean distress score was  $7.0 \pm 4.9$  (range 0–42). In contrast, 33.6% of FC presented significant distress and their mean distress score was  $12.0 \pm 7.2$  ( $P < 0.0001$ ). Proportions of patients and FC with distress remained relatively stable at 6 and 12 months, and at every time point, FC reported higher levels of distress compared to their relative with cancer ( $P < 0.0001$ ). Comparable trends were found when looking at the mean scores of distress, anxiety, and depression throughout the study.

**Significance of results.** Being diagnosed with lung cancer and going through its different phases seems to affect more FC than patients. The psychological impact of such diagnosis appears early after the diagnosis and does not significantly change over time. These findings reinforce the importance for oncology teams, to include FC in their systematic distress screening program, in order to help them cope with their own feelings and be able to play their role in patient support and care throughout the cancer journey.

**Introduction**

Patients diagnosed with cancer often face several life disruptions associated with symptoms, treatments, and financial burdens (Graves *et al.*, 2007; Ellis, 2012; Girgis *et al.*, 2013a). The impact of a cancer diagnosis extends well beyond patients and affects the entire family (Ross *et al.*, 2010; Stenberg *et al.*, 2010; Gröpper *et al.*, 2016). As most cancer treatments are given in outpatient settings, family caregivers (FC) have become key supports for their relative, providing a lot of care for their health and well-being (McMullen *et al.*, 2014). They witness and share much of the illness experience of their loved one (Kershaw *et al.*, 2015). FC of lung cancer patients are particularly vulnerable (Zabora *et al.*, 2001; Wadwa *et al.*, 2013) and likely to be distressed (Siminoff *et al.*, 2010), because the severity and rapid evolution are most often associated with this type of cancer (Persson and Sundin, 2008; Murray *et al.*, 2010; Ellis, 2012; Fujinami *et al.*, 2012). Lung cancer is highly prevalent both in women and men around the world which warrants that researchers study how patients and their family cope with it.

FC have to deal with their own emotions related to their relative's diagnosis and prognosis, and they are frequently putting their own life aside, focusing more on their loved one (Stenberg et al., 2010; Van Ryn et al., 2011). They can experience high distress (Plant et al., 2011) that may impact on their physical, social, and emotional health (Stenberg et al., 2010; Wadwa et al., 2013; Kershaw et al., 2015). Even though many FC are coping quite well, some studies have shown that their distress is often more severe than patients' distress (Price et al., 2010; Chambers et al., 2012; Lambert et al., 2012a; Girgis et al., 2013a; Merckaert et al., 2013; Wadwa et al., 2013). Several personal factors are known to influence FC distress, including a younger age, a female gender, their own health status, their relation to the patient, and their sense of competence (Melin-Johansson et al., 2012; Lee et al., 2013; Gröpper et al., 2016; Kent et al., 2016). Factors related to patients' characteristics can also affect FC distress, like the presence of metastases, the functional status of their relative, or the severity of their symptoms (Given et al., 2004; Stenberg et al., 2010; Gröpper et al., 2016).

Most studies reporting a higher prevalence of significant distress in FC than in patients were cross-sectional and could not inform on the evolution of FC distress over time during the cancer care trajectory (Fletcher et al., 2008; Winterling et al., 2010; Lee et al., 2013). This cohort study compares distress experienced by lung cancer patients and their FC during the first year of their cancer journey. It was hypothesized that: (1) more FC would report significant distress than patients (confirming the prior studies); (2) the proportions of patients and FC with significant distress would decrease overtime as an effect of better coping with the situation, and (3) the difference in proportions of distressed patients and FC would remain throughout the study.

## Methods

### Study design and participant selection

This cohort study was conducted between June 2010 and December 2014 in a pulmonary oncology outpatient clinic at the *Institut universitaire de cardiologie et de pneumologie de Québec* (IUCPQ), in Quebec City, Canada. Patients newly diagnosed with an inoperable lung cancer (representing 85% of all cases) and with an estimated life expectancy of at least 6 months were invited to participate to this study by nurses in the oncology clinic. Patients identified their principal FC and they were also recruited to participate to the study. This study was approved by the IUCPQ Research Ethics Committee.

### Data collection and study instruments

Patients and FC completed validated questionnaires at baseline and every 6 months for a maximum of 12 months or until the patient's death. All data were collected during a regular patient appointment at the oncology clinic or at the patient's or the family caregiver's home, depending on their preference. All participants signed an informed consent form. At baseline, patients and FC responded to basic personal questions. Patients also provided information related to their lung cancer and their medical file was reviewed. At each data collection point, patients' functional status based on the Eastern Collaborative Oncology Group (ECOG) scale (Bowling, 1995) was assessed. Patients and FC also completed the Hospital Anxiety and Depression Scale (HADS) containing two 7-item subscales assessing, respectively,

anxiety and depression during the past week (Zigmond and Snaith, 1983; Savard et al., 1998; Roberge et al., 2013). Score on each subscale ranges from 0 to 21, with scores of 8–10 indicating suspected anxiety or depression and scores equal or higher than 11 denoting clinically significant anxiety or depression. A global score of the 14-item scale (range from 0 to 42) over 15 identifies clinically significant distress (Roberge et al., 2013).

### Analysis

As distress was the primary outcome, the HADS global score served to calculate the sample size. Considering a baseline score of  $10.8 \pm 7.4$  (range 0–42) found in a similar population of French-speaking respondents (Roberge et al., 2013), a level of significance of  $\alpha = 0.05$ , and a power of 80%, a baseline number of 96 persons per group (FC and patients) were necessary to detect a 3-point difference in the HADS score between the groups. Considering an expected high attrition rate because of the vulnerability of this population, the sample size was increased to 130 per group. It was anticipated that 60 persons per group at the end of the study would still allow the detection of a 3.8-point difference in the HADS score between the groups.

Baseline sociodemographic characteristics for patients and their FC were summarized with descriptive statistics. Results on distress, anxiety, and depression (based on the HADS) were analyzed as continuous (scores) and categorical (proportions of patients and FC with anxiety, depression, and distress) variables. Linear mixed models were performed to compare distress, anxiety, and depression between patients and FC throughout the study. They used two fixed factors, group and time, with an interaction term. Subjects were linked to a random effect. The normality assumption was verified with the Shapiro–Wilk tests using residuals from the statistical models and transformed by the Cholesky's metric. The Brown and Forsythe's variation of Levene's test was used to verify the homogeneity of variances. Different variables related to patients' characteristics (gender, age, functional status, type and stage of cancer, type of treatment, and working status) and to FC characteristics (gender, age, relation to the patient, working status, and cohabitation) were integrated into these models to control their respective influence on anxiety, depression, and distress. Missing data for patients who died ( $N = 88$ ) were not imputed, as their participation stopped at their death. Similarly, missing data for FC who withdrew because of their relative's death ( $N = 59$ ) were not imputed. For patients and FC who withdrew ( $N_{\text{patients}} = 10$ ;  $N_{\text{FC}} = 10$ ), their last data collected was carried over to conduct intention-to-treat analyses. Results were equivalent with or without imputing missing data, so only results without imputation are presented. An  $\alpha$  level of 0.05 was used as significance threshold. All statistical analyses were performed using the SAS software, version 9.4 (SAS Institute Inc., Cary, NC).

## Results

### Participants

From the 259 eligible patients, 206 were recruited (participation rate: 79.5%) and from that group, 131 of their FC agreed to participate (63.6%) (Figure 1). Patients had been aware of their diagnosis for 2 months on average ( $9.4 \pm 8.1$  weeks) and half of them already had metastasis at baseline. Most patients received some form of treatment (94.7%) (Table 1). A majority of FC were

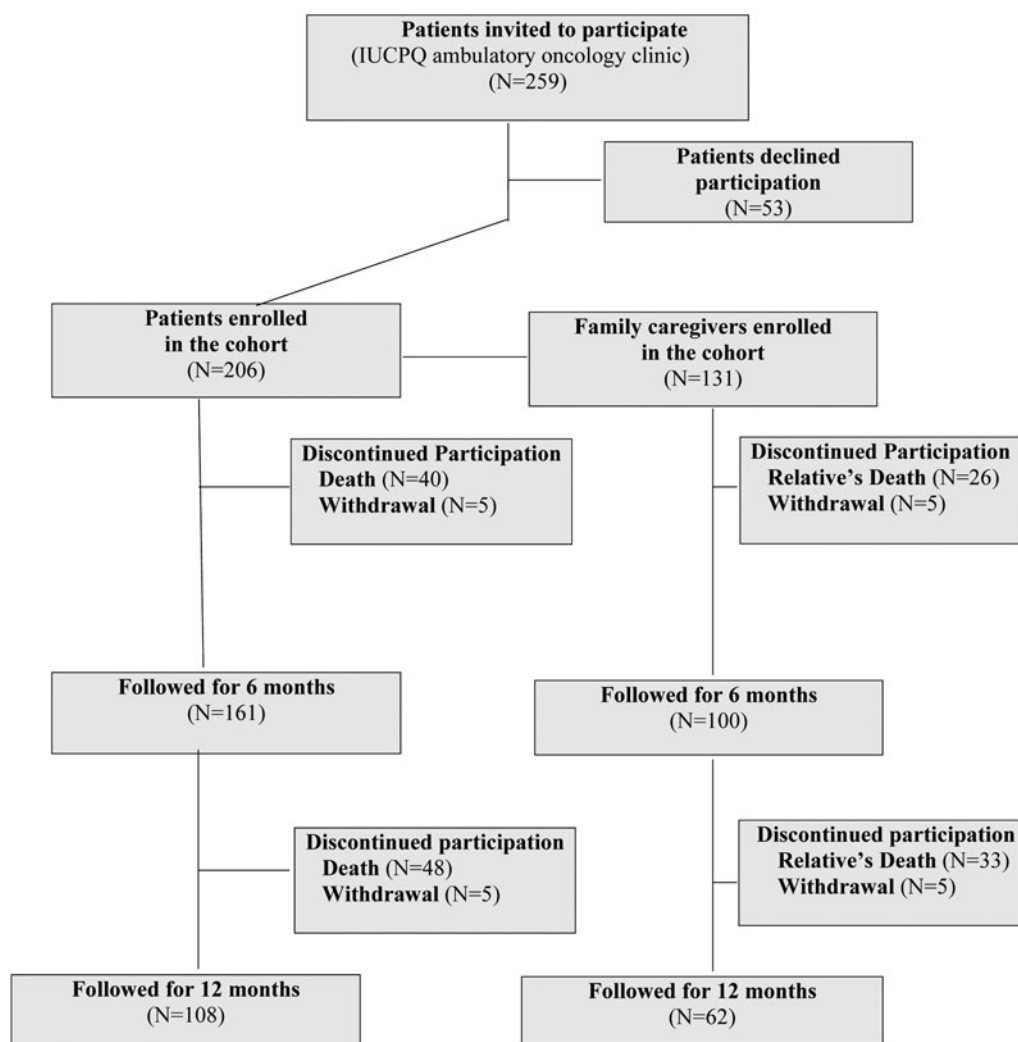


Fig. 1. Flow diagram.

women (69.5%), with a mean age of 59 years. More than three quarters of FC were living with the patient and those not cohabiting reported spending 26 h per week on average with their relative (Table 2).

### Distress in patients and FC

At baseline, near the diagnosis of lung cancer, the mean distress score was higher in FC than in patients (Table 3). Less than 10% of patients reported clinically significant distress compared to almost a third of family caregivers (Table 4). At 6 months, the mean distress score tended to drop in both groups, but remained higher in FC than in patients. This reduction observed in distress was not statistically significant between baseline and 6 months, and the distress score remained stable from 6 to 12 months in both groups, but always higher in FC (Table 3). Similarly, the proportion of patients and FC with distress remained stable at 6 and 12 months, with always a higher proportion of FC being distressed compared to patients. The same pattern described for distress was observed for the outcomes of anxiety and depression (Tables 3 and 4), except that anxiety scores were significantly reduced in both groups from baseline to 6 months and from 6 to 12 months.

Several factors had a significant influence on the proportion of patients with distress, anxiety, and depression. Patients who were female ( $P = 0.003$ ), younger ( $P = 0.02$ ), and still working ( $P = 0.003$ ) experienced anxiety more frequently. Patients with a worse functional status (ECOG 3 or 4) reported being depressed more often ( $P < 0.0001$ ) and experienced distress more frequently ( $P < 0.0001$ ). Regarding FC, none of their personal characteristics significantly influenced the proportion of those with distress, anxiety, or depression ( $P > 0.05$  for gender, age, working status, relation to patient, and cohabitation). Similarly, their relative's functional status or stage of cancer was not significantly associated with their psychological status ( $P > 0.05$ ).

### Discussion

This cohort study provides valuable information on the psychological status of patients with lung cancer and their FC during the first year after their diagnosis. These results confirm those of cross-sectional studies, showing that more FC experience distress than their relative with cancer (Price et al., 2010; Chambers et al., 2012; Girgis et al., 2013b; Wadwa et al., 2013), but they go beyond that, as they inform not only on the respective prevalence of psychological symptoms among patients and FC,

**Table 1.** Baseline patient characteristics

	(n = 206)	
	Mean ± SD	
Age	64.4 ± 8.7	
Education (years)	11.5 ± 3.8	
Delay between investigation and diagnosis (weeks)	3.8 ± 4.4	
Delay between diagnosis and first treatment (days)	31.7 ± 32.9	
	N	%
Gender		
Female	87	42.2
Working status		
Yes, full time	62	30.1
Yes, part time	23	11.2
No	121	58.7
Type of lung cancer		
Squamous cell carcinoma	36	17.5
Adenomatous carcinoma	100	48.5
Small cell carcinoma	47	22.8
Other non-small cell carcinoma	23	11.2
Treatment		
Chemo Tx	79	38.4
Radiation Tx	9	4.4
Chemo Tx and radiation Tx	107	51.9
No treatment	11	5.3
Stage according to TNM classification		
Stage 1 and 2	7	6.7
Stage 3	34	32.7
Stage 4	36	34.6
Unclassified <sup>a</sup>	27	26.0
Functional status <sup>b</sup>		
Active	97	47.1
Ambulatory but bothered by symptoms	69	33.5
<50% Bedridden	23	12.6
≥50% Bedridden	16	7.7
Always bedridden	1	0.05

<sup>a</sup>These patients had a "small cell carcinoma" for which there is no TNM classification.

<sup>b</sup>Functional status measured by the ECOG scale.

but also on how these symptoms evolve over time. Very few longitudinal studies have been conducted in that field and most of those found were limited to a 6-month follow-up (Milbury et al., 2013; Halkett et al., 2017).

Interestingly, proportions of patients and FC with significant distress and depression stayed relatively stable throughout this 1-year study, and the differences found between these two groups remained the same. Findings are almost equivalent when comparing patients' and FCs' scores of distress and depression. However, looking at the evolution of anxiety scores in both groups over time, there was a significant reduction between baseline and 6

**Table 2.** Baseline family caregiver characteristics

	(n = 131)	
	Mean ± SD	
Age	59.0 ± 11.7	
Education (years)	12.4 ± 3.8	
	N	%
Gender		
Female	91	69.5
Relation to patient		
Spouse	98	74.8
Father/mother	18	13.7
Others (child, brother, and sister)	15	11.5
Working status		
Yes, full time	44	33.6
Yes, part time	18	13.7
No	69	52.7
Cohabitation with patient <sup>a</sup>	102	77.9
Perception of self health		
Good	125	95.4
Poor	6	4.6
Psychological support during the last year	19	14.5
Accompany patient at oncology appointments		
Always	101	77.1
Occasionally <sup>b</sup>	28	21.4
No	2	1.5
Accompany patient at family physician appointments		
Always <sup>c</sup>	49	37.4
Occasionally <sup>c</sup>	31	23.7
No	51	38.9

<sup>a</sup>FC not living with the patient spend on average 26.0 h/week with their relative.

<sup>b</sup>Stay with the patient during the oncology appointment (n = 127; 98.4%).

<sup>c</sup>Stay with the patient during the appointment with the family physician (n = 68; 85%).

months as well as between 6 and 12 months. Proportions of patients and FC with significant anxiety tended to decrease over time, but it was not statistically significant. As FC always report higher distress, anxiety and depression than their relative with cancer throughout the study, this highlights the importance of paying attention to their psychological status and not only to the one of patients.

At the IUCPQ ambulatory oncology clinic, the organization of care includes nurse navigators who see all patients at least once and serve as resource persons throughout their cancer care trajectory. Most often, FC accompany their relative to their appointments at the oncology clinic. So, they may receive some support from the nurse navigator or from other members of the oncology team if they request it, or if they express some needs. But there is no systematic mechanism to identify FC with significant distress, and they are not included in the distress screening program offered routinely to patients. It is well known that health professionals working in cancer care settings often underestimate

**Table 3.** Distress, anxiety, and depression (HADS) scores in patients and FC at baseline, 6, and 12 months

	Distress <sup>a</sup>		Anxiety <sup>b</sup>		Depression <sup>b</sup>	
	Patients Mean ± SD	FC Mean ± SD	Patients Mean ± SD	FC Mean ± SD	Patients Mean ± SD	FC Mean ± SD
Baseline	7.0 ± 4.9	12.0 ± 7.2	3.9 ± 3.1	7.4 ± 4.0	3.1 ± 2.7	4.6 ± 3.8
6 months	6.4 ± 5.2	11.8 ± 7.1	3.1 ± 3.2	7.1 ± 3.9	3.3 ± 3.1	4.7 ± 3.9
12 months	6.2 ± 5.1	11.6 ± 7.0	2.8 ± 3.0	6.6 ± 3.7	3.4 ± 3.3	5.0 ± 4.0
Group effect	$P < 0.0001$		$P < 0.0001$		$P < 0.0001$	
Time effect	$P = 0.694$		$P = 0.009$		$P = 0.277$	
Group * time effect <sup>c</sup>	$P = 0.989$		$P = 0.665$		$P = 0.839$	

HADS, Hospital Anxiety and Depression Scale.

<sup>a</sup>Distress = HADS global score; range 0–42.<sup>b</sup>Anxiety and Depression = HADS-specific subscale scores; range 0–21.<sup>c</sup>Group \* Time = interaction between group and time from mixed models for repeated measures.**Table 4.** Proportion of patients and family caregivers reporting distress, anxiety, and depression (HADS) at baseline, 6, and 12 months

	Distress <sup>a</sup>		Anxiety <sup>b</sup>				Depression <sup>c</sup>			
	Significant		Suspected		Significant		Suspected		Significant	
	Patients N (%)	FC N (%)	Patients N (%)	FC N (%)	Patients N (%)	FC N (%)	Patients N (%)	FC N (%)	Patients N (%)	FC N (%)
Baseline	16 (7.8)	44 (33.6)	21 (10.2)	25 (19.1)	6 (2.9)	35 (26.7)	10 (4.9)	17 (12.9)	5 (2.4)	12 (9.2)
6 months	12 (7.5)	32 (32)	13 (8.1)	24 (24)	4 (2.5)	16 (16)	15 (9.3)	16 (16)	4 (2.5)	10 (10)
12 months	6 (5.5)	18 (29)	6 (5.5)	18 (29)	4 (3.7)	8 (12.9)	6 (5.5)	8 (12.9)	7 (6.5)	6 (9.7)
Group effect	$P < 0.0001$		$P < 0.0001$				$P < 0.0001$			
Time effect	$P = 0.71$		$P = 0.36$				$P = 0.09$			
Group * time effect <sup>d</sup>	$P = 0.95$		$P = 0.84$				$P = 0.49$			

HADS, Hospital Anxiety and Depression Scale.

<sup>a</sup>Distress = HADS global score; range 0–42; significant distress: score >15.<sup>b</sup>Anxiety = HADS-specific subscale scores; range 0–21; suspected anxiety: score 8–10 and clinically significant anxiety: score ≥11.<sup>c</sup>Depression = HADS-specific subscale scores; range 0–21; suspected depression: score 8–10 and clinically significant depression: score ≥11.<sup>d</sup>Group \* Time = interaction between group and time from mixed models for repeated measures.

distress in patients (Mitchell et al., 2011; Xiao et al., 2013), so they may do so even more frequently with FC, as they are not considered as “patients” when they attend to their relative’s oncology appointments. In addition, FC often put their emotions aside and try to focus on their relative’s needs (Stenberg et al., 2010; Van Ryn et al., 2011), so very few seek help for themselves or accept to participate to support group sessions (Mosher et al., 2013; Dionne-Odom et al., 2018). This reinforces the need to expand to FC in addition to patients, the distress screening programs implemented in cancer centers. Other authors have also recommended a family approach in cancer care because of the interdependence of patients’ and their family caregivers’ mental health (Shaffer et al., 2016; Caruso et al., 2017). Moreover, some authors have shown that FC reporting distress near the cancer diagnosis of their relative had a decline in their physical health 1 year later (Kim et al., 2014).

Relatively few patients reported clinically significant distress throughout the study even though they had a serious cancer. This finding seems quite surprising, considering that lung cancer is often associated with high distress (Zabora et al., 2001; Siminoff et al., 2010; Ellis, 2012; Wadwa et al., 2013). The organization of care at the IUCPQ ambulatory oncology clinic with nurse

navigators may have contributed to this result, as they act as resource persons for patients and they are available when needed to provide support, information, and referral to respond to patients’ needs. Moreover, all patients participated to the routine distress screening program implemented at the IUCPQ oncology clinic at the time of the study, which may have also contributed to this result. In addition, most patients receive chemo with or without radiation therapy, so they are “in action” to fight against their cancer, as opposed to their FC who may feel like helpless witnesses. This may also explain why more FC than patients report high distress. However, nurse navigators had the possibility of helping FC if they express some needs, as they usually accompanied their relative at their appointments in oncology. But, in the current practice, their interventions mainly target patients. Also, FC may have been reluctant to express their distress and concerns in front of their loved one. FC frequently forget themselves to concentrate on their relative (Stenberg et al., 2010; Van Ryn et al., 2011), so one can assume that they probably do not frequently seek help from nurse navigators.

Contrary to what was hypothesized, the mean scores of distress for both patients and FC remained relatively stable over time, as well as their respective proportion with clinically significant

distress. These findings suggest how difficult it is to cope with this severe type of cancer. Also, it echoes some other recent study results, indicating that patients and FC who report high distress around the time of diagnosis of cancer show prolonged elevations in distress over time (Lambert et al., 2012b; Milbury et al., 2013; Kim et al., 2014; Kershaw et al., 2015; Halkett et al., 2017).

This study had the advantage of being prospective. The patient participation rate was high and few deliberately withdrew, even though they did not get a direct benefit from the study. However, this study has some limitations. The high attrition rate, mainly due to patient death, may have reduced the external validity of these results. Although inevitable, such high attrition rate is well recognized in palliative care studies (Higginson et al., 2013; Dussel et al., 2015). Also, this study was conducted in a single center and limited to lung cancer patients, which precludes a generalization to other types of cancer. However, patient characteristics related to distress, such as a younger age and a female gender, are consistent with other study findings (Morrison et al., 2017). Finally, data from this cohort study were collected several years ago, but the integration of psychosocial care into routine oncology practice has not changed considerably since the study took place. In most centers, distress screening programs continue to target patients only and FC are not included. So, these results probably reflect the actual reality.

Nevertheless, these results support the need to implement a systematic distress screening program not only for patients, but also for FC. It would also be relevant for cancer centers to offer to FC some coaching to help them play their role with their relative throughout their cancer journey. Future research should include the integration and evaluation of such programs of distress screening and coaching for FC into different oncology practice settings treating patients with varied types of cancer.

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- Aubin M, Vézina L, Verreault R, Fillion L, Hudon É, Lacasse Y, Simard S, Tourigny A, Dumont S, Daneault S. Distress experienced by lung cancer patients and their family caregivers in the first year of their cancer journey. 16th World Congress of Psycho-Oncology, Lisbon, Portugal, October 23, 2014.

**Conflict of interest.** All authors have no conflict of interest to declare.

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