





**Citation:** Barbaret C, Brosse C, Rhondali W, Ruer M, Monsarrat L, Michaud P, et al. (2017) Financial distress in patients with advanced cancer. PLoS ONE 12(5): e0176470. https://doi.org/10.1371/journal.pone.0176470

**Editor:** Daniele Santini, Universita Campus Bio-Medico di Roma, ITALY

Received: December 20, 2016

Accepted: April 11, 2017

Published: May 18, 2017

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Data Availability Statement: The data are available upon request because of an ethical consideration (French IRB) and legal restriction. Data are available after request and authorization of Murielle Malbezin (muriel.malbezin@chu-lyon.fr) from the Hospices Civils de Lyon.

**Funding:** Authors received no specific funding for this work.

**Competing interests:** The authors have declared that no competing interests exist.

RESEARCH ARTICLE

# Financial distress in patients with advanced cancer

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### **Abstract**

#### **Purpose**

We examined the frequency and severity of financial distress (FD) and its association with quality of life (QOL) and symptoms among patients with advanced cancer in France.

### Design

In this cross-sectional study, 143 patients with advanced cancer were enrolled. QOL was assessed using the Functional Assessment of Cancer General (FACT-G) and symptoms assessed using Edmonton Assessment System (ESAS) and Hospital Anxiety and Depression Scale (HADS). FD was assessed using a self-rated numeric scale from 0 to 10.

#### Results

Seventy-three (51%) patients reported having FD. Patients reported having FD were most likely to be younger (53.8 (16,7SD) versus 62 (10.5SD), p<0.001), single (33 (62%) versus 40 (44%), p = 0.03) and had a breast cancer (26 (36%), p = 0.024). Patients with FD had a lower FACT-G score (59 versus 70, p = 0.005). FD decreased physical (14 versus 18, p = 0.008), emotional (14 versus 16, p = 0.008), social wellbeing (17 versus 19, p = 0.04). Patients with FD had higher HADS-D (8 versus 6 p = 0.007) and HADS-A (9 versus 7, p = 0.009) scores. FD was linked to increased ESAS score (59 (18SD) versus 67 (18SD), p = 0.005) and spiritual suffering (22(29SD) versus 13(23SD), p = 0.045).

#### Conclusion

The high rate of patient-reported FD was unexpected in our studied population, as the French National Health Insurance covers specific cancer treatments. The FD was associated with a poorer quality of life. Having a systematic assessment, with a simple tool, should lead to future research on interventions that will increase patients' QOL.



#### Introduction

The French healthcare system covers the total cost of specific treatments for cancer patients, but does not include the cost of expenses such as the daily charge for the hospital room, or certain low-risk drugs that are not considered an essential part of cancer treatment. Private insurance provides reimbursement of any such remaining costs incurred by the patient. Persons who cannot afford private insurance due to economic problems are entitled to free 'top-up' universal state medical insurance. As specific cancer treatment is free of charge, financial difficulty is considered to be rare in France, and is not systematically assessed. However, there may be other consequences of cancer that affect the family income, such as loss of salary, which can lead to increased financial burden. A study in 2007 [1] in the United States of America found a correlation between the increase of financial difficulties and the decrease of quality of life (QOL) in patients with advanced cancer. In 2016 Perrone et al [2] highlighted the association between financial difficulties with clinical outcomes in a country with public health system. Literature [3,4] highlighted the need to take into account the subjective distress and the consequences of the objective financial burden. Financial distress (FD) is a subjective social class identification that can lead to lower self-esteem and a lower sense of control over life. It has been said that patients withdrawing themselves from healthcare treatment for economic reasons is not uncommon in France [5-7]. Financial difficulties have recently been found to be the most frequent source of distress by cancer patients in a community cancer center in the USA [8]. Despite these results, one of the less explored effects of cancer is its association on finances, the part of FD in the overall suffering and the consequences of FD on QOL. The goal of this study was to evaluate the association of FD on QOL in patients with advanced cancer in France. The primary objective was to determine the association between FD and QOL. Secondary objectives were to characterize the frequency and intensity of FD in advanced cancer patients in France, to evaluate the association between FD and cancer-related symptoms, to determine the association between FD and subjective financial burden, financial worries and concerns and financial difficulties. We hypothesized that FD is associated with poorer QOL and worse psychological and physical symptoms in patients with advanced cancer.

#### Method and methods

This cross-sectional survey was approved by the French Institutional Review Board (Centre de Protection des Personnes Lyon Sud-Est; CPP number 12/116, A 13–465; 2012-A01405-38) and registered as a clinical trial NCT01868100. No financial compensation was provided to participate in the study. Written informed consent has been obtained from each patient.

#### Definition and assessment

According to literature there are many terms used for describing patients feeling concerning financial issues [9–12]. In this study we used the term FD which defined a subjective experience of distress attributed by the patient to financial burden. Objective financial burden is defined as the percentage of total family income used for direct out-of-pocket expenditure on health care during the last month, which has not been covered by private insurance [13,14] Subjective financial burden is defined as the impact of FD on patients' wellbeing.

#### **Population**

From the 19<sup>th</sup> of March 2013 to 30rd of June 2014, 143 patients were enrolled in the Teaching Hospital (TH) Centre Hospitalo-Universitaire de Lyon Sud (CHLS) and a Comprehensive Cancer Centre, Institut de Cancérologie de la Loire (ICL) in Rhône-Alpes. Outpatients or



hospitalized patients above 18 years old with advanced lung or breast or colorectal or prostate cancer were included. Advanced cancer was determined by the presence of a relapse, or a metastasis or a second-line-treatment chemotherapy, or a local advanced disease. Non-inclusion criteria were applied to patients presenting with cognitive disorders diagnosed by medical staff. Informed consent was obtained for the patients before the inclusion.

## Data collection and survey instruments

Patient demographics including cancer diagnosis and staging and ECOG (Eastern Cooperative Oncology Group) [15] were collected on chart report. We used the following validated instruments. ESAS (Edmonton Symptom Assessment System) measures the intensity of the most common symptoms within the last 24 hours of cancer patients: pain, fatigue, nausea, depression, anxiety, drowsiness, shortness of breath, appetite, sleep, and wellbeing [16–18]. For this study we added an item assessing spiritual pain. The HADS (Hospital Anxiety and Depression Scale) is a self-assessment tool with 14 items, with two separate subscales for anxiety and depression. A score of 16 or higher is suggestive of a severe case of anxiety or depression [19-21]. FACT-G (Functional Assessment of Cancer Therapy-General) is a 27-question tool validated in cancer patients and has four subscales to assess wellbeing. From these subscales a QOL score is obtained. Both the total score and the individual scores have good internal reliability (alpha = 0.72-0,85)[22,23]. No specific scales exist to assess Financial Burden and FD in France. In this study, financial burden was assessed by questions used in previous studies concerning patients with cancer [24,25]. High burden is defined as more than 10% of total family income spent on out-of-pocket expenses [26,27]. The patients were asked to rate from a "strongly agree to strongly disagree" questions concerning their physical, emotional, social and familial distress. The statement was considered positive when they answered "strongly agree, or agree or somewhat agree". Subjective financial burden and FD, financial concerns and worries are measured by an exploratory questionnaire. Patients were asked to score a numeric rating scale from 0 to 10 with 0 being best and 10 being worst. Patients were considered having FD if they quoted 1 or above. High FD was defined quoting 4 and above.

#### Statistical analysis

For the descriptive analysis, categorical variables were expressed with average and standard deviation (SD), continuous variables with proportion and percentage. The Student T test was used to compare the categorical variables and the chi-square test for the continuous variables. When Student T test or chi-square test could not be used the Mann-Whitney test or Fisher test was applied. One hundred and twenty-five patients were necessary to allow us to detect a Pearson correlation between FD and quality of life as small as 0.25 with 80% power at a 5% type I error rate. A 10% dropout rate was expected so we recruited 143 patients. A cancer-related type stratification was used. We estimated a Pearson and Spearman correlation between FD and quality of life. We compared FD with socioeconomic status using ANOVA or Wilcoxon rank sum tests as appropriate. P values less than 0.05 were considered statistically significant. We used a Bonferroni correction for all statistical analyses. For the statistical analysis SPPS software (Chicago, Inc) 19.0 was used.

#### Results

Three hundred and twenty-five patients were screened; of these 124 were not included due to their type of cancer. Twenty-one patients refused to participate. Thirty-seven could not be enrolled due to non-inclusion criteria.



# Baseline characteristics of the patients and patients' FD (Table 1)

The TH recruited 94 patients (66%) and the CCC 49 patients (34%). Of these, 67 patients (47%) were considered ECOG 2. Seventy (49%) patients were female of whom 42 (29%) reported having FD (p = 0.03). The average age was 58 years old. Patients who reported having FD had a lower average age (53.8 (16,7SD)) than patients with no FD (62 (10.5SD), p < 0.001). Fifty-three (37) patients were single. Single patients had more FD (33 (62%)) than those who were married or living with a partner (28 (44%)) (p = 0.003). Eighty-five (59%) of the population did not have

Table 1. Demographics.

	Financial DistressN = 73 (51%)	No Financial DistressN = 70 (49%)	р	TotalN = 143 (%)
Patients characteristics				N = 143
Female	42 (29)	28 (20)	0.03	70 (49)
Male	31 (22)	42 (29)		73 (51)
Average age (years) (SD)	53.83(16.7)	62(10.5)	<0.001	
Average time <sup>a</sup> (days) (SD)	1979 (4997)	1619 (1814)	0.57	
Familial Status				N = 143
Single	33 (23)	20 (14)	0.03	53 (37)
Married	40 (28)	50 (35)		90 (63)
Education level				N = 143
No High school degree	42 (29)	43 (30)	0.27	85 (59)
High school degree	14 (10)	8 (5)		22 (15)
1–3 y College education	13 (9)	10 (7)		23 (16)
>4 y College education	4 (3)	9 (6)		13 (9)
Income				N = 138
< 15000€ a year	34 (24)	19 (14)	0.013	53 (38)
> 15000€ a year	36 (26)	49 (35)		85 (62)
ECOG				N = 143
1	13 (9)	16 (11)	0.16	29 (20)
2	35 (25)	32 (22)		67 (47)
3	18 (13)	12 (14)		39 (27)
4	7 (5)	1 (1)		8 (6)
Cancer Type				N = 143
Breast	26 (18)	10 (7)	0.024	36 (25)
Lung	15 (10)	21 (15)		36 (25)
Prostate	14 (10)	21 (15)		35 (25)
Colorectal	18 (12.5)	18 (12.5)		36 (25)
Cancer Stage				N = 143
Metastasis	64 (45)	58 (40)	0.66	122 (85)
Relapse	2 (1)	4 (3)		6 (4)
Locally Advanced	5 (3)	7 (5)		12 (8)
Other	2 (1)	1 (1)		3 (2)
Treatments				N = 143
Surgery	36 (25)	38 (27)	0.55	74 (52)
Chemotherapy	66 (46)	66 (46)	0.38	132 (92)
Radiotherapy	38 (27)	42 (29)	0.34	80 (56)
Targeted Therapy	5 (4)	3 (2)	0.5	8 (6)

<sup>&</sup>lt;sup>a</sup>Between the diagnosis and the study.

https://doi.org/10.1371/journal.pone.0176470.t001



Table 2. Effects of Financial distress on suffering.

	SUBJECTIVE FINANCIAL BURDEN		
	Financial DistressN = 73 (51%)	No Financial DistressN = 70 (49%)	р
Average Financial difficulties (SD)	4.4 (2.94)	0.18 (0.85)	<0.001
Effect on well-being (SD)	4.61 (2.89)	0.25 (1.26)	<0.001
Average Financial Concerns (SD)	4.73 (2.68)	0.92 (2.1)	<0.001
Actual Financial Worries (SD)	4.55 (2.94)	0.42 (1.77)	<0.001
Effects of financial difficulties on	N = 73	N = 68	
Physical suffering	15 (10.6)	1 (1)	<0.001
Anxiety about physical functioning	16 (11.3)	2 (1.4)	0.001
Social suffering	16 (11.3)	2 (1.4)	0.001
Emotional suffering	16 (11.3)	2 (1.4)	0.001
Spiritual suffering	13 (9.4)	1 (1)	0.001

https://doi.org/10.1371/journal.pone.0176470.t002

a high school leaving qualification. Fifty-three (38%) patients earned less than 15,000 euros a year. Patients earning less than 15,000 euros a year had more FD (34 (64%)) than those earning more (36 (42%), p = 0.013). Patients with breast cancer declared having more FD than patients with other types of cancer (26 (18%) versus 10 (7%), p = 0.024). One hundred and thirty patients (90.9%) had private insurance. Seventy-three (51%) patients declared having FD. Forty-two (30%) had severe FD. Thirty-six (25%) considered their health expenses were greater than they had expected. Thirty-two (22%) said that private insurance did not provide the financial help that they had expected. Twenty-five (17%) patients experienced FD because of healthcare costs. Total family income spent on out-of-pocket expenses went from an average of 6.78 (10.38) before the diagnosis to 9.64 (12.55) after diagnosis. Before diagnosis, 76 (53) patients were employed whereas only 37 (26) were still employed after diagnosis. Patients having FD had a higher average financial burden (p<0.001). Despite these results, there was no significant difference in the percentage of household income spent on health care by patients who reported having FD and those who did not. There was no significant difference between before and after the diagnosis.

# Subjective financial burden is shown in Table 2

The average financial concerns and difficulties rates were 3 (SD 3). Patients having FD had more financial difficulty (4.4 (2.94SD), p<0.001), more financial concerns and worries (respectively 4.73 (2.68SD) and 4.55 (2.94SD), p<0.001) that affect their wellbeing (4.61 (2.89SD), p<0.001). Physical (15 (10.6), p<0.001), social (16 (11.3), p = 0.001), emotional (16 (11.3), p = 0.001) and spiritual suffering (13 (9.4), p = 0.001) scores were significantly increased in patients having FD. Patients reporting FD had greater anxiety about physical functioning scores than patients without FD (15(10.8), p<0.001).

# Association of financial distress on patients' quality of life and symptoms are shown in Table 3

The average score on the FACT-G was 63 (SD 18). Patients with FD have a lower FACT-G score (59 (18SD) versus 67 (18SD), p = 0.005) especially concerning physical (14 (7SD) versus 18 (7SD) p = 0.008), emotional (14 (6SD) versus 16 (5SD), p = 0.008), and social (17 (5SD) versus 19 (4SD), p = 0.04) wellbeing. Patients with FD had a higher score relating to HADS-D (8(4SD) versus 6 (4SD), p = 0.007) and HADS-A (9 (4SD) versus 7 (4SD), p = 0.009). There were significant differences concerning physical (248 (138SD) versus 177 (132SD), p = 0.02), psychological



Table 3. Association of financial distress on patients' qualities of life.

	Financial DistressN = 73 (51%)	No Financial DistressN = 70 (49%)	р
QoL Scale	Mean (SD)	Mean (SD)	
FACT-G	59 (18)	67 (18)	0.005
PWB <sup>a</sup>	14 (7)	18 (7)	0.008
FSWB <sup>b</sup>	17 (5)	19 (4)	0.04
EWB <sup>c</sup>	14 (6)	16 (5)	0.008
FWB <sup>d</sup>	13 (6)	14 (6)	0.224
HADS-A	9 (4)	7 (4)	0.009
HADS-D	8 (4)	6 (4)	0.007
ESAS	N = 70 Mean (SD)	N = 67 Mean (SD)	
PHS <sup>e</sup>	248 (138)	177 (132)	0.02
PSS <sup>f</sup>	106 (73)	66 (67)	0.01
TSDS <sup>g</sup>	354 (196)	244 (189)	0.01
Spiritual	22 (29)	13 (23)	0.045

<sup>a</sup>PWB: Physical Well Being.

<sup>b</sup>FSWB: Social/Familial Well Being.

<sup>c</sup>EWB: Emotional Well Being.

<sup>d</sup>FWB: Functional Well Being.

<sup>e</sup>PHS: Physical Distress Subscore. <sup>f</sup>PSS: Psychological Distress Subscore.

<sup>9</sup>TSDS: Total Symptom Distress Subscore.

https://doi.org/10.1371/journal.pone.0176470.t003

(106 (73SD) versus 66 (67SD), p = 0.01) and spiritual symptoms (22 (29SD) versus 13 (23SD), p = 0.045) among patients with FD.

# Association between patient-reported financial distress and other subjective terms

Table 4 shows the association between the financial distress reported by patients and other subjective terms such as subjective financial burden (r = 0.843, p < 0.001), financial concerns (r = 0.791, p < 0.001), financial worries (r = 0.816, p < 0.001) and financial difficulties (r = 0.88, p < 0.001).

#### **Discussion**

This study shows a correlation between FD and QOL and between FD and psychological symptoms (HADS-A and HADS-D). It shows correlation between FD and spiritual suffering and between FD with the ESAS in patients with advanced cancer. Patients with FD had a lower QOL especially concerning physical, emotional, social wellbeing. Those results are confirmed by previous studies [2,28] studying respectively financial distress and financial difficulty and its association with clinical outcomes. Our study is important because it concerns public health system and its impact of reimbursement policy on patients. This study highlighted that financial distress is not protected at least entirely by the French health care system. So further study should focus on other consequences of cancer on patient finances. In an observational study in 2014 [29], Financial Difficulty correlated with social situation, social discrimination and rejection meaning there is a subjective part that we need to assess when studying Financial Difficulty such as FD. Only 21 patients refused to be included which indicates the importance of this subject to French people. Our study highlighted that 73 patients (51%) had FD, which



Table 4. Association between patient reported financial distress and other subjective terms.

	Financial Distress	Subjective Financial Burden	Financial Concerns	Financial Worries	Actual Financial Difficulty
Financial Distress					
Pearson correlation	1	0.843	0.791	0.816	0.88
p		<0.001	<0.001	<0.001	<0.001
Subjective Financial Burden					
Pearson correlation	0.843	1	0.779	0.825	0.851
p	<0.001		<0.001	<0.001	<0.001
Financial concerns					
Pearson correlation	0.791	0.779	1	0.917	0.78
р	<0.001	<0.001		<0.001	<0.001
Financial worries					
Pearson correlation	0.816	0.825	0.917	1	0.819
p	<0.001	<0.001	<0.001		<0.001
Actual financial difficulty	0.88	0.851	0.78	0.819	1
Pearson correlation	<0.001	<0.001	<0.001	<0.001	
p					

https://doi.org/10.1371/journal.pone.0176470.t004

indicates that this is a common problem for the majority of patients with advanced cancer. Patients with FD have higher scores in assessments of anxiety and depression [30]. Depression in patients with advanced cancer is linked to survival rates [31,32]. Our results suggest that the financial situation of patients with advanced cancer should be systemically assessed. Our study highlighted that non-retired patients, breast cancer patients, single persons, women, and patients earning less than 15,000 euros a year were more prone to FD. A previous study confirmed breast cancer patients have more financial difficulties [33]. Further study should therefore be done on FD focusing on this specific population. In France, patients over 62 years of age may be retired with a stable income, which means that financial effect may be less significant. According to our study single patients and women are more prone to have FD. Studies [34,35] highlighted that single persons and single parents are a population more prone to financial burden and poverty. Before the diagnosis, 76 (53) patients had a job whereas after diagnosis only 37 (26) were still employed. Those results are confirmed by a previous study of the French population, which confirms that 8 out of 10 patients had a job before the diagnosis and only 6 were still in employment 2 years later [29]. This study showed that loss of employment was linked to: the younger and older, active population, those with a low level of education, and those engaged in manual work, or work of a precarious nature, and in small businesses. Prognosis influenced work activity. Patients with good prognoses had maintained job activity at 89% (office work) and 74% (physical work), whereas this was 48% and 28% respectively for patients with poor prognoses [29]. We also acknowledge that cancer type influences our results. Except for lung cancer, other types of cancers chosen in our study do not have the poorer prognoses and previous studies showed that poorer prognosis is associated with a higher Financial Difficulty [32–35]. Further study should involve other types of cancers that are more closely linked to difficult socioeconomic status and poorer prognoses. In 2012, the poverty rate in the Rhône-Alpes region was 12.1% (the national rate is 14%) [36,37]. The unemployment rate is above the national one (9.3%). Despite the fact that Rhône-Alpes is one of the richest regions in France our study shows that patients with advanced cancer are prone to have FD. In order to be more representative of the French population, a major study involving all regions of France should be conducted. In recent literature [28], 130 patients out of 147 in the USA had FD. Of 91% patients with



insurance, 81% patients and 72% caregivers were experiencing FD. The cost of medical care is a frequent cause of bankruptcy in the USA (46.2% in 2001) and increases every year (62.5% in 2007) [38]. Both the American results and ours highlight that FD is not completely explained by the healthcare system but the French healthcare system seems to offer moderate protection against FD. That may be due to the 100% coverage by French healthcare. This study has some limitations linked to the design of this cross-sectional study. The link between the financial distress and the others factors is not a cause effect relationship. The strong association we observed between FD and the subjective report needs to be confirmed in other studies with larger sample sizes. As only two centers were involved we cannot generalize our results and thus more, largerscale studies, based on a mix of public and private hospitals, are needed. Furthermore our study used non validated items due to a lack of existing ones so future studies should focus on the validation of items assessing financial distress and financial difficulty. Even if our FD assessment was exploratory, it is an extremely simple way of expressing FD that should trigger a social worker visit. Validation of tools should be made in order to assess FD among patients with cancer and identify interventions to help them. A new tool, Comprehensive Score for Financial Toxicity [39], may be a new lead but needs further investigation. Despite the fact that cancer treatment costs are largely covered by the French healthcare system, this study shows that FD is frequent and is associated with poorer QOL, and more intense psychological, physical and spiritual symptoms. Thus, FD and Financial Difficulty assessment should be systematic.

# **Supporting information**

**S1** Appendix. This questiondoinaire was used to interview the patients. (DOCX)

#### **Author Contributions**

**Conceptualization:** WR MF EB MD MR CB.

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**Supervision:** MF CB MR.

Validation: SS AMS EB.

Visualization: CB SS MF EB.

**Writing – original draft:** CB MF.

Writing - review & editing: CB MF SS AMS EB.

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