

# Inequalities in Financial Distress, Symptoms, and Quality of Life Among Patients with Advanced Cancer in France and the U.S.

CÉCILE BARBARET<sup>1,2,†</sup>, MARVIN O. DELGADO-GUAY<sup>3,†</sup>, STÉPHANE SANCHEZ<sup>4</sup>, CHRISTELLE BROSSE<sup>5</sup>, MURIELLE RUER<sup>6</sup>, WADIH RHONDALI<sup>6</sup>, LÉA MONSARRAT<sup>6</sup>, PATRICK MICHAUD<sup>7</sup>, ANNE MARIE SCHOTT<sup>8</sup>, EDUARDO BRUERA<sup>9</sup>, MARILÈNE FILBET<sup>6</sup>

<sup>1</sup>Department of Supportive and Palliative Care, Centre Hospitalo-Universitaire de Grenoble, La Tronche, France; <sup>2</sup>Department of Palliative, Rehabilitation, and Integrative Medicine, The University of Texas MD Anderson Cancer Center, Houston, Texas, U.S.A;

<sup>3</sup>Department of Medical Information, Evaluation and Performance, Hôpitaux Champagne Sud, Troyes, France; <sup>4</sup>Department of Palliative Care, Institut de Cancérologie de la Loire, Saint-Etienne, France; <sup>5</sup>Department of Supportive and Palliative Care, Centre Hospitalier Lyon-Sud, Lyon, France; <sup>6</sup>Pôle IMER, Hospices Civils de Lyon, Lyon, France

<sup>†</sup>Contributed equally

Disclosures of potential conflicts of interest may be found at the end of this article.

**Key Words.** Financial distress • Palliative care • Advanced cancer • Symptom distress • Quality of life

## ABSTRACT

**Background.** Financial distress (FD) is common among patients with advanced cancer. Our purpose was to compare the frequency and intensity of FD and its associations with symptom distress and quality of life (QOL) in these patients in France and the U.S.

**Materials and Methods.** In this secondary analysis of two cross-sectional studies, we assessed data on 292 patients who received cancer care at a public hospital or a comprehensive cancer center in France (143 patients) or the U.S. (149 patients). Outpatients and hospitalized patients over 18 years of age with advanced lung or breast or colorectal or prostate cancer were included. Diagnosed cognitive disorder was considered a non-inclusion criterion. Advanced cancer included relapse or metastasis or locally advanced cancer or at least a second-line chemotherapy regimen. Patients self-rated FD and assessed symptoms, psychosocial distress, and QOL on validated questionnaires.

**Results.** The average patient age was 59 years, and 144 (49%) were female. FD and high intensity were reported more frequently in U.S. patients than in French (respectively 129 [88%] vs. 74 [52%],  $p < .001$ ; 100 [98%] vs. 48 [34%],  $p < .001$ ). QOL was rated higher by the U.S. patients than by the French (69 [SD, 18] vs. 63 [SD, 18],  $p = .003$ ). French patients had more psychological symptoms such as anxiety (8 [SD, 4] vs. 6 [SD, 5],  $p = .008$ ). Associations were found between FD and U.S. residence, FD and single status (0.907,  $p = .023$ ), and FD and metastasis (1.538,  $p = .036$ ). In contrast, negative associations were found between FD and older age ( $-0.052$ ,  $p = .003$ ) and FD and France residence ( $-3.376$ ,  $p = .001$ ).

**Conclusion.** Regardless of health care system, FD is frequent in patients with advanced cancer. U.S. patients were more likely to have FD than French patients but reported better QOL. Further research should focus on factors contributing to FD and opportunities for remediation. *The Oncologist* 2019;24:1121–1127

**Implications for Practice:** Suffering is experienced in any component of the lives of patients with a life-threatening illness. Financial distress (FD) is one of the least explored cancer-related symptoms, and there are limited studies describing its impact on this frail population. This study highlights the high frequency and severity of FD in patients with advanced cancer in the U.S. and France as well as its impact on their physical and emotional symptoms and their quality of life in these different health care systems. It is necessary for all health care providers to explore and evaluate the presence of FD in patients living with life-threatening illnesses.

## INTRODUCTION

The impact of physical and psychological symptoms related to cancer on a patient's quality of life (QOL) is undeniable [1–5]. The impact on personal finances and the contribution of financial distress (FD) to overall QOL are some of most important

and least explored effects of cancer. Recent studies in the U.S. [6] and in France [7] showed associations between patients' FD, QOL, and symptom distress. Kendall et al. reported that financial difficulties were a significant and frequent source

Correspondence: Cécile Barbaret, M.D., Department of Supportive and Palliative Care, Centre Hospitalo-Universitaire de Grenoble, Avenue du Maquis du Grésivaudan, 38700 La Tronche, France. Telephone: +33476765667; e-mail: cbarbaret@chu-grenoble.fr Received June 18, 2018; accepted for publication January 25, 2019; published Online First on March 15, 2019. <http://dx.doi.org/10.1634/theoncologist.2018-0353>

of distress among patients undergoing care at a community cancer center in the U.S. [8]. In 2016, Perrone et al. [9] highlighted the association between financial difficulties and clinical outcomes in a country with a public health system.

Patients with cancer and their families frequently need to make financial adjustments in their domestic life. Extreme financial measures have been reported in the U.S. and the U.K., such as home refinancing [10], house repossessions, and even declaring bankruptcy [11]. Therefore, optimal care of patients with advanced cancer is not confined to medical and social support; it includes early and systematic analysis of the patient's socioeconomic situation.

The studies in France and the U.S. already cited [6, 7] showed that FD was frequent among both cohorts, calling into question the capacity of both health care systems to protect patients from financial concerns. The health care systems in the two countries are different. In France, the national health care system provides primary health care coverage for everyone. Private health insurance (PHI) complements or supplements public coverage [10]. Patients with cancer have 100% coverage and complete salary protection for a certain period [12]. In the U.S., the national health system covers only the portion of the population that qualifies, whether by age (Medicare) or income or social situation (Medicaid). With the 2014 health care reform in the U.S., more Americans would have received more benefit from the national health system, but PHI still provides primary health care coverage for a large portion of the population [10]. There is still limited literature regarding the impact of financial distress on the symptoms and quality of life of patients with advanced illness, especially in different health care systems.

We previously conducted studies of financial distress in each of these institutions; all patients had similar clinical characteristics, including advanced cancer, and all patients were treated by a palliative care specialist following a similar approach to assessment and management of physical and psychosocial distress. The main difference between the two cohorts was the type of health care systems where the care was provided. Therefore, we decided to compare financial distress in those patients within those health care systems.

## MATERIALS AND METHODS

This study was approved by the appropriate ethics authorities: in France, the Comité de Protection des Personnes Sud-Est IV, and in the U.S., The University of Texas MD Anderson Cancer Institutional Review Board. Patients with advanced cancer receiving care at a public hospital or a comprehensive cancer center (CCC) in the U.S. and France during the period 2013–2014 were eligible. Both outpatients and hospitalized patients aged 18 years or older with advanced lung, breast, colorectal, or prostate cancer were enrolled. Advanced cancer was defined by relapse, by the presence of locally advanced disease or metastasis, or by treatment with a second-line chemotherapy regimen. Noninclusion criteria included a cognitive disorder diagnosed by medical staff. The U.S. and French research teams used the same questionnaires. A first analysis was done separately in each country [6, 7].

Those previous studies compared two groups of patients with advanced cancer who underwent assessments using the

same tools in France and the U.S. This allowed for a unique comparison of the frequency and severity of financial distress using a methodology that has not been reported before.

This article presents the results of that comparison of both U.S. and French data to highlight differences among the two patient groups and the associations of these differences with FD.

## Data Collection and Survey Instruments (Table 1)

Patient demographic and clinical information, including cancer diagnosis, cancer treatment, cancer staging, and Eastern Cooperative Oncology Group (ECOG) score [13], were collected on chart report. Concerning education level and incomes, the Socioeconomic Status Instrument (SESI) was used. Except for the SESI and financial assessments scales, all instruments used in those two studies had been validated in both the U.S. and France. To collect data on cancer-related symptoms, patients completed the Edmonton Symptom Assessment System (ESAS) and the Hospital Anxiety and Depression Scale (HADS). The ESAS measures the intensity of the most common cancer-related symptoms within the last 24 hours [14–16], and the HADS is a self-assessment tool with 14 items, with two subscales [17, 18].

Each patient's QOL score was calculated from the Functional Assessment of Cancer Therapy-General (FACT-G), a 27-question tool validated in patients with cancer that has four subscales to assess well-being. From these subscales, a QOL score is obtained. Both the total score and the individual scores have good internal reliability ( $\alpha = 0.72\text{--}0.85$ ) [19, 20].

No specific scales were validated at the time of the study to assess financial situation in medical patients. Therefore, financial burden (supplemental online Appendix 1) was assessed by questions used in previous studies of patients with cancer [21, 22]. High financial burden was defined as more than 10% of total family income spent on out-of-pocket expenses related to the cancer [23, 24]. FD was defined as a subjective experience of distress attributed by the patient to financial burden. Subjective financial burden was defined as the impact of FD on a patient's well-being.

Subjective financial burden, FD, and financial concerns and worries were measured by an exploratory questionnaire (supplemental online Appendix 2). Patients were asked to score their FD on a numeric rating scale from 0 to 10, with 0 being best and 10 being worst. Patients were considered to have FD if they scored 1 or greater. High FD was defined as a score of 4 or greater.

## Statistical Analysis

In descriptive analysis, quantitative variables were expressed with means and SDs, qualitative variables with absolute frequencies and percentages. The Student *t* test was used to compare quantitative variables and the chi-squared test for qualitative variables. *p* values less than .05 were considered statistically significant. We used a Bonferroni correction for all statistical analyses. A multivariate analysis by linear regression was carried out with declared FD as the dependent variable. All variables significant at *p* < .05 in bivariate analysis were included in the initial model. We used a stepwise descending regression, with a threshold of 0.05 for exclusion.

**Table 1.** Patient questionnaires

Patient questionnaires	Evaluation	Subscales	Validated (France and U.S.)
Demographics	<ul style="list-style-type: none"> <li>• Age</li> <li>• Date of diagnosis</li> <li>• Stage</li> <li>• Treatment</li> </ul>		
FACT-G	Quality of life	<ul style="list-style-type: none"> <li>• Physical well-being</li> <li>• Emotional well-being</li> <li>• Familial/social well-being</li> <li>• Functional well-being</li> </ul>	Yes
HADS	Psychological symptoms	<ul style="list-style-type: none"> <li>• HADS-A</li> <li>• HADS-D</li> </ul>	Yes
Financial burden	Supplemental online Appendix 1		No validated instrument exists
Subjective financial burden	Supplemental online Appendix 2: <ul style="list-style-type: none"> <li>• Financial distress</li> <li>• Financial worries</li> <li>• Financial concerns</li> </ul>		No validated instrument exists
ESAS	Cancer-related-symptoms		Yes
SESI	Including: <ul style="list-style-type: none"> <li>• Education level</li> <li>• Incomes</li> </ul>		No validation in France

Abbreviations: ESAS, Edmonton Symptom Assessment System; FACT-G, Functional Assessment of Cancer Therapy-General; HADS, Hospital Anxiety and Depression Scale; HADS-A, Hospital Anxiety and Depression Scale-Anxiety; HADS-D, Hospital Anxiety and Depression Scale-Depression; SESI, Socioeconomic Status Instrument.

**Table 2.** Demographic and clinical characteristics of study participants

Characteristic	Overall, <i>n</i> (%) <i>n</i> = 292	French medical institution, <i>n</i> (%) <i>n</i> = 143	U.S. medical institution, <i>n</i> (%) <i>n</i> = 149	<i>p</i> value
Age, years, mean (SD)	59.3 (10)	58 (12)	60 (9)	.192
Sex				
Female	144 (49.3)	70 (49)	74 (50)	.9
Male	148 (50.7)	73 (51)	75 (50)	.9
Cancer				
Breast	75 (26)	36 (25.1)	39 (26)	.9
Colorectal	72 (24)	36 (25.1)	36 (24)	.9
Lung	74 (25)	36 (25.1)	38 (26)	.9
Prostate	71 (24)	35 (24.4)	36 (24)	.9
Metastasis	237 (81)	118 (82)	119 (80)	.4
ECOG status, mean (SD)	1.9 (0.8)	2.2 (0.8)	1.6 (0.8)	<b>&lt;.001</b>
Treatment				
Chemotherapy	247 (84.6)	132 (92)	115 (77)	<b>&lt;.001</b>
Targeted therapy	38 (13)	8 (6)	30 (20)	<b>&lt;.001</b>
Radiation	117 (40.1)	80 (56)	37 (25)	<b>&lt;.001</b>
Surgery	107 (37)	74 (52)	33 (22)	<b>&lt;.001</b>
Marital status				
Married	165 (57)	87 (61)	78 (52)	.061
Single	48 (16)	16 (11)	32 (11)	.061
Divorced	38 (13)	19 (13)	19 (13)	.061
Widowed	33 (11)	17 (12)	16 (11)	.061
Separated	5 (2)	4 (3)	5 (2)	.061
Education				
Advanced degree	44 (15)	13 (9)	31 (21)	<b>&lt;.001</b>
College	63 (22)	23 (16)	40 (27)	<b>&lt;.001</b>
High school or less	179 (61)	106 (74)	73 (49)	<b>&lt;.001</b>
Government (National) insurance	223 (76)	143 (100)	80 (54)	<b>&lt;.001</b>

Bolded *p* values indicate statistical significance.

Abbreviation: ECOG, Eastern Cooperative Oncology Group.

**Table 3.** Effects of financial distress on suffering

Statements	Overall, <i>n</i> (%)	French medical institution, <i>n</i> (%)	U.S. medical institution, <i>n</i> (%)	<i>p</i> value
<i>n</i> =	288	141	147	
I have more financial distress than physical distress	61 (21)	16 (11)	45 (30)	<b>&lt;.001</b>
<i>n</i> =	289	141	148	
I have more financial distress than distress about my physical functioning	82 (28)	18 (13)	64 (43)	<b>&lt;.001</b>
<i>n</i> =	289	141	148	
I have more financial distress than social/family distress	82 (28)	18 (13)	64 (43)	<b>&lt;.001</b>
<i>n</i> =	289	141	148	
I have more financial distress than emotional distress (anxiety/depression)	73 (25)	18 (13)	55 (37)	<b>&lt;.001</b>

Bolded *p* values indicate statistical significance.

Physical well-being and insurance status were kept in the model as clinically important variables. Multicollinearity was assessed using the Variance Inflation Factor (VIF). In the linear regression analysis, no variable had a VIF >5. Reported results were generated using SPSS software v19.0 (IBM Corp, Armonk, NY).

## RESULTS

A total of 292 patients were enrolled in the study. In France, 143 patients were enrolled: 94 (66%) patients receiving care at a public hospital and 49 (34%) at a CCC. In the U.S., 149 patients were enrolled: 72 (48%) receiving care at a public hospital and 77 (52%) at a CCC. Table 2 summarizes the demographic and clinical characteristics of the patients. The ECOG score was higher in France than in the U.S. (2.2 [SD, 0.8] vs. 1.6 [SD, 0.8],  $p < .001$ ). French patients received more chemotherapy (132 [92%] vs. 115 [77%],  $p < .001$ ), more radiation (80 [56%] vs. 37 [25%],  $p < .001$ ), and more surgery (74 [52%] vs. 33 [22%],  $p < .001$ ) than U.S. patients, whereas U.S. patients received more targeted therapy (30 [20%] vs. 8 [6%],  $p < .001$ ) than French patients. There was no significant difference in sex, marital status, type of cancer, or metastatic status between the French and U.S. patients.

Table 3 shows differences in frequency and intensity of FD among patients from the two countries. Whereas 74 (52%) patients from France reported the presence of FD, 129 (88%) patients from the U.S. reported FD ( $p < .001$ ). Whereas 48 (34%) patients in France reported severe FD, 100 (68%) in the U.S. reported severe FD ( $p < .001$ ).

Compared with French patients, a higher proportion of U.S. patients reported having more FD than physical distress (45 [30%] vs. 16 [11%],  $p < .001$ ), more FD than distress about physical functioning (46 [31%] vs. 18 [13%],  $p < .001$ ), more FD than social/familial distress (64 [43%] vs. 18 [13%],  $p < .001$ ), and more FD than emotional distress (55 [37%] vs. 18 [13%],  $p < .001$ ).

Table 4 summarizes the symptom and QOL scores of the patients in both countries. For the patients overall, the average ESAS score was 32.5 (SD, 20.4; a higher ESAS score indicates worse intensity of symptoms). The mean score

for U.S. patients was higher than that for French patients (35 [SD, 20.6] vs. 30 [SD, 19.9],  $p = .036$ ), but the differences on individual symptom scores were not significant except for sleep problems (4 [SD, 3.1] vs. 2.8 [SD, 3.2],  $p = .003$ ). HADS-A (anxiety) and HADS-D (depression) scores were significantly higher in French patients than in U.S. patients (HADS-A, 8 [SD, 4] vs. 6 [SD, 5],  $p = .008$ ; HADS-D, 7 [SD, 4] vs. 6 [SD, 3],  $p = .004$ ). The average FACT-G score was 66 (SD, 19). U.S. patients had a higher FACT-G score than French patients (69 [SD, 18] vs. 63 [SD, 18],  $p = .003$ ).

The results of the multivariate analysis are shown in Table 5. Residence in France ( $p = .001$ ) and greater age ( $p = .003$ ) were associated with lower rate of declared FD. In contrast, declared FD was associated with depression ( $p = .001$ ), anxiety ( $p = .001$ ), single status ( $p = .023$ ), the presence of metastasis ( $p = .036$ ), and surgical treatment ( $p = .039$ ).

## DISCUSSION

Our study highlights interesting differences between patients with advanced cancer in the U.S. and France. The U.S. patients were significantly more likely than the French patients to experience FD overall and to experience FD greater than physical, social/family, or emotional distress. Despite this, the U.S. patients rated their QOL more favorably than the French patients. French patients and older patients were less likely to declare FD, whereas patients with depression or anxiety, those who were single, or those who had undergone surgery or had metastatic disease were more likely to report FD than their counterparts without these factors. The U.S. patients had a more favorable mean ECOG score than the French patients. The French patients were more likely to undergo standard cancer therapies such as chemotherapy, radiation, and surgery.

Our two previous studies [6, 7], separate primary analyses of the FD data for the same patients from the U.S. and France, were the first to evaluate the impact of FD on overall suffering of patients with advanced cancer and analyze the reasons for FD in the U.S. and French health care systems. The French patients' lower rate of FD (and higher rate of cancer treatment) are not surprising considering that the costs of

**Table 4.** Quality of life and cancer-related symptoms

Variable	Overall, <i>n</i> (%)	French medical institution, <i>n</i> (%)	U.S. medical institution, <i>n</i> (%)	<i>p</i> value
ESAS (mean/SD)	<i>n</i> = 292	<i>n</i> = 143	<i>n</i> = 149	
Pain	3.6 (3.1)	3.6 (3.1)	3.7 (3.1)	.6
Fatigue	4.8 (2.9)	4.9 (2.9)	4.8 (2.9)	.8
Nausea	2 (2.7)	1.9 (2.5)	1.8 (2.8)	.7
Depression	2.4 (2.8)	2.1 (2.7)	2.7 (3)	.1
Anxiety	2.9 (3.)	2.9 (2.9)	3 (3)	.8
Drowsiness	3.1 (2.9)	2.8 (2.8)	3.3 (2.9)	.2
Shortness of breath	2.7 (3)	2.8 (2.9)	2.6 (3.1)	.5
Appetite	3.2 (3.1)	2.9 (3.1)	3.6 (3.2)	<b>.05</b>
Sleep	3.4 (3.2)	2.8 (3.2)	4 (3.1)	<b>.003</b>
Feeling of well-being	3.8 (2.9)	3.8 (3.1)	3.8 (2.7)	.8
Spiritual pain	1.7 (2.5)	1.8 (2.7)	1.6 (2.3)	.5
TSDS	32.5 (20.4)	30 (19.9)	35 (20.6)	<b>.036</b>
HADS (mean/SD)	<i>n</i> = 284	<i>n</i> = 143	<i>n</i> = 141	
Anxiety	7 (4)	8 (4)	6 (5)	<b>.008</b>
Depression	7 (4)	7 (5)	6 (3)	<b>.004</b>
FACT-G (mean/SD)	<i>n</i> = 290	<i>n</i> = 143	<i>n</i> = 147	
Quality of life	66 (19)	63 (18)	69 (18)	<b>.003</b>

Bolded *p* values indicate statistical significance.

Abbreviations: ESAS, Edmonton Symptom Assessment System; FACT-G, Functional Assessment of Cancer Therapy-General; HADS, Hospital Anxiety and Depression Scale.

**Table 5.** Multivariate linear regression mode

Variable	Regression coefficient	<i>p</i> value
France residence	−3.376	<b>.001</b>
High HADS-D score	1.932	<b>.001</b>
Low HADS-A score	−1.224	<b>.001</b>
Greater age	−0.052	<b>.003</b>
Single status	0.907	<b>.023</b>
Functional and social well-being	−0.077	<b>.031</b>
Metastasis	1.538	<b>.036</b>
Surgery	0.794	<b>.039</b>
Physical well-being	−0.045	.101
Government insurance	−0.77	.124

Bolded *p* values indicate statistical significance.

cancer treatment are 100% covered by the French health care system. The U.S. patients were more likely than their French counterparts to experience FD as well as severe FD; however, the French patients weren't entirely protected from FD by their national health care system. Because the direct costs of cancer treatment are covered by this system, the FD experienced by French patients is presumably linked to other financial concerns, such as loss of salary, out-of-pocket expenses, and indirect costs. However, further research is needed to confirm the causes of FD in French patients.

Although frequency and intensity of FD were significantly higher for the U.S. patients, the French patients had a lower level of education. This finding differs from those

of other studies showing that lower education level is associated with greater financial difficulty [25, 26]. Our findings suggest that the health care system and social policy in France might cushion patients with cancer with lower educational level somewhat from FD and financial difficulty but do not protect them entirely.

Except for psychological symptoms, which were significantly more frequent in the French patients than in the U.S. patients, cancer-related symptoms were significantly more frequent in the U.S. patients. However, the U.S. patients had a higher FACT-G (QOL) score than the French patients, possibly because of their lower rates of psychological symptoms, their higher educational level, and their lower rates of potentially debilitating cancer treatment. FACT-G measures emotional, social, familial, functional and physical well-being, but there's no direct evaluation of financial well-being. That might explain why the U.S. patients had higher QOL despite more frequent and severe declared FD. Further study should focus on financial evaluation, which needs to be systematic and early in each country.

Sharp et al. [27] reported, from an analysis of data from the National Cancer Registry Ireland, that cancer-related financial stress and strain were consistently associated with increased risk of adverse psychological outcomes; for example, the risk of depression was three times higher in patients reporting a high degree of cancer-related financial stress and strain.

Our research has some limitations. First, this is a secondary analysis of two cross-sectional studies and not all the variables were obtained including the time of diagnosis of advanced cancer. Although it is important to recognize that

in our study all the patients had advanced cancer, there was no significant difference in sex, marital status, type of cancer, or metastatic status; all were referred to a palliative care team by their treating oncologist, and the inception point for the assessment of symptoms of financial distress was defined as the point at which the patient was referred to a palliative care team for evaluation. This is a point in the trajectory of the illness, used by our group and others, at which the primary oncology team feels that the patient has progressive and incurable disease [28, 29]. Second is the difference between the health care settings. In France, there is no completely private establishment for comparison with U.S. private hospitals. Third was our use of the exploratory FD questionnaire, which has not been validated and thus may introduce bias. Our preliminary findings should be confirmed in large studies of patients with advanced cancer in multiple settings.

Even when the cost of cancer treatment is 100% covered, it seems to be not enough to protect patients with cancer from FD and financial difficulty. Despite the availability of the Medicare and Medicaid programs in the U.S., for example, the U.S. patients declared higher rates of FD frequency and intensity than the French patients. Complete cost coverage for cancer treatment, therefore, is not the total answer to preventing FD, but it seems to be a necessary first step. U.S. health care programs should focus on improving reimbursement policies to relieve patients' FD. Because the cost of cancer treatment is already 100% covered by the French health care system, the French should focus on improving social policy to remove other financial concerns for patients with advanced cancer.

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## CONCLUSION

Regardless of health care system, FD is frequent in patients with advanced cancer. U.S. patients were more likely to have FD than French patients but reported better QOL.

Both countries should focus their efforts on availability and access to different resources and the assessment of financial difficulty as part of global support for patients with advanced cancer [30].

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## AUTHOR CONTRIBUTIONS

**Conception/design:** Cécile Barbaret, Marvin O. Delgado-Guay, Marilène Filbet  
**Provision of study material or patients:** Cécile Barbaret, Marvin O. Delgado-Guay, Christelle Brosse, Murielle Ruer, Wadih Rhondali, Léa Monsarrat, Patrick Michaud, Eduardo Bruera, Marilène Filbet  
**Collection and/or assembly of data:** Cécile Barbaret, Marvin O. Delgado-Guay, Christelle Brosse, Murielle Ruer, Wadih Rhondali, Léa Monsarrat  
**Data analysis and interpretation:** Cécile Barbaret, Marvin O. Delgado-Guay, Stéphane Sanchez, Anne Marie Schott, Eduardo Bruera, Marilène Filbet  
**Manuscript writing:** Cécile Barbaret, Marvin O. Delgado-Guay  
**Final approval of manuscript:** Cécile Barbaret, Marvin O. Delgado-Guay, Stéphane Sanchez, Christelle Brosse, Murielle Ruer, Wadih Rhondali, Léa Monsarrat, Patrick Michaud, Anne Marie Schott, Eduardo Bruera, Marilène Filbet

## DISCLOSURES

The authors indicated no financial relationships.

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See <http://www.TheOncologist.com> for supplemental material available online.

#### For Further Reading:

Stuart L. Goldberg, Dhakshila Paramanathan, Raya Khoury et al. A Patient-Reported Outcome Instrument to Assess Symptom Burden and Predict Survival in Patients with Advanced Cancer: Flipping the Paradigm to Improve Timing of Palliative and End-of-Life Discussions and Reduce Unwanted Health Care Costs. *The Oncologist* 2019;24:76–85.

#### Implications for Practice:

A seven-item patient-reported outcome (PRO) instrument was administered to 1,191 patients with advanced cancers. Patients self-reporting higher levels of physical and psychological symptom burden had inferior overall survival rates. High individual item symptom PRO responses should serve as a useful trigger to initiate supportive interventions, but when scores indicate global problems, discussions regarding end-of-life care might be appropriate.