

# Factors associated with self-perceived burden to the primary caregiver in older patients with hematologic malignancies: an exploratory study

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## Abstract

**Objective:** Although cancer patients frequently experience self-perceived burden to others, this perception has not been enough studied. The aim of this study was to investigate the prevalence of self-perceived burden to the primary caregiver (SPB-PC) and associated factors in an older patient population with hematologic malignancies at the time of chemotherapy initiation.

**Methods:** In total, 166 consecutive patients with hematologic malignancies aged  $\geq 65$  years were recruited at the time of chemotherapy initiation. Patients' SPB-PC was assessed using a 100-mm visual analogue scale (VAS). Characteristics potentially associated with SPB-PC, including sociodemographic and medical characteristics, physical functioning status (Karnofsky performance score, activities of daily living (ADL)/instrumental ADL), symptoms (fatigue, pain, nausea, quality of life), psychological distress (Hospital Anxiety and Depression Scale (HADS)), perceived cognitive function (Functional Assessment of Cancer Therapy Cognitive (FACT-Cog) Scale), and patients'/primary caregivers' personal relationship characteristics (family tie, support), were assessed.

**Results:** Thirty-five percent of patients reported moderate to severe SPB-PC (VAS  $\geq 50$  mm). Patients' SPB-PC was associated with lower Karnofsky performance ( $\beta = -0.135$ ,  $p = 0.058$ ) and ADL ( $\beta = -0.148$ ,  $p = 0.037$ ) scores, and higher HADS ( $\beta = 0.283$ ,  $p < 0.001$ ) and FACT-Cog perceived cognitive impairments subscale ( $\beta = 0.211$ ,  $p = 0.004$ ) scores. The proportion of explained variance was 23.5%.

**Conclusions:** Health care professionals should be aware that about one third of older cancer patients experience moderate to severe SPB-PC at the time of chemotherapy initiation. They should adapt their support of patients who report such a feeling.

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## Introduction

Patients with chronic illness frequently worry about being a burden to their families [1]. Although burden has been investigated from the caregiver's perspective [2–7], few studies have addressed patients' feeling of being a burden. Patients' self-perceived burden (SPB) refers to 'an empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self' [8] (p425). SPB can have major consequences on patients' decision making, leading them to choose not to initiate treatment [9], refuse life-extending medical treatment [10], experience a diminished will to live [11], desire hastened death [12,13], and/or prefer to receive end-of-life care in an institutional setting, rather than at home [14,15].

Patients' SPB may develop for various reasons. It may appear among subjects with functional limitations, reflecting social standards and ideals promoting autonomy, productivity, and successful aging [16]. It may arise from an imbalance between what a patient can contribute and what he or she receives in return when perceived possibilities to reduce the imbalance are limited or nonexistent [17,18]. Patients' SPB may also arise from the internalization of different types of social norms and values regarding relationships with others [19].

To our knowledge, SPB has rarely been studied in oncology, except in the context of palliative care. One study demonstrated that 65% of patients with advanced cancer experienced minimal SPB and 19% experienced moderate to extreme SPB [20]. Other studies have been conducted among patients with chronic pain or terminal illness to

assess factors associated with SPB [21–23]. Among sociodemographic characteristics, an association was found with living only with a spouse (suggesting a higher SPB when patients lived only with their spouse *versus* only with other family members *versus* with their spouse and with other family members) [24], whereas associations with age, gender, marital status, and education level have often been contradictory or absent [21–25]. Among psychological characteristics, patients' SPB has been correlated with psychological distress [26], depression, worry about the future, decreased ability to concentrate [21], poor perceived quality of life (QOL) [22], loss of control, loss of dignity, hopelessness [25], and suicidal ideation [27,28]. Associated medical characteristics include a large number of comorbid conditions [22] and the presence of physical symptoms, such as pain, weakness, dyspnea [25], and functional limitation [23,29]. One study found no association between physical symptoms and SPB among terminally ill patients [21]; the authors suggested that the impact of physical symptoms on SPB may have been outweighed by psychological discomfort. Among relationship characteristics, patients' SPB has been associated with greater caregiver burden [23].

Available studies addressing patients' SPB have methodological limitations. They have been conducted as case studies [30], and they have focused mainly on patients with terminal [30,31] or chronic [23,32] illness. Thus, the conclusions of these studies are not generalizable to other medical settings. Moreover, the persons to which patients refer when reporting SPB (primary caregiver *versus* others) have not been identified systematically.

SPB of older patients with cancer requires the attention of researchers and health care professionals for several reasons. First, older patients with cancer are potentially at greater risk of being a burden to their family and friends for long periods of time, considering their frequent loss of autonomy, physical and psychological discomfort, and frailties. Second, SPB may be a factor triggering suicide, which is frequent among older patients with cancer [33]. Third, as SPB has been shown to influence medical decision making, it must be better addressed in settings devoted to the care of older patients with cancer. Knowledge about SPB is important to improve the quality of support provided by health care professionals.

The aim of this study was to assess the prevalence of self-perceived burden to the primary caregiver (SPB-PC) in older patients with hematologic malignancies at the time of chemotherapy initiation. First, it has been chosen to look specifically to SPB-PC to study a precise subjective feeling which may be useful to consider in patients and their primary caregivers support. Second, the time of chemotherapy initiation was chosen because patients were considered by physicians to be sufficiently fit for the initiation of a new treatment, and their treatment response could be considered as a possible positive outcome. The

treatment initiation period was thus considered suitable for the assessment of SPB-PC and associated factors to optimize support provided to patients and caregivers. Third, although there is not a strong rationale to study specifically a hematological population, such a population – *versus* a population presenting solid tumors – was considered for the purpose of this study as illness perception and symptoms burden may be specific [34]. Given the current lack of models to explain SPB-PC in older patients with cancer, we conducted exploratory analyses to assess associations with patient and patients'/primary caregivers' personal relationship characteristics. Most of factors reported in the literature as associated with SPB have been therefore considered.

## Methods

### Patients and setting

This study was conducted in six Belgian hospitals and was approved by the local ethics committee. All consecutive patient volunteers fulfilling the inclusion criteria were invited to participate and provided written informed consent. Recruited patients were aged  $\geq 65$  years, had hematologic malignancies, had been admitted for chemotherapy initiation, and were able to speak French. Patients hospitalized for palliative care, those with diagnoses of severe dementia, and those who could not complete scheduled assessments for physical or psychological reasons were excluded. The assessment conducted by several independent investigators was conducted during the 48 h around chemotherapy initiation and lasted approximately 1 – 1.5 h. Therefore the assessment might have been conducted after the chemotherapy initiation. In order to avoid bias, self-reported questionnaires were used. Moreover the investigators were trained in order to standardize the way to present the study and the assessment. Considering the requirements of the local ethics committee, no information on non-respondents was collected.

### Assessment tools

#### Self-perceived burden to the primary caregiver

As the study was run in French, the use of a 100-mm visual analogue scale (VAS; ranging from 'not at all' to 'a lot') was chosen in order to minimize cross-languages ordinal and interval differences of response choices of a 5-point Likert scale.

#### Patients' sociodemographic and medical characteristics

Patients provided demographic information, including age, gender, educational level, marital status, and living status. Physicians provided patients' medical characteristics including diagnosis, time since diagnosis, disease status, prognosis, and number of comorbidities. Such as

SPB-PC, VAS assessing patients' symptoms were used firstly to minimize cross-languages ordinal and interval differences of response choices and second to avoid a too long assessment period. Four VAS were used in order to assess current patients' levels of fatigue (ranging from 'not at all' to 'a lot'), pain (ranging from 'not at all' to 'a lot'), nausea (ranging from 'not at all' to 'a lot'), and QOL (ranging from 'very bad' to 'excellent').

### Patients' physical functioning status and psychological characteristics

Patients' physical functioning status and psychological characteristics were assessed using validated tools: Karnofsky performance score, activities of daily living (Katz ADL [35] (total score ranged from 6 to 24) and Lawton IADL [36] (total score ranged from 8 to 32); higher score indicated better physical functioning status), Functional Assessment of Cancer Therapy Cognitive Scale version 3 (FACT-Cog), Hospital Anxiety and Depression Scale (HADS; higher score indicated higher psychological distress) [37]. As most of these tools are well known, only the FACT-Cog Scale will be detailed here.

The FACT-Cog Scale is a self-reported measure of cognitive impairments and its impact on patients QOL. This 37-item instrument assesses patients' memory, attention, concentration, language, and thinking abilities during the last 7 days. It consists of four subscales: perceived cognitive impairments (20 items; score range 0–80; higher score indicated frequent perceived impairments) and comments from others (4 items; score range 0–16; higher score indicated frequent comments from others) subscales; and perceived cognitive abilities (9 items; score range 0–36; higher score indicated higher perceived cognitive abilities) and impact on QOL (4 items; score range 0–16; higher score indicated higher impact on QOL) subscales [38]. The FACT-Cog questionnaire has been translated into French and validated with French-speaking patients with cancer [39].

### Patients'/primary caregivers' personal relationship characteristics

Patients were asked to characterize their personal ties with primary caregivers and to report the frequency of encounters (responses were grouped into two categories (a) 'less than every day' *versus* (b) 'every day'), frequency of discussions about the disease (responses were grouped into two categories (a) 'never, rarely or sometimes' *versus* (b) 'often or always'), frequency with which the primary caregiver helped the patient (responses were grouped into two categories (a) 'never, rarely or sometimes' *versus* (b) 'often or always') and assessment of the primary caregiver's ability to perceive the patient's difficulties (responses were grouped into two categories (a) 'excellent, very good or good' *versus* (b) 'average or poor').

### Statistical analysis

There is no available recommendation on how to consider moderate to severe SPB-PC. Therefore, to assess the prevalence of moderate to severe SPB-PC, a cut-off score of  $\geq 50$  mm was chosen to consider a probably clinically significant SPB-PC. To assess associated factors, SPB-PC was considered as a continuous variable. Univariate relationships between patient characteristics and SPB-PC were evaluated using non-parametric tests (e.g. Spearman correlations, Mann–Whitney or Kruskal–Wallis test). All tests were two tailed and alpha was set at 0.05. A backward stepwise linear regression model was then computed to assess relationships between potential predictors and patients' SPB-PC. All variables with univariate *p*-values  $\leq 0.05$  were entered into the model. Variables were not entered in the model as separate blocks and no logtransformation was needed. Analyses were performed with SPSS software (version 20.0 for Windows; SPSS, Chicago, IL).

## Results

### Subjects

Among 293 eligible inpatients, 98 refused to take part in the study. Performance status of patients who refused to take part to a time consuming assessment well described in the consent form was certainly lower than the performance status of included patients. Twenty patients withdrew from assessments for various reasons: three patients considered the duration of the assessment as too long, eight patients considered not being physically able to continue the assessment, three patients considered not being psychologically able to continue the assessment, four patients gave other reasons (personal reasons ...). The two last patients gave multiple reasons (duration of evaluation and physical state *versus* physical, psychological state and other). Nine patients were excluded from statistical analyses because they did not identify their primary caregiver. Thus, analyses included 166 patients who could be admitted in day care or inpatients settings according to their diagnosis and treatments. Table 1 lists patients' sociodemographic, medical, physical functioning status, and psychological (SPB-PC, psychological distress, perceived cognitive function) characteristics.

### Prevalence of self-perceived burden to the primary caregiver (SPB-PC)

At the start of chemotherapy, 35% of participants experienced moderate to severe SPB-PC (VAS  $\geq 50$  mm). The mean VAS score for the total sample (35 mm; Std=35 mm) indicated clinically significant SPB-PC, with 19% of participants scoring in the highest quarter (75–100 mm), 16% in the third quarter (50–74 mm),

**Table 1.** Characteristics of older patients with cancer (n = 166)

	<i>n</i>	%	Mean	Std
<b>Sociodemographic characteristics</b>				
Age			73	6
Gender				
Male	97	58		
Female	69	42		
Marital status				
Single, divorced, separated, or widowed	43	26		
Married	123	74		
Educational level				
Junior high school or less	104	63		
High school graduation or more	62	37		
Living status				
Living alone	39	23		
Not living alone	127	76		
<b>Medical characteristics</b>				
Diagnosis				
Lymphoma, multiple myeloma, chronic lymphocytic leukemia	131	79		
Acute myelogenous leukemia, chronic myelomonocytic leukemia, myelodysplasia	29	17		
Acute lymphocytic leukemia	6	4		
Months since diagnosis			22	46
Disease status				
Complete remission, partial remission, minor remission or no change	16	10		
In progression	28	17		
Too early to evaluate	122	73		
Prognosis				
<1 year	9	5		
≥1 year	58	35		
Too early to evaluate	99	60		
Number of comorbidities			3	2
Treatments				
Chemotherapy	154	93		
Autologous bone marrow transplant	8	5		
Allogeneic bone marrow transplant	4	2		
<b>Symptom assessment<sup>1</sup></b>				
Fatigue			50	31
Pain			19	27
Nausea			8	17
Quality of life			63	27
<b>Physical functioning status</b>				
Karnofsky performance score			81	15
Activities of daily living			24	1
Instrumental activities of daily living			31	1
<b>Psychological characteristics</b>				
Psychological distress <sup>2*</sup>			12	7
<b>Perceived cognitive function<sup>3</sup></b>				
Perceived cognitive impairments			11	12
Comments from others			0.38	1
Perceived cognitive abilities			25	7
Impact on quality of life			3	4
Self-perceived burden to the primary caregiver <sup>1</sup>			35	35

Abbreviation: Std, standard deviation; VAS, visual analogue scale.

<sup>1</sup>Assessed on a visual analogue scale (100 mm).<sup>2</sup>Hospital Anxiety and Depression Scale.<sup>3</sup>Functional Assessment of Cancer Therapy Cognitive Scale.

\*Missing data for one patient.

**Table 2.** Sociodemographic and medical characteristics associated with self-perceived burden to the primary caregiver among older patients with cancer (Mann–Whitney test, Kruskal–Wallis test or Spearman rho as appropriate; n = 166)

	Self-perceived burden to the primary caregiver (100-mm VAS)			
	Mean	Std	Rho	p
<b>Sociodemographic characteristics</b>				
Age			-0.05	0.510
Gender				0.282
Male	32	33		
Female	39	36		
Marital status				0.621
Single, divorced, separated, or widowed	37	37		
Married	34	34		
Educational level				0.418
Junior high school or less	34	35		
High school graduation or more	36	34		
Living status				0.897
Living alone	36	36		
Not living alone	34	35		
<b>Medical characteristics</b>				
Diagnosis				0.523
Lymphoma, multiple myeloma, chronic lymphocytic leukemia	36	34		
Acute myelogenous leukemia, chronic myelomonocytic leukemia, myelodysplasia	34	36		
Acute lymphocytic leukemia	23	35		
Months since diagnosis			0.06	0.444
Disease status				0.506
Complete remission, partial remission, minor remission or no change	38	34		
In progression	38	31		
Too early to evaluate	33	36		
Prognosis				0.158
<1 year	37	37		
≥1 year	32	32		
Too early to evaluate	36	36		
Number of comorbidities			0.10	0.219
Treatments				0.547
Chemotherapy	35	35		
Autologous bone marrow transplant	46	40		
Allogeneic bone marrow transplant	15	12		
<b>Symptom assessment<sup>1</sup></b>				
Fatigue			0.24	0.002
Pain			0.19	0.016
Nausea			0.16	0.040
Quality of life			-0.33	<0.001

Abbreviation: Std, standard deviation; VAS, visual analogue scale.

<sup>1</sup>Assessed on a visual analogue scale (100 mm).

15% in the second quarter (25–49 mm), and 22% in the lowest quarter (1–24 mm). Twenty-eight percent of patients reported no SPB-PC.

**Factors associated with SPB-PC**

Table 2 displays sociodemographic and medical characteristics associated with patients' SPB-PC at the start of chemotherapy. Correlations between SPB-PC and

## Self-perceived burden in older cancer patients

**Table 3.** Functional autonomy, psychological, and relationship characteristics associated with self-perceived burden to the primary caregiver among older patients with cancer (Mann-Whitney test or Spearman rho as appropriate;  $n = 166$ )

	Self-perceived burden to the primary caregiver (100-mm VAS)			
	Mean	Std	Rho	p
<b>Physical functioning status</b>				
Karnofsky performance score			-0.24	0.002
Activities of daily living			-0.23	0.003
Instrumental activities of daily living			-0.24	0.002
<b>Psychological characteristics</b>				
Psychological distress <sup>1</sup> *			0.41	<0.001
<b>Perceived cognitive function<sup>2</sup></b>				
Perceived cognitive impairments			0.29	<0.001
Comments from others			0.18	0.024
Perceived cognitive abilities			-0.23	0.003
Impact on quality of life			0.25	0.001
<b>Patient/primary caregiver relationship characteristics</b>				
Family tie				0.423
Partner	33	34		
Other	38	36		
<b>Frequency of encounters<sup>3</sup></b>				
Less than every day	37	35		
Every day	34	35		
<b>Frequency of discussions about difficulties<sup>3</sup></b>				
Never, rarely, or sometimes	30	33		
Often or always	40	36		
<b>Frequency of caregivers' support<sup>3</sup></b>				
Never, rarely, or sometimes	31	33		
Often or always	37	35		
<b>Caregivers' ability to perceive patients' difficulties<sup>3</sup></b>				
Very good, excellent, or good	34	33		
Average or poor	35	35		

Abbreviation: VAS, visual analogue scale.

<sup>1</sup>Hospital Anxiety and Depression Scale.

<sup>2</sup>Functional Assessment of Cancer Therapy Cognitive Scale.

<sup>3</sup>As reported by patients.

\*Missing data for one patient.

sociodemographic characteristics were not significant. Among medical characteristics, only symptoms (fatigue, pain, nausea, and QOL) were correlated significantly with SPB-PC ( $r=0.16$  to  $0.33$ ).

Table 3 lists physical functioning status, psychological, and patient/primary caregiver relationship characteristics associated with SPB-PC. All physical functioning and psychological variables were correlated significantly ( $r=0.18$  to  $0.41$ ). Some data (HADS) were missing for only one patient. No significant association with relationship characteristics was found.

The backward stepwise linear regression analysis included 12 variables: psychological distress, perceived cognitive impairment, comments from others, perceived cognitive ability, impact of impairments on QOL, QOL, pain, fatigue, nausea, Karnofsky performance

**Table 4.** Characteristics associated with self-perceived burden to the primary caregiver among older patients with cancer (linear regression model,  $n = 165$ )

	Self-perceived burden to the primary caregiver (100-mm VAS)	
	$\beta$	p
<b>Physical functioning status</b>		
Karnofsky performance score	-0.135	0.058
Activities of daily living	-0.148	0.037
<b>Psychological characteristics</b>		
Psychological distress	0.283	<0.001
Perceived cognitive impairments	0.211	0.004

Abbreviation: VAS, visual analogue scale.

Proportion of explained variance: 23.5%.

score, ADL and IADL scores. Older patients' SPB-PC was associated with low Karnofsky performance score ( $\beta=-0.135$ ,  $p=0.058$ ), difficulties in ADL ( $\beta=-0.148$ ,  $p=0.037$ ), psychological distress ( $\beta=0.283$ ,  $p<0.001$ ), and perceived cognitive impairments ( $\beta=0.211$ ,  $p=0.004$ ). The proportion of explained variance was 23.5% (Table 4). The results remain the same if the 12 patients receiving bone marrow transplant are not included in the analysis.

It should be underlined that commonly Karnofsky performance score is grouped into 100/70/40 and ADL/IADL scores are categorized into dependency and independency. In order to assess the linearity assumption of these scores, we conducted a further linear regression model with Karnofsky performance score and ADL/IADL scores as categorical variables according to the hereabove recommended categorical scores. Results considering Karnofsky performance score and ADL/IADL scores as categorical variables are quite similar to results considering the scores as continuous variables. It was therefore decided to include these variables in the regression analysis as continuous variables. Finally several logistic regression analyses were conducted to test the output. The results are quite similar to the linear regression results.

## Conclusions

This study showed that 35% of older patients with hematologic malignancies experienced moderate to severe SPB-PC ( $VAS \geq 50$  mm), and that higher levels of SPB-PC were associated with increased functional and psychological difficulties. By contrast, SPB-PC was not associated with patients' medical or patients'/primary caregivers' personal relationship characteristics. The examined characteristics were associated weakly with SPB-PC, explaining about 25% of the variance. These results suggest that SPB-PC is associated with characteristics that were not assessed in this study. This study is the first to show that about one third older patients with cancer experience moderate to severe SPB-PC prior to the side effects of chemotherapy.

This study confirms the results of previous studies conducted among patients with chronic pain or terminally ill [21,23,26] by showing that older patients with cancer who feel functionally or psychologically impaired may also experience SPB-PC. Participants did not report severe functional, psychological, and cognitive difficulties. Thus, even slight loss of physical functioning status and/or psychological or cognitive difficulties at the time of chemotherapy initiation may be associated with SPB-PC in older patients with cancer.

Surprisingly, we found no association between SPB-PC and the medical characteristics examined. These results may be explained by patients' minimization of the meaning of this type of characteristics, and their expectation that the planned treatment would be effective. Moreover, SPB-PC was not associated with patients'/primary caregivers' personal relationship characteristics examined in this study (e.g. family tie, frequency of encounters, frequency of discussions about difficulties, frequency of caregivers' support, caregivers' ability to perceive patients' difficulties).

Our results have several clinical implications. Health care professionals should be aware that more than one in three older patients may experience moderate to severe SPB-PC at the time of chemotherapy initiation. Professionals should thus be ready to address older patients' SPB, even when they are starting new treatment, and assess underlying factors and consequences in terms of patients' adjustment to treatment and everyday life. When appropriate, health care professionals should also normalize this feeling and adapt their support to the needs of patients and caregivers.

In case of severe SPB-PC with adverse effects on medical decision making, support interventions led by specialized mental health professionals and designed for older patients with cancer should be available and offered. To our knowledge, no recommendation has been designed to specifically support patients experiencing SPB. Potentially useful strategies that could be considered in the development of psychological interventions to support

patients' ability to cope with SPB [8] include inviting patients to take more active roles in their care, prepare themselves for future life steps, recognize the needs of others, and increase awareness of caregivers' desire to help. These interventions should thus also consider facilitating communication between patients and primary caregivers to reduce the potential feeling of inequity.

To conclude, this study is the first to assess the prevalence of moderate to severe SPB-PC exclusively in older patients with cancer at the time of chemotherapy initiation, and to explore characteristics associated with this feeling. The results indicate that SPB-PC is prevalent and may appear even in the initiation of treatment phase, suggesting that SPB-PC should be assessed and addressed. Future studies should involve more precise investigation of other factors potentially underlying SPB-PC, such as perceived efficacy of treatment, financial difficulties, primary caregivers' distress, reciprocity, inequity, guilt, values, social norms, self-esteem, personality traits and past history. Further research should also investigate the effects of SPB-PC on outcomes such as medical decision making, treatment compliance, and place of care in older patients with cancer. Finally future studies should also investigate similarities and differences in patients' and primary caregivers' reports of SPB-PC. The results of such studies may allow to better understand the family caregivers' perception and may be helpful to organize the support of patient/primary caregiver dyad.

## Disclosure

The authors indicate no potential conflict of interest.

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