

Dimitrovová K^{1,2}, Reis A¹, Barbosa I³, Cunha L⁴, Ferreira MF⁵, Oliveira J⁵, Viana DS⁶

¹ MOAI Consulting, Lisbon, Portugal; ² Comprehensive Health Research Center, CHRC, NOVA University Lisbon, Lisbon, Portugal; ³ Associação Portuguesa de Leucemias e Linfomas (APLL), Porto, Portugal; ⁴ Associação Portuguesa Contra a Leucemia (APCL), Lisboa, Portugal; ⁵ Associação de Apoio aos Doentes com Leucemia e Linfoma (ADL), Maia, Portugal; ⁶ Janssen-cilag Farmacêutica, Lda, Oeiras Portugal

INTRODUCTION

In Portugal, the 5-year prevalence (all ages) of non-Hodgkin lymphoma, Hodgkin lymphoma and leukemia is estimated at 6,342 (62.20 per 100,000 inhabitants), 853 (8.37 per 100,000 inhabitants), and 4,228 (41.46 per 100,000 inhabitants), respectively.¹ Leukemia and lymphoma can significantly compromise patients’ health-related quality of life (HRQoL), and impose a substantial burden for their caregivers, who provide critical emotional and instrumental support, with further impact of work productivity and subsequent indirect costs to society.² The lack of evidence, in Portugal, regarding the humanistic and economic burden of these patients and their caregivers, highlights the relevance of studies that aim to characterize this impact.

OBJECTIVE

To estimate overall work impairment, and indirect costs, of Leukemia and Lymphoma patients and caregivers in Portugal, and to explore the relationship of Health-Related Quality of Life (HRQoL) with these variables.

METHODS

This cross-sectional study was based on the application of a **questionnaire** (self-reported) to adult **patients** diagnosed with **leukemia** or **lymphoma** and to adult **caregivers** of patients diagnosed with leukemia or lymphoma.

The questionnaire was shared online, with the support of three national Patient Associations: *Associação Portuguesa de Leucemias e Linfomas* (APLL), *Associação Portuguesa Contra a Leucemia* (APCL), *Associação de Apoio aos Doentes com Leucemia e Linfoma* (ADL);

The questionnaire included brief socio-demographic questions, the Work Productivity and Activity Impairment Specific Health Problem (**WPAI-SHP**) questionnaire, as well as an instrument for HRQoL measurement: the Functional Assessment of Cancer Therapy - General (**FACT-G**) for patients, and the Portuguese instrument *Questionário de Avaliação da Sobrecarga para Cuidadores Informais* (**QASCI**) for caregivers (i.e., Burden Assessment Questionnaire for Informal Caregivers).

Analyses

- **Overall work impairment** and **indirect costs** were computed based on the WPAI-SH questionnaire, and official National unit costs;
- Two generalized linear models (GLM)⁴, for patients and caregivers, were used to explore the **relationship** between **HRQoL** (using FACT-G for patients and QASCI for caregivers) and **overall work impairment**, adjusted by age, sex, education, ongoing treatment, and time since diagnosis (for patients) and duration of care (for caregivers);
- A two-part model (logit and GLM)⁴ was used to explore the **relationship** between **HRQoL** and **indirect costs**, adjusted by the same variables.

RESULTS

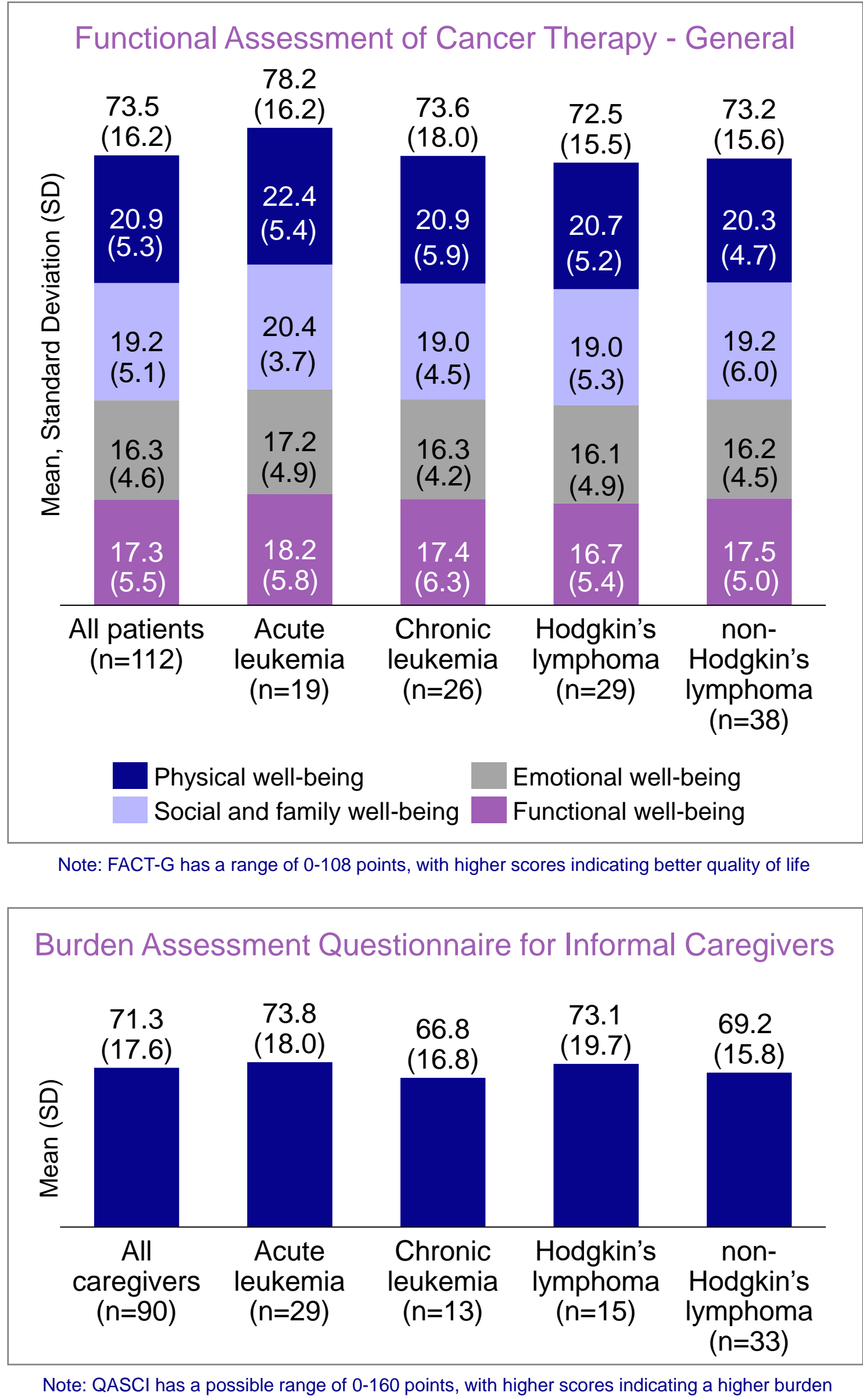
Descriptive analysis

Between October to December 2022, **112 employed patients**, and **90 employed caregivers** answered to the questionnaire.

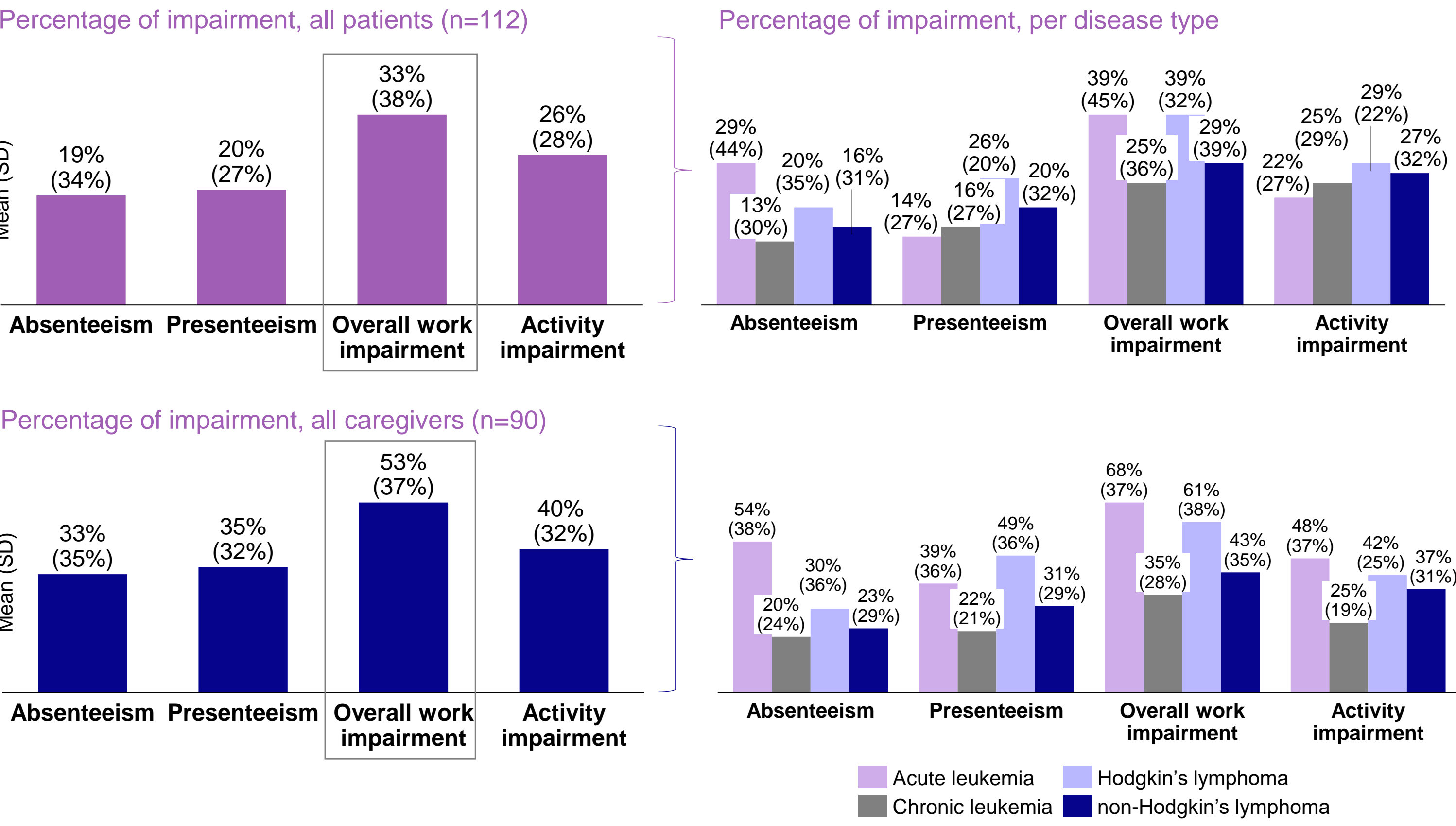
1. Socio-demographic and clinical characteristics

	Patients N=112	Caregivers N=90
	N (%)	N (%)
Sex		
Male	29 (26%)	6 (7%)
Female	83 (74%)	84 (93%)
Age		
18 to 40 years	31 (28%)	23 (26%)
41 to 55 years	55 (49%)	46 (51%)
> 56 years	26 (23%)	21 (23%)
Level of education ³		
Basic or Intermediate	50 (45%)	33 (38%)
Advanced	62 (55%)	54 (62%)
Gross monthly income		
< 1000€	41 (38%)	42 (47%)
1000€-2000€	53 (49%)	33 (37%)
>2000€	15 (14%)	11 (12%)
Diagnosis		
Acute Leukemia	19 (17%)	29 (32%)
Chronic Leukemia	26 (23%)	13 (14%)
Hodgkin's lymphoma	29 (26%)	15 (17%)
non-Hodgkin's lymphoma	38 (34%)	33 (37%)
Treatment		
Ongoing treatment	38 (34%)	38 (42%)
Pre/ post-treatment	74 (66%)	52 (58%)
Time since diagnosis/ duration of care		
< 1 year	24 (22%)	26 (29%)
1 year to 5 years	37 (33%)	44 (49%)
> 5 years	50 (45%)	20 (22%)

2. Health-Related Quality of Life



3. Work Productivity and Activity Impairment



Patients reported an overall work impairment of 33%(SD=38%), and caregivers 53%(SD=37%).

Work hours lost per week and indirect costs

Patients (mean, SD)					
	All patients	Acute leukemia	Chronic leukemia	Hodgkin's lymphoma	non-Hodgkin's lymphoma
Work hours lost per week, per patient	13 (15)	15 (18)	10 (14)	16 (13)	11 (16)
Indirect costs per patient, per year (in Euros)	6,157 € (7,093 €)	7,318 € (8,441 €)	4,650 € (6,810 €)	7,368 € (6,135 €)	5,424 € (7,401 €)
Caregivers (mean, SD)					
	All caregivers	Acute leukemia	Chronic leukemia	Hodgkin's lymphoma	non-Hodgkin's lymphoma
Work hours lost per week, per caregiver	21 (15)	27 (15)	14 (11)	24 (15)	17 (14)
Indirect costs per caregiver, per year (in Euros)	9,951 € (7,025 €)	12,846 € (7,085 €)	6,599 € (5,243 €)	11,498 € (7,178 €)	8,164 € (6,670 €)

Note: SD = standard deviation; For the calculation of productivity losses, 48 annual working weeks and 40 working hours per week were assumed. For the valuation of indirect costs, an average earning of 9.84 € per hour was assumed, based on official National unit costs.⁵

Mean annual indirect cost per patient was 6,157€, and 9,951€ per caregiver.

Multivariate analysis

Relationship between HRQoL and overall work impairment, and with indirect costs

	GLM	Two part-model (logit and GLM)
	Overall work impairment	Indirect Costs (€)
	Marginal Effect [95% CI]	Marginal Effect [95% CI]
Patients ^a		
FACT-G score	-0.0068*** [-0.0114; -0.0022]	-169.3*** [-257.0; -81.5]
Pre/ post-treatment	ref.	ref.
Ongoing treatment	0.2945*** [0.1276; 0.4623]	6,368.1*** [2,590.2; 10,146.0]
Caregivers ^b		
QASCI score	0.0075*** [0.0032; 0.0117]	147.6*** [66.2; 228.9]

Note: ***p<0.01; CI = confidence interval; ^aadjusted by age, sex, education, ongoing treatment, and time since diagnosis; ^badjusted by age, sex, education, ongoing treatment, and duration of care. For the simplicity of interpretation, results are presented as marginal effects. Only statistically significant results, considering a 95% confidence interval, are displayed in the table.

When FACT-G score decreases by one-unit, overall work impairment increases by 0.68 p.p. (p<0.01), and indirect costs increase by 169.3€ (p<0.01). For caregivers, when QASCI score increases by one-unit, overall work impairment increases by 0.75 p.p. (p<0.01), and indirect costs increase by 147.6€ (p<0.01).

Limitations

- This is an exploratory study, based on an online questionnaire. This methodology may have contributed for a selection bias, since patients from lower socio-economic levels have a lower probability of enrollment (a large proportion of respondents have an advanced level of education);
- Leukemias and lymphomas include several diseases with different clinical profiles, however, it was not possible to perform multivariate analysis per disease type;
- Further studies, with a larger number of participants per disease subtype, should be conducted to better explore and quantify the relationship between HRQoL, productivity losses and indirect costs.

TAKE HOME MESSAGES

- Patients reported an overall work impairment of 33%(SD=38%), and caregivers 53%(SD=37%). Mean annual indirect cost per patient and caregiver was 6,157€ (SD=7,093€) and 9,951€ (SD=7,025€), respectively;
- FACT-G and QASCI are significantly related with overall work impairment, and consequently with indirect costs, in patients diagnosed with leukemia and lymphoma, and their caregivers, respectively.