Emotional distress dominates quality of life burden in CML: psychometric validation of patient reported outcomes in a global leukemia experience survey

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- **Emotional Burden was the main driver of quality of life impairment**, with moderate-to-extremely-large effects in 75% of patients.
- **Future health concerns, anxiety, treatment worry, sleep changes, and concentration difficulties** were the most relevant emotional issues.
- **Fatigue remained highly prevalent despite low overall Symptom Score impact**, mainly tiredness and reduced energy

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Introduction

Patients with Chronic Myeloid Leukemia (CML) require lifelong therapy, predominantly with tyrosine kinase inhibitors (TKIs). Although survival has markedly improved, many patients experience persistent physical symptoms, treatment-related adverse events and psychological distress. Ongoing concerns about disease progression, long-term toxicity, and impact on daily life may substantially impair quality of life (QoL). Therefore, systematic evaluation of patient-reported outcomes (PROs) using validated, disease-specific instruments is essential in contemporary CML management. The Hematological Malignancy PRO (HM-PRO) instrument has been validated for use in CML.

The 2023 Acute Leukemia Advocates Network (ALAN) global survey collected patient experiences for 2260 patients, amongst which 660 CML patients participated (Nier S. et al., 2026).

Aim

This survey aims to evaluate the psychometric performance of the HM-PRO in the CML cohort from the 2023 ALAN survey.

Methods

The 2023 ALAN survey was an anonymous global online survey conducted from August 19, 2023, to January 5, 2024, in 13 languages. Patients were recruited through the ALAN, CML Advocates Network (CMLAN) and CLL Advocates Network (CLLAN). For the current analysis, only respondents with a diagnosis of chronic myeloid leukemia (CML) were included. PRO data were analyzed for participants who completed the HM-PRO questionnaire. Non-sensitive demographics, CML characteristics and HM-PRO responses were collected. Reliability and internal consistency were evaluated across HM-PRO domains: Physical Behavior (PB, 7 items), Emotional Behavior (EB, 11 items), Social Well-Being (SW, 3 items), Eating and Drinking (ED, 2 items), Part A (sum of domains) and Symptom Scale (SS, 18 items; PART B). Score banding was defined as: 0–7.5 no effect; >7.5–25.5 small; >25.5–41.5 moderate; >41.5–74.5 very large; >74.5 extremely large.

Results

Patient characteristics

An international cohort of 660 adults with CML responded to the survey. Participants were predominantly female (57%) with a median age of 53 years. Most were in chronic phase (91%) and receiving treatment (83%), mainly targeted therapy (62%). The median disease duration was 5 years, indicating substantial lived experience **(Table 1).**

Table 1 Patient characteristics of the CML study cohort

Characteristic	Overall (n = 660)
Gender, n (%)	
Female	378 (57.3)
Male	226 (34.2)
Prefer not to say	30 (4.5)
Prefer to self-describe	26 (3.9)
Age, years	
Range	20–84
Median (IQR)	53(21)
Country of residence, n (%)	
Brazil	89 (13.5)
Israel	55 (8.4)
United States of America	50 (7.6)
Czechia (Czech Republic)	47 (7.1)
Kenya	43 (6.5)
Netherlands	43 (6.5)
Denmark	38 (5.8)
All other countries	291 (44.2)
Employment status, n (%)	
Full time employment	216 (32.7)
Retired	160 (24.2)
Part time employment	71 (10.8)
Self employment	56 (8.5)
Unemployed and unable to work for health reasons	48 (7.3)
Years with disease	
Range, Median (IQR)	0–68, 5 (10)
Do you know which phase of CML you are in?	
Chronic phase	430 (91.3)
Accelerated phase	16 (3.4)
Blast phase / Blast crisis	5 (1.1)
Don't know / cannot remember	20 (4.2)
Currently receiving treatment, n (%)	549 (83.2)
Current treatment type, n (%)*	
Targeted therapy	407 (61.7)
Chemiotherapy	52 (7.9)
Immunotherapy	13 (2.0)

Distribution of HM-PRO Domain Scores

A broad distribution of scores across all domains was observed. EB showed the highest mean score (43.03 ± 24.88), indicating that emotional concerns represented the most relevant aspect of disease burden in this cohort. PB, SW, and ED showed lower median values than means, together with positive skewness, suggesting that most patients reported relatively low-to-moderate impairment, while a smaller subgroup experienced markedly higher burden. Part A Total scores showed moderate variability (median 26.14; IQR 28.9) with near-normal distribution characteristics (skewness 0.739; kurtosis −0.073), supporting good score dispersion across the study population. In contrast, SS scores demonstrated marked positive skewness (2.032) and high kurtosis (5.447), indicating clustering of responses at lower values with the presence of a smaller subgroup reporting substantially higher social support needs **(Table 2).**

Table 2 Descriptive statistics of HM-PRO domain scores

Domain	N	Mean (SD)	Median (IQR)	Scale range
Physical Behavior	601	22.51 (22.71)	14.29 (35.7)	0–100
Social Well-Being	601	25.04 (28.11)	16.67 (50)	0–100
Emotional Behaviour	601	43.03 (24.88)	40.91 (31.8)	0–100
Eating and Drinking	601	32.61 (31.64)	25 (50)	0–100
Part A Total	601	30.8 (20.57)	26.14 (28.9)	0–93.75
Symptom Scale (Part B)	589	4.91 (6.93)	2.78 (8.3)	0–50

Internal Consistency of HM-PRO Domains

The internal reliability analysis showed consistently strong psychometric performance across the HM-PRO scales. Part A domains demonstrated good to excellent internal consistency, with Cronbach's α ranging from 0.707 to 0.881. EB achieved the highest reliability (α = 0.881), supported by robust inter-item correlations, indicating a well-cohesive construct. PB and SW also showed solid internal consistency (α = 0.832 and 0.742), while ED reached acceptable levels (α = 0.707).

The total Part A score exhibited excellent reliability (α = 0.912), confirming strong coherence across all 24 items. For Part B, the SS scale showed good internal consistency (α = 0.807), though with a wider range of inter-item correlations, reflecting the greater heterogeneity of items assessing support needs (**Table 3).**

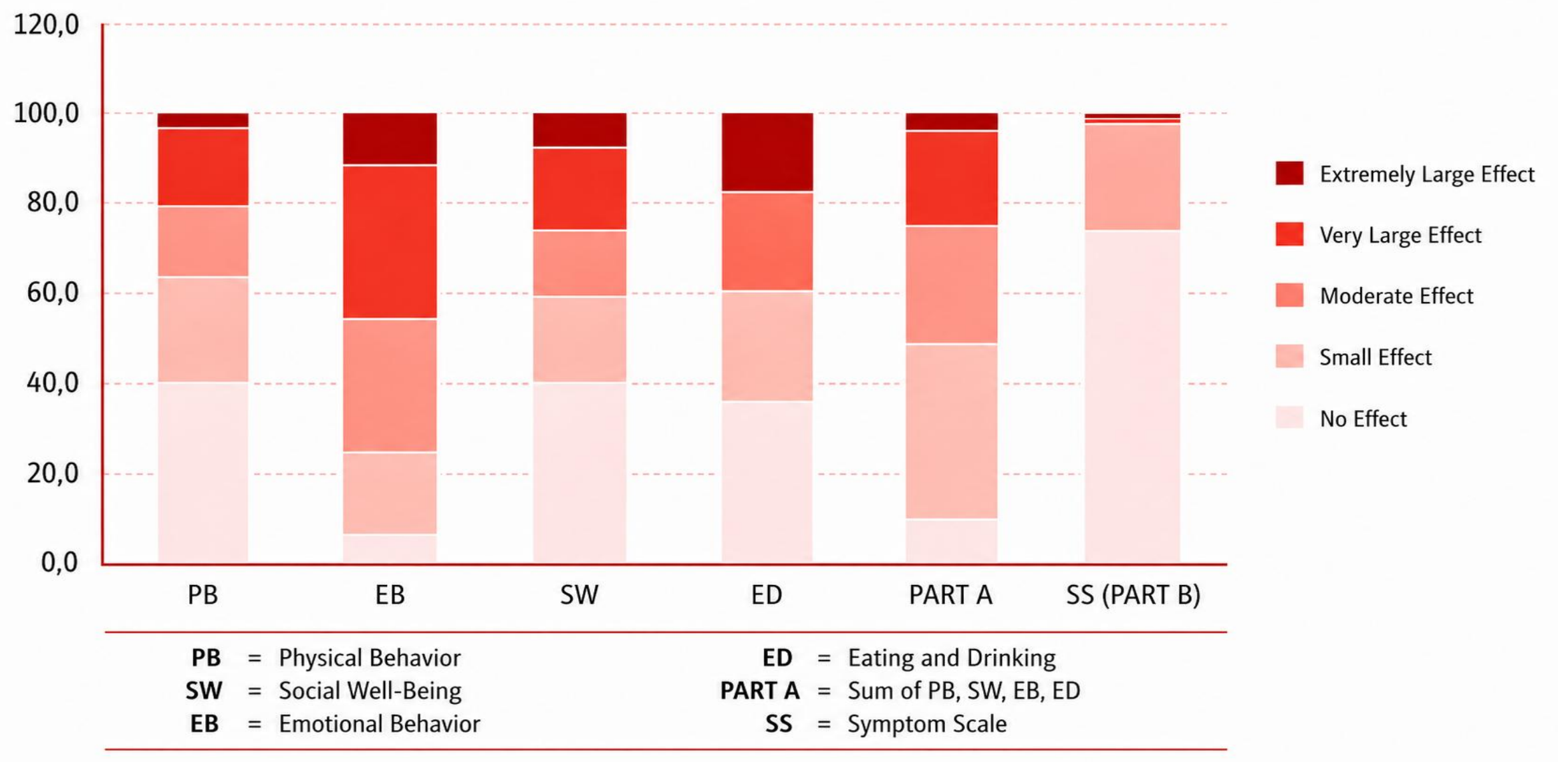
Table 3 Reliability analysis of HM-PRO domains

Domain	N items	Cronbach's α	α standardized	Mean inter-item correlation	Range inter-item correlations
Physical Behavior	7	0.832	0.839	0.426	0.222–0.580
Social Well-Being	3	0.742	0.754	0.505	0.391–0.724
Emotional Behavior	11	0.881	0.881	0.403	0.251–0.710
Eating and Drinking	3	0.707	0.71	0.449	0.291–0.582
Total Part A	24	0.912	0.913	0.305	0.089–0.724
Symptom Scale (Part B)	18	0.807	0.814	0.195	0.021–0.757

Patient-Reported HM-PRO Impact Across Domains

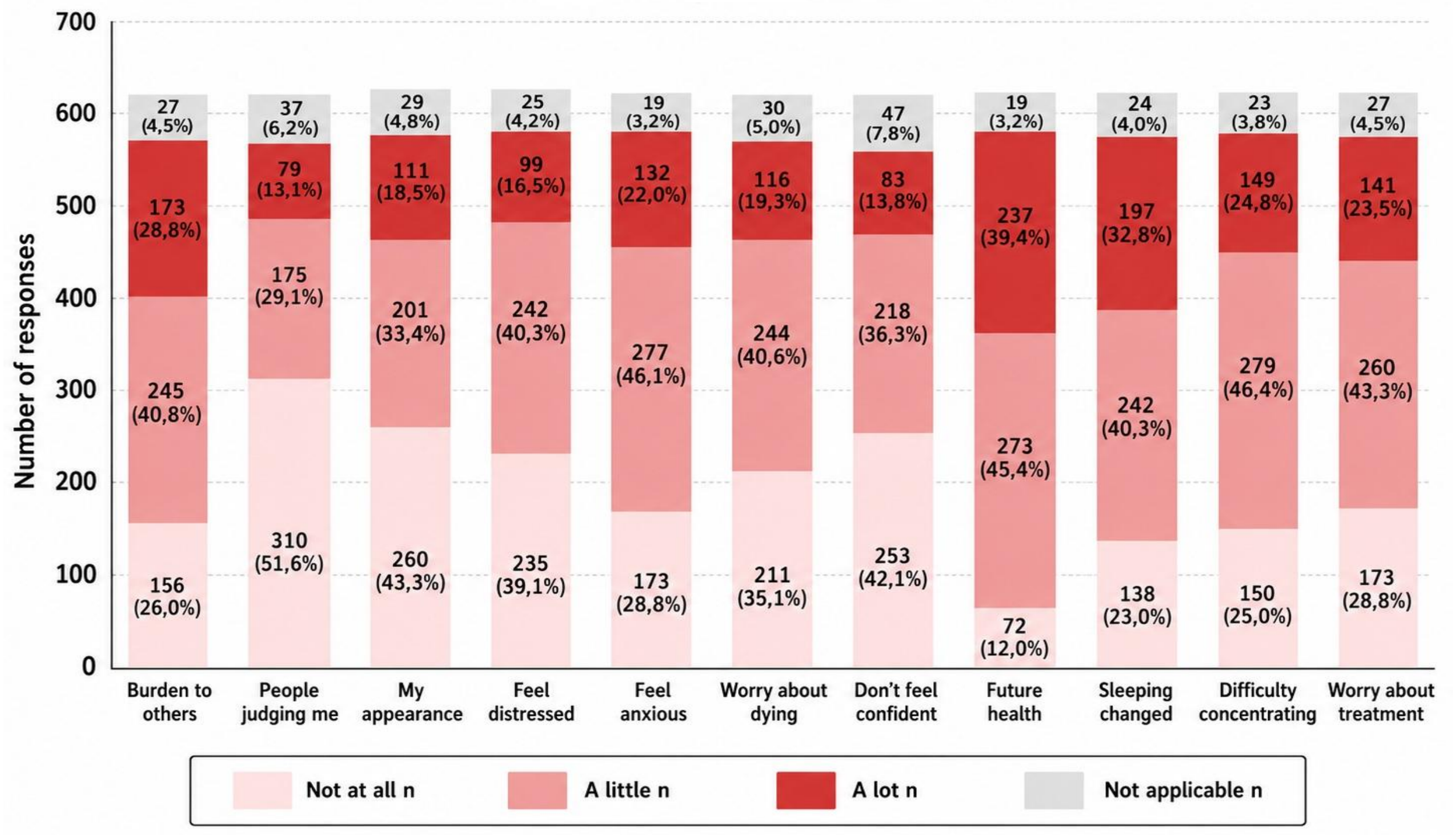
Median HM-PRO scores indicated a moderate overall impact, primarily driven by EB. Small effects were reported for PB (63%), most frequently difficulty with physical activity/sport, SW (59%) driven by problems with sexual life in 46% and ED (60%) due to changes in eating and drinking habits. In contrast, moderate-to-extremely-large effects in the EB domain were reported by 75% of respondents **(Figure 1).**

Figure 1 Reported HM-PRO impact pattern by domain in CML



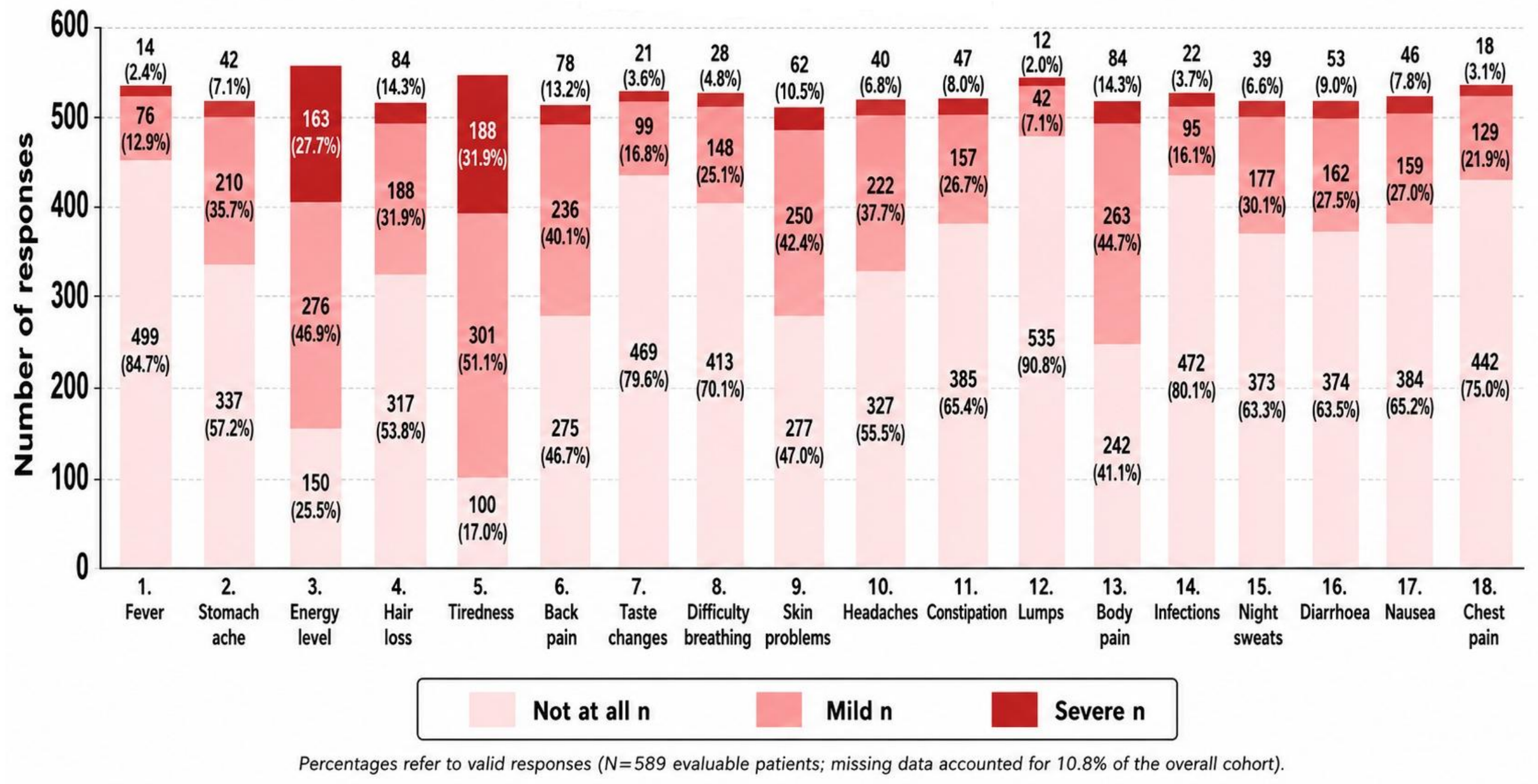
Across individual EB items, "A little" was the most frequent response for several domains: particularly difficulty concentrating (46.4%), feeling anxious (46.1%), concerns about future health (45.4%), and worry about treatment (43.3%). The highest proportion of "A lot" responses was observed for future health concerns (39.4%), followed by sleeping changes (32.8%) and feeling like a burden to others (28.8%, **Figure 2).**

Figure 2 HM-PRO Emotional behaviour items



Although the overall SS indicated no-to-small effect in 98% of cases, fatigue-related symptoms remained prominent. Tiredness (83.0%; 31.9% severe) and reduced energy (74.6%; 27.7% severe) were the most prevalent complaints, followed by body pain (58.9%) and back pain (53.3%, **Figure 3).**

Figure 3HM-PRO Symptom burden items



Percentages refer to valid responses (N=589 evaluable patients; missing data accounted for 10.8% of the overall cohort).

Conclusions

The HM-PRO demonstrated strong internal reliability in CML patients, supporting its validity as a disease-specific PRO instrument. Emotional distress emerged as the most compromised domain and the primary contributor to overall impact (Part A), underscoring the importance of structured psychosocial and QoL assessment within multidisciplinary CML care.

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