ORIGINAL ARTICLE

Validation of the Short-Form Survivor Unmet Needs Survey in older patients with myeloma

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Disclosure: The authors have no potential conflicts of interest to disclose.

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Abstract

Background: Multiple myeloma (MM) affects mainly the older population and is the second most prevalent haematologic cancer. MM patients' unmet needs are diverse, arise at different stages, and are associated with greater psychological distress. This study examined the psychometric properties of the Short-Form Survivor Unmet Needs Survey (SF-SUNS) in Portuguese MM patients.

Methods: This cross-sectional study included 213 MM patients. The internal consistency of the scale was analyzed with Cronbach's α. Principal component analysis and confirmatory factor analysis were used to assess construct validity. Convergent validity was examined by using correlations with quality of life, satisfaction with social support, and psychological morbidity. Multiple regression analyses were conducted to explore the contribution of sociodemographic and clinical variables to unmet needs.

Results: The Portuguese SF-SUNS's factor structure follows the original's structure, although it includes fewer items. For each domain, Cronbach's α was ≤0.70, the minimum acceptable criterion. For construct validity, only unmet relationship and emotional needs had significant correlations ($r \geq 0.40$)—specifically negative associations with quality of life and social support and positive associations with psychological morbidity. Regarding patient variables and SF-SUNS results, only cancer stage contributed significantly to unmet information needs, with patients at stage I reporting more needs than patients at stage III.

Conclusions: The SF-SUNS represents a valid and reliable tool to assess unmet needs among Portuguese MM patients. It may be useful in designing and monitoring interventions to improve well-being in cancer survivors.

INTRODUCTION

Multiple myeloma (MM), a blood cancer arising from a proliferation of malignant plasma cells, is the second most prevalent haematologic cancer worldwide.[1] The median age at diagnosis is 70 years old, making MM predominantly a disease of the older population.[1–3] In Portugal, the age-standardized rate for the incidence of MM was 2.3 per 100 000 individuals and for mortality 1.4 per 100 000.[4]

This type of cancer is incurable, and its treatment occurs mainly in an outpatient setting with the support of a caregiver,[5] often a family member who tends to the patient's physical, emotional, and instrumental demands.[6]

Cancer patients often report having several unmet needs. For example, according to Sanson-Fisher *et al*.,[7] approximately 40% of the cancer population undergoing treatment (surgery, chemotherapy, or radiotherapy) at public treatment centres in Australia experienced a moderate to high level of unmet psychological needs. In patients with MM, unmet psychological and psychosocial needs are among the most frequently reported.[3] Other unmet needs relate to physical symptoms of the disease, such as pain

and fatigue, as well as issues related to sexuality.[8, 9] Molassiotis *et al.* found that 26.5% of MM patients reported at least one unmet need, but they described the level of need as weak to moderate.[5] Most of those unmet needs related to the accessibility of hospital car parks, life and/ or travel insurance; concerns regarding disease relapse; and the support level of basic care.

The literature has also documented the association between unmet needs and greater psychological distress, particularly anxiety and depression, among patients and their caregivers.[9–12] Depressed and anxious patients expressed more unmet needs than MM patients without psychological distress.[5]

Social support is considered an important resource for patients because it directly affects their health.[13] In fact, Wells *et al.* found that in patients with MM, lower levels of social support before haematopoietic stem cell transplantation were associated with higher levels of anxiety and depression.[14]

Among the existing measures for evaluating adult cancer-related needs, the Survivor Unmet Needs Survey Questionnaire (SUNS) is the most commonly used tool to assess cancer survivors' specific needs.[15, 16] However, because SUNS contains 89 items, it can be cumbersome to administer in routine clinical practice.[17] Campbell *et al.* developed and validated a shorter version using a large, independent, and heterogeneous sample of 1589 cancer patients.[18] The shortened version (SF-SUNS) presented strong psychometric proprieties, resulting in a concise and robust measure (30 items) appropriate for routine use. Having been validated in the Canadian and Australian contexts,[18, 19] the Short-Form SUNS (SF-SUNS) is available only for English-speaking cancer survivors.

Different needs arise at different stages,[20] and unmet needs are associated with greater psychological distress.[9, 12] As such, it is important to have validated measures to assess the needs of patients in order to meet them adequately. Therefore, this study aims to validate the SF-SUNS in a sample of Portuguese patients with MM.[18]

METHODS
Participants and procedure
This study used a convenience sample of 213 patients with MM. Patients were recruited from the outpatient medical oncology and haematology medical consultations at five central hospitals in different urban areas of Portugal; each hospital treats myeloma disease. Inclusion criteria were as follows: (i) having a diagnosis of MM; (ii) being at least 18 years old; (iii) being literate; and (iv) having no cognitive deficit as assessed by the Mini-Mental State Examination.

This cross-sectional study followed all ethical principles outlined in the Declaration of Helsinki and was approved by the ethics committee at each hospital where data collection took place. Patients were identified and invited to participate in the study by their physicians. All patients agreed to participate in this study. Data were collected individually on the day a patient had a medical appointment or treatment, in rooms available in the hospital unit. Clinical data, including MM stage,[21] were collected from patients' medical records. All participants were informed regarding the aim of the study and data confidentiality. Participation was voluntary and all participants signed an informed consent form.

The SF-SUNS translation to Portuguese followed the translation and adaptation guidelines.[22]

Measures
Sociodemographic and Clinical Questionnaire
Patients were asked to provide information about sociodemographic characteristics (gender, age, habitation, education, and employment status). Clinical information (myeloma type, cancer stage, and disease duration) was collected from patients' clinical charts.

Short-Form Survivor Unmet Needs Survey[18]
The SF-SUNS consists of 30 items across four domains: information (INF), financial concerns (FIN), access and continuity of care, and relationship and emotional health (REH). Items are scored on a 5-point Likert scale, and each domain's items are summed to provide a score. Higher scores correspond to greater unmet needs.

The European Organization for Research and Treatment of Cancer's Questionnaire C30[23, 24]
Questionnaire C30 (QLQ-C30) is a multidimensional questionnaire with 30 items that are designed to assess the quality of life (QoL) of cancer patients. In addition to evaluate global QoL (summary score), the QLQ-C30 evaluates also function on five subscales

(physical, role, emotional, social, and cognitive), symptoms on nine subscales/items (fatigue, pain, nausea and vomiting, dyspnoea, sleep, appetite loss, constipation, diarrhoea, and financial difficulties), and global health status. Items are scored on a 4-point Likert scale, except for the global health status subscale, which uses a 7-point linear analogue scale. Higher scores on the global scale indicate better QoL. Only the total score was considered in the current study. Cronbach's α was 0.90.

The European Organization for Research and Treatment of Cancer's Multiple Myeloma Module[25, 26]

The original version of the Multiple Myeloma Module (QLQ-MY) consists of 20 items that assess the impact of MM and its treatment on patients. Questions focus on disease symptoms (MYDS; 6 items), side-effects of treatment (MYSE; 10 items), future perspective (MYFP; 3 items), and body image (MYBI; 1 item), using a 4-point Likert scale. There is no overall QLQ-MY score, but higher scores on the symptom scales (MYDS and MYSE) reflect a greater number of symptoms. In contrast, higher scores on the MYFP and MYBI scales indicate better future prospects and body image.

The Portuguese version of the QLQ-MY contains 17 items distributed among the same four dimensions: the MYSE scale has three fewer items than the original version. In the present study, Cronbach's α was 0.86 for MYDS, 0.68 for MYSE, and 0.95 for MYFP.

Hospital Anxiety and Depression Scale[27, 28]

This Hospital Anxiety and Depression Scale consists of 14 items assessing anxiety and depression; seven items focus on each condition. Items are answered on a 4-point Likert scale, where higher scores indicate greater symptoms of anxiety and depression. The total score may be used as a clinical indicator of psychological distress or morbidity. In this study, only the total score was used; Cronbach's α was 0.81.

Satisfaction with Social Support Scale[29]

The Satisfaction with Social Support Scale is a Portuguese instrument that evaluates the satisfaction with social support through 15 items divided into four subscales: satisfaction with friends, intimacy, satisfaction with family, and social activities. Items are evaluated on a 5-point scale and a higher score indicates greater satisfaction with social support. Only the global scale was used in the analysis. Cronbach's α in this study was 0.88.

Data analysis

Descriptive statistics were used to describe patients' demographics and clinical characteristics To test the original factor structure of the SF-SUNS, a principal component analysis (PCA) and confirmatory factor analysis (CFA) were performed. First, a non-rotated PCA was performed and then forced to four factors through varimax rotation, following the authors' original solution. Subsequently, a CFA was performed using a structural equations modelling technique. The refinement of the final model was assessed with χ^2/degrees of freedom, the comparative fit index, the Tucker–Lewis Index, and the root mean square error of approximation. χ^2/degrees of freedom <3, comparative fit index ≥ 0.90, Tucker–Lewis Index ≥ 0.90, and root mean square error of approximation in the range of 0.05–0.08 reflect an adequate fit.[30, 31] Internal consistency was evaluated using Cronbach's α coefficient.

To assess convergent evidence, the relationships between SF-SUNS's subscales and other measures of QoL (QLQ-C30 and QLQ-MY), social support (Satisfaction with Social Support Scale), and psychological morbidity (Hospital Anxiety and Depression Scale) were examined using Pearson's correlation coefficients ≥ 0.40.[32] Finally, separate linear multiple regression analyses were conducted for each SF-SUNS' subscale to explore the contribution of demographics (gender and age) and clinical characteristics (cancer stage and disease duration) to unmet needs. To that end, cancer stage I was used for comparison purposes regarding the cancer stage variable.

All standard statistical analyses were conducted using SPSS version 25.0 (IBM, Armonk, NY, USA), and path analyses were carried out with SPSS AMOS version 25.0 (IBM).

RESULTS
Participants

Participants' sociodemographic and clinical characteristics are presented in Table 1.

Table 1 Demographic and clinical characteristics (N = 213)

Characteristics		Data[†]
Gender	Women	106 (49.8%)
	Men	107 (50.2%)
Age (years)		67.40 ± 10.52
Age group	<40 years	3 (1.4%)
	40–49 years	12 (5.6%)
	50–59 years	25 (11.6%)
	60–69 years	78 (36.6%)
	≥70 years	95 (44.6%)
Habitation	Urban	145 (68.1%)
	Rural	68 (31.9%)
Myeloma type	IgA/L	29 (13.6%)
	IgA/K	41 (19.2%)
	IgG/K	82 (38.5%)
	IgG/L	32 (15.0%)
	Other	29 (13.6%)
Cancer stage	I	76 (35.7%)
	II	59 (27.7%)
	III	53 (24.9%)
Education	≤Primary school	149 (69.9%)
	≤Secondary school	30 (14.1%)
	≤University degree	34 (16.0%)
Professional situation	Employed	24 (11.3%)
	Unemployed	22 (10.3%)
	Retired	167 (78.4%)
Disease duration (months)		46.16 ± 42.80

[†] Data are presented as *n* (%) or mean ± SD. IgG, immunoglobulin G; K, kappa; L, lambda.

Table 2 CFA results for the Portuguese version of the Short-Form Survivor Unmet Needs Survey

Model	Domain: items	Cronbach's α	Statistical fit indices
Original SUNS model[18]	INF: 1–3	0.85	
	FIN: 4–11	0.90	
	ACC: 12–17	0.90	
	REH: 18–30	0.95	
Initial model	INF: 1–3	0.77	χ^2 = 1139.16
	FIN: 4–11	0.71	d.f. = 399
	ACC: 12–17	0.74	CFI = 0.742
	REH: 18–30	0.86	TLI = 0.719
			RMSEA = 0.094 (0.087; 0.100)
Re-specified model	INF: 1–3	0.77	χ^2 = 305.56
	FIN: 4–7	0.92	d.f. = 164
	ACC:13–16	0.73	CFI = 0.924
	REH: 18, 20, 22–24, 26–28, 30	0.81	TLI = 0.912
			RMSEA = 0.064 (0.053; 0.075)

INF, information; FIN, financial concerns; ACC, access and continuity of care; REH, relationship and emotional health; CFA, confirmatory factor analysis; CFI, comparative fit index; d.f., degrees of freedom; RMSEA, root mean square error of approximation; SUNS, Survivor Unmet Needs Survey; TLI, Tucker–Lewis Index.

Construct validity evidence

The results of Bartlett's sphericity test (χ^2 = 3135.29, *P* < 0.001) and the Kaiser-Meyer-Olkin sample
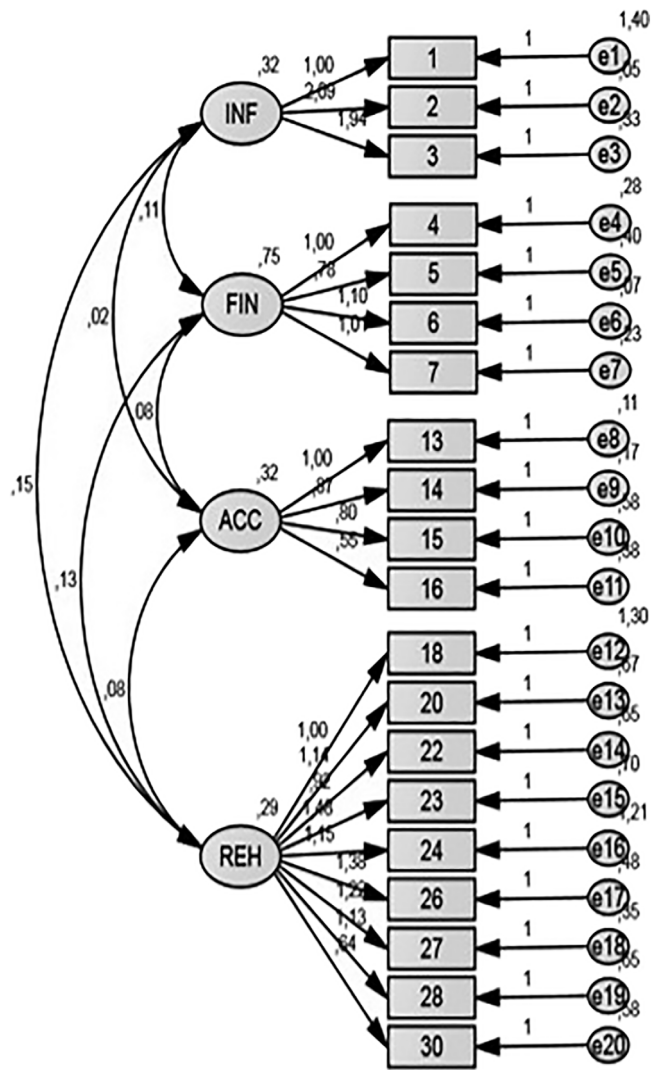

Figure 1 Re-specified model for the Portuguese version of the Short-Form Survivor Unmet Needs Survey. INF, information; FIN, financial concerns; ACC, access and continuity of care; REH, relationship and emotional health.

adequacy test (0.79) confirmed the sample adequacy to proceed with factor analysis. Initial PCA extracted nine factors with eigenvalues <1, explaining 69.12% of the total variance. Given the disperse and confusing item allocation and the results of a scree plot inspection, a second PCA was conducted, forcing the extraction of four factors. The rotated solution was close to the solution found for the original English version of the SF-SUNS, explaining 48.51% of the variance. The item distribution was consistent with the original version, except for items 8, 9, 11, 19 and 21, which had higher loadings on different factors.

The original four-factor structure was not confirmed by CFA, indicating inadequate goodness-of-fit indices (Table 2). Subsequently, an inspection of the modification indices and the quality of the model led to the elimination of 10 items (items 8–12, 17, 19, 21, 25, and 29), resulting in a similar but reduced four-factor structure with a good global adjustment (Table 2 and Fig. 1). Criteria for the items' exclusion included the small factor loadings (<0.40) and high correlations between error variances. The itemsreassignment to another factor was also tested before its removal.

Internal consistency evidence
For each SF-SUNS domain, Cronbach's α indicated acceptable to excellent internal consistency reliability (range: 0.77–0.92) (Table 2).

Convergent validity evidence
Overall the SF-SUNS domains correlated positively with QLQ-MY symptom scales and the Hospital Anxiety and Depression Scale, but negatively with the QLQ-MY functional scales, QLQ-C30, and Satisfaction with Social Support Scale. Only REH had correlations greater than the recommended criterion of 0.40, except for the correlations with the MYDS and MYBI subscales. The remaining SF-SUNS domains had weaker associations (Table 3).

Contribution of patients' gender, age, illness stage and disease duration to unmet needs
According to the standardized regression coefficients, only illness stage contributed significantly to SF-SUNS, specifically to unmet INF needs ($\beta = -0.17$, $P = 0.04$), with the model including all variables explaining approximately 6% of the variance in INF scores ($R^2 = 0.06$, $F_{5,179} = 2.43$, $P = 0.037$). The negative regression coefficient showed that patients report fewer unmet FIN needs in stage III than in stage I. Disease duration also contributed significantly to unmet FIN ($\beta = 0.15$, $P = 0.04$) and REH ($\beta = 0.17$, $P = 0.03$) needs, however both general models were not significant (FIN: $R^2 = 0.05$, $F_{5,179} = 2.04$, $P = 0.08$; REH: $R^2 = 0.03$, $F_{5,179} = 1.26$, $P = 0.28$). Finally, neither gender nor age contributed to unmet needs (Table 4).

DISCUSSION
This study evaluated the psychometric properties of the SF-SUNS in a sample of Portuguese patients with MM. Participants were recruited at five central main hospitals in urban areas thar receive MM patients in Portugal. Sociodemographic characteristics, including gender and age, were consistent with the population of Portuguese patients with MM

Table 3 Correlations of unmet needs (SF-SUNS) with quality of life (QLQ-C30 and QLQ-MY), satisfaction with social support (SSSS) and psychological morbidity (HADS)

		INF	FIN	ACC	REH
QLQ-C30			−0.27**	−0.18*	−0.17*	−0.64**
QLQ-MY	MYDS	0.26**	0.23*	0.19*	0.33**
	MYSE	0.14*	0.08	0.15*	0.41**
	MYBI	−0.12	−0.18*	−0.23**	−0.35**
	MYFP	−0.033**	−0.06	−0.13	−0.45**
SSSS		−0.22**	−0.00	−0.04	−0.47**
HADS		0.28**	0.05	0.11	0.63**

*$P < 0.05$. **$P < 0.001$. INF, Information; FIN, financial concerns; ACC, access and continuity of care; REH, relationship and emotional health; MYSD, disease symptoms; MYSE, side-effects of treatment; MYBI, body image; MYFP, future perspective; SF-SUNS, Short-Form Survivor Unmet Needs Survey; QLQ-C30, Questionnaire C30; QLQ-MY20, Multiple Myeloma Module; SSSS, Satisfaction with Social Support Scale; HADS; Hospital Anxiety and Depression Scale.

Table 4 Contribution of patients' characteristics to SF-SUNS scores

	INF		FIN		ACC		REH	
	β	t	β	t	β	t	β	t
Patients								
Gender	−0.08	−1.02	0.11	1.54	0.09	1.14	0.06	0.78
Age	0.01	0.09	0.04	0.58	0.10	1.36	0.02	0.25
Cancer stage II	0.06	0.68	0.04	0.51	−0.10	−1.22	−0.04	−0.42
Cancer stage III	−0.17	−2.07*	−0.10	−1.27	−0.07	−0.84	−0.07	−0.83
Disease duration	0.13	1.76	0.15	2.03*	0.13	1.75	0.17	2.25*
R^2 (R^2 adjusted)	0.06 (0.04)		0.05 (0.03)		0.04 (0.02)		0.03 (0.01)	
F	2.433*		2.044		1.558		1.264	

*$P < 0.05$. INF, Information; FIN, financial concerns; ACC, access and continuity of care; REH, relationship and emotional health; SF-SUNS, Short-Form Survivor Unmet Needs Survey.

(e.g. mostly >60 years old, nearly equal numbers of men and women).

Although CFA confirmed SF-SUNS's original four-dimension structure with patients' data, only 20 of the original items were included in the revised model. Specifically, the FIN, **access and continuity of care (ACC),** and REH domains contain fewer items, whereas the INF domain maintained all items (Table 2). The FIN subscale includes half of the original items. Given the sample's characteristics, particularly with regard to age, disease duration, and employment status, some FIN items, such as 'Finding car parking that I can afford at the hospital or clinic' (item 8) or 'Knowing how much time I would need away from work' (item 10), may not apply to participants who can no longer drive or are retired.

In general, the final model corresponds closely to the original SF-SUNS and has good data fit. For each domain, Cronbach's α was consistent with previous validation studies,[18, 19] but was predictably lower in the domains of the original version,[18] which included more items. Also, the validation study for the original SF-SUNS involved a significantly larger sample size (*N* = 1589). However, in the present study, Cronbach's α ranged from 0.73 to 0.85, indicating a good internal consistency. Overall, the Portuguese SF-SUNS's factor structure reflects the original model but with fewer items, although the INF and **access and continuity of care** (ACC) subscales remain the same.

In terms of convergent validity evidence, only the REH subscale significantly correlated with QoL, social support, and psychological morbidity. As expected, REH correlated positively with the disease symptom subscale (MYSE) but negatively with the functional subscale (MYFP), QoL, and social support. Cancer patients report needs for emotional support probably due to symptoms, increased social isolation, fear of relapse, and uncertainties about the future.[5] In addition, patients often hide situations that trigger stress and fear from their relatives in an effort to protect them.[34] These circumstances, coupled with the fact that patients often stay home because of the side-effects of treatments (e.g. decreased immunity, bone pain), increase the likelihood of isolation,[33] which in turn can limit social relationships, reduce support, and thus affect QoL.[34] REH also had a significant positive association with psychological morbidity, which is not surprising given that the literature indicates that patients with higher levels of anxiety and depression report more unmet needs.[8, 12] The present study showed that emotional needs werethe most prominent unmet needs among MM patients, which is in accordance with other cancer studies that have identified emotional support as the most common unmet psychological need.[12] Overall, patients' results supported limited convergent evidence because only the REH subscale showed significant correlations with other domains.

Patients' gender and age did not contribute to MM patients unmet needs, as reported in previous studies.[7, 35] There were fewer unmet INF needs at stage III than at stage I. Some studies have shown that patients in advanced disease stages report more needs than patients with a localized disease,[36] especially psychological, medical, and information needs.[37] However, in this study, patients in the initial cancer stage reported more unmet INF needs probably because this stage represents an important threshold regarding one's medical condition (uncertainty about the future). Previous cancer studies have also reported that patients identified a need for more information at this stage to plan for the future.[38, 39] Although none of the models were significant, longer disease duration contributed more to unmet FIN and REH needs, which makes sense due to the financial and emotional impact cancer may have on patients.[5, 12, 37]

Limitations

This study had some limitations, such as the sample size and the exclusive use of self-report measures. Having a small sample size limits the generalizability of the results; therefore, they should be interpreted with caution. Test–retest reliability of the Portuguese version of the SF-SUNS should be assessed in future studies, as recommended by the SF-SUNS authors.[18, 19] Finally, divergent evidence should also be tested in future validation studies.

Conclusion

The Portuguese version of the SF-SUNS presents adequate and promising psychometric properties and represents an important resource for assessing the unmet needs of cancer patients in the Portuguese context.

Overall, the SF-SUNS may be a helpful tool for health-care professionals in designing and monitoring

interventions to improve patients' QoL based on their unmet needs.

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