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Association between requests for supportive care assistance and patients' characteristics, prior to treatment in a comprehensive cancer center

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Abstract

Purpose: Patients with cancer experience a wide array of distress symptoms (emotional, practical, physical, and functional), which often hinders their quality of life and survival. Unfortunately, only a small proportion of these patients request assistance for these problems. This study explored the relationship between requests for supportive care assistance and distress of patients newly diagnosed with cancer.

Methods: This study was conducted at city of hope, an NCI-designated comprehensive cancer center, and included 2658 patients treated between 2009 and 2017. Patients were asked to complete a 30-item biopsychosocial problem-related distress survey via *SupportScreen®*, prior to any treatment. Correlations between requests for assistance and distress domains were evaluated. Primary types of requests were examined for all patients, and general linear modeling was used to determine the significant predictors of requests for assistance. p-values <0.05 were considered significant.

Results: Strong correlations were observed between distress subscales and requests for assistance (r ranging from 0.67 to 0.69). The primary types of requests varied by domain: items such as feeling anxious or fearful, finances, and *sleep* ranked first within the emotional, practical, and physical-functional domains respectively (~20% requests for each item). Verbal assistance was generally preferred to the written form of assistance, with the exception of a few items, including *finances*. Overall, household income of <\$100,000 and completing the survey in Spanish were significant predictors of requests for assistance. Regarding the practical and physical-functional domains, having an advanced stage of disease was significantly related to an increase in demands for assistance. Being older was associated to a decrease in requests for assistance vis-à-vis both the emotional and physical functional subscales.

Conclusion: We demonstrated that distress levels were strongly correlated with requests for assistance. Patients' clinical and demographic characteristics such as age, household income, disease stage and survey language were associated with inquiries for psychosocial support, highlighting the importance of targeting interventions towards those most likely to need them, to better aim patients' needs. Therefore, tailoring supportive care assistance to patients' characteristics could help boost the frequency of requests, reduce distress burden, and improve health outcomes.

KEYWORDS
assistance requested, cancer, emotional distress, oncology, psycho-oncology, screening, supportive care

1 | INTRODUCTION

Emotional distress has been widely studied across different types of cancer. It is estimated that 35% of patients diagnosed with cancer will report moderate to severe emotional distress at some point across the cancer continuum.[1] Patients with poor prognoses (e.g., lung, brain, and pancreatic cancers) are at a notably higher risk of experiencing emotional distress.[1] Whereas the term distress is often used to represent symptoms of emotional stress, depression or anxiety, it can also have a broader and more multifactorial conceptualization that includes stress from other sources, including practical, physical functioning and social domains.[2] Thus, differentiating these various elements of distress and exploring their impact on patients with cancer at the start of their treatment, may provide important insight into their experience.

Ideally, distress screening should be a routine part of comprehensive cancer care and monitored at various times throughout the disease trajectory. This holistic approach was proposed in the early 1990s with the primary goal of identifying patients with heightened biopsychosocial distress and providing timely and appropriate support and referrals.[2,3] Despite the high proportion of patients reporting moderate to severe distress, referral rates and utilization of specific health care services to manage distress, remain surprisingly low.[4–7] Low rates of requests of requests may be due to the stigma of psychosocial support, cultural and spiritual aspects (e.g., gender or age differences) or acceptance of distress as part of a cancer diagnosis and treatment.[4,5] Further, clinicians tend to refer patients who are younger or have less social/family support, those who are depressed and those who express a desire for psychosocial support.[4] Considering the type of assistance requested, some patients are seeking for basic information on diagnosis and treatment to assist them to better cope with their illness.[8] Studies suggest that many patients do not desire assistance with emotionally-based distress,[9–12] however it remains to be seen whether greater desire and higher rates of assistance requests may be found with regard to functional, physical and practical domains of distress. Furthermore, measuring the 'magnitude' of correlation between requests for

assistance and distress could be useful since we ignore how closely these two variables are related within each domain. Exploring the predictors of requests for assistance could be informative when seeking to improve supportive care measures. Are the demographic factors previously noted to impact distress the same as the ones affecting patients' requests for assistance?[13,14] In general, a better understanding of patient factors related to requests for assistance could help tailor useful interventions and ensure that the patients receive timely support.

The current study emphasized multiple domains of distress and requests for assistance, addressing the above literature gaps by1) investigating the correlations between requests for assistance and distress (emotional, practical, physical-functional), 2) examining the clinical and demographic factors associated with requests for support and 3) studying the primary type of requests for assistance (including patients' preferred modality of assistance).

2 | METHODS

A retrospective study was conducted at city of hope (COH), a national cancer institute-designated comprehensive cancer center, between 2009 and 2017. Patients (newly diagnosed with cancer) completed the *SupportScreen*® measure, a previously validated touch-screen biopsychosocial distress screening instrument,[15] prior to their first appointment with their physician, as per the center's distress screening protocol. The instrument was offered in both English and Spanish languages. Patients were eligible if they were 18 years or older and possessed the ability to read in either language. We used the routine screening data previously collected at the center to run a secondary analysis. Patients were included in our study if they had complete demographic and clinical data, as well as complete distress screening responses (per domain). The following types of diagnoses were present: breast (34%), gastrointestinal (15%), gynecological (11%), head and neck (4%), hematological (7%), lung (10%), prostate (14%), and, urinary (5%). A few cancer types (i.e., bones and joints, brain, and other nervous system,

Kaposi sarcoma, skin and soft tissue including heart) with small sample sizes, were automatically excluded in the final sample, due to the data cleaning process (i.e., incomplete demographic or clinical data). No compensation was given, and this study protocol was approved by the COH institutional review board.

2.1 | Measures

Demographic and clinical information was obtained through medical record and patient-reported data. The 30-item *SupportScreen*® survey was used to measure patients' biopsychosocial problem-related distress and requests for assistance. This touch screen-based instrument includes validated scales for emotional (8 items), practical (8 items), and physical-functional (14 items) domains. Patients were asked to rate each problem on a 5-point Likert scale (from 1 = not a problem to 5 = very severe problem).[15] Previous validation studies identified a cutoff score of three as indicative of high distress levels.[15,16] Total scores were summed for each subscale, with a potential range of 8–40 for emotional and practical domains, and 14–70 for the physical functional domain. A higher score indicates a higher level of self-reported distress. All three subscales had good internal consistency (emotional: $\alpha = 0.86$; practical: $\alpha = 0.79$; physical-functional: $\alpha = 0.84$) with the current sample.

Patients also reported whether they desired assistance and in which format. Requests for assistance options included: nothing needed at this time, talk with a member of the team, provide written information, or both written information and talk with the team. Each request for assistance item was coded as 0 = nothing needed at this time or 1 = assistance needed (any type). The items were then summed within each distress domain to generate the variable 'requests for assistance', with a potential range of 0–8 for emotional and practical requests, and 0–14 for physical-functional requests. Notably, unmet needs are addressed following the triage model that was previously published.[17] The psychometric properties of this measure have been previously investigated and a high internal consistency and strong test-retest reliability were reported.[16]

2.2 | Statistical analyses

Descriptive statistics are reported for patients' characteristics and presented for each subscale as mean (± standard deviation [SD] or frequency [n, %]).

First, bivariate correlations (Pearson) were generated for the variables that were examined (distress levels in emotional, practical, physical-functional, and the requests for assistance for each type of distress). Mean and [SD] were reported. Second, the association between requests for assistance (dependent variable, DV) and clinical and demographic characteristics was examined for all patients via multivariate general linear models (GLM). A separate regression model was

generated for each subscale. The independent variables (IVs) consisted of age (continuous), gender (male/female), annual household income (<$40,000, $40,000–100,000, $100,000+), marital status (yes/no), education (>high school [HS], ≤HS), survey language (English/Spanish), and disease stage (early [stages I-II], late [stage III-IV]). Third, for all patients, frequencies of requests were computed per type of distress items (such as feeling anxious or fearful, finances, pain, sleep, etc.), and ranked within each subscale (emotional, practical, and physical-functional). Last, frequencies of preferred forms of assistance (talk with a member of the team, obtain written information, or both) were computed.

Throughout this study, only complete cases were included. Statistical significance was considered for *p*-value <0.05.

3 | RESULTS

A total of 2658 patients (complete cases for demographic and disease stage variables) were included in this analysis (Figure 1). Table 1 includes patients' demographic and clinical characteristics. Overall, patients were mostly female (64%), had a mean age of 60, were married or had a partner (64%), were HS graduates or more (71%), and completed the surveys in English (95%). About 44% had a household income <$40,000, and 45% were at a late stage of the disease. Among patients that responded the survey in English, 75.4% were Non-Hispanic (vs. 16.9% Hispanic and 7.7% unknown). 91% of the patients that took the survey in Spanish were of Hispanic ethnicity (vs. 2.5% Non-Hispanic, and 6.5% unknown). 94% of the participants who responded in Spanish had a household income less than $40,000 (vs. 42% for English responders).

Table 2 describes patients' distress and requests for assistance. It also displays relatively strong correlations between assistance requested and distress subscales: $r = 0.68$ (emotional), $r = 0.69$ (practical), and $r = 0.67$ (physical-functional), with all *p*-values <0.001.

Table 3 includes the predictors of requests for assistance (for all patients). The adjusted GLM models revealed that for all three subscales (emotional, practical, and physical-functional), household income of <$100,000 and survey language (Spanish) were associated with an increase in assistance requests (*p*-values <0.05). For both practical and physical-functional subscales, having an advanced stage of the disease was related to an increase in requests ($b = 0.261$, $p = 0.037$ and $b = 0.770$, $p < 0.001$, respectively). Furthermore, for both emotional and physical-functional subscales, being older was related to a decrease in requests ($b = -0.011$, $p = 0.023$ and $b = -0.024$, $p < 0.001$, respectively). No other variables were significantly related to requests for assistance.

The frequencies computed for types of assistance requested revealed that, the average rate of requests was about 18% for physical functional distress, versus 19.2% and 19% for emotional and practical distress, respectively. The main demands per domain consisted of feeling anxious or fearful (27%), finances (30%), and sleeping (34%) for emotional, practical, and physical-functional domains, respectively. The preferred form of communication was 'verbal' (i.e.,
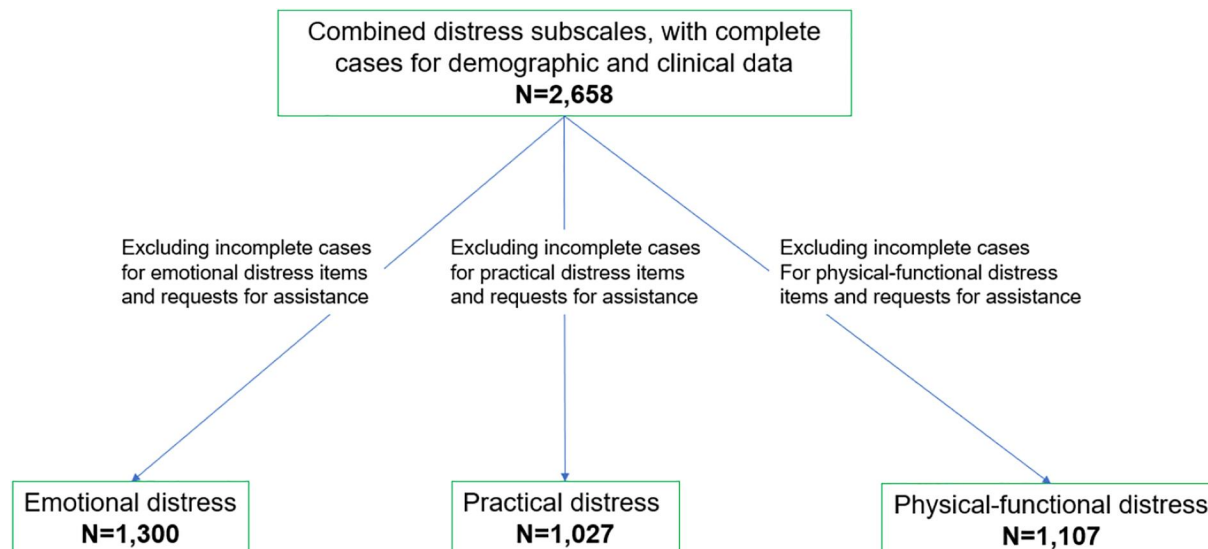
Combined distress subscales, with complete cases for demographic and clinical data N=2,658

Excluding incomplete cases for emotional distress items and requests for assistance

Excluding incomplete cases for practical distress items and requests for assistance

Excluding incomplete cases For physical-functional distress items and requests for assistance

Emotional distress N=1,300

Practical distress N=1,027

Physical-functional distress N=1,107

FIGURE 1 Flow-chart of patients included in this study. Patients with complete demographic and clinical information were included in this study. For each of the above distress domains, listwise deletion was applied if any single item (or more) regarding distress or requests for assistance was missing

TABLE 1 Patients' demographic and clinical characteristics (n = 2658)

Characteristics	Mean (SD) or N (%)
AGE [Mean (SD)]	59.82 (12.76)
GENDER [N(%)]	
Female	1692 (64)
Male	966 (36)
MARRIED/PARTNER [N(%)]	
Yes	1708 (64)
No	950 (36)
SURVEY LANGUAGE [N(%)]	
English	2534 (95)
Spanish	124 (5)
HOUSEHOLD INCOME [N(%)]	
$100,000+	599 (23)
$40,000-$100,000	887 (33)
<$40,000	1172 (44)
EDUCATION [N(%)]	
<= High school	777 (29)
> High school	1881 (71)
DISEASE STAGE [N(%)]	
Early	1470 (55)
Late	1188 (45)

TABLE 2 Distress and requests for assistance: descriptive information and bivariate correlations

	Mean	SD	Range	Correlation
Distress domains				
Emotional (N = 1300)				
Distress	13.27	5.24	8–40	0.68[a]
Requests for assistance	1.61	2.24	0–8	
Practical (N = 1027)				
Distress	11.9	4.52	8–40	0.69[a]
Requests for assistance	1.54	2.1	0–8	
Physical-functional (N = 1107)				
Distress	23.85	7.76	14–70	0.67[a]
Requests for assistance	2.6	3.16	0–14	

[a]$p < 0.001$.

4 | DISCUSSION

This study demonstrates the proportion of patients with cancer requesting different types of assistance. The requests for supports were almost the same (~20%) in each domain. This rate is close to that previously reported (ranging between 20% and 40%).[5,18,19] Importantly, patients appear to be open to asking for help using a computerized touch-screen system, consistent with previous studies which have shown that patients prefer electronic questionnaires to report potentially uncomfortable information.[20–23] In contrast, it appears that a group of patients may lack interest in assistance when distressed, possibly reflecting barriers to assistance and/or hesitance to request assistance for certain problems as they start treatment. Previous findings have shown that patients are often afraid to ask for help,

talk with a member of the team). However, there were a few exceptions: 'written' was the preferred form for finances, community resources and transportation.

TABLE 3 Factors associated with requests for assistance

Variables	Emotional		Practical		Physical/functional	
	β	p-value	β	p-value	β	p-value
Age	−0.011	**0.023**	−0.005	0.284	−0.024	**<0.001**
Gender						
Female	ref.		ref.		ref.	
Male	−0.116	0.381	0.246	0.069	−0.057	0.776
Married/Partner						
Yes	ref.		ref.		ref.	
No	0.057	0.669	0.002	0.987	−0.045	0.824
Income						
100,000+	ref.		ref.		ref.	
0–40,000	0.935	**<0.001**	1.289	**<0.001**	1.701	**<0.001**
40,000–100,000	0.408	**<0.013**	0.405	**0.014**	0.640	**0.009**
Education						
>HS	ref.		ref.		ref.	
<=HS	0.186	0.209	0.157	0.296	−0.135	0.547
Survey language						
English	ref.		ref.		ref.	
Spanish	1.160	**<0.001**	1.719	**<0.001**	1.549	**0.001**
Disease stage						
Early	ref.		ref.		ref.	
Late	0.136	0.269	0.261	**0.037**	0.770	**<0.001**

Note: Separate **multivariate** models (GLM) were generated for each distress subscale (Emotional (*n* = 1300), Practical (*n* = 1027) and Physical functional (*n* = 1107)). In these adjusted GLMs, all demographic and clinical independent variable were considered together. The bold values highlight the significant *p*-values.

Abbreviation: GLM, General Linear Models.

sometimes prefer to manage their own symptoms, or would rather receive social/family support.[12,24–26] By better understanding the relationship between patients' distress and interest in assistance, we can develop effective and targeted interventions that can assist patients to better cope with their diagnoses.

Based on our findings, the period after diagnosis but before treatment commences, may represent a vulnerable period and patients were often distressed and requested assistance, particularly for feeling anxious or fearful, finances, and sleeping problems. Notably, patients more often preferred personal assistance (i.e., talk only) rather than 'written' assistance. The exceptions were for community resources, transportation, and finances problems, for which they requested written information. Since finances were the number one source of requests within the practical domain, and given the fact that patients preferred the written form of support, making flyers (or other types of printed sheets) more readily available and facilitating access to online resources, could help mitigate financial distress from the earliest phases of cancer trajectory. Furthermore, based on previous data, flyers should better address the common lack of knowledge and assistance to better address issues with bureaucracy associated with financial distress.[27]

The demographic and clinical correlates of requesting assistance were also explored and were found to be similar to those identified in previous studies. This similarity could possibly be explained by the magnitude of association observed between distress and requests for assistance: *r*>=0.67 (i.e., relatively large effect size).[28] Several factors were associated with an increase in emotional, practical, or physical-functional requests, such as patients' household income (<$100,000) and survey language (Spanish). To our knowledge, this is a novel association, and may highlight the well-known fact that socioeconomic status affects health.[29] We observed that 91% of the patients who responded in Spanish were of Hispanic descent, and 94% of them were earning less than $40,000. This information suggests that household income and cultural factors may influence patients requests for assistance, however further studies may be necessary to re-evaluate this statement. In addition, and in line with previous publications, younger age was associated with more frequent requests for emotional assistance.[4,5,29] Furthermore, late disease stage was related to higher requests for practical and physical-functional assistance. These findings suggest that we should devote more attention to these groups with the highest needs and develop early tailored interventions that would empower patients to report their

needs and ask for support. Patients with advanced disease stage may also benefit from personalized and tailored supportive care programs, which would boost their requests for practical, physical, or functional assistance in a timely manner. The effect of such interventions should be investigated since previous studies have suggested an association between untreated distress and poorer clinical outcomes.[30,31] In addition, future studies should determine the best intervention components to mitigate these unmet needs.

These results reinforce the need for supportive care programs to be engaged across the continuum of cancer care, with a comprehensive approach that can actively screen unmet needs and effectively provide appropriate services to address and manage distress.[3,32] There is a growing number of effective psychosocial interventions to address various forms of distress in the context of cancer, however further research is needed to assess their suitability for widespread implementation.[33,34] In addition, these results highlight the relevance of asking patients about their desire for psychosocial support, contradicting previous evidence that patients with cancer rarely desire assistance.[8–12] The findings of our study may suggest that this can be an effective strategy for promoting awareness of distress and create an opportunity to challenge the stigma that exists in relation to mental health care.[35]

4.1 | Study limitations

This study has several limitations: a) the results were from a single cancer center between the years 2009 and 2017, and consequently may not be widely generalizable; b) approximately half of the study sample patients had incomplete data regarding distress domains and were excluded through the process of list-wise deletion. While there is no established cutoff from the literature regarding an acceptable percentage of missing data in a dataset for valid statistical inference,[36] we acknowledge that the exclusion of incomplete cases could have introduced a slight bias in our study estimates (in both directions). For example, regarding physical-functional and emotional domains, patients with missing data (vs. patients with available data) were slightly older (by about 1 year) and were at an early stage of the disease. Including them in the study, would have slightly changed the direction of the parameters' estimates towards less requests for assistance. These patients were also earning less income (by about 5%), which would have changed the direction of the estimates towards more requests for assistance. No significant difference between these two groups of patients was observed regarding the remaining explanatory variables, and there was no difference between missing and non-missing data for practical domain. Despite the likelihood of bias in our estimates, we believe that our resulting sample sizes ($N = 1000^+$ per distress subscale) were large enough to provide adequate power for detecting meaningful effects; c) the study data is limited to describing levels of distress at the time of diagnosis and cannot address changes in distress across the disease trajectory; d) there are no data on whether the patient received the

required assistance. The timing of assessment and provision of desired support may be important in reducing distress throughout the cancer care trajectory. In addition, patients with late disease, receiving treatment for a long time, are less willing to receive support despite their unmet needs.[4,9] Perhaps they find other ways to meet their needs or have accepted their situation and do not feel the need for assistance, even if they have identified needs. Despite the above limitations, our results revealed significant and unique information, with implications for clinical care.

4.2 | Clinical implications

The clinical implications of our findings are meaningful. These results suggest that distressed cancer patients desire and may benefit from early interventional programs. Indeed, identifying the specific type of distress affecting patients with cancer at the start of their treatment, and providing them with an action plan immediately after their first visit at the center, may help alleviate their distress and improve their health outcome. Furthermore, it may be helpful to tailor supportive care services to patients that are younger, have lower income, and are not proficient in English, as these patients may have a higher need for resources to cope with their psychological problems.

5 | CONCLUSION

These preliminary findings highlight the factors associated with requests for supportive care assistance. Sociodemographic background is significantly associated with the likelihood of requesting support. Therefore, tailoring supportive care resources based on patients' background could potentially alleviate their distress levels during this vulnerable period.

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