## RESEARCH



# Unmet supportive care needs in patients with advanced cancer and its impact on distress

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### Abstract

**Purpose** Patients with advanced cancer endure considerable physical and emotional distress without sufficient supportive care. This cross-sectional study examined the relationship between cancer-related symptoms, supportive care needs, and distress levels in patients with advanced lung, head and neck, or gastrointestinal cancers.

**Methods** 158 patients were assessed for symptom burden and distress levels using the M.D. Anderson Symptom Inventory (MDASI) and unmet needs using the Supportive Care Needs Survey (SCNS-34) within one month of treatment initiation. Pearson correlations and multiple regression analyses were used to explore associations between supportive care needs and distress.

**Results** Distress levels were moderate across the study population, with fatigue, pain, and disturbed sleep being the most reported symptoms. Patients who lived with their caregivers reported significantly lower needs in four out of five domains. Positive correlations were found between distress levels and supportive care needs in the psychological (r=0.342, p<0.001), health system (r=0.253, p=0.001), patient care and support (r=0.237, p=0.003), and physical and daily living domains (r=0.378, p<0.001). Multiple regression analysis showed that these domains collectively explained a significant portion of the variance in distress levels (R2=0.169, p<0.001).

**Conclusion** Independent of demographic or clinic characteristics, patients with advanced cancer experience moderate distress and unmet supportive care needs, particularly in psychological and health system domains. The association between living with caregivers and lower reported needs suggests that caregiver support may play a crucial role in meeting these needs. Therefore, integrating strategies that involve and support caregivers could potentially reduce distress and improve the quality of life for patients with advanced cancer.

Keywords Advanced cancer, Caregiver, Distress, Supportive care

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### Introduction

While cancer mortality rates have steadily improved over the past four decades, the global burden of cancer is expected to increase to 29.9 million new cases per year by 2040 (NCI). Despite advances in cancer therapy, patients still have considerable unmet supportive care needs at the time of diagnosis and throughout treatment [1]. As patients are diagnosed earlier and living longer with cancer, there has been growing awareness of the considerable psychosocial, financial, and supportive care needs that impact a patient's overall quality of life and level of distress.

Emotional distress is common, yet often overlooked, and negatively impacts quality of life in patients with cancer [2, 3]. Approximately one-third of oncology patients experience high levels of psychological distress [4, 5]. When stratified by cancer type, the prevalence of distress is 43% in lung cancer, 35% in head and neck (H&N) cancer, and 31-35% in various gastrointestinal (GI) malignancies [5]. The National Cancer Institute defines distress as "emotional, social, spiritual, or physical pain or suffering" that may impact a patient's mood and interfere with their ability to cope effectively or manage routine activities of daily living. Furthermore, psychological distress has been associated with cancer mortality [6]. In order to identify patients who may need referrals to psychologists, chaplains, or social workers, the National Comprehensive Cancer Network (NCCN) recommends screening all cancer patients for distress using validated tools such as the Distress Thermometer [7]. In reality, many patients do not receive distress screening at diagnosis, and those who do often face other barriers to intervention, especially if they are uninsured or live in rural or resourcepoor regions [8]. High levels of emotional distress have been associated with physical symptoms such as pain and fatigue [9]. In patients with lung cancer, emotional distress has also been associated with dysfunctional family relationships, problems with emotional functioning, and lack of information about diagnosis and treatment [9].

Palliative care, which focuses on decreasing pain and suffering in patients with advanced or complex illness, has been proposed as a potentially effective intervention for patients experiencing high levels of distress. Consultation with a palliative care specialist has been associated with improved symptom control, enhanced patient understanding of their diagnosis and prognosis, decreased utilization of health care resources, and high satisfaction among patients and their families [10, 11]. In patients with incurable lung or GI cancers, early palliative care referral has yielded improved quality of life and mood [12, 13]. While family-centered psychosocial intervention is at the heart of the palliative care philosophy, many patients still experience suboptimal support [14].

Patients living with advanced cancer and their caregivers critically need effective, patient-centered interventions that reduce distress and enhance quality of life. However, multiple barriers to providing more familycentered care exist, including restricted provider time and availability, a lack of provider training in psychosocial interventions, and limited insurance reimbursement [15]. Approximately one-third of patients with cancer experience mental illnesses such as depression, anxiety, or adjustment disorders, the majority of whom are not treated [16, 17], and those with advanced disease have higher intensity care needs, more severe and debilitating symptoms, increased financial burden, and higher rates of hospitalization and readmission [18]. The psychosocial impact of cancer also has ripple effects on patients' families and healthcare systems. For example, caregivers of cancer patients are more likely to stop working and take on increased household debt compared with non-cancer caregivers [19].

Existing research has established an association between psychological distress and unmet supportive care needs in patients with advanced cancer, but many of these studies were performed in regions with strong collectivistic culture which may influence how patients interact with palliative and supportive care resources [20–22]. Prior studies have also focused on single tumor types or excluded patients who are very ill or have terminal disease, despite evidence that patients with advanced cancer have a different pattern of physical, emotional, and psychosocial needs compared to those with earlystage disease [20-24] Many studies do not account for demographic and clinical characteristics that may influence these factors [25]. This narrow focus limits the development of holistic interventions that address the multifaceted needs of this patient population.

Patients with lung, H&N, and GI malignancies are more likely to experience high levels of distress compared to other cancers [26], perhaps due to intensive multimodal treatment regimens, disease-specific symptom burden, and complex home health needs such as ostomy care, feeding tubes, or supplemental oxygen, all of which contribute to the psychosocial and economic costs of cancer. While previous studies have explored distress or supportive care needs primarily in early-stage cancer patients, few have specifically focused on patients with advanced or incurable lung, H&N, or GI cancers at the time of treatment initiation [27, 28]. Moreover, the interplay between caregiver involvement, specific supportive care needs, cancer-related symptoms, and distress levels remain underexplored. This study uniquely addresses these gaps by evaluating these factors concurrently, with the hope of providing a more nuanced understanding of distress in advanced cancer patients, ultimately guiding

the development of more targeted and effective supportive care interventions.

### Methods

### Study and sample

Eligibility criteria for this cross-sectional study included being an adult (age 18 or over) with advanced lung (at least stage 3 A), H&N (stage 4B or 4C), or GI (stage 4) cancer within one month of treatment initiation, having an Eastern Cooperative Oncology Group (ECOG) performance status of 0–2, having a primary caregiver who was at least 18 years old, having the ability to read and understand English at a 6th grade level, and having the capacity to provide informed consent. Patients were excluded if they had diminished mental capacity, had significant hearing impairment that prevented telephone use, were pregnant, or were currently enrolled in hospice.

### Procedure

The current study, which was part of a larger multisite dyadic intervention designed to improve self-management and coordination of care for patients with advanced cancer and their caregivers, used baseline survey data collected within one month of treatment initiation to assess subjects' cancer-related symptoms, supportive care needs, and distress levels.

The study was conducted at two NCI-designated Comprehensive Cancer Centers located in the Southern and Southwestern United States between 2015 and 2021 after approval by Baylor College of Medicine's Institutional Review Board (H-39002). These centers serve diverse patient populations, including individuals from both urban and rural areas. All procedures adhered to ethical guidelines for research involving human subjects in accordance with the 1964 Declaration of Helsinki and its later amendments, and written informed consent was obtained from all participants prior to enrollment. The results described in this study come from a secondary analysis which was conducted within the parameters of the original ethical approval and participant consent.

Eligible patients were identified by research assistants who reviewed clinic schedules and electronic medical records in the outpatient oncology clinics. After obtaining permission from the treating physicians, patients were approached during their clinic visits to discuss potential participation. In cases where in-person recruitment was not feasible, patients were contacted by telephone.

Consented patients were provided with a baseline questionnaire, which they could complete while waiting for their clinic appointment or complete at home and return to the research team in person or by mail. To provide flexibility in data collection methods, patients also had the option to complete the survey by telephone or

### Demographics and clinical characteristics questionnaire

Items in the baseline questionnaire included gender, race, ethnicity, age, employment status, annual pre-tax household income, level of education, marital status, and caregiver type (i.e. relationship of the primary caregiver to the patient). Medical history was also obtained, encompassing comorbidities, prior mental health diagnoses, medications, and prior attendance in counseling/support groups.

Health literacy was assessed using the Single Item Literacy Screener (SILS) [29], which asks patients how often they need help reading hospital materials. Responses range from 1 ("Never") to 5 ("Always") with a score of 3 or higher indicating limited health literacy. Additional clinical data such as tumor type and stage were obtained from the patient's electronic medical record.

### M.D. Anderson symptom inventory

online

The M.D. Anderson Symptom Inventory (MDASI) [30] includes 13 core items to evaluate symptom severity independent of cancer type: pain, fatigue, disturbed sleep, distress (emotional), shortness of breath, drowsiness, dry mouth, sadness, difficulty remembering, numbness or tingling, lack of appetite, nausea, and vomiting. Each symptom is rated on a 0 to 10 numeric scale, with 0 indicating "not present" and 10 indicating "as bad as you can imagine." Higher scores reflect greater symptom severity.

For patients with GI cancers, 5 additional items included constipation, diarrhea, dysphagia, taste changes, and bloating. For patients with H&N malignancies, 9 additional items were included: mucus production, dysphagia, coughing/choking, dysphonia, skin pain/burning/ rash, constipation, taste changes, mouth/throat sores, and teeth/gum problems. For patients with lung cancer, 3 additional items were included: cough, constipation, and sore throat. The MDASI also assesses how much symptoms interfere with six daily functions: relations with others, enjoyment of life, mood, walking, general activity, and working. Each item is rated on a 0 to 10 numeric scale, with responses ranging from 0 ("Did not interfere") to 10 ("Interfered completely"). The mean score of these six symptom interference items was used as a measure of overall distress. Cronbach alpha was 0.90 indicating excellent reliability.

### Supportive care needs survey

The Supportive Care Needs Survey (SCNS-34) uses 34 items to measure unmet needs across five key domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality

[31]. Responses are rated on a 5-point Likert scale ranging from 1 ("No need") to 5 ("High need"). Scores were summed for each domain and then standardized to a range from 0 to 100 [32]. Cronbach alphas for each of the subscales and ranged from 0.86 to 0.93, indicating high internal consistency.

### Statistical analyses

All statistical analyses were conducted using SPSS version 29.0 software (IBM Corp., Armonk, NY, USA). Descriptive statistics- including means, standard deviations, and frequencies- were calculated to summarize demographic and clinical characteristics of the sample. To compare mean differences in distress levels and supportive care needs across different demographic and clinical groups, Student's t-tests were used for comparisons between two groups, and one-way analysis of variance (ANOVA) was applied for comparisons across multiple groups. Pearson correlation coefficients were calculated to evaluate the relationships between supportive care needs (as measured by the SCNS-34 domains) and distress levels (as measured by the MDASI Core Severity Index). Multiple regression analyses were conducted to determine the predictive value of supportive care needs domains on distress levels, adjusting for potential confounders. All statistical tests were two-sided, and a *p*-value of < 0.05 was considered statistically significant.

### Results

### Patient demographics and clinical characteristics

A total of 158 patients completed the baseline surveys. Demographic and clinical characteristics are detailed in Table 1. The mean age of participants was 61 years, ranging from 35 to 91 years. The majority of participants were male (62%). Regarding race, 71% identified as White, 25% as Black or African American, 2.5% as Asian, and 0.6% as Multiracial. In terms of ethnicity, 16.5% identified as Hispanic or Latino. Limited health literacy was reported by 15.2% of patients. Tumor types included GI (36.7%), lung (38.0%), and H&N cancers (25.3%), with most patients diagnosed at stage IV (84.2%). Caregivers were primarily spouses/partners (67.1%) or adult daughters (17.7%), and 78.5% of patients lived with their caregiver.

### Distress levels and cancer-related symptoms

The MDASI was utilized to assess distress related to cancer symptoms. The three highest scoring symptoms were fatigue (mean score 4.78), pain (mean score 4.13), and disturbed sleep (mean score 3.91) (Table 2). Symptom severity varied by tumor type (Fig. 1): patients with H&N cancer reported more dry mouth (p = 0.012), while those with lung cancer reported more shortness of breath (p < 0.001). The mean MDASI symptom interference score, a composite measure of distress, was 3.20,

indicating moderate distress overall. However, no statistically significant differences in distress were observed across gender, race, age, cancer type, caregiver type, marital status, education level, health literacy, employment status, income, or psychiatric diagnosis (Table 1).

### Supportive care needs and their variation among patients

The baseline SCNS-34 was performed at time of study enrollment to evaluate unmet supportive care needs. The psychological domain had the highest reported needs (mean score 38.20), followed by the health system domain (mean score 35.30) (Table 3). No significant variations in SCNS domain scores were found based on gender, age, race, cancer type, marital status, education level, health literacy, employment status, income, and psychiatric diagnosis history. However, patients who lived with their caregiver reported significantly lower needs in the psychological (p = 0.039), patient care and support (p = 0.005), physical and daily living (p < 0.001), and sexuality domains (p=0.018) compared to those without a live-in caregiver. There was a significant difference in the physical and daily living domain based on caregiver type, with the highest mean score in a patient with an adult son caregiver (n = 1); however, conclusions are limited by the small sample size.

# Associations between supportive care needs and distress levels

To explore the associations between supportive care needs and distress levels, Pearson correlation coefficients were calculated for each SNCS domain using the mean MDASI Symptom Interference. Significant correlations were observed between distress and several domains: psychological (r=0 0.342, p<0.001), health system (r = 0.253, p = 0.001), patient care and support (r = 0.237, p = 0.001)p = 0.003), and physical living and daily living (r = 0.378, p < 0.001). A trend toward significance was noted for the sexuality domain (r = 0.142, p = 0.075). Multiple regression analysis was conducted to further assess the relationship between supportive care needs domains and distress, considering all five SCNS domains together. The analysis showed that the combined domains significantly explained variance in distress levels (R2 = 0.169, p < 0.001) (Table 4).

### Discussion

This study analyzed the association between cancerrelated symptoms, supportive care needs, and distress levels among patients with advanced lung, H&N, or GI cancers at the time of treatment initiation. Additionally, it investigated how specific supportive care needs correlate with distress levels and whether demographic or clinical characteristics influence these associations. Our findings contribute to the growing body of literature on

Demographic	Frequency (%)	MDASI Symptom Interference <sup>a</sup>			
		Mean±SD	t/F/Pearson Coefficient	р	
Total Patients	158 (100%)	3.2±1.8	N/A	N/A	
Gender					
Male	98 (62%)	3.3±1.9	1.039	0.301	
Female	60 (38%)	$3.0 \pm 1.8$			
Age					
<45	8 (5.1%)	$2.4 \pm 1.8$	-0.36	0.650	
45–60	72 (45.6%)	$3.4 \pm 1.9$			
>60	78 (49.4%)	$3.1 \pm 1.8$			
Caregiver Type					
Spouse/Partner	106 (67.1%)	3.2±1.9	1.588	0.143	
Adult Daughter	28 (17.7%)	$3.5 \pm 1.4$			
Adult Son	1 (0.6%)	4.8			
Sibling/Sister	8 (5.1%)	$3.5 \pm 1.9$			
Daughter in Law	1 (0.6%)	3.8			
Mother	3 (1.9%)	$1.7 \pm 1.4$			
Friend/Neighbor	7 (4.4%)	1.8±1.3			
Ex-spouse	4 (2.5%)	4.8±2.8			
Marriage Status					
Single	18 (11.4%)	2.7±1.7	1.843	0.123	
Married	94 (59.5%)	3.1±1.9			
Cohabiting	15 (9.5%)	3.1±1.6			
Divorced/Separated	24 (15.2%)	4.0±1.8			
widowed	7 (4.4%)	3.7±2.0			
Race					
White	113 (/1.5%)	3.2±1.8	0.908	0.439	
Black	40 (25.3%)	3.3±2.0			
Asian	4 (2.5%)	3.3±2.5			
	1 (0.0%)	0.5			
Education		24.45	0.074		
Did not complete HS	12 (7.6%)	3.1±1.5	0.274	0.949	
HS diploma or GED	31 (19.6%)	3.2±1.9			
	10 (0.5%)	3.7 ± 1.4 2 2±20			
BS/BA	42 (20.0%)	3.2±2.0 31+18			
MS/MA/MPH	8 (5 1%)	36+25			
MD/PHD/JD	13 (8.2%)	2.9+1.9			
Employment Status	(012,0)	2.0 = 1.0			
Full time	53 (33 5%)	28+18	1 015	0.402	
Part time	10 (6 3%)	2.0 ± 1.0	1.015	0.402	
Unemployed	36 (22.8%)	3.6+1.7			
Retired	46 (29.1%)	$3.2 \pm 2.0$			
Housewife	10 (6.3%)	$3.5 \pm 1.5$			
Household Annual Income					
<\$50.000	36 (22.8%)	3.4+2.0	0.063	0.491	
\$50.001-100.000	51 (32.3%)	$3.1 \pm 1.6$			
\$100,001-150,000	21 (13.3%)	$3.3 \pm 2.2$			
>\$150,001	12 (7.6%)	$3.6 \pm 1.8$			
Cancer Type					
GI	58 (36.7%)	3.1±1.7	0.312	0.732	
Lung	60 (38.0%)	3.2±2.0			
H&N	40 (25.3%)	$3.4 \pm 1.9$			
Caregiver Lives w/ Patient					
Yes	124 (78.5%)	3.2±1.6	-0.149	0.281	
No	34 (21.5%)	3.2±1.9			

 Table 1
 Distress levels among patients with various demographic and clinical characteristics

### Table 1 (continued)

Demographic

		Mean ± SD	t/F/Pearson Coefficient	р
History of Psych Dx				
Yes	20 (12.7%)	3.6±1.8	-1.042	0.443
No	130 (82.3%)	3.1±1.9		

<sup>a</sup>Distress was measured using the MDASI Symptom Interference Score, which is the mean score of six items asking patients how much their symptoms interfere with daily functions

Table 2	Top 5	most severe	MDASI	core sy	mptoms
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	MDASI Core Item	Mean Score <sup>a</sup>
1	Your fatigue at its worst	4.8
2	Your pain at its worst	4.1
3	Your disturbed sleep at its worst	3.9
4	Your problem with lack of appetite at its worst	3.8
5	Your feeling of being distressed at its worst	3.7

<sup>a</sup>Patients reported symptom severity on a scale from 0 ("not present") to 10 ("as bad as you can imagine")

the psychosocial needs of patients with advanced cancer and highlight important areas for targeted interventions.

The results indicate that distress levels, as measured by the MDASI Core Severity Index, were moderate across the sample, with fatigue, pain, and disturbed sleep being the most prevalent patient-reported symptoms. These findings are consistent with prior research indicating that physical symptoms contribute to distress in cancer patients, particularly those with advanced disease stages [33]. Interestingly, while symptom distress varied by cancer type—with H&N cancer patients reporting more dry mouth and lung cancer patients more shortness of 
 Table 3
 Supportive care domains ranked by highest need

	supportive care domains rainced b	, ingliese need
	SCNS-34 Domains	Mean Score <sup>a</sup>
1	Psychological	38.2
2	Health System	35.3
3	Physical and Daily Living	21.5
4	Patient Care and Support	14.1
5	Sexuality	9.2

<sup>a</sup>Responses are rated on a 5-point Likert scale ranging from 1 ("No need") to 5 ("High need"). Scores were summed for each domain and then standardized to a range from 0 to 100 [17]

breath—there were no statistically significant differences in overall distress levels based on demographic or clinical characteristics. These findings suggest that the emotional burden of advanced cancer is a pervasive experience, transcending factors such as age, gender, race, and cancer type. This contrasts prior literature which has suggested that patients who are female, single/divorced/ widowed, active smokers, low-income, or younger age are more likely to experience high levels of distress [6, 34, 35]. These studies included early-stage cancers though it is well established that patients with metastatic/advanced



Fig. 1 MDASI core symptom severity by cancer type

**Table 4** Multiple regression analysis of supportive care domains as a predictor of distress

SCNS Domain	В	SE	β	t	р
Psychological	0.020	0.010	0.235	1.967	0.051
Health System	0.004	0.011	0.047	0.357	0.721
Patient Care and Support	-0.005	0.023	-0.029	-0.219	0.827
Physical and Daily Living	0.041	0.015	0.265	2.705	0.008
Sexuality	-0.026	0.022	-0.114	-1.192	0.235

R2 = 0.169

B: regression coefficient

SE: standard error of the regression coefficient

β: standardized regression coefficient

disease report higher rates of emotional distress [36]. While a larger sample size may have identified subtle differences between demographic groups, the universality of distress witnessed in this study population may reflect the profound impact of an advanced or incurable cancer diagnosis on patients' psychological well-being, regardless of individual characteristics. It underscores the need for universal screening and interventions for distress in this population.

This analysis suggests that those with higher psychological and health system needs-the domains with the highest reported scores-might benefit most from targeted supportive care interventions, which is consistent with prior studies in advanced cancer [27, 28]. While this cross-sectional study only surveyed patients at time of treatment initiation, longitudinal studies have suggested that unmet needs only increase in these domains with longer time since diagnosis due to decreased psychosocial support access and utilization [1, 37]. Patients living without a caregiver reported higher needs in these domains, possibly attributed to the lack of immediate emotional and practical support. Caregivers often assist with symptom management, provide psychological comfort, and help navigate the healthcare system. Without this support, patients may feel overwhelmed, leading to increased distress and unmet needs. These findings highlight the critical role caregivers play in the well-being of patients with advanced cancer. Thus, interventions should prioritize psychological support and healthcare system navigation assistance for these patients who might lack the emotional and practical support provided by a caregiver.

These findings are particularly relevant in light of the recent enactment of the CARE (Caregiver Advise, Record, and Enable) Act in many states across the U.S., which mandates that hospitals identify a designated caregiver upon a patient's discharge and provide the necessary training and information to support at-home care [38]. Lee et al. found that patients hospitalized in states that had adopted the CARE act reported improved communication with nurses/physicians and more consistent Page 7 of 9

receipt of discharge information when compared to patients in non-CARE states [38]. Our results suggest that complying with this legislation could have additional benefits beyond legal adherence, especially for chronically ill patients with high symptom burden. By involving caregivers in discharge planning and ensuring they are equipped to support patients, hospitals may effectively reduce patient distress and unmet supportive care needs post-discharge. A systematic review by Wang et al. found that one of the most common unmet needs among both patients and caregivers alike included health information needs such as disease and treatment information [39]. This highlights the opportunity for healthcare providers to enhance patient outcomes through structured engagement with and education of caregivers.

The associations between supportive care needs and distress levels were further elucidated through Pearson correlation and regression analyses. Significant correlations were found between distress and several supportive care needs domains, including psychological, health system, patient care and support, and physical and daily living. These findings underscore the interconnectedness of psychological distress and supportive care needs, suggesting that unmet needs in these areas may contribute to higher distress levels among patients. Thus, patients reporting high needs in these domains—particularly psychological and health system needs—may require the greatest intervention to manage distress effectively.

The strengths of this study include its use of validated instruments to assess both symptom burden and supportive care needs and its inclusion of a diverse population of patients across multiple cancer types, thus enhancing the generalizability of its findings. However, there are limitations to consider. The cross-sectional design limits our ability to establish causality or directionality in the relationships between distress and supportive care needs. Furthermore, the reliance on self-reported data may introduce response bias, particularly concerning sensitive topics such as psychological distress and sexual health. Additionally, the exclusion of non-English-speaking patients may limit generalizability to more diverse populations. Larger studies with more diverse cohorts are needed to confirm these associations and enhance generalizability.

Clinically, these findings highlight the importance of integrated care approaches that prioritize both symptom management and supportive care tailored to individual patient needs. Psychological needs may be better addressed by earlier diagnosis and management of mood disorders, early palliative care referral, and improved accessibility to mental health providers in cancer care. Health system needs may be targeted by improving the communication of diagnosis, treatment, and healthcare team information. Given the benefits of caregiver involvement, healthcare systems should prioritize strategies to engage and educate caregivers effectively, particularly at discharge, to reduce patient distress and unmet needs. Future research should consider longitudinal designs to explore causal pathways between distress and supportive care needs over time, as well as the impact of specific interventions on both symptom burden and perceived supportive care needs. Exploring the impact of policies like the CARE Act on patient outcomes could provide valuable insights into optimizing care for patients with advanced cancer. Additionally, robust clinical trials are needed to assess the efficacy and practicality of dyadic interventions which provide education and support to patients and caregivers regarding health information and emotional coping strategies.

In conclusion, this study underscores the potential impact of psychosocial and supportive care needs in advanced cancer. Patients with higher psychological and health system needs, especially those lacking caregiver support, may require the greatest intervention to manage their distress effectively. Addressing these needs through comprehensive, patient-centered care may help mitigate distress and improve quality of life, ultimately enhancing outcomes for both patients and their caregivers.

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### Author contributions

All authors contributed to the study conception and design. Material preparation and data collection were performed by H.B. Data analysis was performed by K.W.M. All authors contributed to drafting the manuscript. All authors read and approved the final manuscript.

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### Data availability

Data is provided within the manuscript.

### Declarations

### Ethics approval and consent to participate

This study was approved by the Institutional Review Board at Baylor College of Medicine (H-39002) and conducted in accordance with the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all individual participants included in the study.

### **Consent for publication**

Not applicable.

### Competing interests

The authors declare no competing interests.

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