

## Original Article

# High anxiety and depression scores and mental health service use among South Asian advanced cancer patients: A multi-country study

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## Abstract

**Context.** Addressing symptoms of anxiety and depression is important in cancer palliative care. However, little information exists on the prevalence of anxiety and depression and mental health service use among advanced cancer patients in South Asia.

**Objectives.** To examine among South Asian advanced cancer patients, the 1) prevalence of high anxiety and depression scores, 2) factors associated with high anxiety and depression scores, and 3) mental health service use.

**Methods.** This cross-sectional, multi-site study recruited patients receiving oncology care across six major public hospitals in India, Bangladesh and Sri Lanka. Participants were adults, diagnosed with stage IV metastatic solid cancer and aware they had cancer. Participants' high anxiety and depression scores (using clinically-relevant Hospital Anxiety and Depression Scale threshold of >10), sociodemographic characteristics, patient-perceived cancer stigma and mental health service use were assessed.

**Results.** In the overall sample ( $N = 1140$ ), 54% met threshold for high anxiety and/or depression scores: 32% reported high anxiety scores and 47% reported high depression scores. Symptom burden ( $OR$ 's [95%  $CI$ 's] = 1.09-1.13 [1.05-1.09, 1.12-1.17]) and perceived stigma (1.11-1.16 [1.06-1.11, 1.16-1.22]) were statistically significantly associated with high anxiety and depression scores. Of the patients with high anxiety and/or depression scores ( $n = 617$ ), 97% had not received mental health services, and 38% of them indicated they were open to a referral.

**Conclusion.** High, clinically-relevant anxiety and depression scores are common among South Asian advanced cancer patients. Efforts should be made to alleviate psychological morbidity, including providing greater access to supportive/palliative medicine teams or mental health services. *J Pain Symptom Manage* 2021;000:1–11. © 2021 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Anxiety, depression, mental health, palliative care, Asia, cross-sectional study

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## Key Message

This cross-sectional multi-country study assessed the prevalence and covariates of high anxiety and depression scores amongst late-stage cancer patients in South Asia. Reports of high anxiety and depression scores are prevalent, with a large majority not receiving mental health services. A proportion were open to referral.

## Introduction

South Asia hosts a quarter of the world's population.<sup>1</sup> This region, which includes India, Bangladesh, and Sri Lanka, reports standardized incidence of cancer<sup>1</sup> and mortality rates ranging between 88.1-105.7 and 51.0-79.1 respectively. Although the incidence rate is relatively low when compared globally,<sup>2,3</sup> the mortality-to-incidence ratios, and number of cases with delayed or late-stage presentation of cancer are higher in this region, with consequent greater psychosocial impact on patients diagnosed with advanced cancer.<sup>4,5</sup> The needs of advanced cancer patients, especially those pertaining to mental health, are of interest in this study.

The international literature indicates that a significant proportion of advanced cancer patients report anxiety and depression.<sup>6,7</sup> Self-report instruments like the Hospital and Anxiety Depression Scale (HADS), allow measurement of symptoms with a score of >10 on either the HADS-Anxiety or HADS-Depression subscale indicating probable caseness.<sup>8</sup> In one systematic review using this threshold, median prevalence rates of anxiety and depression were 28% and 29% respectively among patients with advanced cancer and mixed hospice populations.<sup>9</sup>

A few studies from South Asia report the prevalence rates of high anxiety and depression scores to range between 12%-64% and 2%-70%, respectively.<sup>10-16</sup> The wide range of rates may be due to study samples that included a mix of patients in early and advanced stages of disease,<sup>10,12,13,17</sup> differing measurement instruments<sup>15,16</sup> and different scoring thresholds used.<sup>10,17</sup>

It will be important to establish prevalence of anxiety and depression among advanced cancer patients in this region, and to examine associated factors such as socio-demographic,<sup>21</sup> clinical-related, and patient-perceived factors such as cancer stigma.<sup>13,18</sup> Patient-perceived cancer stigma refers to the patient's perception that they are less socially accepted and that others hold prejudice against them because of their cancer diagnosis.<sup>19,20</sup> Prior studies have shown associations between perceived stigmatization due to cancer and depression.<sup>18,20,21</sup>

The literature on the mental health of advanced cancer patients in South Asian countries is limited, and are often single-country and -site studies with small sample sizes. Conducting a multi-country, multi-site study within a geographical region allows for the examination of associated factors that may be similar or different across the sites. Consequently, being able to identify the correlates of anxiety and/or depression will allow for early identification and treatment of these patients.

Availability of mental healthcare services as part of comprehensive care for cancer is becoming an expected gold standard.<sup>22-24</sup> Receiving mental healthcare has been shown to improve patient quality of life, compliance with treatments, and satisfaction with end-of-life oncology care.<sup>25-27</sup> Mental healthcare services for cancer patients can be varied and include psychiatric medication management, therapeutic counseling, psycho-education, and peer-support groups.<sup>28,29</sup> Reasons for mental healthcare services referral can range from assistance with adjustment to diagnosis, behavioral symptom management, and easing of existential suffering.<sup>26</sup> Currently, however, there is limited information on the proportion of patients receiving mental healthcare services in South Asia, their perceived usefulness, and patients' openness to receiving mental healthcare services. Understanding patient amenability to receiving mental healthcare services can be useful in tackling potential mental healthcare services access barriers.

The current study investigated, among advanced solid cancer patients (stage IV) from six different sites across India, Sri Lanka and Bangladesh, the following: 1) prevalence of high anxiety and depression scores based on the HADS, 2) association of sociodemographic factors (gender, age, marital status, education), clinical-related factors (symptom burden, delayed treatment, inpatient setting, and patient-reported cancer stage), and patient-perceived cancer stigma with high scores on anxiety and depression, 3) rates and types of mental healthcare services use, patient perceived usefulness of mental healthcare services received, and openness to utilizing mental healthcare services. Based on prior literature, we hypothesized that being female, young, unmarried, having fewer years of education, experiencing increased symptom burden, treatment delay, and patient-perceived cancer stigma will be associated with higher anxiety and depression scores.

## Methods

### Study Setting and Participants

This study utilized data from a larger, cross-sectional project called, "Asian Patient Perspectives Regarding Oncology Awareness, Care and Health" (APPROACH). In this study, we included data collected between

<sup>1</sup> Number of new cases per 100000 per year.

January 2017–October 2019 from 6 sites across 3 countries– India, Bangladesh, and Sri Lanka. Ethical approval was sought from site-specific respective institutional review boards: India Site 1– MNJ Institute of Oncology & Regional Cancer Centre, Hyderabad (IRB# ECR/227/INST/AP/2013/RR-16); India Site 2– All India Institute of Medical Sciences (AIIMS), New Delhi, India (IRB# IEC-56/08.01.2016, RP-13/ 2016); India Site 3– Bhagwan Mahaveer Cancer Hospital & Research Centre, Jaipur (IRB# BMH/2016/89); Bangladesh Site 1– Bangabandhu Sheikh Mujib Medical University, Hospital, (IRB# BSMMU/2016/ 5171); Bangladesh Site 2– National Institute of Cancer Research & Hospital (NICRH) (IRB# NICRH/ Ethics/2016/213); Sri Lanka Site 1– National Cancer Institute of Sri Lanka, Maharagama (IRB# EC-17-157). These hospitals are among the major public hospitals treating cancer patients in each country. The study was approved by the Institutional Review Board of the National University of Singapore (IRB# B-15-319) which oversees the institution coordinating the APPROACH project.

Participants were recruited from inpatient and outpatient settings of the medical oncology, radiation oncology, surgical oncology or palliative care departments (Table 1). The participants were screened via medical records or referred by clinicians, and those who were deemed eligible were introduced to the study after providing written informed consent. The survey was conducted by a trained research assistant through face-to-face interviews. The eligibility criteria were that the participants were 21 years or older, were citizens of the country in the recruiting site, diagnosed with stage IV solid cancer, aware that they had cancer, and were able to comprehend the language of the survey. They were excluded if they were too ill to participate, or were assessed by the research assistant to not have been cognitively competent/ or understood the questions.

## Measures

**Anxiety and Depression.** The 14-item Hospital Anxiety and Depression Scale (HADS)<sup>30</sup> was utilized to measure anxiety and depression using the Anxiety subscale (HADS-A) and Depression subscale (HADS-D). Each item is rated on a 4-point scale (0–3), with a maximum score of 21 on each subscale. A score of >10 for either subscale is clinically-relevant and signifies probable caseness; it was used to indicate high scores in this study.<sup>8</sup> The HADS has been translated for use and validated in the countries of interest.<sup>31–34</sup> Previous studies have reported the cutoff of >10 to have a specificity and sensitivity of 68% and 82% for anxiety and 51% and 95% for depression respectively amongst Asian cancer patients.<sup>35</sup>

**Patient-Perceived Cancer Stigma.** The 6-item Sense of Stigma subscale from Kissane's Shame and Stigma Scale that was validated on cancer patients was used.<sup>19</sup> Example items include, "People avoid me because of my cancer" and "I feel others consider me responsible for my cancer". Scores range from 5 to 30, with higher scores indicating greater perceived stigma. The subscale has been shown to be valid with good internal reliability ( $\alpha = 0.89$ ).<sup>19</sup>

**Mental Healthcare Services Use and Openness to Mental Healthcare Services Use.** Patients were asked "Have you seen any of the following mental health care worker as part of their cancer treatment?" with the response options being: psychiatrist, psychologist, medical social worker (for psychological support), community counsellor and others. Those who selected any of the above were asked how helpful they found the mental healthcare services to be with answers ranging from "very helpful" to "not helpful at all". Those who answered "No/Don't Know" were further asked the question "Would you use mental health services if you were referred?" with response options being "Yes", "No" and "Not Sure". Refer to Tables 4 and 5 for further details.

**Sociodemographic- and Clinical-Related Factors.** Patients reported socio-demographic information such as gender, age, religion, marital status and years of education completed. Symptom burden was assessed using items that assessed symptom severity from the FACIT-Pal<sup>36</sup> (3 questions from the physical well-being subscale and 6 questions from the additional concerns subscale). It was calculated by adding patient-reported severity values of nine common cancer symptoms (pain, shortness of breath, constipation, weight loss, nausea, vomiting, swelling, dry throat and/or mouth, fatigue); scores ranged from 0–36, with higher scores indicating greater symptom burden. Patient-reported treatment delay was responded to as "Yes/No". Patients reported their understanding of their disease stage: "Early stage (stage I, II, or III)", "Advanced stage (stage IV)" or "I don't know". Cancer site and recruitment setting (inpatient vs outpatient) were obtained through medical records.

## Statistical Analysis

Descriptive statistics were summarized by site (Table 1). Multi-variable logistic regression models were used to examine the associations between odds of high anxiety and depression scores (outcome variables) with sociodemographic factors, clinical-related factors and patient-perceived cancer stigma as predictors; odds ratios with 95% confidence intervals (95% CI) were presented. One site from India (AIIMS) and one site from Bangladesh (NICRH) were excluded from the multivariable analysis since they had not fielded the questions on stigma and treatment delay

respectively. Regression models controlled for country and religion. For the subset of patients who reported high anxiety and/or depression scores and had not /did not know if they received mental healthcare services, a multivariable logistic regression was performed to determine the predictors of openness to mental healthcare services use. Statistical significance was set at  $P < .05$ . Analyses were conducted using STATA v16.1.

## Results

A total of 1332 patients were approached with 1205 consenting to the study (participation rate = 90%) (Supplementary Figure 1). Participants who did not complete the survey questions pertinent to this study were excluded ( $n = 65$ ). A total of 1140 participants were included in the analyses, and demographic and clinical characteristics are presented (Table 1). The mean age of the sample was 51 years old (SD = 13 years). The majority of the sample were male (53%), married (83%), and were unaware of their advanced disease status (69%). Majority of the patients from India, Bangladesh and Sri Lanka practiced Hinduism, Islam, and Buddhism respectively. Plurality of the overall sample had no formal education (30%). The most common cancer sites in the overall sample were gastrointestinal (19%), followed by lung and/or respiratory-related (17%), and breast (17%). The majority (61%) of patients completed the survey during their inpatient hospitalization.

### Prevalence of High Anxiety and Depression Scores

The descriptive statistics on prevalence of high anxiety and depression scores are presented in Table 2. The overall mean sample scores were 8.31 (SD = 4.33) and 10.21 (SD = 4.21) for HADS-Anxiety, and HADS-Depression respectively. Overall, 54% of the sample had high scores indicative of probable anxiety and/or depression: 32% had probable anxiety and 47% probable depression.

### Factors Associated with High Anxiety and Depression Scores

Symptom burden was associated with increased odds of high anxiety ( $OR$  [95%  $CI$ ] = 1.13 [1.09, 1.16]) and depression (1.09 [1.05, 1.12]) scores. Perceived stigma was also associated with increased odds of high anxiety (1.11 [1.06, 1.16]) and depression (1.16 [1.11, 1.22]) scores. Older age was associated with lower odds of high anxiety scores (0.98 [0.96, 0.99]) while being female was associated with increased odds of high anxiety scores (1.73 [1.16, 2.59]). Treatment delay, patient perceived cancer stage, recruitment setting, or other demographic factors were not statistically significantly associated with high anxiety or depression scores. Refer to Table 3.

### Mental Health Service Use

In the overall sample, only a small minority (42 out of 1137; 4%) of patients reported receiving mental healthcare services. At the country level, 14% of the sample reported receiving mental healthcare services in Sri Lanka and  $\leq 3\%$  in India and Bangladesh (Table 4). The rates decreased when we restricted the sample to those who met symptom threshold scores; only 3% (17 out of 617) of those who reported high anxiety and/or depression scores were aware of receiving mental healthcare services.

Of the patients who reported receiving mental healthcare services ( $n = 42$ , where 28 came from Sri Lanka), about half received care from mental health professionals (52%), while the remainder received care by others, which mainly consisted of religious leaders and medical care providers (i.e., doctors, nurses). The majority of mental healthcare services received consisted of talk-based support (counseling and support groups; 78%) and occurred in a hospital setting (57%). The majority of patients who received mental healthcare services reported the support to be very helpful (60%) or quite helpful (24%) (Table 5).

A large majority of patients with high anxiety and/or depression scores (600 out of 617; 97%) reported not receiving or not knowing if they had received mental healthcare services. Of these patients, 38% reported they were open to mental healthcare services use, 30% reported they were not open to mental healthcare services use, and 32% reported to be unsure. A multivariable logistic regression analysis of those who reported high anxiety and/or depression scores further indicated that being female ( $OR$  [95%  $CI$ ] = 2.01 [1.23, 3.29]) and experiencing greater symptom burden (1.06 [1.02, 1.11]) was associated with openness to mental healthcare services use.

## Discussion

The current study investigated the prevalence of high anxiety and depression scores, risk factors, and mental health service use among advanced cancer patients in India, Bangladesh, and Sri Lanka. The majority of patients (54%) reported clinically-relevant scores; 32% and 47% reported scores indicative of probable anxiety and depression, respectively. Higher symptom burden and patient-perceived cancer stigma were associated with higher risk of high anxiety and depression scores. Female patients and those who were younger were more likely to have high anxiety scores. Of patients with high anxiety and/or depression scores, 3% reported receiving mental healthcare services. Mental healthcare services utilized by the patients varied, with the majority being counseling-based and received in a hospital setting. Of those who had high anxiety and/or depression scores and reported not receiving mental healthcare

Table 1  
Sociodemographic Characteristics (n = 1140)

	Total N = 1140	India Site 1 n = 208	India Site 2 n = 195	India Site 3 n = 195	Bangladesh Site 1 n = 190	Bangladesh Site 2 n = 152	Sri Lanka n = 200
Recruitment setting (for majority of patients)		Radiation oncology, inpatient	Radiation oncology, outpatient	Medical oncology, outpatient	Palliative care unit, inpatient	Radiation oncology, outpatient	Medical oncology, inpatient
<i>M (SD) / n (%)</i>							
<i>Sociodemographic characteristics</i>							
Age, mean	51 (13)	49 (12)	49 (13)	52 (12)	48 (14)	49 (14)	56 (13)
Age, categories <sup>a</sup>							
< 35	143 (13%)	17 (8%)	33 (17%)	16 (8%)	37 (19%)	26 (17%)	14 (7%)
35 – 49	368 (32%)	88 (42%)	71 (36%)	61 (31%)	58 (31%)	43 (28%)	47 (23%)
50 – 64	431 (38%)	76 (37%)	65 (33%)	83 (43%)	65 (34%)	62 (41%)	80 (40%)
≥ 65	197 (17%)	27 (13%)	26 (13%)	34 (17%)	30 (16%)	21 (14%)	59 (29%)
Gender <sup>a</sup>							
Male	605 (53%)	98 (47%)	104 (53%)	113 (58%)	145 (76%)	78 (51%)	67 (34%)
Female	535 (47%)	110 (53%)	91 (47%)	82 (42%)	145 (24%)	74 (49%)	133 (67%)
Marital status <sup>b</sup>							
Married	947 (83%)	157 (75%)	171 (88%)	177 (91%)	167 (88%)	124 (82%)	151 (76%)
Divorced/Separated/ Widowed	139 (12%)	48 (23%)	9 (5%)	14 (7%)	11 (6%)	23 (15%)	34 (17%)
Never married	52 (5%)	3 (1%)	15 (8%)	3 (2%)	12 (6%)	4 (3%)	15 (8%)
Religion <sup>a</sup>							
Hindu	543 (48%)	172 (83%)	166 (85%)	179 (92%)	10 (5%)	5 (3%)	11 (6%)
Islam	405 (36%)	33 (16%)	24 (13%)	11 (6%)	179 (94%)	146 (96%)	12 (6%)
Catholic / Christian	32 (3%)	3 (1%)	2 (1%)		1 (1%)	1 (1%)	25 (13%)
Buddhism	151 (13%)						151 (76%)
Sikh/Jain	9 (1%)		3 (2%)	5 (3%)			1 (1%)
Years of education completed <sup>b</sup>							
0	346 (30%)	138 (66%)	35 (18%)	63 (32%)	32 (16%)	71 (47%)	7 (4%)
1-5	170 (15%)	19 (9%)	26 (13%)	25 (13%)	45 (24%)	27 (14%)	28 (14%)
6-10	285 (25%)	36 (17%)	64 (33%)	49 (25%)	44 (23%)	35 (23%)	57 (29%)
11-15	247 (22%)	11 (5%)	61 (31%)	38 (19%)	34 (18%)	8 (5%)	95 (48%)
≥ 16	92 (8%)	4 (2%)	9 (5%)	20 (10%)	35 (18%)	10 (15%)	13 (7%)
<i>Clinical characteristics</i>							
Cancer site <sup>a</sup>							
Breast	198 (17%)	46 (22%)	32 (16%)	30 (15%)	15 (8%)	28 (18%)	47 (23%)
Gastrointestinal/ colorectal	215 (19%)	12 (6%)	22 (11%)	39 (20%)	88 (46%)	17 (12%)	37 (18%)
Genitourinary	66 (6%)	-	18 (9%)	19 (10%)	15 (8%)	4 (3%)	10 (5%)
Gynaecologic	146 (13%)	34 (16%)	10 (5%)	15 (8%)	10 (5%)	37 (24%)	40 (20%)
Head and Neck	51 (5%)	2 (1%)	16 (8%)	17 (9%)	6 (3%)	5 (3%)	5 (2.5%)
Lung	195 (17%)	45 (22%)	42 (22%)	29 (15%)	23 (12%)	27 (18%)	29 (15%)
Others	269 (24%)	69 (33%)	55 (28%)	46 (24%)	33 (17%)	34 (22%)	32 (16%)

(Continued)



Table 1  
Continued

	Total N = 1140	India Site 1 n = 208	India Site 2 n = 195	India Site 3 n = 195	Bangladesh Site 1 n = 190	Bangladesh Site 2 n = 152	Sri Lanka n = 200
Recruitment setting (for majority of patients)		Radiation oncology, inpatient	Radiation oncology, outpatient	Medical oncology, outpatient	Palliative care unit, inpatient	Radiation oncology, outpatient	Medical oncology, inpatient
<i>M (SD) / n (%)</i>							
Patient understanding of diagnosis <sup>b</sup>							
Early stage (I, II, III)	96 (8%)	10 (5%)	9 (5%)	15 (8%)	8 (4%)	3 (2%)	51 (26%)
Advanced stage (IV)	252 (22%)	7 (3%)	43 (22%)	44 (23%)	82 (43%)	11 (7%)	65 (33%)
Don't know	792 (69%)	191 (92%)	143 (73%)	136 (70%)	100 (53%)	138 (91%)	84 (42%)
Comorbidities <sup>a,c</sup>							
Diabetes	142 (12%)	25 (12%)	19 (10%)	9 (5%)	28 (15%)	13 (9%)	48 (24%)
Heart condition	116 (10%)	12 (6%)	11 (6%)	3 (2%)	18 (9%)	0 (0%)	72 (36%)
Lung or Liver disease	32 (3%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)	0 (0%)	30 (15%)
Symptom burden							
Mean (SD)	13 (6)	8 (5)	12 (6)	13 (6)	18 (4)	14 (5)	13 (7)
Stigma <sup>d</sup>							
Mean (SD)	10 (4)	8 (3)	-	9 (4)	9 (4)	12 (4)	11 (4)
Delayed medical treatment <sup>b</sup>	162 (17%)	3 (1%)	22 (11%)	21 (11%)	76 (41%)	-	40 (20%)
Study recruitment location <sup>a</sup>							
Outpatient	448 (39%)	26 (12%)	194 (99%)	117 (60%)	0 (0%)	96 (63%)	15 (8%)
Inpatient	692 (61%)	182 (88%)	1 (1%)	78 (40%)	190 (100%)	56 (37%)	185 (93%)

<sup>a</sup>Percentages do not add up to 100 as they are rounded off to the whole number.

<sup>b</sup>Percentages do not add up to 100 due to missing data/refusal to answer.

<sup>c</sup>Percentages do not add up to 100 because participants are supposed to check all options that apply.

<sup>d</sup>This question not administered at site.

Table 2  
Anxiety and Depression Scores and Prevalence of High Scores (N = 1140)

	Total N = 1140	India Site 1 n = 208	India Site 2 n = 195	India Site 3 n = 195	Bangladesh Site 1 n = 190	Bangladesh Site 2 n = 152	Sri Lanka n = 200
Recruitment setting (majority)		Radiation oncology, inpatient	Radiation oncology, outpatient	Medical oncology, outpatient	Palliative care unit, inpatient	Radiation oncology, outpatient	Medical oncology, inpatient
HADS Anxiety Mean (SD)	8.31 (4.33)	5.58 (3.09)	7.82 (4.35)	8.54 (4.32)	10.51 (3.26)	10.74 (3.96)	7.44 (4.56)
Median (IQR)	8 (5,11)	6 (3,7)	8 (5,10)	8 (6,12)	11 (8,13)	11 (8,14)	6.5 (4,10.5)
HADS-A > 10	364 (32%)	14 (7%)	44 (23%)	68 (35%)	104 (55%)	84 (55%)	50 (25%)
HADS Depression Mean (SD)	10.21 (4.21)	9.69 (3.30)	9.30 (4.96)	10.13 (4.19)	12.46 (2.94)	11.05 (3.09)	8.96 (5.04)
Median (IQR)	10 (8,13)	9 (8,12)	9 (6,11)	10 (7,13)	12 (10,14)	11 (9,13)	8 (5,12)
HADS-D > 10	533 (47%)	82 (39%)	62 (32%)	88 (45%)	140 (74%)	90 (59%)	70 (35%)
HADS-A and/or HADS-D > 10	617 (54%)	84 (40%)	76 (39%)	104 (53%)	155 (82%)	116 (76%)	82 (41%)

HADS-A= Hospital Anxiety Depression Scale, Anxiety subscale; HADS-D= Hospital Anxiety Depression Scale, Depression subscale.

Table 3  
Factors Associated with High Anxiety and Depression Scores (N = 772)

	Anxiety		Depression	
	OR <sup>a</sup>	95% CI	OR <sup>a</sup>	95% CI
<i>Sociodemographic factors</i>				
Female	1.73	1.16, 2.59	1.23	0.87, 1.75
Age	0.98	0.96, 0.99	1.00	0.98, 1.01
Married (ref: not married)	1.47	0.89, 2.42	0.70	0.46, 1.06
Education years	1.00	0.97, 1.04	0.98	0.95, 1.01
<i>Clinical-related factors</i>				
Symptom burden	1.13	1.09, 1.16	1.09	1.05, 1.12
Delayed treatment	1.10	0.70, 1.74	1.38	0.87, 2.17
Inpatient setting (ref: outpatient)	0.66	0.40, 1.10	1.54	0.99, 2.40
<i>Patient-reported diagnosis (ref: early stage)</i>				
Advanced stage	0.86	0.43, 1.71	1.36	0.72, 2.57
Not sure/Don't know	0.83	0.43, 1.60	1.16	0.65, 2.09
Perceived cancer stigma	1.11	1.06, 1.16	1.16	1.11, 1.22

<sup>a</sup>Odds ratios adjusted for country and religion.

services, 38% were open to a referral, while the rest were not open and/or not sure.

This study provides an overview of the prevalence of high anxiety and depression scores among South Asian advanced cancer patients. While the anxiety rate is generally similar, the depression rate is higher compared to the median prevalence rates in a systematic review of advanced cancer/hospice patients using the same measure and threshold that consisted mostly of Western samples (28% anxiety, 29% depression).<sup>9</sup> The rates were higher than the pooled prevalence rates of anxiety (27%) and depression (37%) in a meta-analysis study of cancer patients from India and Pakistan, however that study included cancers of all stages.<sup>37</sup>

Although our study consisted of patients with stage IV solid cancer, there was variation in rates of high anxiety and depression scores across the study sites. A potential reason is differences in recruitment setting; the study site reporting the highest prevalence of high anxiety and/or depression scores recruited solely from an inpatient palliative care unit, where one would expect higher rates of patient distress.

We also found that Sri Lanka reported the highest proportion of patients receiving mental health services at 14%. Potential reasons include a more general cultural awareness of the importance of mental well-being, and a greater openness to mental health support in the Buddhist-majority society. The Sri Lankan site also has a psychological support unit that works closely with the oncology team and there is active involvement of religious services and institutions to provide support to advanced cancer patients.

Table 4  
Access and Openness to Mental Health Services (MHS) Referral

	Total <sup>a</sup> N=1137	India Site 1 n = 208	India Site 2 n = 194	India Site 3 n = 195	BGD Site 1 n = 188	BGD Site 2 n = 152	Sri Lanka n = 200
Received MHS <sup>b</sup>							
Yes	42 (4%)	0	3 (2%)	2 (1%)	4 (2%)	5 (3%)	28 (14%)
No/ Don't know	1095 (96%)	208 (100%)	191 (97%)	193 (98%)	184 (97%)	147 (97%)	172 (86%)
Reported high anxiety and/or depression score and received MHS	17 (3%)	0	1 (1%)	1 (1%)	3 (2%)	4 (3%)	8 (10%)
Openness to MHS if referred <sup>c</sup>							
Yes	226 (38%)	25 (30%)	68 (92%)	32 (33%)	32 (21%)	23 (20%)	46 (61%)
No	180 (30%)	0	5 (7%)	10 (10%)	62 (41%)	85 (74%)	18 (24%)
Not sure	190 (32%)	59 (70%)	1 (1%)	54 (56%)	58 (38%)	7 (6%)	11 (15%)
	Total N = 596	India Site 1 n = 84	India Site 2 n = 74	India Site 3 n = 96	BGD Site 1 n = 152	BGD Site 2 n = 115	Sri Lanka n = 75

BGD= Bangladesh. Percentages do not add up to 100 due to rounding.

<sup>a</sup>3 participants did not respond to the question.

<sup>b</sup>Patients were asked if they have seen any of the following mental health care worker as part of their cancer treatment: psychiatrist, psychologist, medical social worker (for psychological support), community counsellor, others.

<sup>c</sup>Among patients who reported high anxiety and/or depression score and did not receive MHS.

Our findings on the risk factors of high anxiety and/or depression scores add to the literature as previous studies from this region tend to examine sociodemographic and medical information<sup>13,16,17</sup> without considering symptom burden and psychological factors such as stigma. In this study, symptom burden captured the combination of range and severity of the symptoms, with the top 3 complaints being pain, fatigue, and weight loss. Our findings underscore how intertwined physical and psychological states are and the importance of management of physical symptoms in this patient population.

Patient-perceived cancer stigma assessed in this study included how patients (accurately or inaccurately) believe how others both viewed them, (e.g., the patient's behavior was responsible for their cancer) and treated them (e.g., avoided them) because of cancer. Our findings are consistent with previous studies conducted from other cultural settings,<sup>18,21</sup> and qualitative studies investigating stigmatization among cancer patients in India.<sup>38,39</sup> Taken together, stigma surrounding cancer will be important to address in two ways: firstly, providing mental health services to cancer patients with stigma-related distress, and secondly, reshaping public perception of cancer through awareness and anti-stigma campaigns. Understanding these factors also allows clinicians to review and/or consider them as part of standard clinical assessment, and to identify patients at higher risk for psychological morbidity.

Our findings highlight the psychological needs of advanced cancer patients in this region. Over half the patients in this study (54%) reported clinically-relevant anxiety and/or depression scores, and only 3% reported receiving mental healthcare services. It is possible that those who were distressed were unaware they were receiving treatment for their mood, (e.g., pharmacotherapy) especially if managed by their primary oncology provider together with other symptoms. It is also possible that patients are receiving mental healthcare informally in their support networks. However, the mental healthcare services receipt-to-distress ratios across the study sites suggest patient psychological needs are not being met. Future studies may also consider looking at the role informal sources of support amongst advanced cancer patients in South Asia.

The number of advanced patients who reported receiving mental healthcare services from mental health professionals was small. It is unclear if this is a reflection of healthcare system barriers such as lack of identification processes, availability of services, cost, etc.<sup>40,41</sup> Anecdotal reports from the leads of the different countries in the study indicate that psychological services are available in their hospitals. Additionally, psychosocial care is viewed as part of the services provided by their respective palliative care units, although



Table 5  
Mental Health Services (MHS) use Characteristics (N = 42)

Study sites <sup>a</sup> Sample Size	Total N = 42	India Site 2 n = 3	India Site 3 n = 2	Bangladesh Site 1 n = 4	Bangladesh Site 2 n = 5	Sri Lanka n = 28
n (%)						
Mental health service						
Psychiatrist	7 (17%)	2			4	1
Psychologist	6 (14%)		1		1	4
Medical social worker <sup>c</sup>	6 (14%)	1		4		1
Community counsellor	3 (7%)		1			2
Others <sup>d</sup>	20 (48%)					20
Type of MHS intervention <sup>b</sup>						
Medications	4 (10%)	1		1	1	1
Counselling	27 (64%)	1	1		1	24
Support group	6 (14%)	1	1	3		1
Others	2 (5%)					2
Location of MHS received <sup>b</sup>						
Hospital, inpatient	13 (31%)			3		10
Hospital, outpatient	11 (26%)	3	1		2	5
Private	2 (5%)			1		1
Homecare service	13 (31%)		1			12
Perceived usefulness of MHS <sup>b,c</sup>						
Very helpful	25 (60%)	2	1	1	1	20
Quite helpful	10 (24%)	1		3		6
Not sure	1 (2%)				1	
Not helpful at all	3 (7%)		1			2

<sup>a</sup>India Site 1 is not displayed because no patient indicated receiving MHS.

<sup>b</sup>Percentages do not add up to 100 due to missing data.

<sup>c</sup>specified for psychological support.

<sup>d</sup>Text responses indicated 14 to be of faith-based professions and 4 medical care providers.

<sup>e</sup>Participants were asked, "How helpful did you find receiving mental health services?".

only 2 sites reported providing systematic psychosocial support. Nevertheless, it is encouraging that the majority of those who received mental healthcare services found them to be helpful. Our findings underscore the role palliative and supportive care teams could play in addressing patient psychological distress, both directly through treating anxiety and depression symptoms, and indirectly via management of physical symptom burden.<sup>42</sup>

There are also patient-level barriers that are apparent. The majority of patients who have high anxiety and/or depression scores reported they would not, or are unsure if they would, utilize mental healthcare services if referred. Future studies may want to specifically examine stigma surrounding mental illness/ mental healthcare services use as a barrier to access. Being male halved the odds of being open to a mental healthcare services referral, perhaps reflecting culturally-embedded and culturally-embedded masculinity-related beliefs that men are expected to be strong and not to need help.<sup>43,44</sup> Interestingly, greater symptom burden increased the odds of openness to a mental healthcare services referral in a small, but statistically significant way. This may be looked upon as promising, as there are psychological-based therapies that are

effective for symptom management (e.g., pain, insomnia, fatigue) that may serve as a gateway to addressing anxiety and depression symptoms.<sup>26</sup>

Our study further highlights the opportunity to grow and develop psychological services for oncological care. An average of 38% (ranging 20-92% across the study sites) of patients who reported high anxiety and/or depression scores reported openness in receiving a mental healthcare services referral, indicating likelihood of mental healthcare services uptake if referred. An important clinical implication and future direction is the use of psychological screening mechanisms to identify those in need and who may benefit from mental healthcare services. Brief screening tools such as the National Comprehensive Cancer Network distress thermometer (DT) and problem check list (PCL) have been used widely for this purpose.<sup>23</sup> Yet, in order to initiate screening practices, the receiving referral services and access to appropriate treatments need to be in place.

### Study Limitations

Our cross-sectional data does not allow us to draw causal conclusions. Our prevalence rates were based on "probable case" thresholds using self-report

measures, and may not be as accurate as clinical diagnostic interviews; however, the instruments utilized are validated and widely used. We believe our findings provide an indicator of distress among advanced cancer patients that is worthy of attention regardless of if they meet clinical diagnostic criteria. Another limitation is not including clinical factors such as time since cancer diagnosis and previous treatments in our model due to limited data. It is also unclear how the health literacy of the patients under study may have affected study findings; majority of patients reported perceiving their cancer to be in early stages and that there was no treatment delay. However, we posit that for these patients, perception and/or subjective judgment rather than actual cancer severity and treatment delay may be more relevant in predicting psychological states.

## Conclusion

Our findings underscore the unmet mental healthcare need among South Asian advanced cancer patients. This presents an opportunity for development and growth in mental healthcare-based services offered, while providing future directions on barriers to tackle surrounding mental healthcare in this patient population.

## Authors' contribution

IT conceived the study idea, performed data analyses and led the writing of the manuscript. SO, CM, GMY, RRO, SB, TH, AKJ, LM, GP, RR, EAF contributed to the drafting and revision of the manuscript. All authors read and approved the final manuscript.

## Disclosures

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The Authors declare that there is no conflict of interest.

## Data management and sharing

The data from this study is available upon reasonable request from the lead author.

## Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2021.04.005](https://doi.org/10.1016/j.jpainsymman.2021.04.005).

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