

Learnings From “Asian Patient Perspectives Regarding Oncology Awareness, Care and Health (APPROACH)”

**25 September 2020 (FRIDAY)
2 – 3 PM**



Background

- At the time we started APPROACH, LCPC was a young research and education focused palliative care centre with the following vision:
To be the leading academic centre delivering and facilitating palliative care research and education in the region.
- But without a single research project outside of Singapore
- Beyond Singapore, palliative care research was (and is) in it's infancy with few academics dedicated to palliative care research in the entire region
- Question: how can we fulfill our vision, build research capacity in the region, and do something useful?
- Answer: APPROACH...at least as a place to start

APPROACH Background

Stated Aim

To fill the knowledge gap in the understanding of cancer patients' perspectives on end-of-life care and treatments

Methods

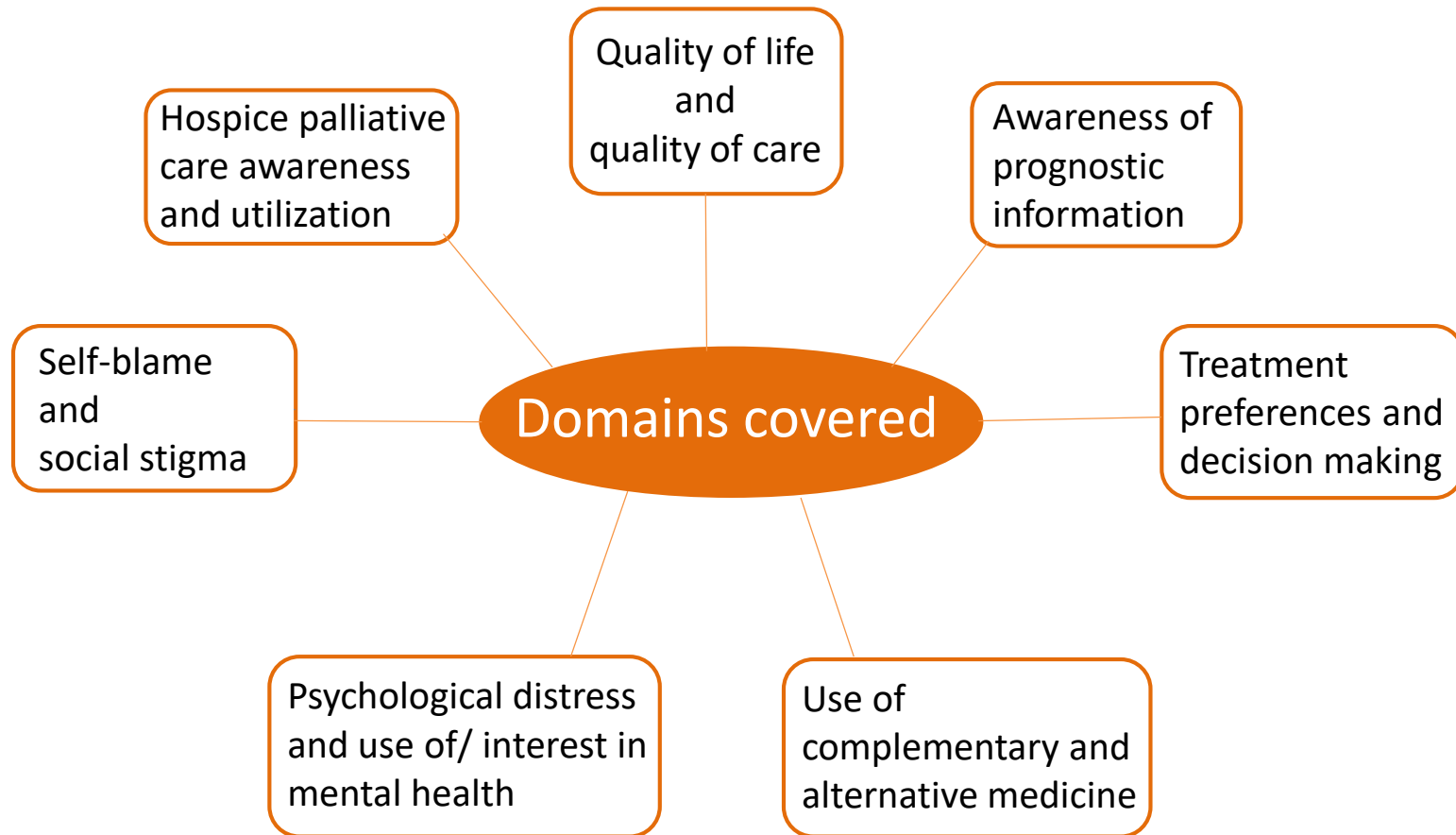
A cross-sectional study of 200 adults from cancer hospitals in various sites who meet the following inclusion criteria:

- ✓ Diagnosed with solid stage IV cancer
- ✓ Aware of cancer diagnosis
- ✓ Can understand and speak the language used in the survey instrument

Funding

- We got a bit of funding from Asia Pacific Hospice Palliative Care Network (US\$9,203) but largely funded through LCPC
- We sent some money overseas (roughly \$5K to \$10K per study) but the real costs was manpower by our team (and it adds up)
- **We required cost sharing for every site. That's key.**

Survey Domains



These domains were chosen based on the expertise of our team, who each put in their own sets of questions.

APPROACH Background (cont)

Recruitment of collaborators

- Publicized the study via APHN (i.e. flyers)
- Met and networked with potential partners at the Asia Pacific Hospice Conference (a biennial event hosted by APHN)
- Used our network in SG to connect with potential PIs from other countries in Asia

Collaboration

- LCPC
 - Provided funding
 - Assisted with translation
 - Provided on-site training on conducting field work and data entry
 - Assisted with data analyses and manuscript writing
- Site PIs
 - Provided feedback on the translated survey instrument
 - Obtained IRB approval (prior to getting any \$)
 - Were responsible for subject recruitment and data collection
- Each site PI was paired with an LCPC PI to assist with writing of a site/country manuscript

APPROACH Participants

Country	Institution	Collaborator
Myanmar	Department of Medical Research, Ministry of Health and Yangon General Hospital (YGH)	Dr Ssu Wynn Mon
India	MNJ Institute of Oncology and Regional Cancer Centre (MNJIORCC)	Dr Gayatri Palat
	Dr B.R.A. Institute Rotary Cancer Hospital, AIIMS	Dr Sushma Bhatnagar
	Bhagwan Mahaveer Cancer Hospital and Research Centre (BMCHRC)	Dr Anjum Khan Joad
China	Peking Union Medical College Hospital (PUMCH)	Dr Ning Xiao Hong
Sri Lanka	National Cancer Institute Maharagama (NCIM)	Dr Thushari Hapuarachchi
Vietnam	Hue Central Hospital (HCH)	Dr Pham Nguyen Tuong
Bangladesh	Bangabandhu Sheikh Mujib Medical University (BSMMU)	Dr Rubayat Rahman
	National Institute of Cancer Research and Hospital (NICRH)	Dr Lubna Mariam
Philippines	The Medical City (TMC)	Dr Liza Manalo
Indonesia	Rumah Sakit Umum Pusat Nasional (RSUPN) Dr. Cipto Mangunkusumo [RSCM]	Dr Rudi Putranto
Nepal	Nepal Cancer Hospital and Research Centre (NCHRC)	Dr Murari Shrestha
Thailand	Silpakorn University (SU)	Dr Nattiya Kapol

13 sites representing 10 countries

With funding from DGHI we also recently added Moi Teaching and Referral Hospital in Kenya

Research Outputs To Date



5 Published Papers

4 Manuscripts under review

6 Manuscripts In Progress

Several more are planned

Research Highlights



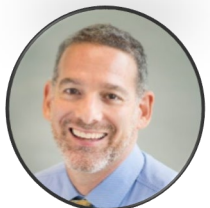
Prognostic awareness and its association with health outcomes, and Role in decision making among Asian advanced cancer patients
presented by **Semra Ozdemir**, Asst Professor, LCPC



Inequalities in end of life cancer care by public hospitals in low and middle income countries in Asia
presented by **Chetna Malhotra**, Asst Professor, LCPC



Anxiety, depression and mental health service use among advanced cancer patients in South Asia
presented by **Irene Teo**, Asst Professor, LCPC



The association of self-blame with treatment preferences
presented by **Eric Finkelstein**, Professor and Executive Director, LCPC

Prognostic Awareness and its Associations with Anxiety, Depression and Spiritual Well-being

**Semra Ozdemir, Wei Han Melvin Wong,
Sean Ng Yong Wen, Irene Teo, Chetna Malhotra,
Jean Jacob Mathews, Gerald Koh Choon Huat,
Lee Lai Heng, Anjum S. Khan Joad,
Thushari Hapuarachchi, Gayatri Palat,
Pham Nguyen Tuong, Sushma Bhatnagar,
Xiaohong Ning, Eric Andrew Finkelstein**

Aims

- To investigate whether prognostic awareness (PA) is associated with anxiety, depressive symptoms and spiritual well-being among advanced cancer patients from various Asian countries.
- To investigate whether acceptance of illness moderates these relationships.

Measures

Prognostic Awareness	The current treatments you are taking for your cancer will cure you
	<input type="checkbox"/> Yes – Accurate PA <input type="checkbox"/> No/Not sure – Inaccurate PA
Acceptance of Illness	I have accepted my illness
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Somewhat <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
Anxiety Symptoms	Hospital Anxiety and Depression Scale – Anxiety (HADS – A)
Depressive Symptoms	Hospital Anxiety and Depression Scale – Depression (HADS – D)
Spiritual Well-Being	Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT – SP)

Prognostic Awareness and Acceptance of Illness

Prognostic Awareness						
	China	India	Singapore	Sri Lanka	Vietnam	Total
Inaccurate PA	83	93	71	96	83	84
Accurate PA	17	7	29	4	18	16
Acceptance of Illness						
Very much/ quite a bit	90	76	92	97	67	84
Somewhat/ Little bit/ Not at all	10	23	9	5	34	16

16% accurate PA: Singapore highest, India & Sri Lanka lowest.

84% “very much” or “quite a bit accepting”: Sri Lanka highest, Vietnam lowest.

Prognostic Awareness and Psychological outcomes

	Anxiety	Depression	Spiritual Meaning	Spiritual Faith
Accurate PA (vs inaccurate)	3.36 (p < 0.01)	1.85 (p < 0.01)	-9.82 (p < 0.01)	-4.68 (p < 0.01)

Accurate PA was associated with higher anxiety, higher depressive symptoms and poorer spiritual well-being.

Acceptance as a Moderating Variable

	Anxiety	Depression	Spiritual Meaning	Spiritual Faith
Accurate PA (vs inaccurate)	3.36 ($p < 0.01$)	1.85 ($p < 0.01$)	-9.82 ($p < 0.01$)	-4.68 ($p < 0.01$)
Interaction between PA and acceptance of illness	-0.79 ($p < 0.01$)	-0.20 ($p = 0.41$)	2.46 ($p < 0.01$)	0.98 ($p = 0.05$)

Compared to patients with accurate PA and lower acceptance of illness, those with accurate PA and higher acceptance of illness reported lower anxiety and higher spiritual well-being.

Acceptance of illness moderated PA-related negative psychological outcomes

Discussion

- PA should be promoted alongside psychosocial interventions targeted at enhancing acceptance of illness.
- Important because physicians in Asia more likely to withhold PA for fear of worsening the patient's condition.
- Interventions must be sensitive to social and cultural differences of participants.

Role in Treatment Decision Making among Asian Advanced Cancer Patients

**Semra Ozdemir, Chetna Malhotra, Irene Teo,
Jean Jacob Mathews, Anjum S. Khan Joad,
Sushma Bhatnagar, Gayatri Palat,
Thushari Hapuarachchi, Pham Nguyen Tuong,
Xiaohong Ning, Rubayat Rahman, Lubna Mariam,
Liza Manalo, Eric Andrew Finkelstein**

Aims

- To investigate patient-reported roles in decision making for families, physician and themselves.
- To investigate the associations between roles in decision making and patient characteristics, perceived quality of life (QoL) and quality of care (QoC).

Classification of Role in Decision Making

Patient Experienced Decision-Making

Since diagnosis, who has been responsible for the most important decisions about your treatment?

Check all that apply

Myself

My family

My doctors

Which statement best describes the **role each person (among patients, caregivers and physicians) played** when making decisions about your treatment?

I/my family/my doctor made the decisions after considering my/my family/my doctor's opinion

Decision-making classifications

No patient involvement

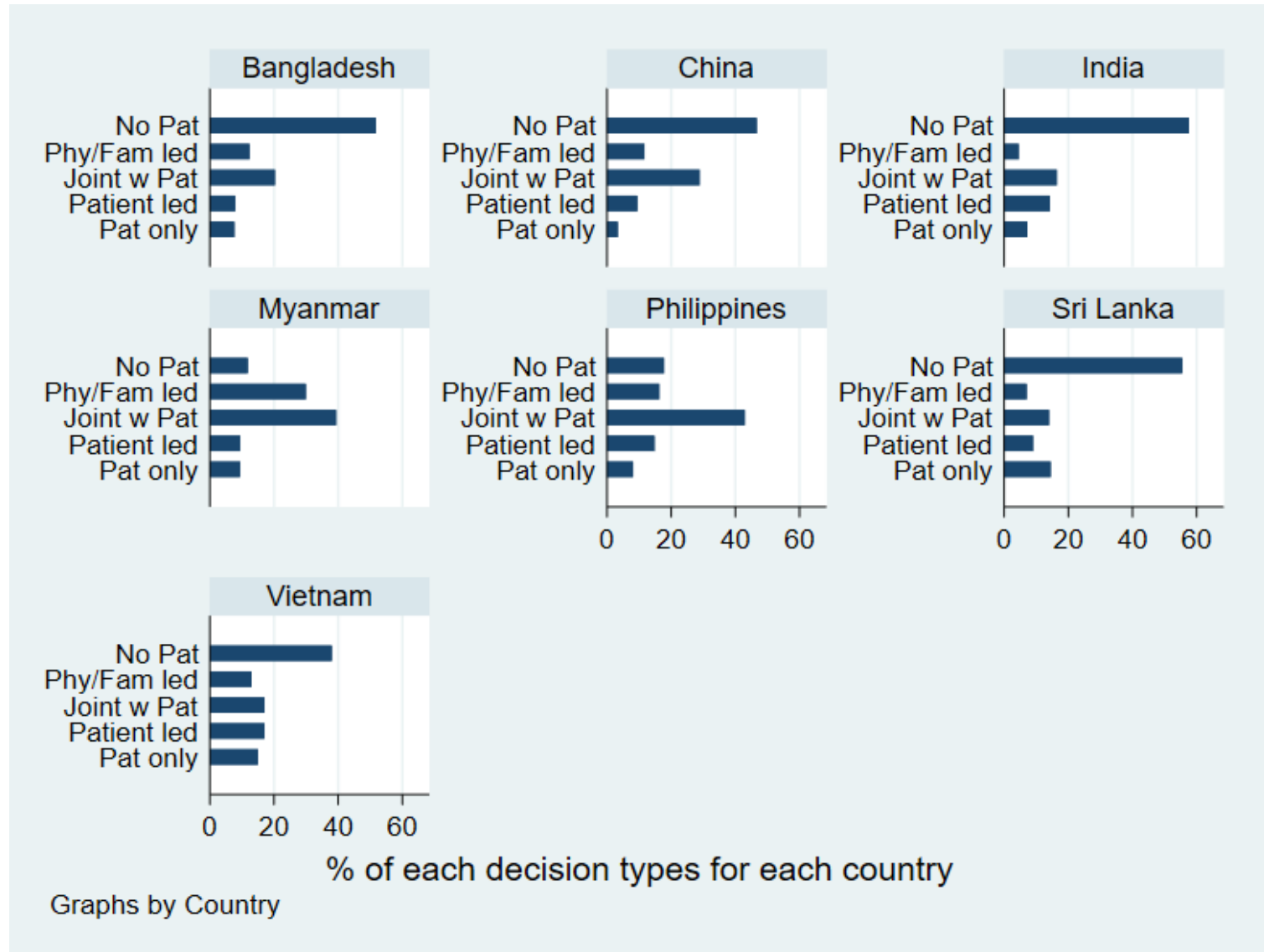
Family/Physician led

Collaborative

Patient-led

Patient alone

Roles in Decision Making by Country



Main Findings

- Among Asians, being male, educated and coming from majority/higher caste groups were associated with experiencing active roles in decision making.
 - These are characteristics commonly associated with privilege – more focus should be on empowering socially disadvantaged groups in Asia.
- Engaging in shared decision making (i.e. collaborative decision making) was associated with higher social and functional well-being, and higher perceived quality of care.
 - However, any involvement in decision making was also associated lower emotional well-being.

Inequalities in responsiveness of cancer care services provided by public hospitals

**Chetna Malhotra, Jeselin Putri Andono,
Semra Ozdemir, Thushari Hapuarachchi,
Anjum Khan, Pham Nguyen Tuong,
Eric Finkelstein, APPROACH study group**

Goal of end of life (EOL) cancer care services

1. Improve patient health- survival and quality of life
2. Be responsive to patients' expectations in non-health domains
 - Dignity
 - Clarity of information
 - Involvement in decision making

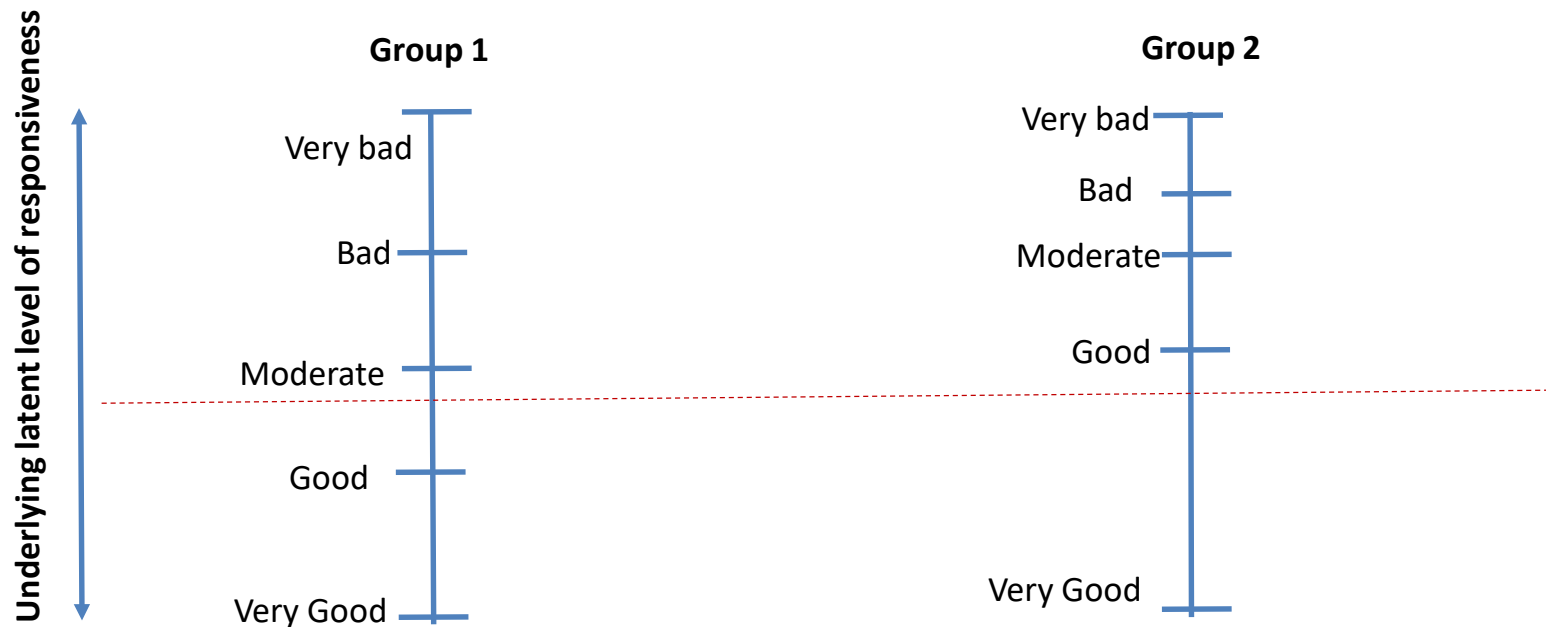
EOL cancer care services: Public health care system

- Public hospitals in low income countries-
 - Main institutions for delivering cancer care
 - Founded to ensure equity in health care access to all
 - irrespective of ability to pay for services
 - But often criticized for poor responsiveness

Measuring responsiveness of services

- Essential for improving quality of services provided
 - Improve care provided – patient-centered
 - Compare performance and benchmarking
- Traditionally focused on measurement of satisfaction with services provided
- ISSUE:
 - Self-reported
 - Biased by patients' expectations from the health system
(REPORTING HETEROGENEITY)

Challenges in measuring responsiveness

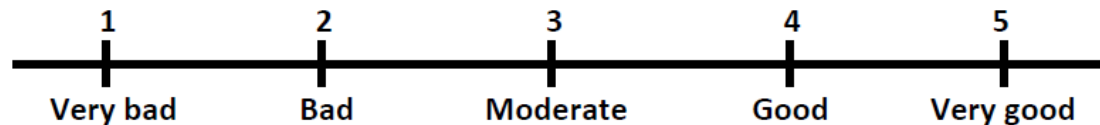


Examples

- Inequalities in responsiveness by socio-economic status (SES)
 - Patients from low SES may have lower expectations regarding care
 - This may underestimate the magnitude of inequality between low and high SES
- Studies show that advanced cancer patients with high quality of life and inaccurate prognostic understanding (perceive that their current treatments can cure them) report cancer care services to be more responsive than others.
 - Might be due to reporting heterogeneity?

Solution

- Use anchoring vignettes
 - *Vignette: “The doctor has very briefly explained to [name of hypothetical patient] about his illness. He is very busy and there is a queue of patients waiting to see him. [Name of hypothetical patient] would like to know more about his illness, but feels that there is no time to ask questions. The doctor says goodbye to [name of hypothetical patient], and [name of hypothetical patient] leaves the office.”*
 - *Question: “How would you rate [name of hypothetical patient] experience of how clearly health care providers explained things to him?”*



Objective

To assess inequalities in responsiveness of cancer care services by patients' socio-economic status, age, gender, quality of life and prognostic understanding after correcting for potential reporting heterogeneity

Data

- 1184 Stage IV cancer patients from six major public hospitals in China, India, Sri Lanka, and Vietnam.
 - Sri Lanka: National Cancer Institute Maharagama, Maharagama
 - India:
 - MNJ Institute of Oncology & Regional Cancer Centre, Hyderabad;
 - All-India Institute of Medical Sciences, New Delhi;
 - Bhagwan Mahaveer Cancer Hospital & Research Centre, Jaipur
 - Vietnam: Hue Central Hospital, Hue
 - China: Peking Union Medical College Hospital, Beijing

Data

- We assessed patient-reported responsiveness in 3 domains - dignity, clarity of information and involvement and decision making
- We gave them vignettes describing a hypothetical patient's experience and asked them to rate patient's experience in terms of dignity, clarity of information and involvement in decision making

Statistical analysis

- Ordered Probit model - associations between responsiveness domains (dignity, clarity of information, involvement in decision making) and patients' age, gender, SES, quality of life and prognostic understanding.
- Hierarchical Ordered Probit (HOPIT) model – to estimate these associations after correcting for reporting heterogeneity using vignettes responses

Results

- After correcting for reporting heterogeneity
 - Patients from low and middle SES perceived lower 'dignity' and 'involvement in decision making', compared to those from high SES
 - Females perceived 'dignity' to be lower
 - No differences seen between males and females when uncorrected for reporting heterogeneity
 - No difference in responsiveness by quality of life and prognostic understanding
 - When uncorrected – patients with high quality of life and with incorrect prognostic understanding reported better responsiveness than those with low quality of life and correct prognostic understanding

Implications

- In public hospitals in low and middle-income Asian countries, there are inequalities in responsiveness of care by gender and SES.
- Reasons for these inequalities:
 - Patient-related factors – low health literacy limiting provider-patient communication, high out-of-pocket costs and untreated symptoms
 - Provider-related factors – physician implicit bias based on gender and SES
 - Societal inequalities

Implications

- To truly achieve universal health coverage of EOL services, focus on removing inequalities in responsiveness, especially within public hospitals
- Examples:
 - Infrastructural changes to improve ‘dignity’ of female patients
 - Improve provider communication with low SES patients
 - Improve awareness of ‘implicit bias’
- Continuous monitoring of quality of non-clinical care – equity lens

Anxiety, Depression and Mental Health Service (MHS) Use Among South Asian Advanced Cancer Patients

**Irene Teo, Semra Ozdemir, Chetna Malhotra,
Remee R. Ocampo, Anjum Khan Joad,
Gayatri Palat, Lubna Mariam, Rubaiyat Rahman,
Sushma Bhatnagar, Thushari Hapuarachchi,
Eric A. Finkelstein and APPROACH study group**

Background

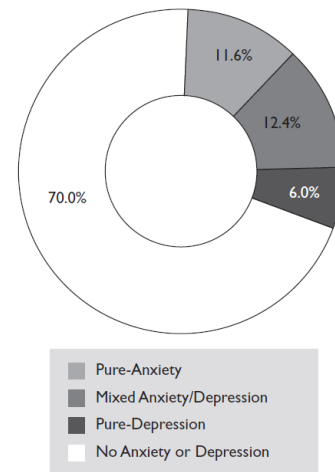
- A significant proportion of advanced cancer patients report anxiety and depression¹⁻⁴
- Most data come from North America, Europe, East Asia
- Common to see mixed anxiety-depression⁴

Anxiety 28% (18-66%)

Depression 29% (16-50%)

Hotopf et al. (2002)
Palliative Medicine

FIGURE 1. Prevalence of Anxiety, Depression, and Mixed State (N=8,265)



1. Caruso et al. *Acta Oncol* 2017
2. Linden et al. *J Affect Disord* 2012
3. Hotopf et al. *Palliative Med* 2002
4. Brintzenhofe-Szoc *Psychosomatics* 2009

Study aims

To examine among South Asian advanced cancer patients:

1. The prevalence of anxiety, depression and mixed anxiety-depression

2. Any associated risk factors?

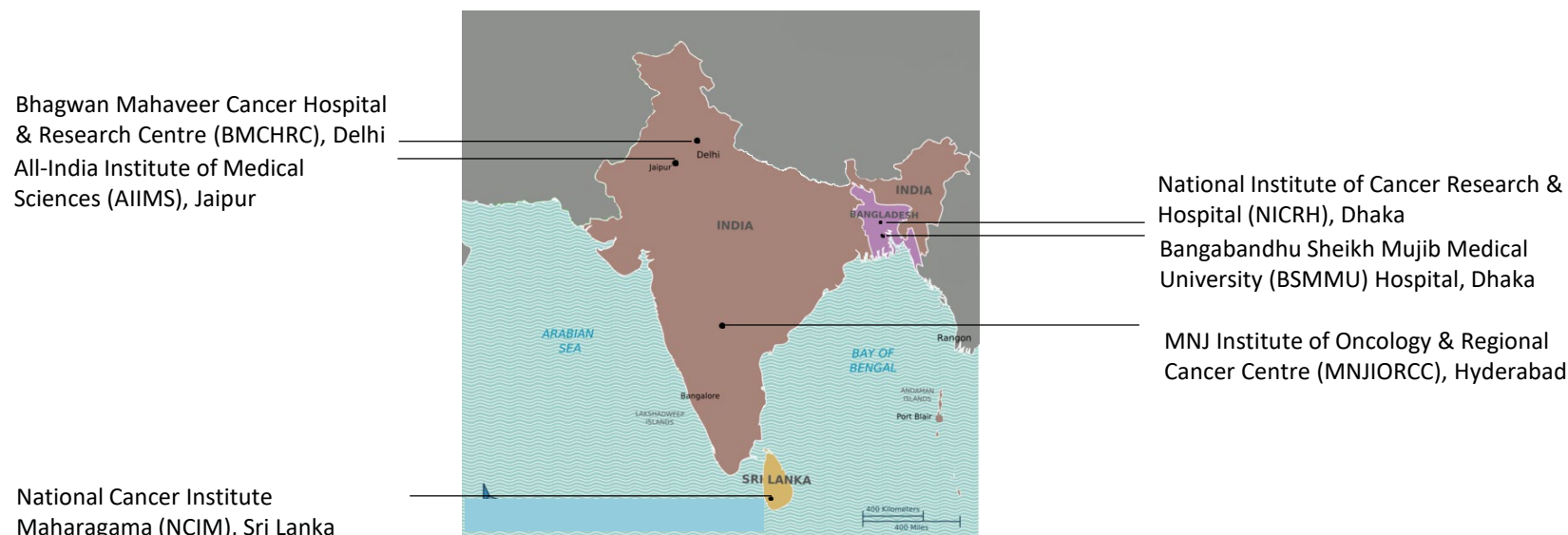
- Sociodemographic factors
- Clinical-related factors
- Patient-perceived cancer stigma

3. Mental health service (MHS) use

- Rate of MHS use
- Perceived usefulness of MHS
- Openness in receiving a MHS referral

Methods

Data collected between January 2017-October 2019



Measures

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

- 2 subscales: Anxiety (HADS-A) and Depression (HADS-D)
- Scores >10 on HADS-A and HADS-D indicate probable caseness

Sense of Stigma subscale (from Kissane's Shame & Stigma Scale, 2013)

- Higher score, greater perceived cancer stigma

Sociodemographic characteristics

Study sites	Total	India	India	India	BGD	BGD	Sri Lanka
Sample size	n = 1140	Site 1 n =208	Site 2 n = 195	Site 3 n = 195	Site 1 n = 190	Site 2 n = 152	n = 200
	M (SD) / N (%)						
Age, mean	51 (13)	49 (12)	49 (12)	52 (12)	48 (14)	49 (14)	56 (13)
Gender ¹							
Male	605 (53%)	98 (47%)	104 (53%)	113 (58%)	145 (76%)	78 (51%)	67 (34%)
Female	536 (47%)	110 (53%)	92 (47%)	82 (42%)	145 (24%)	74 (49%)	133 (67%)
Marital status ^{1,3}							
Married	948 (83%)	157 (75%)	172 (88%)	177 (91%)	167 (88%)	124 (82%)	151 (76%)
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 ¹							
Hindu	544 (48%)	172 (83%)	167 (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 ^{1,3}							
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	286 (25%)	36(17%)	65 (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%)

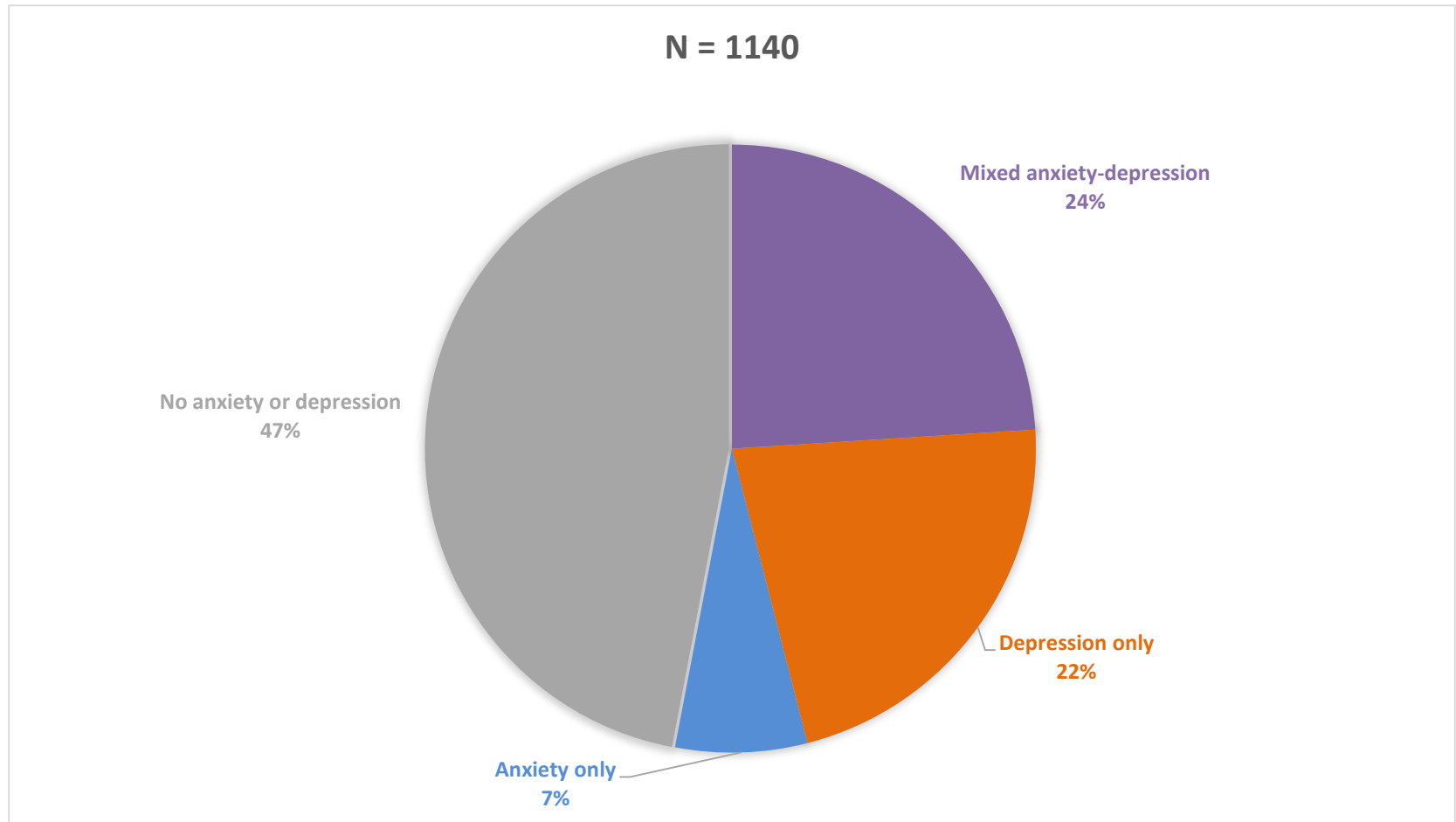
¹Percentages do not add up to 100 as they are rounded off to the whole number; ²Percentages do not add up to 100 because participants are supposed to check all options that apply; ³Percentages do not add up to 100 due to missing data/refusal to answer

Clinical characteristics

Study sites	Total	India Site 1	India Site 2	India Site 3	Banglades h Site 1	Banglades h Site 2	Sri Lanka
Sample size	n = 1141	n = 208	n = 196	n = 195	n = 190	n = 152	n = 200
M (SD) / N (%)							
Cancer site¹							
Breast	199 (17%)	46 (22%)	33 (17%)	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%)
Respiratory	195 (17%)	45 (22%)	42 (21%)	29 (15%)	23 (12%)	27 (18%)	29 (15%)
Others	269 (24%)	69 (33%)	55 (28%)	46 (24%)	33 (17%)	34 (22%)	32 (16%)
Patient's understanding of diagnosis¹							
Early Stage (I, II, III)	96 (8%)	10 (5%)	9 (5%)	15 (8%)	8 (4%)	3 (2%)	51 (26%)
Advanced Stage (IV)	253 (22%)	7 (3%)	44 (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%)
Symptom burden							
Mean (SD)	13 (6)	8 (5)	12 (6)	13 (6)	18 (4)	14 (5)	13 (7)
Delayed medical treatment							
Yes	162 (17%)	3 (1%)	22 (11%)	21 (11%)	76 (41%)	-	40 (20%)
No	819 (83%)	205 (99%)	172 (89%)	171 (89%)	110 (59%)	-	160 (80%)

¹Percentages do not add up to 100 as they are rounded off to the whole number; ²Percentages do not add up to 100 because participants are supposed to check all options that apply; ³Percentages do not add up to 100 due to missing data/refusal to answer

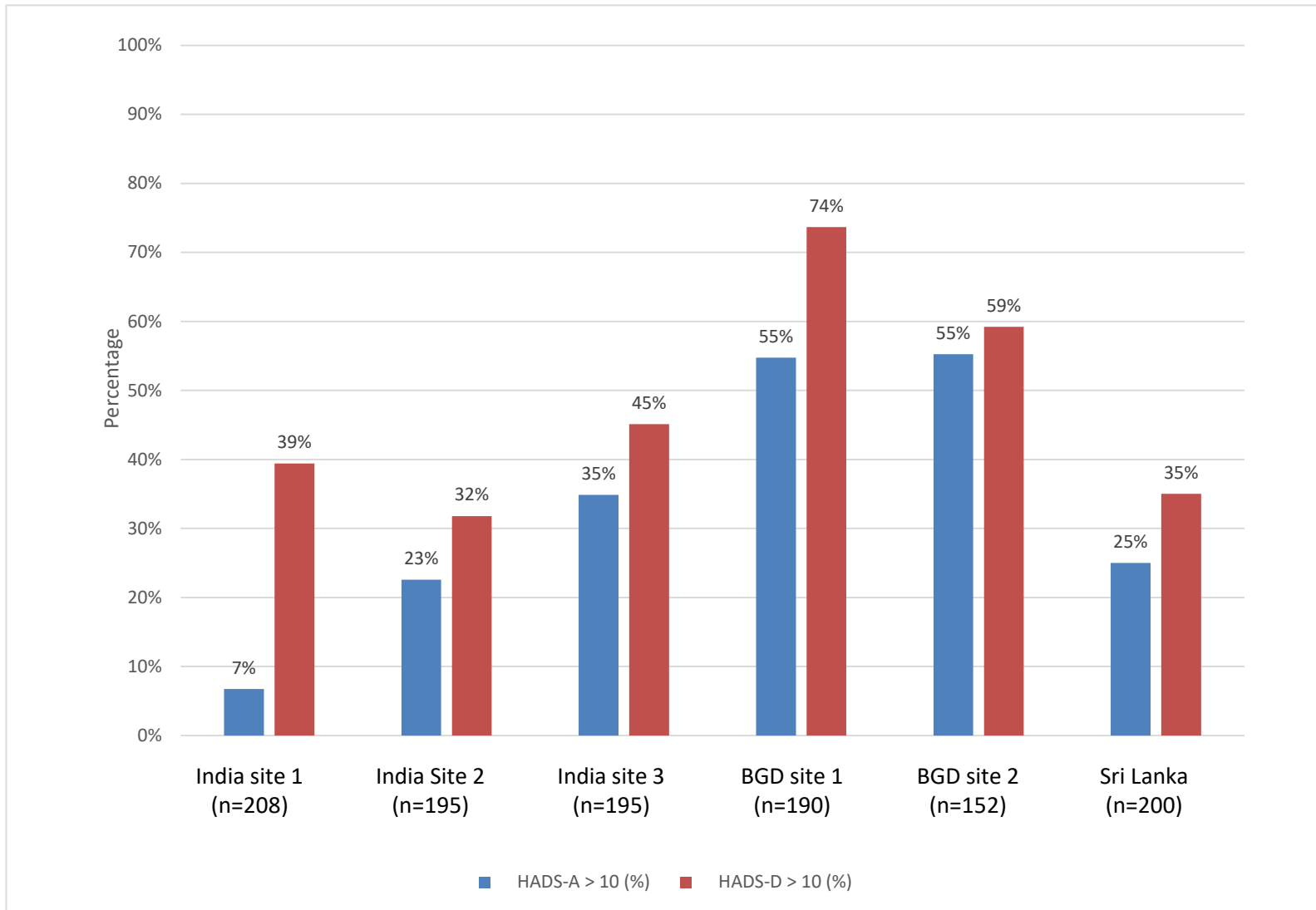
Prevalence of Anxiety, Depression, and Mixed anxiety-depression[◇]



[◇]HADS-A/ HADS-D score > 10

Data from *MNJIORCC, AIIMS, BMCHRC, BSMMU, NICRH, NCIM*

% Anxiety and Depression by Site



Factors associated with Anxiety, Depression, and Mixed-AD

	Anxiety		Depression		Mixed Anxiety-Depression	
	OR	95% CI	OR	95% CI	OR	95% CI
Female	1.73	1.16, 2.59	1.23	0.87, 1.75	1.50	0.98, 2.30
Age	0.98	0.96, 0.99	1.00	0.98, 1.01	0.98	0.96, 0.99
Married (ref: not married)	1.47	0.89, 2.42	0.70	0.46, 1.06	1.04	0.62, 1.75
Education years	1.00	0.97, 1.04	0.98	0.95, 1.01	1.01	0.97, 1.04
Symptom burden	1.13	1.09, 1.16	1.09	1.05, 1.12	1.13	1.09, 1.17
Delayed treatment	1.10	0.70, 1.74	1.38	0.87, 2.17	1.06	0.66, 1.71
Inpatient setting (ref: outpatient)	0.66	0.40, 1.10	1.54	0.99, 2.40	0.75	0.43, 1.31
Patient-reported cancer stage (ref: early stage)						
Advanced stage (IV)	0.86	0.43, 1.71	1.36	0.72, 2.57	1.14	0.53, 2.44
Not sure/Don't know	0.83	0.43, 1.60	1.16	0.65, 2.09	0.97	0.47, 2.01
Perceived stigma	1.11	1.06, 1.16	1.16	1.11, 1.22	1.12	1.07, 1.18

Use of Mental Health Services

Study sites	Total	India Site 1	India Site 2	India Site 3	BGD Site 1	BGD Site 2	Sri Lanka
	n (%)						
Anxiety and/or depression	617	84	76	104	155	116	82
Received MHS ¹	17 (3%)	0	1(1%)	1 (1%)	3 (2%)	4 (3%)	8 (10%)

BGD= Bangladesh; ¹Patients 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; ²Percentages do not add up to 100 due to rounding

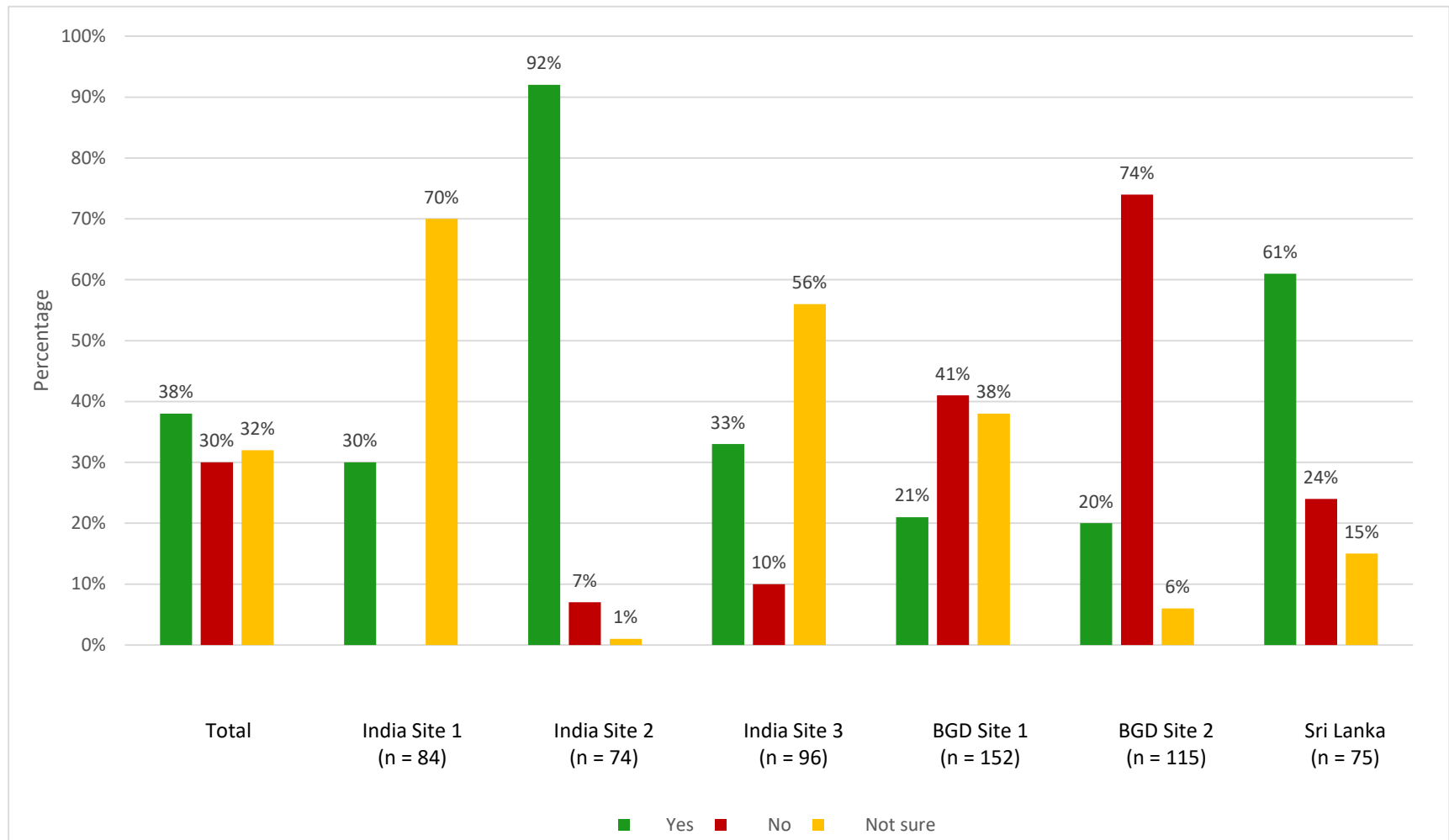
MHS use and perceived usefulness

Study sites ¹ Sample size	Total	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 ³	6 (14%)	1		4		1
Community counsellor	3 (7%)		1			2
Others ⁴	20 (48%)					20
Type of MHS intervention ²						
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 ²						
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 ^{2, 3}						
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

¹India Site 1 is not displayed because no patient indicated receiving MHS

Amenability to MHS referral

Patients who reported anxiety and/or depression and did not receive MHS (n=596)



BGD= Bangladesh; ¹Patients 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.

Summary points

- **53%** of South Asian advanced cancer patients reported some distress
 - 46% depression
 - 31% anxiety

Of those who were distressed:

- **3%** are aware of receiving MHS, **majority reported usefulness (85%)**
 - Those not aware of receiving MHS, **38% open to receiving MHS**

Implications for practice and policy

- High symptom burden/ cancer stigma increase odds of distress
- Systematic screening for distress in clinics
- Initiatives to tackle stigma from *cancer* and *mental health use*

The association of self-blame with treatment preferences

**Brett Doble, Eden Lau, Chetna Malhotra,
Semra Ozdemir, Irene Teo, Eric Finkelstein
and APPROACH Study Group**

Aims

- To understand the prevalence of behavioral and characterological self-blame
 - Behavioral self-blame: outcomes are a result of an individual's actions
 - Characterological self-blame: outcomes are a result of personal characteristics that cannot be altered
- To determine the association between self-blame and two treatment-related outcomes:
 - patients' stated preference for life-extension; and
 - patients' use of pain-relief medication in the last 24-hours.
- Hypotheses: Patients with either type of self-blame will be less likely to
 - Prefer treatments associated with life-extension;
 - Use pain-relief medication.

Methods: Study Sample

Sample size: 968 advanced cancer patients enrolled in 5 sites, 4 countries

Country	Institution	Collaborator
India	MNJ Institute of Oncology and Regional Cancer Centre (MNJIORCC)	Dr Gayatri Palat
	Bhagwan Mahaveer Cancer Hospital and Research Centre (BMCHRC)	Dr Anjum Khan Joad
China	Peking Union Medical College Hospital (PUMCH)	Dr Ning Xiao Hong
Sri Lanka	National Cancer Institute Maharagama (NCIM)	Dr Thushari Hapuarachchi
Vietnam	Hue Central Hospital (HCH)	Dr Pham Nguyen Tuong

Methods: Self-blame Questions

F4 *We have found that some people blame themselves for their cancer and some people don't blame themselves at all.*
How much do you blame yourself for:

	Not at all (1)	Somewhat (2)	Very much (3)	Completely (4)
i. Any behaviour that may have led to your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii. The kind of person you are (e.g., being the unlucky person who has things like cancer happen to them)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

F5 To the extent of your knowledge, which of the following (if any) are reasons for the type of illness you have? Check all that apply.

1	Smoking	<input type="checkbox"/>
2	Chewing betel nut/tobacco	<input type="checkbox"/>
3	Consumption of alcohol	<input type="checkbox"/>
4	Being overweight	<input type="checkbox"/>
5	Stress/ Anxiety	<input type="checkbox"/>
6	Previous bad deeds	<input type="checkbox"/>
7	God's will	<input type="checkbox"/>
8	Old age	<input type="checkbox"/>
9	Others, please specify _____	

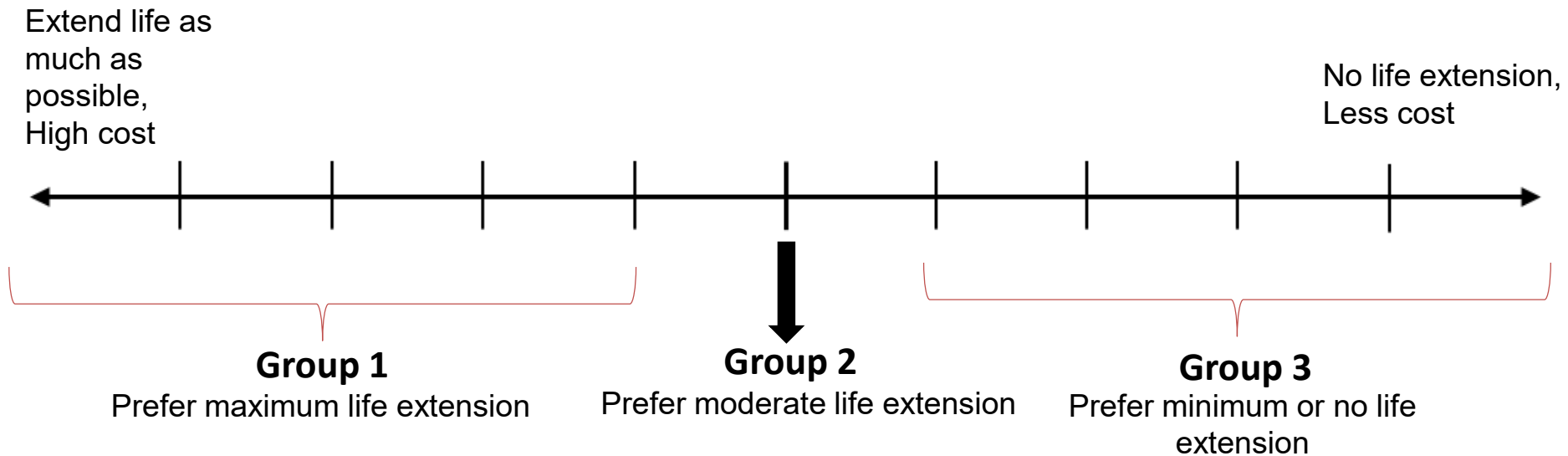
Behavioural
self-blame

Characterological
self-blame

Methods: Treatment Preference

Patients stratified into three groups based on responses to the following baseline survey question:

If you had to make a choice now, would you prefer treatment that extends life as much as possible, or would you want treatment that costs you less? Please choose a point in the scale below.



Methods: Use of Pain Medicine

B10.1	In the last 24 hours, have you taken any medication for pain relief?	
<input type="checkbox"/> 1	Yes	
<input type="checkbox"/> 2	No	

- Ordered probit and logistic regressions were used to determine associations between each type of self-blame and two treatment-related outcomes: patients' stated preference for life-extension and the use of pain-relief medication in the last 24 hours.

Results: Prevalence of Self-Blame

Type of Self-Blame	Main analyses, % [N = 968]	With logically consistent reason, %
Behavioral	41%	19%
Characterological	49%	2%

- Behavioral and characterological self-blame were reported by 41% and 49% of the participants respectively,
- Only 19% and 2% of participants providing a logically consistent reason

Regression Results

- Results were largely not statistically significant.
- Participants reporting characterological self-blame reported being more likely (odds ratio of 9.7, ($p = 0.014$)) to report using pain-relief medication compared to participants not reporting characterological self-blame.
 - Result not consistent with our hypothesis.

Conclusion

- Self-blame is common among these patients
- Most of it appears unearned
- Patients reporting characterological self-blame are more likely to use pain medication.
- They are also more like to score high on the Hospital Anxiety and Depression Scale (HADS) which may promote greater use of meds.

Implications

- Addressing self-blame may minimize anxiety and depression and perhaps reduce inappropriate use of pain meds

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Manuscripts are pending publication. Slides are not for distribution.