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Title:

**Mapping unmet supportive care needs, quality of life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: Results from the international STEP study**

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## **Abstract**

### **BACKGROUND:**

To assess the supportive care needs, quality of life (QOL) and symptoms of patients with cancer after the end of first line treatments and into survivorship in Asian countries using Australian data as benchmark.

### **PATIENTS AND METHODS:**

A cross-sectional survey was carried out in Australia and eight high income (HICs) and low/middle income (LMICs) Asian countries (China, Japan, Hong Kong SAR, South Korea, Myanmar, Thailand, India, Philippines) using validated scales (Cancer Survivors Unmet Needs scale-CaSUN), physical-symptom concerns (Cancer Survivors Survey of Needs-CSSN subscale) and a single-item measure of global QOL perception.

### **RESULTS:**

Data was collected from 1,748 patients from nine countries. QOL was highest in Australia and all other countries had significantly lower QOL than Australia (all  $P < 0.001$ ). One-quarter of the patients reported low QOL (scores 1-3/10). The most frequently reported symptoms were fatigue (66.6%), loss of strength (61.8%), pain (61.6%), sleep disturbance (60.1%), and weight changes (57.7%), with no difference in symptom experience between Australian data and all other countries, or between HICs and LMICs. Unmet needs of moderate/strong level were particularly high in all aspects assessed, particularly in the area of existential survivorship (psychosocial care) and receiving comprehensive cancer care. Australia and HICs were similar in terms of unmet needs (all low), but LMICs had a significantly higher number of needs both compared to Australia and HICs (all  $P < 0.001$ ).

### **CONCLUSION:**

Health care systems in Asian countries need to re-think and prioritise survivorship cancer care and put action plans in place to overcome some of the challenges surrounding the delivery of optimal supportive cancer care, use available resource-stratified guidelines for supportive care and test efficient and cost-effective models of survivorship care.

**Keywords:**

Cancer Survivorship, Asia Pacific Region, Supportive care needs, , Symptoms, Quality of Life, Care Provision

**Key message:** This is the first cross-Asian study assessing unmet supportive care needs in cancer survivors (Australia and 9 Asian countries) and the largest such study internationally (n=1873). Key findings indicate that needs are high, particularly around comprehensive cancer care services. Low and middle income countries had more needs than high income ones, but some high income countries also showed high level of need.

## **Mapping unmet supportive care needs, quality of life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: Results from the international STEP study.**

### **INTRODUCTION**

The culturally and socioeconomically diverse Asia-Pacific region has a substantial cancer burden, accounting for over 30% of all cases worldwide<sup>1</sup>, and this is projected to almost double in the next decade. Cancer accounts for one out of every three deaths in Japan and has been the leading cause of death for the past two decades in South Korea and Taiwan<sup>2</sup>. In China, the national data surveys from the 1970s, 1990s and 2006–2008 provide a grave picture of its cancer burden, showing cancer morbidity to have rapidly increased over these past three decades<sup>3</sup>. The continuing efforts devoted to improving cancer services including prevention, early detection and screening, and treatment have resulted in a growing population of cancer survivors across the region<sup>4</sup>. Changing lifestyle patterns, diet, urbanisation, smoking, an increasingly ageing population and poverty are some of the key reasons behind this shift in cancer incidence. However, as a result of diverse economic development, healthcare policies and investments in this region, Asian countries have highly variable health services development and healthcare infrastructures.<sup>5</sup> The cancer burden is also projected to be more substantial in low and middle income countries<sup>5</sup>, where, while the incidence of cancer is ever increasing, there are limited services and health budgets to manage cancer survivors well, and health care planning and expenditure are low priority.

The cure or control of cancer does not necessarily guarantee a full restoration of health, with many survivors continuing to experience impaired quality-of-life as a result of the disease itself, or treatment interventions. Treatment/cancer-related effects can have a significant impact on the psychosocial experiences of cancer survivors, including depression, anxiety, fear of relapse, reduced income, sexual dysfunction, relationship issues, and limited capacity to engage in full-time employment, social activities and household duties<sup>6,7</sup>. For many years however, this phase of the cancer trajectory has been relatively neglected, with post-treatment follow up traditionally directing focus towards surveillance for recurrence and second cancers<sup>8</sup>. Indeed, patient-reports suggest follow-up care needs to be more tailored to psychological and physical needs, including education regarding management of common symptoms such as fatigue and anxiety<sup>9</sup>. Furthermore, there is minimal research to inform any national and international approaches to delivering comprehensive and coordinated survivorship care. The outcome of this non-system is

that, some patients receive excellent follow-up care, whilst others are left to manage and seek resources as they are able<sup>9</sup>. Work on identifying supportive care needs in Asian patients with cancer is limited, primarily since 2010, with publications deriving from Hong Kong, Taiwan and Japan<sup>10-14</sup>, all of which countries are high resource countries with well-funded health care systems. Hence, the aim of this study is to explore the supportive care needs, quality of life perceptions and physical health status of cancer survivors in Asian countries of different resource levels, using data from Australia as benchmark. More specifically, we wanted to assess common needs across health care systems and cultures; explore if country income plays a role in the level of unmet needs experienced; understand concerns with physical symptoms and global quality of life perceptions, and evaluate factors that are linked with more unmet needs.

International data on quality of cancer survivorship care could assist countries to compare their performance to that of other countries, as policy makers may think, question and reflect on their health services provision and it may be possible that by seeing the 'best' (or better outcomes) can stimulate change and improvements. Australia was used as a benchmark country as it is in the same region with the other countries, has a world class effective and efficient health care ranking consistently at the best performing countries by the World Health Organisation, and in terms of cancer care it has a strong focus on survivorship care relatively for longer than many other countries in the region. Although this system could be further improved, it nevertheless allows us to have a comparative sense of the needs of people and if there are similarities between countries that may go beyond health care financing and culture, allowing countries to learn from more developed international experiences and for individual countries to identify areas that could be improved. This international evaluation is about understanding equity of needs rather than equality across different health care systems and cultures.

## **METHODS**

### **Design**

Cross-sectional survey of patients with cancer post-curative treatment.

### **Sample size**

This study was administered via paper-based questionnaires. Sample sizes were based on feasibility in consultation with the respective international principal investigators, with participating sites being advised to aim for at least 150 participants. The sampling frame included convenience samples of adult cancer survivors, who were >18 years old, with a

definitive cancer diagnosis, and having completed first line treatment. Patients were excluded if they had cognitive impairment that prevented them from participating in the survey, if they were at their end of life, and if they could not understand the language to complete the survey.

### **Survey questionnaire**

The survey questionnaire consisted of (i) the Cancer Survivors' Unmet Needs measure (CaSUN)<sup>15</sup> (ii) the physical effects subscale of the Cancer Survivors Survey of Needs (CSSN)<sup>16</sup>, and (iii) a single item global quality of life measure. The CaSUN was developed to directly assess unmet needs and the strength of unmet needs of cancer survivors<sup>15,17</sup>. It includes 35 unmet need items and 6 positive change items. Unlike other similar measures, it provides information not only on presence of need but also strength of need alongside assessment of a wider range of needs domains. The scale has good acceptability, internal consistency and validity in its English language validation. A methodological review of unmet needs scales suggests that the CaSUN performs as well or better than any other measure of supportive care needs<sup>18</sup>. The physical effects subscale of CSSN was used to complement the CaSUN<sup>16</sup>, assessing 19 symptoms on the day of completing the survey on a numeric analogue scale (0= No Concerns, 5= Extreme Concerns). (iii) A single 10-point numerical rating scale was also used to assess overall quality of life over the past week, with higher scores indicating higher quality of life, being part of the CSSN. The operational definition of unmet needs used in this survey is "those problems or issues with which cancer survivors want or need help, but are unable to get the assistance needed"<sup>18</sup>.

Principal investigators at the participating countries were responsible for translating the scales to the language of their country. A standardised protocol was developed for the purpose of this international study as informed by the World Health Organization<sup>19</sup>. This included forward and backward translation to establish linguistic equivalence, and pre-testing with ten patients to assess face validity. Minor changes took place after this to accommodate for any culturally-relevant wording.

Cronbach alpha analysis of the scales in the current study suggested that they had high internal reliability, with the CSSN subscale having an alpha=0.91 and the CaSUN 0.97 in the overall sample, and similar values across each country's datasets.

### **Procedures**

Asian countries were selected to represent different economic and health care systems in East and South East Asia. Clinicians at the participating sites (mostly outpatient clinics in metropolitan hospitals) informed eligible patients at the hospital clinics/wards, when patients were coming for regular follow-ups. If the patient was interested in participating, the research team made contact with the patient for informed consent. Data in most countries was collected from more than one site, primarily outpatient clinics of regional city hospitals. If consented, patients were invited to complete the survey and did it in the clinic while they were waiting to be seen by the doctor, returning the questionnaires back to the research team as soon as they were completed. The study was approved by the ethics committee/institutional review boards of all participating sites. Patients were provided with written information and consent to participate was sought.

### **Data analysis**

All analyses were conducted using SPSS v.22. Descriptive statistics were calculated to summarise the data overall and per country. All patients' perceived unmet needs were ranked by country, cancer type and other relevant patient characteristics through cross-tabulations. T-tests were used to compare the Australian (benchmarking) data with all other countries as a single group; and between HICs and LMICs. A generalised estimating equation (GEE) model was used to assess variables that contributed to higher level of supportive care unmet needs, controlling for country that data came from and including as independent variables the sample characteristics, perception of quality of life, and total score for symptom concerns. Countries were grouped together as per World Bank classification<sup>20</sup> in low and middle income countries (Myanmar, China, Thailand, Philippines, India) [LMICs] and high income countries (Australia, Japan, South Korea, Hong Kong, Singapore) [HICs] for comparisons, in order to explore whether unmet needs were linked with country income.

## **Results**

### **Sample characteristics**

Ten countries participated (Australia, China, Hong Kong, Japan, South Korea, Myanmar, Thailand, India, Singapore, Philippines) out of 12 that initially agreed to participate, contributing 1873 completed surveys. Most patients had breast, colorectal and gastric/genitourinary cancers, were female) and had received chemotherapy (Table 1). There were at a mean age of 55.8 years (SD=12.5) and 62 (SD=71) months post treatment.



INSERT TABLE 1 HERE

### **Quality of Life perceptions**

Patients generally perceived to have a good quality of life, however 26% of patients had a score of three or less in the scale, indicating poor quality of life. The Australian data had the highest mean score on quality of life (mean=7.8, SD=2), and was significantly different from that of all other countries (mean=5.6, SD=3.3,  $P<0.001$ ), as it was quality of life perception in HICs (mean=7.1, SD=1.8) versus LMICs (mean=6.65, SD=2.7) ( $P<0.001$ ).

### **Physical symptoms**

The top five symptoms present in the past week from the assessment day included fatigue (66.6%), loss of strength (61.8%), pain (61.6%), sleep disturbance (60.1%), and weight changes (57.7%) (Table 2). There were no significant differences between the Australian dataset (mean=18.5, SD=14) and all other countries (mean=20.5, SD=16.5), nor between HICs and LMICs (all  $P>0.05$ ).

INSERT TABLE 2 HERE

### **Supportive Care Unmet Needs**

The most common unmet need across all patients was related to concerns about the cancer coming back (moderate & strong need=40.2%). This was followed by four other unmet needs that were all related to comprehensive cancer care (=36-40%). The top five unmet needs in each country are shown in Table 3. Patients from HICs reported significantly less unmet needs than LMICs (all  $P<0.001$ ). Within HICs, South Korean patients reported a high level of unmet need, similar to that of some LMICs. The unmet needs related to accessing legal services; hospital parking and problems with sex life were the only three needs that were similar across HICs and LMICs ( $P>0.05$ ). In terms of frequency of reported needs, Australia and Hong Kong reported low level of unmet need, between 8.6-16% for each need item (Australia) and 11-19.7% (Hong Kong). Japan and India patients reported a moderate level of unmet need (ranging from 18.4-25.3% and 24.7-35.7% respectively), whereas all other countries showed a very high/strong level of unmet need (China=45.2-59.1%; South Korea=48.7-57.3%, Thailand=43.3-66%; Myanmar=49-66%; Philippines=47.3-62.7%). The strength of unmet need (shown as

mean scores) across all countries is shown in Table 4. Based on the total need mean score, the lowest score was observed in Australia (=17), with Hong Kong and Japan having scores close to that (=21 & 25 respectively), and with Thailand, Singapore and India having double the Australian mean score (=34-38). The highest level of total need was observed in South Korea, followed by Myanmar, Philippines and China at three times higher mean scores than Australia (=52-61).

INSERT TABLE 3 & 4

Among the different cancer diagnostic groups, accessible local health services were among the top five unmet needs across cancer groups; concerns about the cancer coming back was in top five in all but prostate cancer; and needs with best medical care was in top five in breast, colorectal, lung, gynaecological and genitourinary cancers. Need for doctors talking to each other was in top five in breast, lung, gynaecological and genitourinary cancers. High strength of needs (total score) was significantly related to lower quality of life levels and higher symptom experience with all symptoms (all at  $P < 0.001$ ). GEE analysis showed that higher level of unmet need was associated with younger age ( $P = 0.017$ ), less months post-treatments ( $P < 0.001$ ), lower QOL perception ( $p < 0.001$ ), higher total symptom score ( $P < 0.001$ ), not receiving chemotherapy ( $P = 0.006$ ), not receiving radiotherapy ( $P = 0.007$ ), cancer diagnostic group (lower in colorectal cancer ( $P = 0.016$ ), higher in multiple myeloma ( $P = 0.005$ ) and lymphoma ( $P = 0.018$ ) than overall sample), and country (all countries but Japan, compared to Australian data,  $P < 0.001$ ). Gender was not associated with differential needs.

## **Discussion**

This is the first study that provides evidence of supportive care unmet needs in a range of Asian countries as well as using benchmark data (from Australia). This goes beyond the few single-country single-centre reports available in the literature, which often also have small sample sizes and do not allow for comparisons with other studies due to the use of different scales. Key findings indicate that while patients from Hong Kong and Japan have generally reported low level of unmet needs, similar to that of the benchmark data (Australia), all other countries have shown a significant number of unmet needs in existential/psychosocial needs and in receiving comprehensive cancer care.. South Korea, despite being HIC, topped the list of countries with the highest level of unmet needs reported. This suggests that even high resource countries with relatively well established health care systems may not have prioritized or organized well cancer

survivorship, and re-thinking of health care delivery to meet cancer patients' unmet needs is important.

Needs related to information and comprehensive cancer care were double or triple from that reported in similar studies from western countries<sup>21-24</sup>. The very high frequency of needs reported at moderate/strong level suggests that the quality of survivorship is impaired resulting in lower quality of life for patients and the inability of the health care system to attend to even some basic needs of the survivors, particularly in LMICs. While the top need was related to concerns for the cancer returning (psychological component) similar to most studies from around the world, the key needs were related to existential survivorship/psychosocial care and receiving comprehensive cancer care. This contradicts findings from an integrative review suggesting that Asian women with breast cancer report higher health system and informational needs whereas Caucasian women report more psychological needs<sup>25</sup>. These should be areas of primary attention by policy makers. Also, the results from this study, both across and within countries, show areas to be targeted/prioritized when resources are limited and cannot cover all areas of patient need. Relationships, in the limited way measured by CASUN, did not seem to be highly affected in our sample, although relationship issues that were faced by these survivors may not have been fully covered by the specific items in the CaSUN. Positive changes were also present in patients across countries but all to a lesser degree than our benchmark data.

Physical symptoms (fatigue, pain, weight changes, sleep problems, and cognitive and neurological changes) were reported by more than half the patients. This finding was similar between HICs and LMICs and similar between the Australian benchmark data and all other Asian countries. The reported rates are also higher than those reported in western countries, ie. as with pain where typical rates are 10-20% less than in the current study<sup>26</sup>. The unavailability or limited access to supportive care medication in some of our participating countries may be a reason for that, for example several essential opioid formulations are not available in rural China and Myanmar or patients have to bear the full cost as in the Philippines<sup>27</sup>. Survivorship plans need to focus more on the management of symptoms, be it psychosocial or physical in nature. As the majority of cancer patients in Asia live in LMICs where healthcare resources are limited, a great emphasis on teaching self-management approaches should be placed as well as empowering patients with education to take more control of their ill-health. Younger survivors and those in the early stages of survivorship alongside patients having received chemotherapy reported more needs. This is a group that health services need to attend carefully, as they are

trying to return to work, re-integrate with the community and have or raise families/children, adding an extra layer of complexity to their survivorship experience. It is also clear from our data that certain cancer diagnostic groups are linked with more unmet needs than others, and this needs further exploration in future research, although it may likely be linked with cancers that have less visibility in the media and older age.

How best to meet the needs of cancer survivors is widely debated in the international arena. There are different models of care that can be introduced, but all show variable success. For example, survivorship care plans have shown some positive results in a number of studies (ie.ref<sup>28</sup>), although a systematic review of all such trials suggests improvements only in the patients' satisfaction<sup>29</sup>. Patients need to be supported in the transition between active treatment and return back to the community. Partnerships with primary health and community organisations may be necessary alongside early preparation for survivorship and shared-care models may enhance outcomes<sup>30</sup>. Identification of patient-related barriers to receiving optimal survivorship care in different contexts is also important, as a partnership between patient and clinicians is necessary before positive results are realized.

A meeting discussing challenges of supportive cancer care in Asia, convened by the Multinational Association for Supportive Care in Cancer in late 2015, identified the key challenges to be the suboptimal treatment of cancer symptoms and treatment toxicities, limited access to supportive care drugs, under-evaluation (and undervaluing) of supportive care, inadequate understanding of supportive care interventions, and limitations in treatment access<sup>31</sup>. The 2012 Asia Oncology Summit discussed supportive and palliative care in Asia and produced a set of resource-stratified guidelines<sup>32</sup> that can be further considered by health ministries, particularly in resource-poor countries. A recent survey in LMICs in South East Asia (n=5249)<sup>33</sup> also showed that cancer survivors have major impairments in QOL, particularly those at lower socioeconomic status and younger. There is an acute need for several (primarily LMICs) Asian countries to self-organise and develop country-specific action plans<sup>31</sup>, learn from each other and (re)prioritise supportive care or (re)evaluate existing approaches to supportive care to address some of the serious, significant and chronic challenges in the region to providing optimal supportive cancer care. More attention and discussion is needed in relationship to survivorship care in Asia, where this concept is still novel. It is clear that more effective approaches to providing survivorship care and meeting the needs of cancer patients is

required. The World Health Organization may need to be involved in shaping policies of cancer survivorship in the developing nations and influencing governments to act on these plans.

While this large study can stimulate further research on cancer survivorship care and highlight service gaps particularly in Asia, limitations of the study include the largely convenience sampling, the limited surveys from a small number of cancer centres in each country, differences in the study hospitals and differences in each country's health care provision, health expenditure and culture. The scales used were not validated in each language in the participating countries, although reliability coefficients were high and there was minimal, if any, missing data. The physical subscale of CNNS measures 'concern' with symptoms and we implied this may be linked with need, although this may not have been the case. Furthermore, three countries provided data well above the average sample of all the other countries, and there was a predominance of female patients in the sample, that may skew the collected data. Also, the Australian sample showed a low level of unmet need, perhaps the lowest. However, this study can be the basis to build further research on the topic and explore country-specific issues in more detail in the future.

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**Disclosures:**

The authors declared no conflicts of interest.



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**Table 1. Sample characteristics (n=1873)**

		<b>N (%)</b>
Country	China	330 (17.6)
	Hong Kong SAR	300 (16.0)
	Thailand	300 (16.0)
	Japan	168 (9.0)
	India	154 (8.2)
	Myanmar	151 (8.1)
	South Korea	150 (8.0)
	Singapore	125 (6.7)
	Australia	103 (5.5)
	Philippines	92 (4.9)
Diagnosis	Breast cancer	612 (33)
	Colorectal cancer	270 (14.6)
	Gastric & urological cancers	231 (12.5)
	Gynaecological cancers	209 (11.3)
	Haematological cancers	150 (8.1)
	Lung cancer	142 (7.7)
	Prostate cancer	44 (2.4)
	Others	215 (11.4)
Sex	Females	1206 (64.4)
	Males	667 (35.6)
Treatment received	Chemotherapy	1118 (59.9)
	Surgery	939 (50.3)
	Radiation therapy	645 (34.6)
	Hormone replacement therapy	286 (15.3)
	Bone marrow transplant	20 (1.9)

**Table 2. Symptom concerns in the past week**

<b>Symptom</b>	<b>%, Extreme concern (scores 3-5)</b>	<b>%, Some concern (scores 1-2)</b>	<b>%, Total</b>
Pain	29.6	32	61.6 (3)
Fatigue	33.9	32.7	66.6 (1)
Sleep disturbance	29.1	31.0	60.1 (4)
Memory & concentration	24.4	28.5	52.9
Nausea/Vomiting	17.4	23.4	40.8
Poor appetite	20.6	26.3	46.9
Trouble swallowing	13.3	22.2	35.5
Dental & mouth problems	19.6	27.3	46.9
Weight changes	25.5	32.2	57.7 (5)
Balance/walking/mobility	18.9	31.1	50.0
Loss of strength	26.1	35.7	61.8 (2)
Tingling or numbness in hands/feet (Neuropathy)	22.4	29.0	51.4
Swelling in legs or arms (Lymphedema)	15.1	21.4	36.5
Osteoporosis/bone health	19.2	28.5	47.7
Hair or skin care issues	23.9	27.0	50.9
Body changes	22.5	26.2	48.7
Hot flushes	16.5	23.1	39.6
Sexual issues	12.6	14.6	27.2
Fertility issues	10.0	15.3	25.3

Note: Numbers in brackets indicate the ranking of the symptom for the top five symptoms

**Table 3. Top five (moderate-to-strong) unmet needs in each country\***

Unmet Need	AUS	CN	HK	JP	KR	TH	MY	IND	PH	SG
1st	18	19	18	1	8	4	5	16	14	19
2nd	7	4	27	5	19	5	15	19	4	1
3rd	11	9	6	3	9	19	30	15	8	3
4th	9	30	2	19	7	3	24	17	25	7
5th	19	32	10	6	6	7	29	5	24	4

\*The number in each box corresponds with the number in the below list of CASUN items. Shaded boxes represent top five unmet needs across all countries together (need item 19, 5, 4, 6 & 7 in descending order).  
 AUS: Australia; CN: China; HK: Hong Kong SAR; JP: Japan; KR: S. Korea; TH: Thailand; MY: Myanmar; IND: India; PH: Philippines; SG: Singapore.

<p><b>Factor 1 Existential Survivorship (14 items)</b></p> <p>10 reduce stress in my life</p> <p>19 concerns about the cancer coming back</p> <p>20 emotional support for me</p> <p>23 new relationships</p> <p>24 talk to others</p> <p>25 handle social/work situations</p> <p>26 changes to my body</p> <p>29 move on with my life</p> <p>30 changes to beliefs</p> <p>31 acknowledging the impact</p> <p>32 survivor expectations</p> <p>33 decisions about my life</p> <p>34 spiritual beliefs</p> <p>35 make my life count</p> <p><b>Factor 2 Comprehensive Cancer Care (6 items)</b></p> <p>4 best medical care</p> <p>5 local health care services</p> <p>6 manage health with team</p> <p>7 doctors talk to each other</p> <p>8 complaints addressed</p> <p>18 accessible hospital parking</p>	<p><b>Factor 3 Information (3 items)</b></p> <p>1 up to date information</p> <p>2 information for others</p> <p>3 understandable information</p> <p><b>Factor 4 Quality of Life (2 items)</b></p> <p>11 manage side effects</p> <p>12 changes to quality of life</p> <p><b>Factor 5 Relationships (3 items)</b></p> <p>21 support partner/family</p> <p>22 impact on my relationship</p> <p>27 problems with sex life</p> <p><b>Other</b></p> <p>9 access to complementary therapy services</p> <p>15 help to find out financial support and/or benefit I am entitled to</p> <p>17 Due to cancer, I need help to access legal services</p> <p>14 assistance with getting &amp; maintaining employment</p>
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**Table 4. Mean scores (SD) of unmet needs across countries**

	<b>Australia</b>	<b>China</b>	<b>Hong Kong</b>	<b>Japan</b>	<b>S. Korea</b>	<b>Thailand</b>	<b>Myanmar</b>	<b>India</b>	<b>Philippines</b>	<b>Singapore</b>	<b>HICs</b>	<b>LMICs</b>
Existential survivorship	6.6 (9.5)	26 (20)	9 (8.5)	12 (12.1)	30 (17)	15.7(14.9)	27.4 (16)	18.5 (14.3)	20.8 (16.9)	16.1 (15.4)	17.6 (17.1)	22.0 (16.6)
Comprehensive cancer care	5.7 (5)	12.3(7.5)	6.3 (4.6)	6.9 (5.6)	14.6 (7.1)	12.6 (8.7)	12.4 (5.8)	7.5 (5.8)	10.27 (7.3)	8.8 (7)	8.13 (6.5)	11.7 (7.5)
Information	1.9 (2.5)	6 (4.1)	3.3 (2.6)	4 (3.5)	6.9 (3.9)	5.4 (4.6)	6.4 (3.7)	3.3 (2.9)	4.9 (4)	4.5 (3.7)	4.02 (3.5)	5.5 (4.2)
Quality of Life	1.4 (1.6)	4 (2.9)	1.3 (1.4)	2.3 (2.3)	4.5 (2.9)	3.4 (3.5)	4.2 (2.8)	2.8 (2.5)	3.2 (2.2)	3 (2.7)	2.2 (2.4)	3.6 (3)
Relationships	1.4 (2.4)	4.5 (3.8)	1.8 (1.6)	1.7 (2.4)	5.3 (3.4)	1.7 (2.7)	2.9 (3.1)	2.9 (3.3)	6.3 (3.5)	2.4 (2.9)	2.4 (2.8)	3.3 (3.6)
Positive changes	12.2 (4)	6 (3.6)	*	6 (3.4)	10.9 (3.5)	6.7 (9.6)	*	5.2 (3.2)	6 (3.4)	7.6 (4.8)	9.2 (4.5)	6.0 (6.3)

\*Myanmar & Hong Kong did not provide data on this area as due to an administrative error this part of the scale was not completed by patients.