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Household cost incurred by households of female breast cancer patients followed-up in the government health sector of Western Province, Sri Lanka

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Abstract

Introduction: High health care cost is a problem, even in the context of free health in Sri Lankan. Only limited evidence is available on the household cost incurred by cancer patients and no research have been done for cost estimation of breast cancer.

Objectives: To assess the household cost of breast cancer incurred by households of female breast cancer patients followed-up in the government health sector of Western Province

Methods: A descriptive cross-sectional study was carried out among breast cancer patients residing in Western Province and followed-up at Apeksha Hospital, Maharagama. Samples of 106, 106 and 120 were selected out of eligible patients who were in the initial, 2nd to 6th and 7th to 10th treatment years respectively, using a disproportionate stratified random sampling technique. Data collection was done using a validated pre-tested interviewer-administrated questionnaire. Household cost incurred by breast cancer patients during the previous one-month period and associated factors were assessed. The percentage experiancing a catastrophic health expenditure was calculated.

Results: The total monthly household cost incurred by households of breast cancer survivors during initial, 2nd to 6th, and 7th to 10th treatment years were Rs. 13 365.32 (SD=28 749.30), Rs. 9032.12 (SD=11 259.20) and Rs. 1835.40 (SD=5379.10); out of which 62.9%, 70.7% and 40.6% were direct costs respectively. Catastrophic expenditure was present among 65.6% (n=59), 52.2% (n=49) and 5.7% (n=5) of the households in the initial, 2nd to 6th, and 7th to 10th treatment years, respectively. Family income less than Rs. 30 000 ($p<0.001$), absence of insurance coverage ($p=0.044$) and being on chemotherapy or radiotherapy ($p<0.001$) were the significant associated factors for the presence of catastrophic expenditure.

Conclusions & Recommendations: Household cost is high among households of breast cancer patients, especially those who are with lower income and in the initial treatment year.

Key words: *breast cancer, household cost, catastrophic expenditure*

Introduction

Total household cost includes direct cost and indirect cost incurred by households. Direct household cost is the cost incurred by households for receiving health care and accessing health care services. Indirect cost is due to the missed opportunities as a result of the disease (1). Catastrophic expenditure represents the out-of-pocket payments for health care which exceeds a specific threshold of income or household's capacity to pay(2).

Many studies revealed that the catastrophic health expenditure is highly prevalent among cancer patients. A retrospective study conducted in USA among Medicare beneficiaries using pooled data from 1997 through 2007 showed that more than 25% of the cancer patients faced high out-of-pocket expenditure (defined as spending >20% of one's income) compared to 16% among the other group ($p<0.001$). Further, 49.9% of the cancer patients faced catastrophic expenditure when it was defined as 10% of their income (6). Another study done in USA among 4243 participants found that the prevalence of high out-of-pocket expenditure, which was defined as more than 20% of income on health care, was 13.4% for cancer patients; 9.7% for those with other chronic diseases; and 4.4% for well people (people without any chronic disease including cancer(7). The ACTION study, a prospective longitudinal study carried out in Southeast Asia among 9513 newly diagnosed adult cancer patients found that out of all the participants whose outcome data were available, 48% were found to have experienced a financial catastrophe. For patients with breast cancer, 26% were experiencing a financial catastrophe(8).

Financial burden compels patients to borrow money, deplete savings, and in the worst, it leads to nonadherence to prescribed treatment. Even though health care is provided free for all citizens in Sri Lanka, out-of-pocket expenditure of health care is significant (1) and the economic burden on families, as a result of the loss of productivity exaggerates the issue. On average, 7.0% of the total non-food expenditure was spent on health and personal care by the average Sri Lankan household in 2016 (9). However, the evidence is limited on the household cost incurred by cancer patients even though cost estimations were done for most of other diseases.

With the reported rising trends of breast cancer incidence, it would be worth to consider further expansion of current breast cancer screening programs and introduction of more advanced and sensitive new screening methods such as mammogram. Cost of illness studies on breast cancer which estimate both direct and indirect costs incurred by both the health system and the households provide essential input data for cost evaluation, rational justification required for such decisions, and for monitoring and evaluation of ongoing interventions. Objective of this study was to assess the household cost of breast cancer incurred by households of female breast cancer survivors followed-up in the government health sector in Western Province.

Methods

A descriptive cross-sectional study was carried out in Apeksha Hospital, Maharagama, which is one of the nine cancer treatment centres in Sri Lanka. Participants were female breast cancer patients registered and followed-up in this hospital and permanently residing in Western Province. The exclusion criteria included patients diagnosed with another primary cancer other than breast cancer (as it is difficult to differentiate the cost incurred on breast cancer and other cancer); those who were below the age of 40 at the time of diagnosis (breast cancer in young people are considered as a different disease entity (10)); and those not mentally or physically capable for the participation.

Breast cancer patients undergo different treatment modalities during their cancer trajectory. All the intensive treatments including surgery, chemotherapy and radiotherapy are given during the first year after the diagnosis. During the next five years, she is given hormonal therapy. There onwards, for another four years she is being followed up for cancer recurrence and she is not given any treatment. This is the usual treatment course, however if the patient develops a recurrence, treatment modalities get changed (personal communication with

oncologist). Based on above difference in the treatment regime, the household cost estimation was carried out for breast cancer patients who have been diagnosed within past one year (patients in the initial treatment year), 2-6 years (patients in the 2nd to 6th treatment years) and 7-10 years (patients in the 7th to 10th treatment years) separately. Above three groups were considered as three different strata. The study used a disproportionate stratified sampling technique with equal proportions from each stratum.

Sample sizes were calculated based on the prevalence of catastrophic health expenditure with an expected prevalence of 50%, precision of 10% and confidence level of 95%. After adjusting for a non-response rate of 10%, 10% and 20% for the patients in the initial, 2nd to 6th and 7th to 10th treatment years respectively, the required sample sizes were 106 from the initial treatment year, 106 from the 2nd to 6th treatment years and 120 from 7th to 10th treatment years. With 95% confidence interval (CI) and SD of Rs. 11 000.00 (based on the findings of a pilot study), the above decided sample size for estimation of catastrophic expenditure is adequate to detect the household cost of each group with a precision of Rs. 2200.00, which was considered adequate. The required number of eligible participants from each group was randomly selected from three sampling frames developed using the information on clinic attendees obtained from the hospital.

Data collection was done using an interviewer-administrated questionnaire. Participants of all three groups were inquired on the expenditures and loses in relation to breast cancer, and monthly income during the previous month. Face and content validity have been assessed by a multidisciplinary panel of experts and reliability was assessed through test-retest and inter-observer reliability. Kappa Coefficients were 0.95 and 0.75 for inter-observer and test-retest reliability respectively and were above the desired value of 0.7(13). The study instrument was pre-tested among 20 patients and minor changes were done accordingly.

The questionnaire inquired all the expenditures incurred by the patient and family members on breast cancer treatment. Specifically, cost incurred on clinic, chemotherapy and radiotherapy visits. It included cost incurred for travelling (bus fare or fare for the hired vehicle), medicines, surgical and other consumables purchased, cost on investigations and hospital charges in case of visit to private hospitals and foods and beverages for the patient and the accompanying persons. Similarly, all the costs incurred during hospital admissions including cost for travelling, food and beverages for the patient and caregivers, medicines, surgical and other consumables, cost for investigations and hospital charges in case of admission to private hospitals were included as well. In addition to above, any cost incurred on medicines, investigations, consumables purchased during the home stay, any home modifications to facilitate the patient, religious and cultural activities and special food which are believed to be beneficial for the patient were the other cost items included. All these were considered as direct costs. Indirect costs included income loss borne by the patient and family members due to no pay leave, days off in case of daily paid or self-employed persons, and losses due to early retirement or resignation.

Data collection was done by three pre-intern medical officers after been trained by the Principal Investigator. Majority of the participants were interviewed at the clinics, and the rest were in the field. Informed written consent was obtained before the data collection. The analysis was done using Statistical Package for Social Sciences (SPSS) (version 20). Direct and indirect cost incurred by patients in the initial treatment year, 2nd to 6th treatemnt years and 7th to 10th treatemnt years were calculated and presented as means with standarard deviations. The percentage experiencing a catastrophic expenditure were calculated and the associated factors were assessed using the Chi-squared test. Health expenditures on breast cancer exceeding 10% of the total income was taken as the catastrophic health expenditure due to breast cancer, in the current study.

Results

Out of the total sample of 332, 22 were later found to

be residing outside the province, thus were not eligible to participate. Out of the remaining 310, 272 participated in the study with a response rate of 87%. Out of the 272, 90, 94 and 88 were from initial, 2nd to 6th and 7th to 10th treatment years, respectively.

The mean age of the participants was 56.5 years (SD=9.98). Majority of the participants were from Colombo district (n=144; weighted percentage=51.5%). Out of the total sample, 40 (weighted percentage=15.6%) were currently employed or retired with a pension (receiving a regular monthly income). The mean income was Rs. 36 850.00 (SD=30 749.00). Only 23 participants (weighted percentage=9.4%) had an insurance coverage.

Hormonal therapy was the commonest treatment modality followed by chemotherapy. Only 53 had recorded evidence of surgery according to the clinic records and out of the total, only three (weighted percentage=0.01%) had surgery within last month. There were 16 participants (weighted percentage =8.3%) who have been diagnosed with recurrence or contralateral breast cancer.

The direct cost incurred by the households of breast cancer survivors (patients) per month during initial, 2nd to 6th and 7th to 10th treatment years

Table 1 describes the average direct cost incurred by the households of breast cancer survivors per month during each treatment year. On average a household of a breast cancer patient in the initial treatment year had spent Rs. 8402.00 (SD=10 611.24) (median=Rs. 4858.00; IQR=2387.50-9000.00) as the direct cost, per month. The average monthly direct cost incurred by a household during the 2nd to 6th treatment year was Rs. 6382.00 (SD=7965.59) (median=Rs. 2800.00; IQR=Rs. 930.00-7837.50). During the 7th to 10th treatment (follow up) years, the average direct household cost per month was Rs. 744.00 (SD=2705.89) (median=Rs. 67.00; IQR= Rs 0.00-497.50).

The indirect cost incurred by households of breast cancer survivors

Table 2 describes the average indirect cost incurred by the households per month during the initial, 2nd to 6th, and 7th to 10th treatment (follow up) years respectively. The average indirect cost incurred by the household was Rs 4963.32 (median=Rs. 0.00; IQR=0.00-0.00) per month during the initial year. The average indirect cost incurred by the members of the household was Rs. 2650.00 (median=Rs.0.00; IQR=0.00-0.00) per month during the 2nd to 6th years. During the 7th to 10thtreatment (follow up) years, leaving the occupation by the patient was the only contributory factor for the household indirect cost and it was Rs. 1090.90 (median=Rs.0.00; IQR=Rs 0.00-0.00).

Experience of the catastrophic health expenditure by treatment year

In the current study, a household health care expenditure of more than 10% of the total family income was considered a catastrophic health expenditure. Table 3 describes the experience of catastrophic health expenditure by each treatment year. Catastrophic expenditure was present among 65.6% (n=59) of the households in the initial year and 52.2% (n=49) of the households in the 2nd to 6th treatment years. However, among the households of the breast cancer survivors in the 7th to 10th year, the prevalence of catastrophic expenditure was 5.7% (n=5) only.

Associated factors of catastrophic expenditure by households of breast cancer survivors

Table 4 describes the associated factors to catastrophic expenditure by socio-demographic, economic, and clinical characteristics respectively. Low family income ($p<0.001$), unavailability of insurance coverage ($p=0.004$) and current treatment modality being chemotherapy or radiotherapy ($p<0.001$) were the significant associated factors to have catastrophic expenditure in health. Probability of having a catastrophic expenditure gradually drops from the initial treatment year, 2nd to 6th treatment year to 7th to 10th treatment year and that trend was significant.

Table 1: Average direct cost incurred by the households of breast cancer survivors per month during each treatment year

Cost item	Cost incurred by a participant (Rs.)			
	Mean	SD	Median	IQ range
Initial treatment year (n=90)				
Hospital visits (Not admissions)	3381.22	3667.53	2100	1000.00-4555.00
Hospital admissions	378.42	1506.60	0.00	0.00-0.00
Drugs (Other than those purchased during hospital visits and hospital admissions)	749.44	3726.04	0.00	0.00-0.00
Investigations (Other than those done during hospital visits and hospital admissions)	159.33	433.31	0.00	0.00-0.00
Surgical consumables (Other than those purchased during hospital visits and hospital admissions)	97.77	927.60	0.00	0.00-0.00
Other consumables (Other than those consumed during hospital visits and hospital admissions)	1514.44	5872.87	0.00	0.00-0.00
Religious activities	1066.55	2498.22	0.00	0.00-1725.00
Special food	938.11	1690.36	0.00	0.00-0.00
Other costs	116.6	572.54	0.00	0.00-0.00
Total	**8401.88***	**10611.24**	**4858.00**	**2387.50-9000.00**
2nd to 6th treatment year (n=94)				
Hospital visits (No admissions)	2189.28	3224.58	900.00	385.00-2012.00
Hospital admissions	161.48	1320.23	0.00	0.00-0.00
Drugs (Other than those purchased during hospital visits and hospital admissions)	192.55	758.25	0.00	0.00-0.00
Investigations (Other than those done during hospital visits and hospital admissions)	282.44	1190.32	0.00	0.00-0.00
Other consumables (Other than those consumed during hospital visits and hospital admissions)	1351.06	5002.59	0.00	0.00-0.00
Religious activities	1301.70	3555.83	0.00	0.00-0.00
Ayurvedic treatment	21.27	206.28	0.00	0.00-0.00
Special food	631.61	1198.14	0.00	0.00-600.00
Other costs	244.68	1175.88	0.00	0.00-0.00
Total	**6382.11***	**7965.59**	**2800.00**	**930.00-7837.50**
7th to 10th treatment year (n=88)				
Hospital visits (No admissions)	326.76	589.65	0.00	0.00-452.00
Hospital admissions	0.00	0.00	0.00	0.00-0.00
Drugs (Other than those purchased during hospital visits and hospital admissions)	21.59	125.44	0.00	0.00-0.00
Other consumables (Other than those consumed during hospital visits and hospital admissions)	204.54	1918.80	0.00	0.00-0.00
Religious activities	62.04	317.47	0.00	0.00-0.00
Special food	64.77	307.02	0.00	0.00-0.00
Other costs	64.77	607.62	0.00	0.00-0.00
Total	**744.48***	**2705.89**	**67.00**	**0.00-497.50**

* Cost items for which the participants had not incurred any cost are not included in Table.

Table 2: Average indirect cost incurred by the households per month by treatment year

Cost item		Loss of income (Rs.)			
		Mean	SD	Median	IQ range
Initial treatment year (n=90)					
Cost of loss of income by the participant	No pay leaves and loss of production	66.66	632.45	0.00	0.00-0.00
	Leaving the job	1333.33	5507.911	0.00	0.00-0.00
Cost of loss of income by the household members	No pay leaves and loss of production	612.22	872.19	0.00	0.00-0.00
	Leaving the job	2951.11	26366.71	0.00	0.00-0.00
Total		**4963.32**	**26749.25**	**0.00**	**0.00-2000.00**
2nd to 6th treatment year (n=94)					
Cost of loss of income by the participant	No pay leaves and loss of production	57.44	394.17	0.00	0.00-0.00
	Leaving the job	1787.23	6731.20	0.00	0.00-0.00
Cost of loss of income by the household members	No pay leaves and loss of production	294.68	1705.54	0.00	0.00-0.00
	Leaving the job	510.63	2872.72	0.00	0.00-0.00
Total		**2649.98**	**7331.86**	**0.00**	**0.00-0.00**
7th to 10th treatment year (n=88)					
Cost of loss of income by the participant	No pay leaves and loss of production	0.00	0.00	0.00	0.00-0.00
	Leaving the job	1090.90	4822.94	0.00	0.00-0.00
Cost of loss of income by the household members	No pay leaves and loss of production	0.00	0.00	0.00	0.00-0.00
	Leaving the job	0.00	0.00	0.00	0.00-0.00
Total		**1090.90**	**4822.44**	**0.00**	**0.00-0.00**

Table 3*:* Experience of the catastrophic expenditure by households of breast cancer patients by treatment year

Treatment year	No catastrophic expenditure		Catastrophic expenditure present		95% CI	
	No	%	No	%	Lower (%)	Upper (%)
Initial treatment year	31	34.4	59	65.6	50.0	74.5
2-6th treatment year	45	47.8	49	52.2	41.3	62.1
7th to 10th treatment (follow up) year	83	94.3	5	5.7	1.2	11.2

Table 4: Associated factors of catastrophic expenditure

Characteristic	Catastrophic expenditure				Significance
	Present		Not present		
	No	%	No	%	
Socio-demographic characteristics					
Age group					$\chi 2$ =0.019
≤ 60 Years	73	41.2	104	58.8	df=1
> 60 Years	40	42.1	55	57.9	p=0.89
Province of residency					
Colombo	54	37.5	90	62.5	$\chi 2$=3.83
Gampaha	44	50.0	44	50.0	df=2
Kalutara	15	37.5	25	62.5	P=0.15
Ethnicity					$\chi 2$=2.294
Sinhala	100	43.5	130	56.5	df=1
Other ethnicities[1]	13	31.0	29	69.0	p=0.13
Religion					$\chi 2$=0.334
Buddhism	88	42.5	119	57.5	df=1
Other religions[2]	25	38.5	40	61.5	p=0.56
Highest level of education[5]					$\chi 2$=0.066
Up to GCE.A/L[3]	81	42.0	112	58.0	df=1
Passed GCE A/L or more [3]	31	40.3	46	59.7	p=0.79
Civil Status[5]					Fisher's Exact
Ever married[4]	108	41.1	154	58.9	p=1.00
Unmarried	3	42.9	4	57.1	
Economic characteristics					
Insurance coverage					**$\chi 2$=4.05**
No	108	43.3	141	56.7	**df=1**
Yes/Yes partially	5	21.7	18	78.3	**p<0.04**
Family income (Rs.)					**$\chi 2$=15.17**
≤ 30,000	66	54.5	55	45.5	**df=1**
> 30,000	47	31.1	104	68.9	**p<0.001**
Clinical characteristics					
Treatment year					
Initial year	59	65.6	31	34.4	**$\chi 2$ for trend=65.16**
1 year to 6 years	49	52.1	45	47.9	**df=1**
> 6 years 10 years	5	5.7	83	94.3	**p<0.001**
Current treatment modality					**$\chi 2$=22.7**
Chemotherapy or radiotherapy	48	64.9	26	35.1	**df= 1**
Hormonal therapy or no treatment	65	32.8	133	67.2	**p<0.001**
Recurrence or CBC[6]					$\chi 2$=0.034
Yes	7	43.8	9	56.2	df=1
No	106	41.4	150	58.6	p=0.85
Total	**113**	**41.5**	**159**	**58.5**	

[1]Tamil, Muslim, and Burgher amalgamated; [2]Christianity Hinduism and Islam were amalgamated; [3]General Certificate of Education (Advanced Level); [4]married, divorced/living separated, and widowed were amalgamated; [5]Three missing values in civil status and 2 missing values in educational level; [6]contralateral breast cancer

Discussion

The study aimed at assessing the household cost incurred by the breast cancer patients and the percentage experiencing a catastrophic health expenditure. Adequate sample sizes calculated using standard formula and disproportionate stratified sampling technique improved the precision of the findings in each of the initial, 2nd to 6th and 7th to 10th treatment year groups. Only the patients residing in the Western Province were included as the patients referred from other provinces are thought to be severe patients seeking highly specialized care. Random sampling technique was used to minimize the selection bias. Non responders were traced in the field. Data were collected using a validated questionnaire, by trained pre-intern Medical Officers under the supervision of the principal investigator. One month recall period was used, which is accepted by the experts in the field(12).

It has been observed that the cancer patients incur higher cost at the initial phase (initial year) and relatively low cost was incurred after that in studies done in Western countries (14). In line with those findings, the current study revealed that a breast cancer Patient in the initial treatment year incurred a mean total household cost of Rs. 13 365.00 (SD=28 749.00) monthly compared to a breast cancer patient in the 2nd to 6th treatment years and 7th to 10th treatment years who incurred a monthly mean total cost of Rs. 9 032.00 (SD=11 259.00) and Rs. 1835.00 (SD=5379.00), respectively.

According to the findings of the current study, the indirect cost contributed only to 37% of the total cost during the initial treatment year and, 29% during the 2nd to 6th treatment years. During 7th to 10th treatment (follow up) years the contribution of the `indirect cost exceeded the direct cost. Out of the total household cost, 59% was indirect cost in this group. Previous studies reported that on average the proportion of indirect cost was 26% for chronic diseases and 83% for acute disease (12). After the 6th treatment year patients undergo periodic follow-up visits only, which explains the low contribution of the direct cost for breast cancer patients compared to patients with other chronic diseases.

The significant economic burden due to cost of travelling, religious activities and special food has been highlighted by a review of costing studies as well, similar to the current study (1). When a household has to reduce its basic expenditure overtime to cope up with health costs, it is considered as a catastrophic expenditure (3). The current study defined the catastrophic health expenditure as an expenditure on health of more than 10% of the total household income. Accordingly, out of the breast cancer survivors of initial treatment year 65.5% (95% CI: 50.0, 74.0) faced a catastrophic expenditure while the prevalence of catastrophic expenditure among breast cancer survivors of 2nd to 6th treatment years was 49% (95% CI: 41, 62). In contrast, the prevalence of catastrophic expenditure among 7th to 10th treatment (follow up) year was only 5.7% (95% CI: 1.2, 11.2).

When catastrophic expenditure was defined as 20% of the total household income, the prevalence of catastrophic expenditure among all cancer patients, in general, ranged between 13.4% and 25% in two studies done in the USA(6-7). Using a cut-off point of more than 10% of the total household income, the catastrophic expenditure was 49.9% among cancer patients in USA (8). A Korean study, which used the cut-off point of more than 10% of the total household income and done among patients who were within 2 years post-diagnosis revealed a prevalence of catastrophic expenditure of 39.8% among cancer patients (15). Differences in the economic background of countries could have resulted in the observed difference.

According to the findings of the current study, family income ≤ Rs. 30 000.00, being a patient in the initial treatment year, and treatment modality being chemotherapy or radiotherapy were the significant correlated factors associated with a higher risk for catastrophic expenditure. Having an insurance coverage was the only protective factor found against catastrophic expenditure. Similar findings were observed in previous studies. Having an insurance coverage (6, 16), even the type of insurance (7) and income —(6-8) have been found consistently as associated factors for catastrophic expenditure. A study done in the USA among cancer patients

revealed that the patients who were on radiotherapy and anti-neoplastic treatment had a higher risk for catastrophic expenditure(6).

Cancer patients, especially during the initial years after the diagnosis have a high prevalence of catastrophic health expenditure despite the availability of free health services. The possibility of expansion of cancer treatment centres while maintaining the quality need to be explored as the cost incurred on traveling to health care institutions is a major contribution. Nutrition value and cost-effectiveness of 'food items claimed to be beneficial for the cure' need to be assessed and the community should be made aware of the findings.

Loss of job by the patient and family members is one of the main contributory factors for household cost, suggest the need for improving the employers' responsibility towards the welfare of employees. Even though all possible steps were taken to improve the generalizability, the results may not be applicable to the populations which are considerably different from the study population, including breast cancer patients from different cultural backgrounds such as the estate sector residencies. Further, the expenditures of the patients who are in the very early period after the diagnosis are expected to be different. As there is a time gap between the diagnosis and attending Apeksha Hospital, current study findings cannot be generalized to this group as well.

Conclusions & Recommendations

Despite the free health care delivery in Sri Lankan setting, significant proportion of the breast cancer patients face a catastrophic health expenditure especially during their initial treatment year. Other risk factors for a catastrophic expenditure were poor family income and lack of insurance coverage. Higher level policy decisions must be taken to prevent the high health related costs among breast cancer patients, especially those who are more vulnerable to catastrophic expenditure.

Public Health Implications

- Higher level policy decisions need to be taken as an urgent measure to protect breast cancer patients from catastrophic expenditure and subsequent impoverishment.
- It is especially important to ensure job security when employees or their immediate household members face health catastrophes.
- Considering the high travel cost incurred by patients, it would be cost effective to expand cancer treatment centres at least for less intensive treatment modalities.

Author Declaration

Competing interests: The authors declare that they have no competing interests.

Ethics approval and consent to participate: Ethical approval was obtained from the Ethics Review Committee of University of Kelaniya, Sri Lanka (Reference No: P/13/02/2014). Informed written consent was obtained from each participant prior to data collection.

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Author contributions: PJ was the principal Investigator and was involved with the designing of the study, development of the scale and statistical analysis; SG and SW were the supervisors and provided the technical guidance and supervision at each step.

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