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Fear of progression, coping strategies, and associated factors among a sample of Malaysian women with breast cancer

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Fear of progression (FoP) is a stressful psychosocial condition that affects health and quality of life. Breast cancer is recognized as the most prevalent cancer among women globally. This study aims to determine the prevalence of FoP, coping strategies, and associated factors among Malaysian female breast cancer survivors. A cross-sectional survey was conducted among 242 female breast cancer patients recruited from the south of Malaysia using simple random sampling method. The questionnaire captured sociodemographic characteristics, clinical factors, coping strategies and FoP level. Factors associated with FoP were investigated using multiple logistic regression analysis. The mean age was 55.1 ($\pm$ 10.9) years. Majority of them were Malays, attained secondary ducation and above, married, unemployed, and in advanced cancer stages. Most patients had low FoP levels, with a smaller proportion having moderate-to-high FoP levels (10.7%). Higher education (AOR = 5.10, P = 0.050), being employed (AOR = 3.85, P = 0.020), advanced can cer stage (AOR = 4.23, P = 0.030), and adoption of avoidant coping strategy (AOR = 1.19, P = 0.009), were associated with higher FoP level. The level of FoP is low among Malaysian females with breast cancer. Higher levels of FoP were associated with higher educational levels, employment status, advanced cancer stage, and utilization of avoidant coping strategies. The fundamental cognitive process mainly affects FoP, rather than disease-related factors.

Keywords Fear of progression, FoP, Breast cancer, Coping, Coping strategies

Breast cancer (BC) is a recognised as the most common cancer in women in in 2022[1]. Advancements in cancer treatment have resulted in better prognosis and a higher survival rate[2,3]. However, modern therapeutic options do not guarantee complete recovery, patients continue to experience a spectrum of mental and physical distress brought on by the disease itself, the diagnostic process, and the side effects of therapy[4–6]. In this context, BC survivors have reported that one of their most prevalent unmet needs, and the most distressing one, is the fear of cancer progression (FoP)[4,7–9]. It refers to the fear that the illness will progress with all its biopsychosocial consequences, or that it will recur[10].

Theories explaining the occurrence of FoP[11–14] stipulate that FoP-related cognitive schemas are triggered by external signals like medical information, previous history of serious illness, social support, and follow-up appointments or internal cues like disease process, physical symptoms, and treatment-related conditions[15]. These are followed by the interpretation process, which might result in more or less adaptive coping mechanisms[15]. Collectively, FoP is considered as a reasonable and appropriate response to the risks and uncertainties faced during cancer survivorship[2,10] in which cancer patients may benefit from the adaptation process induced by low levels of fear[4]. On the other hand, higher levels of FoP can be dysfunctional and substantially impact an individual's well-being[16].

The varying prevalence of FoP has been reported from different methodological approaches. An absolute prevalence of 25–97% was reported from the United States of America and Taiwan[17,18]. In terms of the level of FoP, a rate of 17% of moderate-high FoP was reported in Germany[19]to as high as 70% from Australia[20]. Those affected face recurring thoughts of cancer progression and become fixated on them, which in turn leads

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to emotional disturbances like anxiety, stress, and depression[4,7,16]. It is also associated with a poorer quality of life[4,21]. Besides that, FoP is linked to reassurance-seeking behaviours such as extra follow-up visits to the doctor, demand for more medications, and additional diagnostic investigations, leading to increased expenditure on healthcare services[22,23].

Factors that play a role in the level of FoP range from demographic factors, disease characteristics, and coping methods[2,9,24]. There is strong and consistent evidence that younger, unemployed cancer patients with low monthly income have higher FoP[2,25–27]. Cancer staging, which is one of the prognostic factors, has also been positively correlated with FoP[28,29]. Avoidance or denial coping was reported to boost the FoP[2,30], while religious coping strategies are significantly linked to lower FoP[9].

BC continues to pose a significant burden on patients and the healthcare system in Malaysia. FoP may lead to unnecessary health-seeking practices and waste of resources. There is lack of literature that evaluates the prevalence of FoP and its associated factors in the local context. The identification of factors associated with FoP, and the relevant coping strategies would help inform public health professionals and clinicians on approaches to reduce FoP and improve quality of life. We undertook this study to address this gaps, hoping to provide insights into this problem.

Methods

Study design and participants

A cross-sectional study was conducted in the Oncology Department, Hospital Sultan Ismail, Johor Bahru (HSIJB) from March to April 2023. The hospital serves as the main oncology centre in the southern part of Peninsular Malaysia which provides oncologist consultation service, radiotherapy, and chemotherapy treatment.

The inclusion criteria were set as Malaysian females, having pathological diagnosis of breast cancer from all disease stages (stage 1 to stage 4) and were able to read, understand and speak the Malay language. Meanwhile, those who were blind, deaf, or in Eastern Cooperative Oncology Group (ECOG) Performance Status 3 [(capable of only limited self-care; confined to bed or chair more than 50% of waking hours) or Stage 4 (completely disabled; cannot carry on any self-care; confined to bed or chair) were excluded.

Sample size and sampling method

The sampling frame consisted of a list of breast cancer patients scheduled for upcoming doctor appointments at the breast clinic, radiotherapy, and chemotherapy at the HSIJB Oncology Clinic. Simple random sampling was used to select the study subjects. The daily lists of breast cancer patients were compiled and patients were selected randomly from the compiled list based on random numbers generated in Microsoft Excel.

The minimum sample size was determined for each of the study objectives, whereby the largest sample size was generated for the prevalence of FoP using the following formula:

$$n = deff \times \frac{N\widehat{pq}}{\frac{d^2}{1.96^2}(N-1) + \widehat{pq}}$$

where design effect, *deff* was 1, population size, *N* was 3264[31], estimated proportion, *p̂* was 17%[19], *q* was 83% and desired absolute precision, *d* was 5%. With the anticipation of 20% non-response rate, the total respondents required was 245.

Data collection instrument

To assess the burden of FoP and it is associated factors, a validated Malay language questionnaire was used in this study, which composed of five sections. The first two sections are related to sociodemographic factors (age, ethnicity, education level, marital status, employment status, monthly income status, family history of cancer, cancer support group membership) and disease-related factors (cancer stage, treatment modalities like surgery, chemotherapy, radiotherapy, hormonal therapy, and time post-diagnosis).

The patients' coping strategies were assessed using the Brief Coping Orientation to Problems Experienced Inventory (COPE) questionnaire. The Brief COPE scale includes 28 items, which are categorized into 14 different coping strategies. Each coping strategy is made of two items. The 14 strategies are ; acceptance, active coping, behavioral disengagement, denial, humor, planning, positive reframing, religion, self-blame, self-distraction, substance use, use of emotional support, use of instrumental support and venting[32]. The present 14 coping subscales can further form a three higher-order coping subscales: Emotion-Focused, Problem-Focused and Avoidant coping. The Emotion-Focused, includes venting, use of emotional support, humour, acceptance, self-blame, and religion. Problem-Focused on the other hand includes active coping, use of informational support, planning, and positive reframing. Lastly, Avoidant Coping includes self-distraction, denial, substance use, and behavioural disengagement[33]. The scoring was based on a 4-point Likert scale, which ranged from 1 = "I haven't been doing this at all" to 4 = "I have been doing this a lot"[32]. The mean score of each coping strategy was derived from the sum of the scores for each of the two items within it. Higher total scores in a particular subscale, indicates greater use of that coping strategy[32]. In this study, the Malay language version of Brief COPE was used. The Malay version was previously proven to be valid and reliable tool among Malaysian breast cancer patients. The Cronbach's α values of internal consistency range from 0.51 to 0.99 with high correlation for test-retest reliability. Discriminant validity was also ensured[34]. It was also validated among secondary school students employing exploratory factor analysis[35].

On the other hand, FoP level was assessed using a twelve-item FoP Short-Form Questionnaire (FoP-Q-SF)[36]. The items were scored on a five-point Likert scale, which ranged from 1 = "never" to 5 = "very often"[36]. The total score is usually categorized into three levels; Patient scoring ≥ 4 ('often' and very often') on less than 6 items

is defined as having low level of FoP. scoring ≥ 4 on six to eight items are categorised as having moderate FoP, and scores of ≥ 4 on nine or more items categorised as high FOP. Accordingly, FoP was then dichotomized into low and moderate-to-high levels[37]. This questionnaire has been translated into the Malay language, validated among Malaysian cancer patients, and has shown to have excellent validity and internal consistency (Cronbach's $\alpha = 0.927$) confirmed with exploratory factor analysis and internal consistency analysis[38].

Statistical analysis

Data analysis was done using IBM Statistical Package for the Social Science (SPSS) version 27. Frequencies and percentages were used to describe categorical variables, while normally distributed numerical variables were presented in means and standard deviations (SD). Simple and multiple logistic regression, with variables selected using the "enter method", were utilized to identify variables associated with FoP level. The 95% confidence intervals are presented where applicable. The significance level was set as 0.05.

Ethics statement

The study was conducted in line with the World Medical Association's ethical principles of conducting research among human beings (Helsinki Declaration). Institutional ethics approval was granted by the Ethics Committee of IMU University (No.: MSPH I-2022(10)) and the Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR ID-23–00105-GM3). All participants provided written informed consent before participating.

Results

Sample characteristics & prevalence of FoP

Two hundred forty two patients with BC completed the questionnaire, yielding a response rate of 98.8%. Table 1 shows the sociodemographic profiles and clinical characteristics of study subjects. The respondents' mean age was 55.1 (± 10.9) years. They were predominantly unemployed, did not have any family history of breast cancer, and did not join any cancer support group. The majority of them were in the advanced stage of cancer (stage III / stage IV), had less than 12 months of disease duration, had undergone breast surgery, and received chemotherapy treatment. Most of the respondents had low levels of FoP (89.3%), and the rest had moderate-high levels of FoP .

Table 2 shows that the most commonly adopted coping strategy by the respondents was "Religion", which had the highest mean of 6.83 (SD ± 1.74), following that was "Use of emotional support" with a mean score of 6.33 (SD ± 1.66), and "Acceptance" with a mean score of 6.31 (SD ± 1.33). Substance abuse was the least adopted coping strategy, with a mean score of 2.05 (SD ± 0.37), followed by behavioral disengagement with a mean score of 2.57 (SD ± 1.12), and denial, 3.37 (SD ± 1.73).

Multiple logistic regression analysis was performed using the enter method to examine the relationship between Fear of Progression (FoP) levels and potential predictors. Table 3 shows the crude (COR) and adjusted odds ratio (AOR) obtained from simple and multiple logistic regression analyses, respectively. Variables entered into the model were sociodemographic profiles, clinical factors, and coping strategies with FoP levels being the dependent variable. The model fitted the data well based on Hosmer and Lemeshow Test (P value $= 0.694$) and achieved an R^2 of 0.372[39]. FoP was higher among respondents who completed secondary education and above (AOR $= 5.10$, $P = 0.05$), were employed (AOR $= 3.85$, $P = 0.020$), was in advanced cancer stage (AOR $= 4.23$, $P = 0.030$), and used avoidant coping strategy (AOR $= 1.19$, $P = 0.002$).

Discussion

Breast cancer remains a significant concern for patients, healthcare providers and stakeholders, impacting a large number of females from various backgrounds. The lower-than-expected prevalence of FoP in this study was surprising. As the most common malignancy among women, breast cancer imposes substantial physical and psychological consequences. Social norms often perpetuate expectations for women to display passivity and emotional vulnerability, which may shape their coping mechanisms and reporting behaviors[40]. The relatively small proportion of high FoP observed in our sample might be attributed to adequate health literacy and availability of reliable information regarding the disease course and prognosis. The adoption of certain coping strategies, which are discussed later below, also likely played an important role in alleviating FoP. The provision of counseling services seems to help patients understand the course of disease and reduce anxiety[41,42]. Moreover, effective communication between patients and healthcare providers would empower patients and encourage them to counter any negative thoughts and emotions.

The affordability and accessibility of healthcare in Malaysia[43] may also contribute to the reduced prevalence of FoP. Regular follow-ups and timely diagnostic tests, such as blood test and imaging, reassure patients that potential signs of cancer progression will be detected early, allowing prompt intervention. Despite differing study settings, these findings align with studies from China[44] and Germany[19].

In contrast, studies from Western countries reported a higher prevalence of FoP. For instance, over half (52.3%) of a sample of American and (56.0%) of Norwegian breast cancer patients experienced moderate-to-high fear[25,45] with rates as high as 66.7% in Russia[5]. This disparity could be attributed to cultural differences in patients' attitudes and expression of emotional distress and fear[46]. People from western cultures are perhaps more vocal about their needs and emotions, which is not the case with Asian people[47], and this may lead to potential under-reporting of fear by Asian patients. The varying methodological approaches and use of different measurement tools or cut-off values shouldn't also be overlooked when drawing comparisons.

Our finding that higher education is significantly correlated with FoP concurs with other published reports[48,49]. Individuals with higher level of literacy often have greater access to information readily available from various sources. The overload of information may overwhelm them and negatively affect disease perception, triggering worries which in turn leads to pathological FoP[42,48]. The role of effective patient-doctor communication and

Variables	n	%
Age ≤ 55	119	49.2
> 55	123	50.8
Ethnicity Malay	128	52.9
Chinese	83	34.3
Indian	29	12
Others	2	0.8
Education Primary	82	33.9
Secondary	126	52.1
College/university	34	14
Marital Status Single/Divorced	17	7
Married	225	93
Employment status Unemployed	196	81
Employed	46	19
Monthly income (MYR) ≤4850	231	95.5
>4850	11	4.5
Family history of cancer No	162	66.9
Yes	80	33.1
Cancer support group membership No	211	87.9
Yes	29	12.1
Cancer stage I	13	5.5
II	58	24.4
III	83	34.9
IV	84	35.3
Surgery No	89	36.8
Yes	153	63.2
Chemotherapy No	7	2.9
Yes	235	97.1
Radiotherapy No	124	51.2
Yes	118	48.8
Hormonal therapy No	172	71.1
Yes	70	28.9
Time since diagnosis (months) ≤ 12	152	64.1
> 12	85	35.9
Level of FoP Low	216	89.3
Moderate-High	26	10.7

Table 1. Sociodemographic and clinical profile of participants ($N = 242$).

knowledge transfer is crucial and should be emphasized as a fundamental strategy to alleviate negative thoughts and worry among patients[50]. Interestingly, some studies suggest that higher education can also facilitate better understanding of disease prognosis, reducing uncertainty and emotional distress[51–53]. These conflicting results highlight the complexity of the relationship between education and psychological outcomes.

Employment status was another factor significantly associated with higher FoP levels. Cancer patients face numerous challenges, including dealing with new therapies, managing side effects, financial burdens, and reduced well-being, all of which can threaten job security and income. These concerns may amplify fear of progression among employed individuals. Additionally, work commitments can hinder treatment compliance, further intensifying worries about disease outcomes. This finding is consistent with studies by Janz et al.[54] and Shay et al.[55].

Coping Strategy	Mean Score	SD	95% CI	Possible Score
Problem-focused	17.11	3.63	16.65–17.57	6–24
Planning	5.25	1.64	5.04–5.46	2–8
Active Coping	5.69	1.57	5.49–5.89	2–8
Use of instrumental support	6.17	1.62	5.97–6.38	2–8
Emotion-focused	29.38	4.67	28.79–29.97	16–38
Acceptance	6.31	1.33	6.14–6.48	2–8
Religion	6.83	1.74	6.61–7.05	2–8
Use of emotional support	6.33	1.66	6.12–6.54	2–8
Humour	3.75	0.98	3.63–3.88	2–8
Positive reframing	6.16	1.65	5.95–6.37	2–8
Avoidant	23.27	4.37	22.71–23.82	14–37
Behavioural disengagement	2.57	1.12	2.42–2.71	2–8
Denial	3.37	1.73	3.15–3.59	2–8
Self-blame	4.53	1.10	4.39–4.67	2–8
Self-distraction	5.83	1.78	5.61–6.06	2–8
Substance use	2.05	0.37	2.00–2.10	2–8
Venting	4.92	1.59	4.72–5.12	2–8

Table 2. Mean scores for coping strategy ($N = 242$). [a]SD = standard deviation. [b]CI = confidence interval.

Notably, our study did not find significant associations between FoP and clinical factors such as surgery, chemotherapy, radiotherapy, and hormonal therapy. These findings corroborate with the existing literature[2,10,21,25,26,54,56–61], which suggests that treatment-related variables play a relatively minor role in influencing FoP.

The adoption of avoidant coping strategies (which includes behavioral disengagement, denial, self-blame, self-distraction, substance use, and venting) was associated with a higher level of FoP in this study, which concurs with previous studies[59,61]. Among these strategies, self-distraction had the highest mean score. This involves shifting attention towards work or other tasks to distract oneself from one's thoughts and to switch from one conscious activity to another[62]. In avoidant coping, the patient attempts to escape from stressors rather than dealing with them[63]. While avoidance may offer temporary relief, it undermines confidence in one's ability to cope and can lead to delays in seeking potentially life-saving medical interventions[64]. Poor psychological adjustment following a breast cancer diagnosis may also lead to increased distress and fear. These negative implications add to the challenges of cancer survivors, and cause a vicious cycle of having higher FoP. Addressing avoidant coping behaviors is crucial to improving patients' psychological well-being and overall quality of life.

The findings of our study should be interpreted with caution as several limitations need to be considered. First, the use of self-report method is subject to 'social desirability' bias, where participants tend to reflect positive outcomes. However, efforts to minimize this bias were made by ensuring anonymity of the response, and the absence of personal identifiers. Second, these findings were obtained from a single public tertiary center, generalization is limited to those seeking treatment at similar public healthcare facilities. Nonetheless, the adoption of the probability sampling method reduces potential bias. Lastly, the use of a shortened FoP questionnaire may limit comparison to other studies which have used a different version of it or a different questionnaire altogether. There is no concensus on a gold standard questionnaire to be used across different cultural and linguistic backgrounds. The shortened Malay version of the FoP questionnaire was the only one available for this study.

To conclude, the prevalence of FoP among Malaysian breast cancer patients appears low. Higher levels of FoP were associated with higher educational levels, employment status, advanced cancer stage, and utilization of avoidant coping strategy. Despite its limitations, this study provides valuable insights into the psychological state of cancer patients, which could inform clinicians and public health professionals in designing relevant interventions that improve patients' coping strategies. Further research should incorporate qualitative components to explore the experiences of cancer patients and understand their coping mechanisms more deeply.

Factor		COR	95% CI	P value	AOR	95% CI	P value
Age	≤ 55	1	0.07–0.54	0.002*	1	0.16–1.92	0.353
	> 55	0.20			0.56		
Ethnicity	Non - Malay	1	1.56 − 11.76	0.005*	1	0.33–4.10	0.820
	Malay	4.28			1.16		
Education	Primary	1	1.63 − 30.66	0.009*	1	1.00–25.94	0.050*
	Secondary and above	7.06			5.10		
Marital status	Single/ Divorced	1	0.19–4.16	0.888	1	0.19–8.05	0.826
	Married	0.90			1.23		
Employment status	Unemployed	1	1.61–8.95	0.002*	1	1.23–12.05	0.020*
	Employed	3.79			3.85		
Monthly income (MRM)	≤ 4850	1	0.84–13.68	0.086	1	0.16–8.63	0.880
	> 4850	3.39			1.17		
Family history of cancer	No	1	0.37–2.14	0.793	1	0.14–1.32	0.138
	Yes	0.89			0.43		
Cancer support group membership	No	1	0.91–6.84	0.076	1	0.19–2.78	0.646
	Yes	2.49			0.73		
Cancer stage	Early	1	0.69–5.25	0.217	1	1.15–15.53	0.030*
	Advanced	1.90			4.23		
Surgery	No	1	0.56–3.25	0.503	1	0.63–6.84	0.234
	Yes	1.35			2.07		
Chemotherapy	No	1	0.083–6.177	0.760	1	0	0.999
	Yes	0.71			58878554.56		
Radiotherapy	No	1	0.27–1.44	0.269	1	0.14–1.64	0.246
	Yes	0.63			0.49		
Hormonal therapy	No	1	0.20–1.53	0.254	1	0.14–1.70	0.263
	Yes	0.55			0.49		
Time since diagnosis	≤ 12 months	1	0.27–1.67	0.388	1	0.30–3.93	0.904
	> 12 months	0.67			1.08		
Coping strategies							
Problem-Focused		1.18	1.04–1.33	0.009*	0.99	0.82–1.18	0.885
Emotion-Focused		1.21	1.08–1.35	< 0.001*	1.13	0.96–1.35	0.153
Avoidant		1.19	1.08–1.31	< 0.001*	1.19	1.05–1.36	0.009*

Table 3. Factors Associated with FoP. [a] COR = crude odds ratio. [b] AOR = adjusted odds ratio. [c] CI = confidence interval. *P value is significant @0.05. Note: The assumptions for multiple logistic regression—independence of observations, no. multicollinearity, and model fit were all met.

Data availability
The datasets generated during and/or analysed during the current study are available from the corresponding author upon reasonable request.

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Declarations

Competing interests

The authors declare no competing interests.

Additional information

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