ORIGINAL ARTICLE

Validation of the Malay Version of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF-M) in Malaysian Cancer Patients

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ABSTRACT

Introduction: Fear of cancer progression may lead to worsening of psychological complications of cancer and affects the quality of life of cancer patients. Hence, fear of cancer progression needs to be monitored. This study translated the original English version of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) into the Malay language and investigated the reliability and validity of the Malay version of the FoP-Q-SF (FoP-Q-SF-M) among Malaysian cancer patients. **Methods:** Concurrent translation and back translation of the English version of the FoP-Q-SF to the FoP-Q-SF-M was performed, and the FoP-Q-SF-M and the Malay version of the Cancer Therapy Satisfaction Questionnaire (CTSQ-M) (as a comparison to assess the discriminant validity of the FoP-Q-SF-M) were administered to 200 cancer patients with different sites, stages, and duration of cancer diagnosis. **Results:** The CTSQ-M exhibited excellent internal consistency (Cronbach's α = 0.927) as well as demonstrated good convergent and discriminant validity. Exploratory factor analysis of the FoP-Q-SF-M extracted one factor with twelfth items, thereby this supports the single-factor model reported by the English version of the FoP-Q-SF. **Conclusion:** The FoP-Q-SF-M exhibited acceptable psychometric properties and valid for use to assess fear of cancer progression in the Malaysian cancer population.

Keywords: Validity, Reliability, Malay version of the Fear of Progression Questionnaire-Short Form, Malaysian cancer patients

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INTRODUCTION

Cancer is a life-threatening chronic disease which affects millions of people around the world and has been the second commonest cause of death affecting 1 in 6 deaths and causing 9.6 million deaths worldwide (1). It is not surprising that the disease leads to enormous stress among the cancer survivors and resulting in various psychological complications (2). Despite advancement of cancer treatment, the deadly consequence and recurrent nature of this illness lead to fear of disease progression and recurrence among the cancer patients. Fear of disease progression is defined as a conscious and reactive perceived fear in response to any serious and life-threatening illness (2). The worry, fear, and anxiety related to cancer progression and recurrence are describing the same concept and hence, the term of 'fear of progression' describe both the fear of progression and also the recurrence of the illness (3, 4). Fear of cancer progression, if left unmanaged in cancer patients may lead to poor quality of life and worsened the psychological complications of cancer. Hence, it is important to evaluate the level of fear of cancer progression in cancer patients.

To the best of our knowledge, to date, there is lack of study which investigate the fear of cancer progression or recurrence in Malaysian cancer patients. However, a study conducted in neighboring Singapore reported that 43.6% of the cancer survivors had clinical level of fear of cancer recurrence, while 32.1% had severe or pathological fear of cancer recurrence (5). Studies in Malaysian breast cancer patients have indicated that they felt uncertain about their illness outcome and fear of cancer consequences is one of the reasons which led to delay in presentation of patients to the healthcare facility to seek treatment (6). Hence, it is necessary to screen for fear of cancer progression and recurrence in the Malaysian cancer population and there is a need to translate and validate fear of cancer progression or recurrence screening instruments in the Malay language. There are various instruments use to measure fear of disease progression, but two of the common instruments use to evaluate fear of cancer progression or recurrence are the Fear of Progression Questionnaire (FoP-Q) (7)

and the Fear of Cancer Recurrence Inventory (FCRI) (8). There is no gold standard available to measure the fear of cancer progression or recurrence. The 42-item Fear of Cancer Recurrence Inventory (FCRI) may not be suitable for assessing cancer patients as it is long and required a longer duration of administration which may lead to responder bias, as cancer patients may experience some amount of discomfort stemming from cancer complications or from the adverse effects of cancer treatment. Hence, the 12-item Fear of Progression Questionnaire-Short Form (FoP-Q-SF) which required a shorter duration of administration is a better choice for assessment of cancer patients. While for the shorter 9-item Fear of Cancer Recurrence Inventory, it has low specificity (9). As for the 7-item Fear of Cancer Recurrence Inventory and the ultra-short 4-item Fear of Cancer Recurrence Inventory, they are designed only to measure the fear of cancer recurrence and they are not suitable to assess the fear of cancer progression (10).

The original version of the FoP-Q is a 43-item selfadministered instrument with five subscales (7). The Fear of Progression Questionnaire-Short Form (FoP-Q-SF) derived from the FoP-Q is the shorter version with 12 items in a single domain which is an important and a more suitable tool for assessment of fear of cancer progression as it requires shorter duration of administration and it is as good as the original FoP-Q to gather data on fear of cancer progression without significant loss of information. It has been validated in breast cancer patients and also in cancer patients of various sites of cancer (11, 12). This study aimed to translate the original English version of the FoP-Q-SF into the Malay language and assess the reliability and validity of the Malay version of the FoP-Q-SF (FoP-Q-SF-M) among Malaysia cancer patients.

MATERIALS AND METHODS

Study design and data collection

This cross-sectional validation study was conducted from October 2019 to July 2020. It received approval from the Human Research Ethics Committee of Universiti Sains Malaysia (code: USM/JEPeM/18100483). All participants were recruited through convenient sampling from the Oncology outpatient clinic and inpatient ward of Advanced Medical and Dental Institute (AMDI), Universiti Sains Malaysia. AMDI is a tertiary referral centre for northern Peninsular Malaysia located in the state of Penang with an estimated total number of cancer patients ranging from 2000 to 3000 patients. Initially, cancer patients who were: (a) diagnosed with cancer of any sites, stages, and duration of diagnosis confirmed by histopathological report except for brain tumour or metastasis to the brain, (b) at least 18 years old, (c) able to read and write in Bahasa Melayu, and (d) capable of answering questionnaires were offered to participate in the study. They were explained about the study details by the research team before the participants signed

the informed consent to participate in the study. Then, they were administered with the socio-demographic and clinical factor questionnaires (which include information on age, gender, ethnicity, monthly income, education level, site of cancer, stage of cancer, and duration of cancer diagnosis), the Malay version of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF-M), and the Malay version of the Cancer Therapy Satisfaction Questionnaire (CTSQ-M) (as a comparison instrument to assess discriminant validity of the FoP-Q-SF-M).

Measuring tools

The Fear of Progression Questionnaire-Short Form (FoP-Q-SF) is a self-administered questionnaire which derived from the 43-item Fear of Progression Questionnaire to assess the degree of fear of cancer progression among cancer patients. The advantage of the FoP-Q-SF is that it requires shorter time of administration as it consists of only 12 items which is suitable for assessment of cancer patients as they may have various discomfort. The FoP-Q-SF has been validated in cancer patients with various site of cancer and made up of only a single domain (it is a uni-dimensional questionnaire). Each item is rated in a Likert scale ranging from 1 (never) to 5 (very often) and hence, the possible total score ranged from 12 to 60. A score of 34 and above indicates dysfunctional fear of cancer progression. The internal consistency of the FoP-Q-SF is excellent (Cronbach's $\alpha = 0.90$) and confirmatory factor analysis indicated that the 1-factor model is the best-fitting model (11, 12).

The Cancer Therapy Satisfaction Questionnaire (CTSQ) is a self-administered tool use to assess the degree of satisfaction with cancer treatment among cancer patients. It consists of 16 items in 3 domains. Each item is scored in a Likert scale ranging from 1 (associated with the worse response) to 5 (associated with the best response). The internal consistencies of its domains are acceptable (Cronbach's α ranging from 0.77 to 0.87) (13). The Malay version of the CTSQ (CTSQ-M) was used in this study as a comparison instrument to assess the discriminant validity of the FoP-Q-SF-M.

Translation and back-translation of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF)

The original English version of the FoP-Q-SF was translated by a native Malay bilingual language expert from the School of Language and Literacy, Universiti Sains Malaysia and a native Malay and bilingual speaker in the research team independently. Then, their translations were compared and harmonized to create a harmonized third joint translation copy. This is followed by the back-translation of the translated harmonized copy of the questionnaire from the Malay version into English version by a native English and bilingual language expert from the same school who has not seen the original English version of the FoP-Q-SF. Then, the research project leader discussed the translated

and the back-translated copies of the FoP-Q-SF with all the translators and back-translator to create a new harmonized translated and back-translated copies of the FoP-Q-SF. Then, a group of content experts consists of two oncologist and a psychiatrist reviewed the new harmonized translated and back-translated copies of the questionnaire to construct the first draft of the Malay version of the FoP-Q-SF (FoP-Q-SF-M).

Then, a group of 20 native Malay speaking cancer patients were selected to answer the drafted FoP-Q-SF-M and they were asked to comment on the wording and sentence structure of the content, the semantic quality, and time of administration in an interview after they had answered the questionnaire. They were asked to rate whether the words, sentences, and instructions of the FoP-Q-SF-M were "not appropriate", "appropriate", or "very appropriate" and to comment on any wording and sentences which need to be amended. We found that 70% of the participants commented that the questionnaire was "appropriate" and another 30% commented that the questionnaire was "very appropriate". None of them commented that any wording and sentence structure need to be amended. As a result, the FoP-Q-SF-M was finalized and there was no need for the team of experts to amend the FoP-Q-SF-M draft.

Statistical analysis

The data was analysed with the Statistical Package for Social Sciences version 26 (SPSS version 26). Descriptive statistics was reported for socio-demographic and clinical factors of the participants, and the FoP-Q-SF-M score, in which categorical data were reported in frequency and percentage and continuous data were reported in mean and standard deviation. The reliability of the FoP-Q-SF-M was assessed with internal consistency where Cronbach's α was reported and a value of > 0.7 was considered as acceptable (14). The convergent validity was assessed by comparing the Pearson's correlation coefficient of each item with the total score of the FoP-Q-SF-M, in which high correlations indicate good convergent validity. The discriminant validity was examined by comparing the Pearson's correlation coefficient of the FoP-Q-SF-M with each domains of the CTSQ-M where low correlations indicate good discriminant validity. Construct validity was assessed with exploratory factor analysis to determine the number of factors extracted and allocation of items. In exploratory factor analysis, the Kaiser-Meyer-Olkin measure of sample adequacy of > 0.6, Barlett's test of sphericity with p < 0.05, factor extracted with eigenvalue of > 1.0, and factor loading of item of > 0.4 were considered as acceptable (15).

RESULTS

Table I summarizes the socio-demographic and clinical characteristics of all the participants. A total of 200 participants completed this study. Majority of the participants were above 45 years old (n= 177, 88.5%)

Table I: Socio-demographic and clinical characteristics of the participants

Variables	Number of	Percentage
	participants (n)	(%)
Age:		
≤ 45 years	58	29.0
46-65 years	119	59.5
> 65 years	23	11.5
Gender:		
Male	73	36.5
Female	127	63.5
Ethnicity:		
Malays	153	76.5
Chinese	22	11.0
Indians	21	10.5
Others	4	2.0
Monthly income:		
≤ RM 3000	144	72.0
> RM 3000	56	28.0
Education status:		
Primary education	24	12.0
Up to secondary education	91	45.5
Tertiary education and above	85	42.5
Site of cancer:		
Breast carcinoma	100	50.0
Lung cancer	24	12.0
Colorectal carcinoma	50	25.0
Others	26	13.0
Duration of diagnosis:		
< 1 year of diagnosis	119	59.5
≥ 1 year of diagnosis	81	40.5
Stage of cancer:		
Stage 1	21	10.5
Stage 2	91	45.5
Stage 3	46	23.0
Stage 4	42	21.0
Mean FoP-Q-SF-M score	26.19ª	11.10 ^b

a mean, b standard deviation

and more than half of them were females (n= 127, 63.5%). Majority of participants were Malays (n= 153, 76.5%) and had low monthly income with \leq RM 3000 (n= 144, 72.0%), but most of them had education up to at least secondary education and above (n= 176, 88.0%). Breast carcinoma (n= 100, 50.0%), colorectal carcinoma (n= 50, 25.0%), and lung cancer (n= 24, 12.0%) were the commonest site of cancer. More than half of the participants were diagnosed with cancer less than 1 year (n= 119, 59.5%) and almost half of them were in stage 2 of cancer (n= 91, 45.5%). The mean score of the FoP-Q-SF-M was 26.19 \pm 11.10.

The reliability of the FoP-Q-SF-M was assessed by internal consistency in which its Cronbach's α was 0.927. Assessment of the convergent validity of the FoP-Q-SF-M revealed that the Pearson's correlation coefficient between all the items and its total score ranged from 0.646 to 0.813 with p < 0.05. Table II illustrates the Pearson's correlation coefficient between all items and the total FoP-Q-SF-M score. Assessment of the discriminant validity of the FoP-Q-SF-M demonstrated that the Pearson's correlation coefficient between the total FoP-Q-SF-M score and all the domains of the CTSQ-M ranged from - 0.230 to 0.281 with p < 0.05. Table III describes the Pearson's correlation coefficient between the FoP-Q-SF-M and the domains of the CTSQ-M.

Table II: Pearson's correlation coefficient between items and the total FoP-Q-SF-M score

Items	Total FoP-Q-SF-M score
Item 1 (Saya menjadi bimbang jika saya fikir penyakit saya mungkin menjadi lebih teruk)	0.708*
Item 2 (Saya berasa gementar sebelum temujanji doktor atau pemeriksaan berkala)	0.754*
Item 3 (Saya takut sakit)	0.691*
Item 4 (Saya bimbang terhadap percapaian matlamat kerjaya saya kerana penyakit saya)	0.667*
Item 5 (Apabila saya resah, saya ada tanda-tanda fizikal seperti denyutan jantung laju, sakit perut atau menggeletar)	0.646*
Item 6 (Kemungkinan anak-anak saya mewarisi penyakit ini mengganggu saya)	0.706*
Item 7 (Ia mengganggu saya kerana saya mungkin perlu bergantung kepada orang lain untuk melakukan aktiviti harian saya)	0.795*
Item 8 (Saya risau pada suatu masa, saya tidak lagi mampu untuk melakukan hobi-hobi saya kerana penyakit yang saya alami)	0.807*
Item 9 (Saya takut akan rawatan perubatan yang teruk sepanjang tempoh penyakit ini)	0.798*
Item 10 (Saya risau rawatan yang saya terima boleh memudaratkan badan saya)	0.813*
Item 11 (Saya risau apa yang akan terjadi kepada keluarga saya sekiranya berlaku sesuatu ke atas diri saya)	0.808*
Item 12 (Pemikiran yang saya mungkin tidak lagi mampu bekerja disebabkan oleh penyakit ini mengganggu saya)	0.738*

^{*} statistical significance at p < 0.05

Table III. Pearson's correlation coefficient between the FoP-Q-SF-M and the domains of the CTSO-M

FoP-Q-SF-M	Expectation of therapy (CTSQ-M domain 1)	Feelings about side effects (CTSQ-M domain 2)	Satisfac- tion with therapy (CTSQ-M domain 3)
Total FoP-Q-SF-M score	-0.209*	0.281*	-0.230*

^{*} statistical significance at p < 0.05

Exploratory factor analysis of the FoP-Q-SF-M reported a Kaiser-Meyer-Olkin measure of sampling adequacy of 0.900 and the Bartlett's test of sphericity demonstrated p < 0.001. There was only one factor extracted with an eigenvalue of 6.69 representing a total variance of 55.75%. The factor loadings of all the items ranged from 0.65 to 0.82. Table IV summarizes the exploratory factor analysis with Kaiser normalization for the FoP-Q-SF-M. The FoP-Q-SF-M was unrotated as there was only one factor extracted.

DISCUSSION

This study translated the original English version of the FoP-Q-SF into the Malay language and investigated the reliability and validity of the FoP-Q-SF-M among the Malaysian cancer population. The FoP-Q-SF-M demonstrated excellent internal consistency with Cronbach's α of 0.927. In fact, the internal consistency of the FoP-Q-SF-M was comparable to that of the original English version of the FoP-Q-SF (Cronbach's α = 0.90) (11), and better than the internal consistency of the Chinese version (Cronbach's α = 0.88) (16) and

Table IV: Exploratory factor analysis with Kaiser normalization for the FoP-Q-SF-M

Items	FoP-Q-SF-M
Item 1	0.71
Item 2	0.75
Item 3	0.68
Item 4	0.66
Item 5	0.65
Item 6	0.70
Item 7	0.79
Item 8	0.81
Item 9	0.81
Item 10	0.82
Item 11	0.81
Item 12	0.74
Eigenvalue	6.69
Total variance (%)	55.75

the Dutch version of the FoP-Q-SF (Cronbach's α = 0.86) (17). Hence, the FoP-Q-SF-M had achieved good reliability.

The translation of the original English version of the FoP-Q-SF into the Malay language followed the standard procedures of translation of questionnaires recommended by the World Health Organization and existing literature to achieve the face and content validity i.e. translation and back-translation of the questionnaire with harmonization followed by assessment by a team of content experts and a pilot study with 20 subjects to evaluate the wordings and sentence structures, semantic quality, comprehensibility, and time of administration of the translated questionnaire, and finally re-examination of the questionnaire based on the comments by the participants from the pilot study by the team of content experts (18, 19). In this study, all the pilot study

participants agreed that the FoP-Q-SF-M wordings, sentence structures and instructions were acceptable with no comments on any deficiency in its content. Hence, the face and content validity of the FoP-Q-SF-M were achieved.

In addition, all the items of the FoP-Q-SF-M were highly positively correlated to the total score of the FoP-Q-SF-M indicating that the FoP-Q-SF-M had good convergent validity (20). On the contrary, the total score of the FoP-Q-SF-M only had low correlations with all the domains of the CTSQ-M which measures different construct in cancer patients. Hence, this finding denotes that the FoP-Q-SF-M had good discriminant validity (20).

Exploratory factor analysis of the FoP-Q-SF-M reported a Kaiser-Meyer-Olkin measure of sample adequacy of > 0.6 indicating the characteristic of a good factor analysis and the Barlett's test of sphericity was statistically significant which denotes that the factor analysis was valid. There was only one factor extracted for the FoP-Q-SF-M with an Eigenvalue of > 1.0 and all the items had factor loading of > 0.4, indicating good factor loading of all the items (15). Hence, these findings further strengthen the notion that the FoP-Q-SF is a unidimensional tool as suggested by the original English, the Chinese, and the Dutch versions of the FoP-Q-SF (11, 12, 16, 17).

There were a few limitations to consider in this study. First, the socio-demographic and clinical characteristics of this study were not representative of the socio-demographic and clinical factors distribution of the Malaysian cancer population. Moreover, the participants in the assessment of face validity was also not recruited according to different education background and ethnicity representative of the multicultural and multiethnic distribution of Malaysia. Hence, the findings of this study may not be generalized to the entire Malaysia cancer population. Second, criterion validity was not assessed in this study as the Fear of Cancer Recurrence Inventory, an instrument for comparison which measure similar construct as the FoP-Q-SF, has not been translated and validated in the Malay language. Finally, a few psychological complications of cancer and its treatment, such as depression, anxiety and posttraumatic stress symptoms were not assessed in this study. These complications could act as confounding factors which may affect the evaluation of the psychometric properties of the FoP-Q-SF-M leading to unreliable findings. Hence, we recommend future validation studies of the FoP-Q-SF-M to control for these psychological complications.

The FoP-Q-SF has been translated to and validated in only a few languages, such as in Chinese (16), Dutch (17), and Korean (21). The Chinese version of the FoP-Q-SF was validated in the Singaporean cancer patient population. Similar to Malaysia, Singapore is a country with diverse cultures and ethnicity. This validation study conducted

in Singapore also pointed out the difficulty to recruit a sample representative of the Singaporean cancer patient population, identical to the difficulty encountered in our study (16). In addition, the validation study of the Dutch version of the FoP-Q-SF highlighted the absence of a cutoff score of the FoP-Q-SF to identify high level fear of cancer progression. This is a major disadvantage which limit the use of the FoP-Q-SF to monitor the therapeutic response of psychosocial intervention to manage dysfunctional level of fear of cancer progression in future studies (17). Hence, the limitations identified in our study as well as those mentioned in the validation studies of the Chinese and Dutch versions of the FoP-Q-SF, must be taken into consideration when designing future studies for further assessment of the measurement quality of the questionnaire.

Despite these limitations, the study has a few clinical implications as it translated and validated the FoP-Q-SF-M for use in the cancer population in Malaysia to assess fear of cancer progression. This would give valuable data to researchers and treating clinicians regarding the degree of fear among cancer patients and how this variable is related to various psychological complications and positive psychology in cancer patients. Data on fear of cancer progression may also act as a guidance for investigating the efficacy of psychosocial interventions for management of this negative outcome among cancer patients.

CONCLUSION

This study successfully translated the English version of the Fear of Progression Questionnaire-Short Form (FoP-Q-SF-M) into the Malay language and validated the psychometric properties of the FoP-Q-SF-M. Our findings concluded that the FoP-Q-SF-M achieved excellent reliability in term of internal consistency and had good face, content, convergent, and discriminant validity. Construct validity of the FoP-Q-SF-M also indicated that it is a unidimensional instrument similar to the original English version and a few translated versions of the questionnaire. Hence, the FoP-Q-SF-M is a valid tool for use to assess the degree of fear of cancer progression among Malaysian cancer patients.

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