

PARTICIPATION RESTRICTION IN CANCER SURVIVORS: A CROSS-CULTURAL ADAPTATION AND PSYCHOMETRIC EVALUATION OF OCCUPATIONAL GAP QUESTIONNAIRE

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Abstract

Cancer survivors have unmet needs of preexisting functional limitations but there is very limited knowledge of the participation in daily occupation. The study aimed to translate and cross culturally-adapt, of the Occupational gap Questionnaire (OGQ) which measures restriction in daily life into Malay language. Second aimed is to evaluate the psychometric properties of the Malay version of OGQ on 33 cancer survivors aged from 18 to 70 years old attending a community program between February to April 2014. A cross-sectional study and non-random sampling was conducted in two phases: 1) Translation and Cross-cultural adaptation that involved backward and forward translation of OGQ from English into Malay, and process of face and content validation that involved a several pre and post-test. 2) Construct validation and further validated of a Reflective Measurement Model of OGQ-M using Partial Least Square –Structural Equation Modeling (PLS-SEM) analysis. A five point Likert scale of (1: 'Very minimal participation' to 5: 'Very High participation) was added and some items were simplified and modified. The result showed good content validity index (CVI) value of 0.8 for new tool. Intra-correlation coefficients (ICC) for all subscales was good in IADL (0.72 – 0.96) ;Leisure (0.44 - 1.00); Social (0.78 – 1.00) and Work (0.76 -0.78). Further purifying of 30 reflective OGQ-M's items resulted in 19 items, due to the low loading of 11 items from the recommended value of 0.4. Adequate reliability, convergent and discriminant validity were established. The OGQ-M is psychometrically sound, culturally sensitive and user friendly. Therefore, the final OGQ-M can be used for measuring participation restrictions in daily life occupation among Malaysian cancer survivors, and helps enhance occupational therapy intervention for better quality of life.

Keywords: Occupational Gaps Questionnaire, participation restriction, reliability, validity, cancer survivors

Abstrak

Survivor kanser mempunyai keperluan yang tidak dipenuhi yang wujud akibat limitasi kefungsi dan pengetahuan tentang penyertaan dalam aktiviti harian sangat terhad. Matlamat kajian ini adalah untuk menterjemah dan menyesuaikan silang budaya Soal Selidik Jurang Pekerjaan (OGQ) yang mengukur batasan penyertaan dalam aktiviti kehidupan harian. Matlamat kedua adalah menjalankan penilaian psikometrik untuk versi Melayu OGQ ke atas 33 survivor kanser berusia dari 18 hingga 70 tahun yang menghadiri program komuniti di antara bulan Februari hingga April 2014. Kajian rintis keratan rentas dan persamplean bukan kebarangkalian telah dijalankan dalam dua fasa: 1) Terjemahan dan adaptasi silang budaya yang melibatkan terjemahan ke belakang dan ke hadapan OGQ dari Bahasa Inggeris ke dalam Bahasa Melayu, dan proses pengesahan muka dan kandungan yang terlibat beberapa siri pra dan pasca ujian; 2) Kesahan konstruk dan pemurnian konstruk reflektif OGQ-M dianalisa menggunakan Pemodelan Persamaan Struktur Kuasa Dua Terkecil Separa (PLS-SEM). Skala

Likert 5–mata (1: 'Penyertaan paling minimum' hingga 5: 'Penyertaan tertinggi) ditambah dan beberapa item dipermudah dan diubahsuai. Keputusan menunjukkan indeks kesahan kandungan (CVI) yang baik iaitu 0.8 bagi alat baharu. Pekali antara korelasi (ICC) untuk semua sub skala adalah baik dalam IADL (0.72-0.96); Riadah (0.44 - 1.00); Sosial (0.78 - 1.00) dan Kerja (0.76 - 0.78). Pemurniaan 30 item reflektif OGQ-M, menghasilkan 19 item, akibat penyingkiran 11 item kerana faktor loading yang rendah dari nilai 0.4 seperti yang dicadangkan. Justerui kebolehppercayaan yang memadai, penumpuan dan kesahan diskriminan telah diperolehi. OGQ-M terakhir, terbukti secara psikometri, sensitif budaya dan mesra pengguna. Ia boleh digunakan untuk mengukur batasan penyertaan dalam aktiviti kehidupan seharian survivor kanser di Malaysia, dan membantu meningkatkan intervensi Terapi Pekerjaan untuk kualiti hidup yang lebih baik.

Kata kunci: Soal selidik jurang pekerjaan, batasan penyertaan, kebolehppercayaan, kesahan, survivor kanser

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1.0 INTRODUCTION

Cancer survivor is a growing population, with breast, prostate and colorectal cancer as the most common cancer diagnosed among survivors. Daily activities participation restrictions, also aggravated by comorbid age-related health condition are primarily due to functional difficulties [1, 2]. With two-thirds of cancer survivors at above 65 years of age [3] and about one third of those with functional restriction will experienced long term disabilities, such as restricted participation in self-care, domestic, social life, work and leisure activities. There are many unmet needs of cancer survivors are not well addressed [4], including the needs for rehabilitation services [5-7]. Despite functional limitations were frequently reported among survivors, research on the disruption of daily life flow was limited.

With cancer taking a form of a major chronic disease and the increase of life expectancies of more than ten years [3, 8] because of modern and better treatment, the need to manage living with illness effectively is now warranted as it affect their health quality of life. The Malaysia government has developed strategies to address this neglect [9] and there is a huge unmet rehabilitation needs for disease prevention and chronic disease self-management to enhance quality of life of cancer survivors [10, 11].

Occupational therapy for the prevention and management of long term chronic diseases [12-14] can be optimised fully, since the ability to participate in daily life activities is positive correlated with good quality of life and wellbeing of people with disabilities [15].

This study is guided by the theoretical framework from the WHO's International Classification of Functioning, Disability and Health (ICF) [16] which define participation as "involvement in a life situation" [17] has asserted that ICF guides health professionals to choose appropriate assessment and intervention strategies for patient with cancer, where "participation" was highlighted as the main outcome measure in rehabilitation and occupational therapy.

Participation restriction in daily occupation can be measured by using Occupational Gap Questionnaire [18-20] which was developed by a team of Swedish

Occupational Therapists. To our knowledge, no studies have been published in Malaysia, regarding how participation in everyday occupation affected after survive from cancer. From a cultural perspective, it would be interesting to examine whether the gaps in participation differ between socio-cultural backgrounds, especially between Asian and European countries. Findings from previous study revealed that there were some possible cultural effects of participation in everyday life after stroke [21].

Most Malaysian understand Malay language, thus translation to Malay enable to reach out greater group of people. It's important to cross-culturally adapt for local community to ensure properties of the tools are robust and closely maintain [22]

Therefore, the aim of this study was to translate and cross-culturally adapt OGQ into Malay language, evaluate the psychometric properties of OGQ among adult with cancer.

2.0 MATERIAL AND METHODS

2.1 Study Design, Setting and Subject

Upon ethical approval from the Medical Ethics Committee of the University of Malaya Medical Centre (MEC 201311-0508), a cross sectional pilot study conducted from February to April 2014, with purposive sampling on a group of cancers survivors at the Keep Able Cancer Community Centre (KAP), Kuala Lumpur. The KAP is a non-profit organization focusing on providing community-based supportive care services to cancer survivors'.

The sample size for this pilot study was 33 participants as suggested by [23], a minimum of 30 representative of participation for initial scale development survey. A minimum sample size of 33 respondents was calculate using recommendation by [24] in Partial Least Square (PLS), Structural Equation Modeling for a statistical power of 80%; at a significance level 0.05. The inclusion criteria were male and female adults: (i) aged between 18 years and above (ii) had been diagnosed breast, colorectal or other cancers with no metastasis for past one year and (iii) Able to read and write in Malay language.

2.2 Tools

The OGQ is a checklist consist of 30 difference activities and four subscale of Instrumental Activity of Daily Living (IADL), Leisure, Social and Work activities. It has a dichotomous scale of Yes and & No answer to questions "Do you perform the activity now?" and "Do you want to perform the activity now? This measures to what extent individuals perceived a discrepancy between what they want to do and what they actually do, and represent occupational gap. OGQ was proven reliable and valid tool in its original form and in Persia [18, 19, 21].The OGQ has been examined with Rasch analysis previously, where all items demonstrated acceptable goodness of fit supporting internal scale validity and person response validity ($r=0.99$; $z < 1.96$), and was proven valid to measures perceived occupational gaps across different diagnostic groups. Permission to translate and validate the questionnaire into Malay language was obtained from the developer.

2.3 Data Collection Procedure

The development and validation of OGQ involves linguistic and psychometric validation process according to guidelines for cross-cultural adaptation of health instruments [25, 26].Measurement model specification and scale purification and refinement were applied for evaluating the Malay version of Occupational Gaps Questionnaire (OGQ-M) constructs with reflective indicators as explained by [27].

All participants gave their written informed consent before completed questionnaire at the KAP Centre. A baseline demographic questionnaire was used to collect participants' socio-demographic information. To examine test-retest reliability, 30 cancer survivors out of 33 participants were answered the OGQ-M and retest again after two to four week interval. This time interval is acceptable according to [28] to ensure participants were clinically health stable and not memories the questionnaire. Participants rated their agreement using a five-point scale and answered all 30 items representing four construct of instrumental activity of daily living, social, leisure and work activities. The OGQ-M was evaluated in two phase:1) Translation, face and content validation 2)Test-retest reliability and evaluation of the Reflective Measurement Model for convergent validity, composite reliability and discriminant validity.

2.4 Data Analysis

Participants' characteristics were analysed by using descriptive analysis. Intra class correlation coefficient (ICC) was computed to examine test-retest reliability. An ICC value greater than 0.80 indicated good test-retest reliability and stability [29].The construct validity of the questionnaire was performed using variance based Structural Equation Modelling (SEM), and specifically Partial Least Square path modelling (PLS).

The OGQ-M's items were measured using Likert scale and multidimensional, which are small and unknown distribution of data [30].Therefore, PLS-SEM was preferable to variance based SEM. The software SmartPLS 3.0 was used to validate reflective measurement model [31].

The reliability of the reflective measure of OGQ-M was assessed at construct and indicator level. Internal consistency of each indicator was determined using composite reliability (CR). CR value of 0.7 or above was considered to be satisfactory for established constructs and above 0.6 value for new construct[24].

Validity was evaluated by using convergent and discriminant validity. Convergent validity was established by examining the outer loadings of the measurement indicators (higher than 0.70) and average variance extracted (AVE) (higher than 0.5) of the model's constructs. Indicator reliability is shown by high outer loadings, value of 0.70 or higher is recommended. However, a value of 0.40 or higher was acceptable in exploratory research[32].Removing indicators from the construct was considered to increase CR and AVE above the suggestion threshold and construct's content validity. Thus, indicator that have very low outer loading values (below 0.40) were eliminated from the construct [32].Discriminant validity is demonstrated when a construct shares more variance with its measurements variables than with other constructs. Two criteria were used to appraise the reflective constructs were sufficiently distinct from each other. First, the Fornell-Lacker criterion, where discriminant validity was confirmed when the AVE of a composite construct is higher than the construct's highest squared correlation with any other composite construct. Second, the cross-loadings of each indicator was compared to see whether the loadings highest on its associated construct [33].There was an issue of discriminant validity if the loadings exceeded the indicators' outer loadings.

3.0 RESULTS

3.1 Sample Characteristics

There were 33 cancer survivors agreed and consented to participate in this study. The mean and standard deviation of age and duration after surgery was 52.0 ± 9.9 year and 2.0 ± 0.84 respectively. Female participant were the majority (69.7%) compared male respondents 30.3%. The participants were 51.5% Malay, followed by 39.4% Chinese and 9.1% Indian. Majority of the samples were diagnosed as Breast cancer (51.5%), followed by Colorectal cancer (36.5%) and other cancer (12.1%).

3.2 Phase One

3.2.1 Translation and Cross-Cultural Adaptation

Initially, a professional translators and a team of four bilingual health professionals (two occupational

therapists) and two nurses from clinical and education setting) that familiar with the health terminology involved in forward and translation process. A meeting involving those translator and the panels met to review, reconcile and harmonize the forward translation version of OGQ-M. Next, another two independent bilingual translators translated the questionnaire back into English. After that, a multidisciplinary committee comprising of researchers (first and second author), occupational therapists, nurses and physiotherapists met to compare the translated versions and resolved any ambiguities and discrepancies. Items that did not retain the original meaning were forward-translated and back translated again.

3.2.2 Face Validity

The OGQ-M was pretested to three cancer survivors, five caregivers of the target population and two occupational therapists who had experience in cancer rehabilitation. This was aimed to establish the acceptability of the scale in the context where it will be applied and to ensure the scale measures what it supposed to measure. Participants were asked to rate the instructions and items of the questionnaire using a dichotomous scale (clear and unclear) and they were also asked to make suggestions for improvement. Some items were slightly simplified and modified.

3.2.3 Content Validity

Next, a group of panels consisting of rehabilitation experts further examined the content validity of the questionnaire and the clarity of instruction, items and response format. The content validity index for items (I-CVI) and for scales (S-CVI) were calculated according the method suggested by [28]. Overall content validity (CVI) for OGQ-M was calculated by using the mean percentage of items with a score of three or four, divided by the total number of panels. The panels scored each of the 30 items based on clarity, simplicity and relevance using four point scale. For six to ten experts, the minimum value of CVI is 0.78, while 0.90 or higher is consider excellent content validity [28]. In this study, six experts completed the content validity score sheet and achieved acceptable CVI of 0.8. The final OGQ-M was modified in term of questioning: Do you participate in this activity? If the response is Yes, items were further evaluated using a 5 –point Likert scale from 1 (very minimal participation) to 5 (very high

participation) in rating the activity participation. While if the response is No, it indicates participant not participate or has a gap in the activity.

3.3 Phase Two

3.3.1 Test – Retest Intra-Correlation Coefficient (ICC) Reliability

The test-retest was satisfactory to good, with ICC value range from 0.72 to 0.96; 0.78 to 1.00 for IADL and Leisure; and 0.76 to 0.98; 0.76 to 0.98 for Social and Work scale.

3.3.2 Evaluation of the Reflective Measurement Model

In this study, eleven indicators with low outer loading value lower than 0.4 were deleted in order to achieve the recommended level of indicator reliability. Table 1 shows, the CR values of IADL (0.905), Leisure (0.892), Social (0.941) and Work (0.883). The values indicates that all four reflective constructs have high internal consistency reliability. Convergent validity assessment builds that was determined by AVE values were (higher than 0.5), which were above minimum requirement. In this study, the AVE values were of 0.659 (IADL), 0.674 (Leisure), 0.801 (Social), 0.715 (Work). Therefore, it can be said that the measurement for four reflective constructs have high level of convergent validity.

Table 2 shows the diagonal (in bold) values, which represents the AVE and the squared correlations of reflective constructs according to Fornell Larcker approach. Generally, the square roots of the AVEs for the reflective constructs were 0.744 (IADL), 0.819 (Leisure), 0.815 (Social), 0.755 (Work) which were higher than the correlations of these constructs.

In addition, the table shows the loadings and cross loadings for each indicators (in bold) that indicates discriminant validity established when an indicator's loading on a construct was higher than all cross loading with other constructs. Overall, cross loadings and Fornell-Lacker criterion provided evidence for reflective construct's discriminant validity of OGQ-M.

In conclusion, the results of the reflective measurement model met all model evaluation criteria, providing support for the reliability and validity of the OGQ-M. Table 3 shows the indicators of OGQ-M which is much shorter (19 indicators) than the original OGQ.

Table 1 Reflective measurement model's reliability and validity

Latent variables	Indicators	Loadings >0.4	Indicator Reliability (=Loadings ²)	Composite Reliability >0.7	AVE ≥0.5	Discriminant Analysis
Activity of Daily Living (IADL)	IADL1-Grocery shopping	0.827	0.683	0.905	0.659	Yes
	IADL2-Cooking/Preparing meal	0.787	0.619			
	IADL3-Doing laundry	0.886	0.784			
	IADL4-House cleaning	0.587	0.345			
	IADL7- Managing personal finances	0.687	0.472			
Leisure Activities	IADL8-Transporting oneself	0.553	0.305	0.892	0.674	Yes
	LEIS3- Participating Outdoors activities	0.757	0.573			
	LEIS5-Cultural activities	0.837	0.700			
	LEIS6-Listening to radio	0.837	0.700			
Social Activities	LEIS7-Reading newspaper	0.891	0.794	0.941	0.801	Yes
	SOC1-Visiting partner/children with	0.792	0.627			
	SOC2-Visiting relatives/friends/neighbor	0.946	0.941			
	SOC3-Helping & support others	0.926	0.857			
	SOC5-Participating in religious activities	0.593	0.351			
	SOC6-Visiting restaurants	0.806	0.650			
	SOC7-Travelling for pleasure	0.687	0.472			
Work Activities	WORK1-Working full time/part time	0.842	0.682	0.883	0.715	Yes
	WORK3-Taking care of and raising children	0.826	0.682			
	WORK4-Performing voluntary work	0.874	0.764			

Note: IADL5, IADL6, LEIS1, LEIS2, LEIS4, LEIS8, LEIS9, LEIS10, LEIS11, SOC4, and WORK2 were deleted due to low loadings; AVE= Average Variance Extract

Table 2 Discriminant Validity of reflective constructs

	IADL	LEISURE	SOCIAL	WORK
Fornell-Larcker criterion				
IADL	0.744			
LEISURE	0.627	0.819		
SOCIAL	0.575	0.684	0.815	
WORK	0.496	0.724	0.700	0.755
Cross loadings				
IADL1	0.804	0.534	0.531	0.570
IADL2	0.715	0.440	0.209	0.194
IADL3	0.813	0.630	0.403	0.428
IADL4	0.810	0.541	0.437	0.451
IADL7	0.743	0.677	0.643	0.514
IADL8	0.540	0.414	0.420	0.257
LEIS2	0.454	0.754	0.441	0.625
LEIS5	0.712	0.840	0.643	0.544
LEIS6	0.598	0.874	0.709	0.640
LEIS7	0.598	0.805	0.541	0.652
SOC1	0.484	0.617	0.936	0.777
SOC2	0.626	0.686	0.914	0.779
SOC3	0.508	0.550	0.857	0.716
SOC5	0.256	0.402	0.644	0.532
SOC6	0.618	0.671	0.769	0.689
SOC7	0.288	0.199	0.730	0.415
WORK1	0.288	0.647	0.6684	0.888
WORK3	0.341	0.637	0.585	0.717
WORK4	0.334	0.554	0.803	0.897

Note: Value in bold indicate i. the squared root value of AVE of each construct higher than its highest correlation with other constructs (Fornell-Larcker) ii. An indicator's outer loadings on a construct should be higher than all its cross loadings with other constructs.

Table 3 Items Included and Excluded in the Malay Translation of the Perceived Occupational Gaps Questionnaire (OGQ-M) ^a

Constructs	Indicators/Items
Items included in the OGQ-M scale	
Instrumental Activity of Daily Living(IADL)	IADL1-Grocery shopping IADL2-Cooking IADL3-Doing laundry IADL4-Cleaning IADL7-Managing personal finances IADL8-Transporting oneself
Leisure Activity (LEIS)	LEIS3-Participating in outdoors activities LEIS5-Participating in cultural activities LEIS6-Listening to radio/watching TV/videos LEIS7-Reading newspapers/news /magazines
Social Activities (SOC)	SOC1-Visiting with partner/children SOC2-Visiting relatives/friends /neighbors SOC3-Helping and supporting others SOC4-Involvement in activities in societies/clubs/unions SOC5-Participating in religious activities SOC6-Visiting restaurants and café SOC7-Travelling for pleasure
Work Activities (WORK)	WORK1-Working, full or part time WORK2-Studying full or part time WORK3-Taking care and raising children Work4-.Performing voluntary work
Items not included in the OGQ-M due to low loading (<0.40)	
Instrumental Activity of Daily Living(IADL)	IADL5-Doing light maintenance of home, garden, car IADL6-Doing heavy duty maintenance of home, garden and car
Leisure Activity (LEIS)	LEIS1-Shopping LEIS2-Participating in sports LEIS4-Participating in hobbies LEIS8-Reading books/ periodicals LEIS9-Writing LEIS10-Playing indoor games LEIS11-Playing computer/surfing internet
Social Activities(SOC)	SOC4-Involvement in activities in societies/clubs/unions
Work Activities(WORK)	WORK2 –Studying full or part time

^aParticipants answer questions: Do you performed this activity? Yes/No. If Yes participants rate each item on a Likert-type scale of 1:“Very minimal participation” to 5:“Very High participation.”

4.0 DISCUSSION

The Malay version of the OGQ was found to be valid and reliable to assess participation restriction of survivors with cancer in Malaysia as it shows good construct validity and reliability.

. The face and content validity of the questionnaire were confirmed after revisions including developing five Likert scales range from of very little to highly participate in the activities. Test-retest reliability coefficients were satisfactory to good, which ranged from 0.719 to 1.00. Eleven indicators were deleted due to very low outer loadings (below than 0.40). Removing the indicators contributed to increase in the composite reliability and variance extracted above threshold value. [34]asserted that dropping an indicators in reflective constructs, should not alter the

conceptual domain of the construct. Therefore, the shorter reflective scale OGQ-M with 19 indicators shows good indicator reliability, internal consistency, and able to discriminate across different constructs. [35] asserted that a few best indicators, more than three were rarely warranted because the redundant indicators provide less research benefit than single indicators of additional latent variables.

Even though the QGQ–M is different from the Sweden version, the psychometric properties were satisfactory compare to previous studies. It can be said that this succinct Malay scale is the most appropriate for capturing perceived occupational gaps in the Malay-speaking population. The limitation of this study are non-random sampling and a small sample size that restrict the generalization of the results.

5.0 CONCLUSION

This OGQ-M shows evidence of internal consistency and indicator reliability, convergent and discriminant validity indicating this questionnaire generate valid and reliable measure. It is short, acceptable and culturally meaningful to the Malay speaking cancer survivors. Further large scale studies in healthy subjects and varied patient diagnosis are recommended to generalize the findings.

6.0 DECLARATION OF INTEREST

The authors have no conflict interest to report. The first author was sponsored by Ministry of Health, Malaysia and this study is a part of her master degree project at the University of Malaya, Malaysia.

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