

ORIGINAL ARTICLE

QUALITY OF LIFE AMONG PREINVASIVE & INVASIVE  
CERVICAL CANCER IN MALAYSIA

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Abstract

**Objective:** This study aims to determine the quality of life (QOL) of Malaysian women based on their physical and mental scores and correlates with age and cervical disease severity. **Methods:** This is a cross-sectional study from Nov 2006 till Dec 2007 from participating Gynecology-Oncology outpatient and in patient's wards. QOL interviews used the SF-36 questionnaires. Main domains were the Physical Composite Scores (PCS) and the Mental Composite Scores (MCS). **Results:** A total of 396 participated in the study. Mean respondents age were  $53.31 \pm 11.21$  years, educated till secondary level (39.4%), Malays (44.2%) with mean marriage duration of  $27.73 \pm 12.12$  years. Among pre-invasive diseases, the cervical intra epithelial neoplasia (CIN) 1 was the highest in percentage of cases (8.1%). Among invasive cancer, stage 1 cancer was highest (31.1%), followed with stage 2 (28.3%), stage 3 (7.3%) and stage 4 cancers (5.8%). PCS scores are highest among the pre-invasive and stage 1 cancer ( $F=4.357$ ;  $p<0.0001$ ) and influenced by age and income. MCS were not significantly influenced by age or stage of cervical diseases ( $F= 1.393$ ;  $p=0.206$ ) but the regression model showed that amount spent on health care was a significant factor. **Conclusion:** Cervical diseases posed a substantial cause in reducing QOL with increasing age and disease severity. This disability can be reduced with early screening and intervention to prevent disease progression. Reducing disease burden play a role to improve QOL among at risk women before developing late stages of disease. *ASEAN Journal of Psychiatry, Vol.10, No.2, July – Dec 2009: XX XX*

**Keywords:** Cervical cancer, quality of life, physical composite scores, mental composite scores.

## **Introduction**

Cervical cancers are the second top cancers affecting females in Malaysia following breast cancers in the year 2003. The standardized incidence rate is 19.7/100,000 population [1]. The figure is not the best as developed countries with established screening either opportunistic or mandatory has a much lower incidence of cervical cancer. The Pap smear coverage that is only around 30-40% of women in Malaysia contributes to this problem [1].

As with any cancer, the social, emotional and economic impact of management of this disease to either individual basis or the population is tremendous. The events that occurred after cancer, does not only affect the physical body but also to the mind and the overall quality of life of affected women.

This study is justified to increase local research of burden of cancer disease. This study aims to determine the quality of life (QOL) of Malaysian women based on their physical and mental scores and correlates with age and cervical disease severity.

## **Methods**

The multicentre cross sectional study commenced from November 2006 until December 2007. Prior to the study initiation, approvals were obtained from the central ethics committee of the University Kebangsaan Malaysia

Medical Centre (UKMMC) and Ministry of Health (MOH) Malaysia [1].

The SF-36 (Short form-36) is an appropriate tool for assessing quality of life of women. It has been validated for local use [2,3] thus it was the tool of choice for this study. Eight specific domains (physical, social and role functioning, mental health, health perceptions, energy fatigue, pain and general health) were obtained from this tool, all eight scales are first standardized, and then z-scores are multiplied by the factor score coefficient for each scale. In the last step, transformation of physical and mental composite summary scores to a mean of 50 with a standard deviation of 10 was done [4].

The respondents, included women aged 18 years and above with established cervical pre invasive and invasive diseases from six public tertiary hospitals in Malaysia. The exclusion criteria were women who did not want to participate for whatever reason to their discretions and respondents who were too ill to participate.

Purposive samplings of public hospitals in this study are from hospitals involved in clinical managements of treating pre invasive and invasive disease that provides investigative procedures, surgical operational treatments, chemotherapy and radiotherapy. The hospitals must also possess sufficient technical skills in gynae-oncology specialty and Consultants as permanent

staffs, not visiting or rotating basis. These hospitals were Kuala Lumpur Hospital, Tuanku Jaafar Hospital Seremban, Tuanku Bahiyah Alor Star Hospital, University Kebangsaan Malaysia Medical Centre (UKMMC), Tengku Ampuan Afzan Kuantan Hospital and Tuanku Fauziah Kangar Hospital.

After meticulous training, research assistants were dispatched to these hospitals to carry out the guided direct interviews with respondents. The SF-36 interviews took place in the in patients wards and out patients clinics when the respondents come for their clinic appointments, follow-ups or procedures. The interviewers were taught to be discrete but attentive to the patients and answers were filled in the questionnaires. Respondents' basic demographic data and disease stage were also collected. The domains in the SF-36 (physical or mental health) were as follow:

1. Limitations in physical activities (physical health).
2. Limitations in usual role activities because of physical / emotional problems (physical health).
3. Bodily pain (physical health).
4. General health perceptions (physical health).
5. Limitations in social activities (mental health)
6. General mental health (mental health)
7. Limitations in usual role activities because of emotional problems (mental health)
8. Vitality - energy and fatigue (mental health)

The analysis was done using the Statistical Package for Social Studies (SPSS) version 15 assuming normality data, ANOVA and LSD post hoc analysis.

For estimation of life years that can be saved (if they do not develop cervical cancers or its pre-invasive diseases), the respondents current age were then estimated to live their full life based on the Malaysian populations statistics [5]. A new life table based on life expectancies (if they have cancers) was calculated [6] based on United Kingdom 2005 cervical cancers mortality and morbidity data. The life tables were calculated between women who did not develop cancers and compared with life expectancy when they did get cancer generated the amount of life years that saved.

The cervical disease stages were determined from collaborative clinicians and experts' discussions, based on the local Clinical Practice Guideline [7] and their clinical management expertise on cervical cancers and its pre-invasive stages. The stages were as follows: Atypical Squamous Cell of Unknown Significance (ASCUS), Low-Grade Squamous Intraepithelial Lesion (CIN 1) and High-Grade Squamous Intraepithelial Lesions (CIN 2-3) were later combined as the pre-invasive stage category. Invasive cancers were described as stage 1A1 (carcinoma in situ), 1A2, 1B-2A, 2B-4A and lastly stage 4B as the most severe form of advanced stage of cancer and highest mortality. This staging was based on previous clinical pathway experts' group discussion and published elsewhere [8]

Lastly, analysis of factors thought to influence the quality of life in linear regression analysis modeling, to determine the influencing factors of Physical Composite Scores (PCS) and Mental Composite Scores (MCS) in our Malaysian women. The independent variables taken into account were patient's age, length of marriage duration, patients' education, patients and spouse's income, disease stage and amount spent on healthcare. Modeling of variables was by 'enter' method.

## **Results**

### ***Socio Demographic Profiles of Respondents***

Three hundred ninety six respondents participated in this study. Respondents came from Kuala Lumpur Hospital (34.3%), Hospital Tuanku Jaafar Seremban (22.5%), Tuanku Ampuan Bahiyah Hospital Kedah (19.7%), UKMMC (16.4%), Hospital Tuanku Fauziah Kangar (5.1%) and Hospital Tengku Ampuan Afzan Kuantan (2.0%).

Mean age of respondents were  $53.31 \pm 11.21$  years i.e. the slightly older women. The highest percentage came from the 45-54 age group (31.8%), from 55-64 age group (27.8%), 65 years old and older age group (17.7%) and 35-44 years age range (17.7%). Only 0.51% of women were from less than 25 years old

women. The mean age by cervical cancer, stages are as follows. In the Pre-Invasive Stages, the mean age is 47.2 years  $\pm 11.34$ . From stage 1A1 (or carcinoma in situ) mean age is 54 years  $\pm 10.17$ , stage 1A2 the mean age is 57.8 years  $\pm 9.56$ , stage 1B -2A the mean age is 55.4 years  $\pm 10.48$ , stage 2B-4A the mean age is 55.9 years  $\pm 10.38$  and stage 4B the mean age is 55.6 years  $\pm 7.9$ . It shows that the pre invasive stages are mainly sufferers from the younger age group.

Majority were educated until secondary school level (39.4%), followed by the primary school level (37.9%), never been to school (21.0%) and tertiary educational level (1.8%). By ethnicity the Malays is the largest proportion of respondents (44.2%), followed by the Chinese (40.7%), Indian (13.6%) and others (1.5%). This reflects the country's ethnic profile as the Malays are the largest ethnic group in Malaysia, followed by the Chinese and Indians. The mean duration of marriages is  $27.73 \pm 12.12$  years.

By cervical disease stages, most of the patients are from the stage 2B-4A (34.1%), stage 1B until 2A (30.8%), stage HSIL (14.4%) and LSIL (8.10%). Stage 1A2 (2.0%) and advanced stage 4B (2.5%) are the least seen amongst our respondents because of survival factors.

**Table 1: Distribution by Stages of Pre-Invasive and Invasive Cancers**

<i>Cervical cancers Stages</i>	<i>Clinical Pathway Cervical Cancers Stage</i>	<i>Frequency</i>	<i>Percent</i>
Pre-Invasive Cancers	ASCUS	20	5.1
	LSIL (CIN 1)	32	8.1
	HSIL (CIN 2 and 3)	57	14.4
Invasive Cancers	Stage 1A1	12	3.0
	Stage IA2	8	2.0
	Stage 1B till 2A	122	30.8
	Stage 2 B-4A	135	34.1
	Stage 4B	10	2.5
Total		396	100.0

Based on table 2, majority of respondents are not working (74.5%), had retired and are now full time house wives; 11.1% are still working full time, 8.8% are working part time, 4.8% are self employed and 0.8% are working on and off basis when health permits. Thus formal income from work is not normally distributed. Besides their own income they were also supported by spouse and family members. Thus its not a surprise that majority of respondents do not have a steady income or no income at all (78.8%). For those who were still working, the mean monthly value for a person's self income is RM 739.9 ± 427.60.

Respondents quality of life was compared between normal women's QOL [3] and showed a decrease of QOL among cervical diseases and cancer (as higher scores on scales reflect a better health state). The published paper on Malaysian's QOL<sup>3</sup> was to represent the whole country's dynamic population using nationwide household community

survey. Samples were selected together with the Department of Statistics through enumeration blocks and living quarters. Level of education and employment was supposedly well represented in the survey however the income status of these women population was not noted.

#### *Quality of Life and Age*

Based on table 3, mean PCS was 39.77±10.19. PCS is significantly associated with age (F=7.590; p<0.0001). Post hoc analysis with LSD showed that PCS was significantly different in all categories of age except in women less than 25 years of age.

Correlation shows that as age increases, PCS scores decreases at r=-0.307 and this is significant at p<0.0001. Mean MCS was 47.43 ± 8.37. However, MCS was not associated with age at r= 0.037 (F=0.569; p=0.724). The mental component was not affected by women's age

**Table 2: Comparative QOL Domains between Normal Women and Cervical Diseases**

Domains of SF-36	Normal Population	Pre-invasive & Invasive Disease
PF(Physical Functioning)	86	52.88
REP(Role Limitation-Physical)	82	47.03
BP(Bodily Pain)	70	61.6
GH(General Health)	66.7	58.36
VT(Vitality)	66.8	59.37
SF(Social Functioning)	83.7	72.54
REE(Role Limitation-Emotional)	79.2	51.94
MH(Mental Health)	74.7	66.31

**Table 3: QOL relationship with Age of Patients (Years)**

Age Range	N	PCS		F	p	MCS		F	p
		Mean	SD			Mean	SD		
<25	2	49.17	3.45	7.590	<0.0001*	43.99	10.62	0.569	0.724
25-34	18	48.43	7.32			47.95	5.68		
35-44	70	43.07	10.94			46.24	7.66		
45-54	126	39.84	10.27			47.33	7.85		
55-64	110	38.65	8.91			48.23	8.79		
65 >=	70	35.61	9.61			47.50	9.84		
Total	396	39.77	10.19			47.43	8.37		

\*p is significant if <0.05 SD = Standard deviation

### Quality Of Life And Disease Severity

Through the cancer stages, the highest PCS is among the respondents from the pre-invasive cervical cancers and stage 1 cancers. Advanced stage of diseases i.e. stage 4 has the least scores on PCS (F=4.357; p<0.0001) and proved

physical functions deteriorates with increasing severity of diseases.

MCS showed no association with increasing severity (F=1.393; p=0.206) as if the mental component was not affected with increasing stages of diseases (table 4).

**Table 4: QOL relationship with Disease Severity**

Age Range	N	PCS		F	p	MCS		F	p
		Mean	SD			Mean	SD		
Pre-Invasive Cancers	109	42.58	10.42	4.357	<0.0001*	47.15	7.33	1.393	0.206
Stage 1	123	41.11	10.05			48.82	8.10		
Stage 2	112	36.92	9.20			45.95	8.87		
Stage 3	29	37.59	9.26			49.18	7.56		
Stage 4	23	35.88	11.08			46.33	11.59		
Total	396	39.77	10.19			47.43	8.37		

\*p is significant if <0.05 SD = Standard deviation

**Life Years Saved**

Life expectancy for women without cancers, were based on the life expectancies by different age groups of normal women in Malaysia [5,6,9]. The mean age for these women was the ripe old age of 81.40 ± 2.66 years. However, with cervical cancers, their life expectancies were shortened due to the

disease, subsequent management and complications, to the age of only 68.31 ± 3.83 years. From the differences between normal life expectancies compared with life expectancies when they develop cervical cancers, the mean life years saved was 13.06 years ± 3.2. This difference was significant at p<0.0001 (table 5).

**Table 5: Life Years Saved between Normal Women and Cervical Cancers**

Age (Years)	Life Expectancy (Years)		Life Years Saved
	Normal women	Women with cervical cancer	
20-24	56.96	44.79	12.18
25-29	52.09	39.81	12.28
30-34	47.22	34.83	12.39
35-39	42.38	29.85	12.53
40-44	37.58	24.89	12.69
45-49	32.87	19.92	12.95
50-54	28.29	14.95	13.34
55-59	23.85	9.98	13.87
60-64+	19.64	4.99	14.64

From the multiple regression analysis, the significant factors in predicting patients PCS were patient's age -0.224 (95% CI: -0.317 to -0.131) at  $p < 0.0001$  and patient's income 0.001 (95% CI: 0.0001 to 0.003) at  $p = 0.037$ . The adjusted R square was 11.2%. All other factors are not found to be significant in

influencing PCS in this model. See table 6. These results are not surprising as patients age is negatively correlated with physical scores. Increase in age will reduce physical perception and how they score it in this study. Patients income will increase physical scores in our studied patients (table 6).

**Table 6: Factors Affecting PCS of Cervical Pre-invasive and Cancer Patients**

<i>Factors in the Model</i>	<i>Coefficient B</i>	<i>95% CI</i>		<i>p value</i>
Patients Age	-0.224	-0.317	-0.131	0.000*
Marriage Duration	0.035	-0.025	0.094	0.251
Patients Income	0.001	0.0001	0.003	0.037*
Spouse Income	0.000	0.000	0.001	0.213
Disease Stage	-0.539	-1.094	0.016	0.057
% of Income Spent on Health care	0.042	-0.089	0.174	0.527

\*p is significant if  $< 0.05$  CI = Confidence interval

In factors affecting MCS, the Adjusted R square was 1.1 % only (table 7). The significant factor was how much percentage spent on health care with B at -0.132 (95% CI: -0.245 to -0.018) at

$p = 0.023$ . All other factors were not significant in affecting MCS. Collinearity statistics showed that all the above factors do not show multicollinearity.

**Table 7: Factors Affecting MCS of Cervical Pre-invasive and Cancer Patients**

<i>Factors in Model</i>	<i>Coefficient B</i>	<i>95% CI</i>		<i>p value</i>
Patients Age	0.040	-0.040	0.121	0.326
Marriage Duration	0.033	-0.019	0.085	0.209
Patients Income	1.09E-006	-0.001	0.001	0.998
Spouse Income	0.00005	0.0002	0.001	0.069
Disease Stage	-0.080	-0.561	0.400	0.743
% of Income Spent on Health care	-0.132	-0.245	-0.018	0.023*

\*p is significant if  $< 0.05$  CI = Confidence interval

## **Discussion**

Cervical cancer or pre invasive diseases are a burden to the survivors of this disease. Once inflicted, survivors have reduced quality of lives and life years [10,11]. The women studied consisted mainly of elderly women spending most of their time within family surroundings. Education wise, high proportion of our women received secondary level education. These women were sampled from public hospitals which receive funding through the government's tax payers money. This makes most of the health care services accessible to them, be it primary care to highly subsidised governments' tertiary care [5-9]. Health care and services received are free or fee is paid through a very small percentage from the total hospital billings.

The Asian culture, which places a significant amount of responsibility of caring for the women or wife on the shoulder of a male spouse, sometimes through extended family, we can see that these patients are highly dependable on their children for the extra income they need. Eventhough Malaysia is based on multiple payer health care system, health care in the public system is not funded through the compulsory or voluntary insurance [5-9]. Most women would not have to pay any fee however small it may be, and by subsidising health care for cancer women in Malaysia, the government is shouldering most of risk of monetary resources. Questions on whether these women had access to traditional/complemenatry/Chinese medications, or purchase retail pharmaceutical vitamins for health care showed dismal responses as most of our women fully utilises public health care, does not access private health care

services and does not engage in traditional/ complimentary practices. This is not in accordance with other studies that show women receiving complimentary medicine to alleviate the diseases however unworthy that it actually may be [12].

It was noted that the scores by domains of our women are definitely lower compared to the healthy women population of Malaysia [2-3]. This is distinctively seen among the physical domains that constitutes PCS composite score.that are significantly seen to be associated with age and disease severity. Higher scores, showed better perception on physical function. Examples of physical functions activities that were asked in our questionnaire were walking, carrying heavy load and other vigorous activities. The preinvasive diseases and early stage of cancer showed better perception and scoring of physical domains and PCS showed significant decline with increasing age and disease severity. Following thorough analysis with multiple linear regression showed that patients age and income affected physical function perception scores of our women. Age showed decrease relationship with physical function but higher income had some increment in physical functions scores perception. Patients higher income is related with better logistics and availability of resources either for care or support. In comparison with the general women population of Malaysia, all domains showed that women affected with cancers had lower QOL at all domains. This difference is supposedly attributed to the disease presence in cervical cancer women and assuming all other sociodemographic variables are controlled.

Our questionnaire was not able to show and evaluate depression, anxiety or sexual dysfunction that was commonly seen in cervical cancer survivors [13,14]. We also did not assess the social support of these women. However in this study, the MCS does not show any significant changes with age or increasing severity. Our cervical disease survivors came from different cultures and religious background. Studies have shown that long term survivors have adapted to cope with the disease and developed mental preparedness on its outcome and progress of disease [12]. Based on individual beliefs, respondents have high external locus of control, seeing themselves as pawns, thus leaving everything to faith. Mentally this allows them to accept, perpetuated high hopes and positive perception toward this deadly disease. Since most of our respondents are married and have children, these social factors would also have contributed to their mental preparations on the disease, hence not showing MCS changes with increasing age and disease severity. Linear regression analysis showed that percentage of income spent on health care significantly contributed to MCS, whereby as MCS reduced with increased burden of health care spent by out of pocket payment method. This method of payment increases risk of catastrophic poverty by increasing risk to the payer's household. Surprisingly patients and spouse income did not seem to influence or affect mental scores of patients. It seem that how much a person has to pay for health care affects the mental state of these women.

Without cancers, these women would have lived to their full extent of the lives [15]. However, with reduced years

secondary to cancer, its treatment or other non related causes [16] had shown that cancer survivors had an increased chance of earlier death compared to the normal population. The loss of years to cancer could have been avoided if the women comes early for screening, allowing detection of diseases and interventions hence improving survival outcomes [8].

### ***Conclusion and Recommendations***

Patients quality of life and loss of life years to cancer is much affected, especially so with increased stage of cervical cancers. The PCS is more affected than MCS in our Malaysian women and this might be exceptional for Malaysia. In order to reduce this effect and as dramatic eradication of cervical cancers is a future possibility with the introduction of cervical cancers vaccination, it would not be a far fetched idea that the life years lost to cancer and lost in quality of lives of cancer stricken patients can be prevented in our society.

### **Acknowledgement**

We would like to thank Dr. Maimoon Alias, Dr. Majdah Mohamed from the Ministry of Health. Dr. Murali G. Muralitharan from the Kuala Lumpur Hospital, Dr. Fuad Ismail, Dr Sharifah Noor Akmar, Dr Nur Ismah, Dr. Seri Suniza Sufian and Dr. Ahmad Zailani Mohd Dali from the National University of Malaysia Medical Centre for their input during the first clinical pathway workshop. We would also like to thank the various hospital directors namely Kuala Lumpur Hospital, Tuanku Jaafar Hospital Seremban, Tuanku Bahiyah Alor Star Hospital, UKM Medical Center, Tengku Ampuan Afzan Kuantan Hospital and Tuanku Fauziah Kangar

Hospital and head of O&G departments for allowing this study to proceed in the various units in Malaysia. This study was funded by the Merck, Sharp and Dome through the Public Health Specialist Association of Malaysia.

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Received: 12 February

Accepted: 16 Mac 2009