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Socio-Demographic Factors and Quality of Life of Head and Neck Cancer Patients Before and After Treatment in the East Coast of Malaysia

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ABSTRACT

Objective: This study aimed to determine the association of socio-demographic factors and quality of life (QOL) of HNC survivors before and after treatment in Malaysia. **Methods:** 40 HNC patients were recruited, and assessed for their with QOL with Life Cancer Survivor (QLQ-CS) Head & Neck 35 (QLQ-H&N35) questionnaire pre-treatment and six months post-treatment. One way analysis of variance (ANOVA) and paired t-test were done to analyse the data. **Results**: The result shows that the QOL of HNC patients were at medium level (total mean score M= 6.22) before treatment, and reduced (total mean score M= 4.84) at 6 months after treatment) . Only health history was seen significantly associated with QOL of HNC patients, both pre and post-treatment. Post treatment showed only marital status factor associated with QOL of HNC patients. The paired sample t-test result shows that the symptoms /problem pre- treatment (M = 255.10, SD = 20.405)was lower than post treatment (M = 201.80, SD = 22.025)(t (49) = 9.337; p =0.001). **Conclusions:** The present research suggested that the patients' QOL is reduced after treatment (medium level). This could be due to the advancement of the cancer and evidence when the health history and symptoms found significantly associated with the QOL. Thus, socio-demographic factors is very crucial factors that must be considered during patients' assessment in improving patients' care and optimum QOL pre and post treatment.

KEYWORDS: Socio-Demographic; Head and Neck Cancer; Quality of Life; Treatment

INTRODUCTION

There are several different definitions of quality of life (QOL) across the literature. However, the similarities reflect from their view of QOL which details from various perspectives of an individual's life and attempt for holistic view. One of the most well-known definition is from World Health Organization (WHO) which defines of QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (1).

Ferrell (2) model of QOL have four domains which are (1) physical well-being; the control or relief of symptoms and the maintenance of function and independence, (2) psychological well-being; the attempt to maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes, (3) social well-being; the effort to deal with the impact of cancer on individuals and their roles and relationships, and (4) spiritual well-being; the ability to maintain hope and derive meaning from the cancer experience and characterized by uncertainty.

Quality of life measures the effects of chronic illness, treatments, and short and long-term disabilities and its assessment is an important aspect of the current care for cancer patient. Most studies of the outcomes of cancer treatment have included disease-free survival, tumor response, and overall survival. However, clinicians and researchers have come to realize these outcomes are inadequate for assessing the impact of cancer and its treatment on the patient's daily life, as well as for identifying interventions to improve or maintain the patient's QOL.

In order to enhance the effectiveness of interventions to promote better QOL, identification of the associated factors contribute to head and neck (HNC) patient's QOL is undoubtedly crucial. Many studies found that certain socio-demographic factors related to QOL of HNC patients throughout their cancer survivorship, but varies across cultures(3-6). Malaysia is well-known for its multi-racial country, with total population was 28.3 million of which 91.8 % were Malaysian and 8.2 % were non-citizens. Malaysian consist of the ethnic groups Bumiputera (including Malays) (67.4%), Chinese (24.6%), Indians (7.3%) and Others (0.7%)(7).

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The multi-racial population may give insight into the understanding of socio-demographic factors with relation to QOL of the head and neck cancer population in Malaysia. Thus, this study was carried out to identify the socio-demographic factors and QOL of HNC survivors before and after treatment in Malaysia and examine the association between these two variables.

Socio-demographic factors

Age is one of the factors identified from some studies. Persons who were more than 70 years old had the highest score of QOL compared to other range of age(8). Gender also is one of the factors identified as related to QOL. Among general type of cancer persons in Korea, male had better QOL score compared to female subjects(8). However, there was also a study in Japan that suggested a weak relationship between gender and ethnicity with QOL of head and neck patients(9).

Economic status was clearly described as one of these factors in Fang et al. (5) study on persons with nasopharyngeal cancer where it was significantly related to the level of QOL among them. Patients with higher economic status perceived that they had a better QOL score. Economic status related significantly with head and neck functioning e.g. swallowing, hearing, salivation, taste, and neck stiffness. More adequate economic status described, less severe impairment of head and neck functioning indicated by the patients with HNC.

There was also a study that revealed affective support/emotional and informational support is associated with less fatigue among cancer person which also contribute to better QOL. Network or having social relation and positive interaction found to be the factors which determine level of social support of a cancer person and help in improvement of QOL(10). So et al (11) study demonstrated that number of somatic symptoms, household income, eating ability, support from others, whether the cancer is under control or not and travelling time from home to hospital have direct or indirect effects on quality of life of head and neck cancer survivors.

Health history and tumor/treatment related factors

Tumor-related factors can be characterized by number of cancer symptoms experienced by the patients and the existence of comorbidities (5,8). The most usual cancer symptom was pain, but there were also other experienced symptoms depending on the site of the cancer, e.g. hearing problem, visual problem, loss of appetite, unpleasantness etc. (8,12). More number of the symptoms experienced, lower level of QOL (8). Use of pain killer was also one of the factors which are classified as tumor-related(8).

Treatment-related factors among HNC include salivation, hearing, and swallowing dysfunctions which affect their QOL significantly (5). These three dysfunctions were common complication among the HNC patients(13). Clinical significant improvements in health related QOL were not found between 1 and 5 years and the problems with teeth, opening of the mouth, dryness in the mouth, and sticky saliva were persistent or worsening (14). Nagy et al (15) studied the QOL of HNC patients after treatment found swallowing scored the highest, followed by dry mouth, social contacts, sticky saliva, mouth opening and pain. Thus, to summarize, various aspects of socio-demographic factors could be seen from the literature that may contribute to QOL of HNC patients in various countries. An individual QOL is sourced from many aspects of their lives(16) which clearly surrounds by different belief, culture and even different atmosphere of their lifetime upbringing which contribute to how they value things in lives. Thus, it is worth to examine these factors among researcher's local population to instigate the situation among them.

METHODS

This study aimed to determine the association of socio-demographic factors and QOL of head and neck cancer patients before and after treatment in Malaysian hospitals. A cohort study design was implemented for this study using a self-reported, health – related QOL questionnaire for evaluation. Questionnaire was distributed to the patients before treatment and after 6 months follow-up treatment. 40 patients included were who being first time diagnosed with HNC, age 18 years old and older, and able to understand Malay or English. Non Malaysian, recurrent or metastasized cancer, and refused treatment were excluded.

The study population included was from otorhinolaryngology departments of two general hospitals in East Coast Malaysia who willing to complete the Quality of Life Cancer Survivor (QLQ-CS) and Questionnaire-Head & Neck 35 (QLQ-H&N35) for their QOL measurement. Socio-demographic factors analyzed were; age, gender, race, employment status, marital status, education level, smoking/alcohol habits and health histories from different aspects, including tumor and treatment-related factors (tumor site, tumor type, and treatment type) for their association with QOL before and after treatment.

Quality-of-Life Cancer Survivor (QOL-CS)

The Quality of Life Cancer Survivor instrument is a forty one-item ordinal scale that measures the QOL for general cancer patient. This tool can be useful in clinical practice as well as for research because it has spiritual domain which hardly covered in other instruments. The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (16).

This instrument was revised in cancer survivorship studies and includes 41 items representing the four domains of QOL including physical well-being, psychological well-being, social well-being and spiritual well-being. The overall test re-test reliability was .89 with subscales of physical r=.88, psychological r=.88, social r=.81, spiritual r=.90 and overall analysis using Cronbach's alpha so-efficient was r=.93 with subscales alphas of spiritual r=.71, physical r=.77, social r=.81 and r=.89 for psychological (16).

Questionnaire-Head & Neck 35 (QLQ-H&N35)

The QLQ-H&N35 comprises 35 questions incorporating 7 multi-item scales and 11 single items which is specific tool for head and neck cancer survivors. The multi-item scales are pain, swallowing, senses, speech, social eating, social contact, and sexuality. The single items are teeth, opening mouth, dry mouth, sticky saliva, coughing, felt ill, pain killers, nutritional supplements, feeding tube, weight loss, and weight gain. For all items and scales, high scores indicate more problems. Chaukar et al (17) agreed that QLQ-H&N35 were reliable and valid questionnaires when applied to a sample of head and neck cancer patient because the tool demonstrated a high alpha coefficient (>0.70) when measured using Cronbach's alpha coefficient.

Statistical analysis

Descriptive analysis has been carried out for socio-demographic characteristic and QOL data from both questionnaires and ANOVA and Paired t-test had been used to determine the association between socio-demographic data and QOL. P value is set at p□0.05.

RESULTS

Socio-demographic factors

Majority of the participants were aged 46 to 60 (47.5%), male (65.0%), diversify ethnicity with Malay as the major representative (77.5%) of HNC patients who obtained treatment from the two hospitals. Almost all (85%) were married, more than half of them (55%) were unemployed during the time they first included in the study. Almost half of them (47.5%) had obtained tertiary education level.

Even though 42.5% of them were admitted smoking, 55% of them were admitted not smoking nor consume alcohol. 60% of them had no known disease or family cancer history (90%). Most of the patients were diagnosed with pharynx/larynx cancer (50%) followed by oral cavity cancer (37.5%) of squamous cell carcinoma (80%). 67.5% of them had undergone surgery, 10% chemotherapy, 2.5% radiotherapy and the rest 20% received combination of treatments.

The level of quality of life and symptoms or problems that persist before and after treament

The Cut-off point used for mean score analysis level are: 1.00-1.86 (Low), 1.87-2.93 (medium), 2.94-4.00 (high). Based on the ANOVA test done, the patients' QOL before the treatment were at medium level (Total mean score of 6.22) the QOL of HNC patients after the treatment, even though very different but it was still maintained at medium level (mean score of 4.84). The symptoms or problems that occurs were also reduced after treatment compared to before the treatment (from mean sore of 1.58 to 1.25).

Association between demographic characteristics, quality of life and symptoms or problems that persist before and after treament

The ANOVA test results also shows that the health history is significant and associated to the QOL of HNC patients (p=0.011,); and after the treatment (p-value=0.012). Post treatment shows only marital status (p-value=0.001) factor was associated with QOL of HNC patients after the treatment. The result also shows that patients' ethnicity do have an associatiom to the patients' symptoms or problem after the treatment (p= 0,039); while the pre treatment type shows an association to the patients' symptom or problems before the treatment (p= 0.009).

The paired sample t-test were employed to test the hypothesis that the pre treatment symptoms or problems of HNC patients before treatment (M = 255.10, SD = 20.405) and post treatment

Table 1: Socio-Demographic Factors of Head and Neck Cancer Patients

	DEMOGRAPHICS	FREQUENCIES	PERCENTAGE
Age	18 to 45	8	20
	46 to 60	19	47.5
	> 60	13	32.5
Gender	Male	26	65.0
	Female	14	35.0
Race	Malay	31	77.5
	Chinese	7	17.5
	Others	2	5.0
Employment Status	Employed	18	45.0
	Unemployed	22	55.0
Marital Status	Single	5	12.5
	Married	34	85.0
	Widow	1	2.5
Education	No Formal Educa-	2	35.0
	Primary	14	5.0
	Secondary	19	47.5
	Tertiary	5	12.5
Habits	Smoking	17	42.5
	Alcohol Intake	1	2.5
	Not Smoking nor Consume Alcohol	22	55.0
Health History	Cardiac Disease	2	5.0
	Lung Cancer	1	2.5
	Diabetes	6	15.0
	Others	7	17.5
	No Known Disease	24	60.0
Family Cancer History	Yes	4	10.0
	No	36	90.0
Tumor Site	Oral Cavity	15	37.5
	Pharynx / Larynx	20	50.0
	Others	5	12.5
Tumor Type	Squamous Cell Carcinoma	32	80.0
	Others	6	15.0
	NA	2	5.0
Treatment Type	Surgery	27	67.5
	Radiotherapy	1	2.5
	Chemotherapy	4	10.0
	Combination	8	20.0

symptoms or problems of HNC after treatment (M = 201.80, SD = 22.025) were different. The null hypothesis of equal health conditions of HNC patients was rejected when the result shows that t (49) = 9.337, p =0.001. Thus, the post treatment was statistically significant lower that the pre treatment mean.

DISCUSSION

The aim of this study was to determine the association of socio-demographic factors i.e. age, gender, race, employment status, marital status, education level, smoking/alcohol habits, health history, as well as tumor and treatment-related factors (tumor site, tumor type, and treatment type) for their association with QOL before and after treatment among HNC patients. QOL is very subjective and unique between one people to another. Therefore, it is best evaluated from patients own perspective first rather than taking others' opinion around them.

Quality of life of the patients enrolled was obtained two times; before getting treatment and after six months getting the treatment. Mean scores of overall QOL showed medium QOL before and after the treatment i. e 6.22 and 4.84. However, it was clearly shown reduced of perceived QOL of HNC patients after receiving the treatment. Although symptoms or problems indicated better mean score (1.58 to 1.25) if compared before and after treatment, which reflected they had experienced better physical QOL, overall QOL was still reduced. This situation may be related to many factors studied in this research.

One significant finding from this study was health history with QOL before and after treatment. In this study, patients were asked whether they have had any co-morbidity before this e.g. cardiac disease, diabetes mellitus, other type of cancer or others. Even though most of them (60%) had no known disease before, but it seemed that it significantly affects their QOL. Bilal at al. (9) proposed one of the important aspects to detail study on QOL among certain population is the population characteristic including comorbid conditions when analyzing QOL related data. It had been identified the importance of this variable on QOL especially among cancer patients.

In this current study, health history of the patients was chronic diseases. After receiving the treatment, any kind of cancer treatment, it will have further impact on QOL of the patients. Co-morbidity, unfortunately will further disturb their QOL because cancer patients (especially elderly) do not tolerate chemotherapy as well as younger patients and experience a higher symptom burden, may likely due to higher prevalence of comorbid conditions and organ failure (18). In this current study, 32.5% patients were more than 61 years old and 47.5% were between 46 to 60 years old indicating that majority of them also fall in elderly cancer patients.

Marital status factor was significantly associated with QOL after treatment. With most of them were married (85% of them), it was an expected result since ill patients (especially cancer patients) needs support from their significant others and in this study their spouses to help and support them throughout the cancer treatment and manage the symptoms and problems due to the disease and treatment itself (8,19). Marital status would offer a kind of social support which acts as an important factor that will help the patients to believe/have faith that they able to confront the difficult situation (in this case the situation would be cancer and treatment of HNC as well as the impacts of it) better (19).

Bilal et al (9) studied among 361 Pakistani with HNC had similar results with current study where moderate associated marital status factor with their OOL. They also found out that divorced and widowed patients had worse QOL compared to married patients. This findings also supported by another study in China suggesting that family companion during treatment resulted in increasing comfort level (p, 0.05) among 200 HNC patients receiving radiotherapy (20). These studies reflect the similarities of the neediness of HNC patients towards spouse support in their lives.

Fear of cancer or cancer recurrence is always one of the major psychological distress to HNC patients (21) and studies have shown that this fear can arise even before the initiation of treatment, then often remaining stable over a period of several years beyond the conclusion of treatment (22,23). They may have witnessed the impact of the cancer and treatment to their family members and this experience may affect their psychological wellbeing and QOL.

However, after some times, perception towards the disease and experience throughout the process of treatment and rehabilitation may alleviate their fear and they start to cope with their own situation which enhances their perceived QOL after treatment. Dempster et al (24) found that after adjustment for age, gender, physical comorbidities, and time since diagnosis, changes in disease perceptions over time were associated with changes in depression and anxiety over time in their study among 189 HNC patients when assessed at two times, twelve months apart.

Ethnicity also showed significant association with symptoms and problems after treatment. Almost all of the participants in this current study were Malays which may introduce bias to this factor. However, there is study previously which concur with the current study findings regarding association of ethnicity with QOL of cancer patient (9). Ethnicity may be explained associated with QOL because it usually links to culture diverse which may contribute to response to the cancer and treatments.

In this current study, symptoms and problems asked were generally pertaining problems in eating and swallowing, and whether the disturbances affect their socialization. This is an important aspect among HNC patients as well since it affect their self-image and impaired their self-confident(25- 27). Thus, as known, different ethnic has different kind of food they usually eat and serve for ill patients for example, and they have their own unique socialization style and boundaries(26).

Other socio demographic factors studied i.e. gender, employment status, education level, and habits did not show any significant association with QOL before or after treatment either in QLQ -QS or QLQ-H&N35. This finding was contrary with previous study which used almost the same instruments which showed deterioration of almost all scales and items in the QLQ-C30 and QLQ-

H&N35 questionnaire at the end of radiotherapy treatment to HNC squamous cell carcinoma patients. They found out that female gender (p =0.05) was negatively affect QOL of the patients (6). Gender and education were significant associated with QOL among 361 HNC Pakistani patients, with marital status, employment status and ethnicity had weak association (9).

For tumor/treatment related factors, tumor type showed the significant association to symptoms or problems before treatment (p = 0.009). In view of most of them (80%) were sufferings from squamous cell carcinoma of HNC, the most common disabilities affected significantly were to taste, swallow, salivate, and participate in activities and recreation. It may suggest from the findings that many of the symptoms and problems resolve after the treatment.

CONCLUSION

In this current study, the results shows that the soci—demographic factors did have an impact to the cancer patients' quality of life before and after the treatment. The present research suggested that the patients' quality of life is reduced after treatment (medium level). This could be due to the advancement of the cancer and evidence when the health history and symptoms found found significantly associated with the QOL before and after treatment. Although most of the HNC cancer survivors recover after treatment (evidence by lower paired t test result) that shows lower symptoms or problem after the treatment, they often struggle with problems affecting their physical and psychological functioning, which may persist throughout their lifetime and may be affecting their QOL. However, some domains in QOL scale did show some improvement after treatments.

Thus, socio-demographic factors is very crucial factors that must be considered during patients' assessment in improving patients' care and optimum quality of life before and after the treatment. By understanding patients' quality of life, nurses can potentially design interventions that lessen the adverse impact of this disease process and more accurately support those in active treatment, survivors, and caregivers.

Statement of human rights

Ethical approval was obtained from National Medical Research Registry (NMRR) level which is Medical Research Ethic Committee (MREC) as well as informed consent was obtained from the patients.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare with regard to this work.

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