

ORIGINAL ARTICLE

Head and Neck Cancer Survivors' Perceptions of Cancer Treatment and Posttraumatic Growth

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ABSTRACT

Introduction: Cancer patients' perception on the treatment they received is vital to determine their adherence to cancer treatment, but important data on how this variable affects posttraumatic growth (PTG) experience by cancer patients is lacking. This cross-sectional study aimed to evaluate the degree of PTG among a cohort of head and neck cancer (HNC) survivors who were within first year of diagnosis and determined the association between perception of cancer treatment received (expectation and satisfaction with cancer treatment received and the feeling about the adverse effects) and PTG controlling for socio-demographic and clinical characteristics. **Methods:** HNC survivors were recruited from two oncology referral centres, and they were administered socio-demographic and clinical characteristics questionnaire, the Malay version of the Cancer Therapy Satisfaction Questionnaire (CTSQ) (to assess the satisfaction, expectation and feeling about the adverse effects of cancer treatment received) and the Malay version of the Posttraumatic Growth Inventory-Short Form (PTGi-SF) (to measure the degree of PTG). **Results:** A total of 200 HNC survivors participated in the study. The mean total PTGI-SF score was 39.5 (standard deviation [SD] = 9.3). Greater degree of positive expectation of cancer treatment and satisfaction with cancer treatment received significantly contributed to higher level of PTG, whereas feeling about side effects of treatment was not associated with PTG, after controlling for socio-demographic and clinical characteristics. **Conclusion:** Incorporating psychosocial interventions (such as education on cancer treatment and counselling) into the treatment regimen may facilitate development of PTG and hence, safeguard the mental well-being of HNC patients.

Malaysian Journal of Medicine and Health Sciences (2023) 19(5):82-88. doi:10.47836/mjmhs19.5.12

Keywords: Posttraumatic growth, Head and neck cancer, Expectation of cancer treatment, Satisfaction with cancer treatment, Concerns about the side effects of cancer treatment

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INTRODUCTION

Cancer diagnosis is a stressful event that may lead to long-term psychological complications (such as depression, anxiety, and posttraumatic stress disorder), as well as social and functional impairments (such as problem with social interaction, cognitive impairment, loss of ability to perform daily routine and instrumental activities of daily living) (1). Cancer treatments are often administer in a multimodal manner, aggressive and

associated with various side effects (such as nausea and vomiting, fatigue, oral and gastrointestinal mucositis, hypersensitivity reactions and chemotherapy-induced peripheral neuropathy) (2). Although cancer is no longer necessarily fatal, but as a recurrent and chronic illness, it still changes patients' lives. Head and neck cancer (HNC) is a group of biologically similar cancer diagnoses that affect various areas of the head and neck, such as the paranasal sinuses, pharynx, larynx, nasal cavity, oral cavity and lips. Overall, head and neck cancer affects 878,348 people worldwide annually, comprising 4.6% of cancer's total incidence in 2020 (3).

HNC patients are susceptible to various complications of the disease itself, as well as adverse treatment effects,

such as mucositis, xerostomia, speech and swallowing problems, breathing complications, trismus, fatigue and pain. Such complications and adverse effects impair patients' daily functioning, increasing the risk of depression and deteriorating quality of life (4-7). Hence, HNC patients are likely to experience psychological distress as a result of the illness itself or their treatment. Psychological distress among cancer patients is defined as a multifactorial and unpleasant experience in psychological, spiritual, social and physical aspects which interfere with one's ability to cope with cancer, its physical symptoms and treatment. It runs in a continuum ranging from normal sadness, feelings of vulnerability and fear, to conditions which could burden patients such as anxiety, depression, posttraumatic stress disorder, spiritual and existential crisis (8, 9).

Posttraumatic growth (PTG) describes positive psychological changes that a person develops in response to trauma or highly stressful events. PTG is a transformational process, wherein one who experiences PTG would exhibit greater degree of psychological functioning and well-being compared with the degree before occurrence of trauma or highly stressful events. Hence, one who experiences the occurrence of PTG would display any, some or all of the positive psychological changes such as greater spiritual development, improved personal strength, increase in new possibilities in life, greater appreciation of life and improved relationship with others. As psychological distress occurred in a continuum, milder psychological distress may not be sufficient to facilitate occurrence of PTG in HNC patients. Hence, only psychological distress that is perceived as traumatic may trigger the occurrence of PTG in a cancer patient if the cancer survivor reflects on the traumatic event (cancer diagnosis, physical symptoms of cancer and/or adverse effects of treatment) and successfully finds meaning out of the trauma (10, 11).

In managing a chronic, recurrent illness, such as cancer—for which treatment is associated with a limited increase in patients' survival—information about patients' expectations, satisfaction, and side-effect concerns regarding cancer treatment is critical because it allows treating clinicians to effectively manage adverse effects, individualize each cancer patient's course of treatment, and improve the patient's adherence to their treatment (12). For cancer patients, PTG has been reported to significantly predict lower psychological distress only if perceived vulnerability—such as concerns about a treatment's side effects is resolved (13). A systematic review of studies on PTG among cancer patients also highlighted a lack of data about the relationship between cancer patients' medical treatment and PTG (14). Hence, determining whether HNC patients' expectations, satisfaction, and side-effect concerns regarding their treatment are associated with PTG is critical because related data are lacking and

cancer-treatment perceptions play a vital role in ensuring patients' adherence to future treatment as dissatisfaction with cancer treatment and concerns about the side effects affect daily routine and functioning as well as may result in drop out before completion of treatment (15). Accordingly, the current study attempted to fill this research gap by adopting two objectives: [Objective 1] evaluating the degree of PTG among HNC survivors in the first year after their diagnosis and [Objective 2] determining the association between cancer-treatment expectations and satisfaction, perceptions about treatment's adverse effects, and PTG after controlling for sociodemographic and clinical characteristics.

MATERIALS AND METHODS

Study design

This cross-sectional study was conducted from March 2019 to December 2020. Participants were recruited from a population of HNC patients who were registered at the otorhinolaryngology and oncology departments of two tertiary referral centres for oncology patients in Peninsular Malaysia. The two targeted medical centres were in Peninsular Malaysia's northern and central regions, and they accepted oncology referrals from primary care centres, district hospitals, and state hospitals. This study's sample size was calculated based on the study's two objectives. First, the estimated sample size needed to fulfill Objective 1 was based on the formula for sample size estimation for a single group mean: $n = (Z_{\alpha/2})^2 S^2/d^2$, in which $Z_{\alpha/2}$ = the normal deviation for a two-tailed alternative hypothesis at a significance level of 1.96, S = the standard deviation obtained for a study of PTG among Malaysian cancer patients (16) = 9, and d = estimation accuracy of 1.5. Hence, the estimated sample size to fulfill Objective 1 was 177 subjects (allowing for a 30% drop-out rate). Second, the estimated sample size needed to fulfill Objective 2 was based on the G*Power 3.1.9.7 calculator sample size estimation for multiple linear regression, for which the Type I error = 0.05, power = 0.95, number of predictors = 12, and effect size = 0.1. Hence, the estimated sample size needed to fulfill Objective 2 was 172 subjects (allowing for a 30% drop-out rate). Since Objective 1 required a larger estimated sample size, the study's final estimated sample size was 177 subjects.

Patients were recruited via consecutive sampling. A research assistant who was not otherwise involved in this study approached prospective participants who had been diagnosed with HNC and attended the otorhinolaryngology and oncology outpatient clinics and the in-patient wards in the two targeted referral centres every workday from 9 am to 5pm. The assistant explained the study to each HNC patient that she approached and screened them for their eligibility to participate. The study's inclusion criteria were: [1] an HNC diagnosis confirmed by a histopathological report and cancer at any stage, [2] an HNC diagnosis within

the past year, [3] the ability to read and write in the Malay language, and [4] the completion of cancer treatment. The study's exclusion criterion was a history of psychiatric illness (patients were screened by the research team's psychiatrist to identify any history of psychiatric illness). For patients who met all the inclusion criteria without meeting the exclusion criterion, the study's purpose, procedures, and participation risks were further explained, and anonymity was assured. Patients who volunteered to participate signed an informed consent form before enrolling in this study. This study was approved by the human research ethics committees of both its targeted institutions, and abide by the regulations of the 1964 Declaration of Helsinki and its amendments.

Data collection

Participants were administered the sociodemographic and clinical characteristics questionnaire, the Malay version of the Posttraumatic Growth Inventory – Short Form (PTGI-SF) to measure their degree of PTG, and the Malay version of the Cancer Treatment Satisfaction Questionnaire (CTSQ) to assess their cancer-treatment satisfaction, cancer-treatment expectations, and perceptions concerning any side effects they had experienced.

Measures

Outcome variable (posttraumatic growth)

The PTGI-SF is a self-administered questionnaire that measures respondents' degree of posttraumatic growth. It comprises 10 items across five domains (appreciation of life, spiritual development, personal strength, new possibilities in life and relationship with others). Two items are assigned to each domain. The PTGI-SF is the shorter form of the posttraumatic growth inventory (PTGI), and it was developed to allow for faster completion than the original PTGI without losing any significant information about PTG. Each item is scored on a Likert scale ranging from 0 to 5. Hence, a respondent's total PTGI-SF score ranged from 0 to 50. The higher the total score, the greater the degree of PTG a respondent has experienced. The PTGI-SF's internal consistency was found to be good with a Cronbach's α of 0.89 (17). The Malay version of the PTGI-SF was validated with cancer patients in Malaysia, registering good internal consistency with a Cronbach's α of 0.89 (18).

Explanatory variables

The CTSQ is a self-administered questionnaire that assesses a respondent's degree of satisfaction with their cancer treatment, their expectations concerning cancer treatment, and their perceptions concerning the adverse effects of the cancer treatment they have received. The CTSQ comprises 16 items across three domains (satisfaction with cancer treatment, feeling about side

effects, and expectation of treatment). Each domain is scored separately with a score ranging from 0 to 100. The higher the score for each respective domain, the greater the degree of a respondent's satisfaction with their cancer treatment, dissatisfaction with side effects, and positive expectations concerning the cancer treatment they have received. All three CTSQ domains were found to have acceptable internal consistency with a Cronbach's α of more than 0.7 (19). The Malay version of the CTSQ was validated with cancer patients in Malaysia, and all three domains showed acceptable internal consistency with Cronbach's α as ranging from 0.72 to 0.88 (20).

The sociodemographic and clinical characteristics questionnaire registered participants' age, gender, monthly household income, education status, ethnicity, elapsed duration since their diagnosis, HNC types, cancer stage and received mode of treatment. Each participant was asked to describe their gender as "male" or "female." Each respondent's age could be reported as "18 to 60 years" or "> 60 years." Monthly household income could be documented as " \leq RM 3,000" or "> RM 3,000." Meanwhile, education status could be reported as "up to secondary education or lower" or "up to tertiary education." Respondents' ethnicity could be reported as "Malay" or "non-Malay." The elapsed duration since a respondent's diagnosis could be reported as "< 6 months" or "6 to 12 months." HNC types could be documented as "nasopharyngeal carcinoma" or "other types of HNC." Cancer stages could be recorded as "Stage 1 and Stage 2" or "Stage 3 and Stage 4." Finally, participants could describe the mode of treatment they had received as "one mode of treatment," "two modes of treatment," or "three modes of treatment."

Statistical analysis

All data analysis was performed using the Statistical Package for the Social Sciences, Version 26 (SPSS 26, SPSS Inc., Chicago, Illinois, United States). To achieve Objective 1, descriptive statistics were computed for respondents' sociodemographic and clinical characteristics, CTSQ domains, and total PTGI-SF score. All nominal variables were reported as frequencies and percentages, while all continuous variables were reported as means and standard deviations. No data were missing. To achieve Objective 2, the associations between sociodemographic and clinical characteristics, CTSQ domains (independent variables), and total PTGI-SF scores (dependent variables) were determined using a general linear model. Statistical significance was set to $p < 0.05$ and was two-sided.

Ethical clearance

This study was approved by the Human Research Ethics Committee, Universiti Sains Malaysia (code: USM/JEPeM/18100483) and the Medical Research Committee of Faculty of Medicine Universiti Kebangsaan Malaysia (code: FF-2019-279).

RESULTS

Participants

Initially, 250 HNC patients were approached as prospective participants at the study's two targeted medical centres. However, 35 patients were excluded because they did not fulfill all of the study's eligibility criteria. Another 15 subjects refused to participate for various reasons. Hence, 200 patients were recruited and completed the study. All participants' sociodemographic and clinical characteristics are summarized in Table I. The majority of participants were adults (aged 18 to 60 years, n = 154, 77%) and ethnically Malay (n = 147, 73.5%). Slightly more male (n = 109, 54.5%) patients participated than female patients (n = 91, 45.5%). Participants' clinical characteristics revealed that slightly more participants with nasopharyngeal carcinoma (n = 107, 53.5%) participated, and about half of the participants had completed two modes of treatment (n = 101, 55.5%). Participants' mean total PTGI-SF score was 39.5 (SD = 9.13). Their mean satisfaction with their treatment, concerns about side effects and treatment expectation CTSQ domain scores were 73.17 (SD = 27.72), 62.21 (SD = 26.07) and 71.27 (SD = 16.16), respectively.

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

Variables	Number of participants (n)	Percentage (%)
Age:		
18 to 60 years old	154	77.0
> 60 years old	46	23.0
Gender:		
Male	109	54.5
Female	91	45.5
Ethnicity:		
Malay	147	73.5
Non-Malay	53	26.5
Education status:		
Up to secondary education or lower	137	68.5
Tertiary education and above	63	31.5
Monthly household income:		
≤ RM 3000	155	77.5
> RM 3000	45	22.5
Types of HNC:		
Nasopharyngeal carcinoma	107	53.5
Other types of head and neck cancer	93	46.5
Duration since cancer diagnosis:		
≤ 6 months	113	56.5
6 months to 12 months	87	43.5
Stage of cancer:		
Stage 1 and 2	97	48.5
Stage 3 and 4	103	51.5
Mode of treatment received:		
1 mode of treatment	77	38.5
2 modes of treatment	101	50.5
3 modes of treatment	22	11.0
CTSQ domains:		
Expectation of treatment	73.17 ^a	27.73 ^b
Feeling about side effects	62.21 ^a	26.07 ^b
Satisfaction with treatment	71.27 ^a	16.16 ^b
Total PTGI-SF score	39.5 ^a	9.31 ^b

^a Mean, ^b standard deviation

The association between sociodemographic and clinical characteristics, “Cancer Therapy Satisfaction Questionnaire” domain scores, and total “Posttraumatic Growth Inventory – Short Form” scores

The study's general linear model of the associations between sociodemographic and clinical characteristics, CTSQ domain scores (independent variables), and total PTGI-SF score (dependent variable) are presented in Table II. Higher satisfaction with their cancer treatment (B = 0.161, 95% CI = 0.063–0.260, SE = 0.050, t = 3.226, p = 0.001) and greater degree of positive expectations concerning the cancer treatment received (B = 0.103, 95% CI = 0.049 to 0.157, SE = 0.028, t = 3.735, p = 0.001) were significantly associated with higher PTG among the HNC participants. No sociodemographic or clinical characteristics contributed to PTG.

DISCUSSION

This cross-sectional study investigated PTG levels among a cohort of HNC survivors during the first year after their diagnosis. It determined the association between these patients' satisfaction with their cancer treatment, concerns about cancer-treatment side effects, positive expectations concerning their cancer treatment and PTG after controlling for their sociodemographic and clinical characteristics. We found that HNC survivors had high levels of PTG during their first year post-diagnosis. The mean total PTGI-SF score reported in this study [39.5] was comparable to the score reported in a study that investigated PTG among cancer survivors with mixed cancer diagnoses in Malaysia [39.87] that used a fairly similar methodology, such as most of the cancer survivors had been diagnosed up to a year previously [70%] and using the PTGI-SF to measure the degree of PTG (21). Similarly, a longitudinal study of positive psychological changes among HNC survivors also revealed that PTG tended to increase during the first 18 months after diagnosis and treatment (22).

Regarding the context of perceptions concerning the cancer treatment that the HNC survivors had received, our findings indicated that more positive expectations regarding cancer therapy significantly increase PTG among HNC survivors. This reciprocal association between positive expectations regarding cancer therapy and PTG among HNC survivors may be mediated by higher hope among patients with positive expectations for their cancer therapy. Cancer patients with more positive expectations about symptom reduction after receiving and completing cancer therapy have been reported to exhibit a higher degree of hope (23). Moreover, greater hope has been reported to predict a higher level of PTG among HNC patients (24). Cancer patients with higher degrees of hope may be more likely

Table II: The multivariate general linear model between socio-demographic and clinical characteristics, CTSQ domain scores (independent variables) and total PTGI-SF score (dependent variable)

Variables	B (95% CI)	Standard error	t	p-value
Age:				
18 to 60 years old	Reference			
> 60 years old	-2.764 (-5.918 to 0.390)	1.599	-1.729	0.086
Gender:				
Male	Reference			
Female	2.283 (-0.377 to 4.943)	1.348	1.693	0.092
Ethnicity:				
Malay	Reference			
Non-Malay	-0.845 (-3.814 to 2.124)	1.505	-0.561	0.575
Education status:				
Up to secondary education	Reference			
Tertiary education and above	-0.708 (-4.021 to 2.606)	1.680	-0.421	0.674
Monthly household income:				
≤ RM 3000	Reference			
> RM 3000	-1.161 (-4.642 to 2.320)	1.765	-0.658	0.511
Diagnosis:				
Other types of head and neck cancer	Reference			
Nasopharyngeal carcinoma	-0.270 (-2.963 to 2.423)	1.365	-0.198	0.843
Duration since cancer diagnosis:				
≤ 6 months	Reference			
6 months to 12 months	1.323 (-1.272 to 3.919)	1.316	1.006	0.316
Stage of cancer:				
Stage 1 and 2	Reference			
Stage 3 and 4	-1.026 (-3.657 to 1.604)	1.333	-0.770	0.442
Mode of treatment received:				
1 mode of treatment	Reference			
2 modes of treatment	-0.864 (-4.984 to 3.256)	2.089	-0.414	0.680
3 modes of treatment	0.437 (-2.747 to 3.621)	1.614	0.271	0.787
CTSQ domains:				
Expectation of treatment	0.103 (0.049 to 0.157)	0.028	3.735	< 0.001*
Feeling about side effects	0.044 (-0.011 to 0.098)	0.028	1.581	0.116
Satisfaction with treatment	0.161 (0.063 to 0.260)	0.050	3.226	0.001*

*Statistical significance at $p < 0.05$

to engage in cognitive reappraisal, which facilitates the accommodation process during which patients search for meaning in the traumatic experience of living with cancer and incorporate new, trauma-related information in the reconstruction of an assumptive worldview about the self, others and the surrounding world, thus facilitating PTG development (21).

Similarly, greater cancer-treatment satisfaction also contributed to greater PTG among HNC survivors in this study. Cancer-treatment satisfaction is the degree of congruency between a patient's expectations of ideal cancer treatment and their perceptions about the actual cancer treatment they have received. In the context of cancer-treatment goals, cancer-treatment satisfaction describes the appraisal of goals during cancer treatment, while hope describes the expectation to realize a future goal (25). Studies on the relationship between hope and life satisfaction among cancer patients have reported that hope is moderately correlated with patients' satisfaction with the quality of healthcare that they have received (26). Studies have documented that a greater degree of hope among cancer patients enhances PTG (22, 24). Hence, hope may mediate the reciprocal association between treatment satisfaction and PTG among HNC survivors.

As cancer is a chronic and recurrent illness associated

with poor prognosis and various burdening adverse effects of its treatment, assessing how patient perceived the treatment they received is pivotal not only to guide treatment-decision making and ensure compliance, but also to determine how it affects positive psychological change such as PTG. Our findings pointed out the importance of enhancing positive cancer-treatment expectations and ensuring HNC patients' satisfaction with their treatment, in order to enhance PTG. Contrastingly, changes in PTG among cancer patients was independent of the perception of treatment adverse effects. Hence, incorporating psychosocial interventions into cancer treatment regimens—such as educating patients about cancer treatment and counseling that may enhance patients' satisfaction—may effectively increase PTG among HNC survivors (27) and, in turn, improve their mental well-being. Further studies are warranted to explore whether the relationship between cancer patients' treatment expectations, satisfaction of treatment and PTG is mediated by the degree of hope.

Our study faced a few limitations. First, its cross-sectional design did not allow us to determine causal inference when assessing the relationship between cancer-treatment perceptions and PTG. Second, some of the sociodemographic and clinical characteristics of the HNC survivors who participated in this study were not representative of the Malaysian HNC population such

as ethnicity, cancer stage and HNC type. Moreover, we employed a non-probability sampling method to recruit participants which may lead to the sample size of this study to be non-representation of the HNC population in the targeted centres. Thus, these shortcomings may affect the generalizability of our findings. Third, although hope may mediate the relationship between satisfaction, cancer-treatment expectations, and PTG, this study did not assess hope.

Despite these limitations, our study was the first to assess the association between cancer-treatment perceptions and PTG among HNC survivors. Moreover, this study recruited a respectable sample size with a total of 200 HNC survivors completed the study with no missing data. This study also adjusted for confounding socio-demographic and clinical characteristics that may affect PTG and utilized validated rating instruments to measure cancer patients' expectation, satisfaction, and perception about side effects of the treatment they received, and to assess their degree of PTG.

CONCLUSION

This cross-sectional study was the first to report how cancer-treatment perceptions may contribute to PTG among HNC survivors during the first year after their diagnosis. Greater positive cancer-treatment expectations and treatment satisfaction were found to potentially lead to a surge in PTG, while patients' concerns about adverse treatment effects were not, after controlling for HNC survivors' sociodemographic and clinical characteristics. These findings can inform treating clinicians about the pivotal role of assessing patients' cancer-treatment perceptions and including psychosocial interventions that may facilitate treatment satisfaction in management plans for HNC patients.

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