

Effects of stigma, hope and social support on quality of life among Chinese patients diagnosed with oral cancer: A multi-center, cross-sectional study

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Research

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Abstract

Background

Improvement of quality of life (QoL) has been one of goals in health care for people living with oral cancer. This study aimed at assessing the QoL and investigate the effects of stigma, hope, social support on QoL among Chinese oral cancer patients.

Methods

A multiple center cross-sectional study was conducted at the Department of Stomatology, Shengjing Hospital of China Medical University and Stomatology Hospital of China Medical University in Liaoning province, China between May 2016 and October 2017. A total of 230 oral cancer patients were recruited to complete a questionnaire including the Functional Assessment of Cancer Therapy-Head and Neck (FACT-H&N), the Social Impact Scale (SIS), the Herth Hope Index (HHI) and the Multidimensional Scale of Perceived Social Support (MSPSS). Univariate one-way ANOVA/t-test, Person's r and hierarchical linear regression analysis were conducted to explore the influence factors of QoL and the relationships between stigma, hope, perceived social support and QoL.

Results

The mean QoL score was 90.85 ± 20.15 among the patients with oral cancer. Stigma was negatively related to QoL, explaining 39.3% of the variance. In addition, hope and perceived social support were positively associated with QoL, explaining 8.1% of the variance.

Conclusion

Overall, Chinese patients with oral cancer are suffering from a relatively low level of QoL. Stigma was significantly and negatively associated with QoL, while hope and perceived social support were positively associated with QoL. Oral cancer patients' psychological status should be addressed and adequate intervention based on positive psychological resources should be provided to improve the QoL of patients with oral cancer.

Introduction

Oral cancer is a broad term for malignant tumors in oral cavity, which may arise as a primary lesion in any part of the oral cavity or oropharynx such as lip, cheek, gingiva, tongue and the floor of mouth ^[1]. According to World Health Organization (WHO), there were approximately 350,000 new cases and 170,000 deaths of oral cancer worldwide in 2018^[2]. Furthermore, it's estimated by National Central Cancer Registry of China (NCCRC) that oral cancer death accounting for about 1.13% of all cancer death in China, 2013^[3]. Although incidence and mortality of oral cancer in China were not high, due to the large population basis much attention also should be attracted to oral cancer. Compared with patients with other types of cancer, patients with oral cancer always face substantial challenges including problems

with speaking, eating, breathing and facial disfigurement, which may significantly impact patient' quality of life (QoL).

QoL is defined by WHO as "individuals' perception of their position in life in the context of culture and the value systems where they live, and in relation to their goals, expectations, standards, and concerns" [4]. Accordingly, QoL for oral cancer patients is a reflection of patients' life status after diagnosed with this disease. Besides, QoL also has become a significant factor in monitoring the treatment and therapeutic procedure success in recently decades [5]. Poor QoL of oral cancer patients was always shown to have longer hospital stays, poor postoperative performance, increased narcotic use and complications with treatment, decreased treatment compliance [6]. Therefore, researchers are increasingly aware of the value of considering how to improve level of QoL and extend survival length in patients with oral cancer [7]. Based on the literature review, we found that not only the general impacts of clinical and demographic differences, but the psychological factors also influence the QoL.

Stigma is defined as "an attribute that is deeply discrediting" or a mark that reduces the sufferer "from a whole and usual person to a trained, discounted one." [8] It has been found to be associated with various types of illness, including but not limited to HIV/AIDS, tuberculosis, and cancers [9]. In fact, several studies reported that cancer stigma was prevalent [10]. Cancer is recognized as a stigma when it conveys deviation from the normal state. Once individuals are stigmatized, they are often stripped from their social status, and become stereotyped, discriminated, and isolated or even felt exclusion from the society [11]. Stigma in cancer patients was proved to be strongly and consistently associated with negative psychological health, including depressive symptoms [12], anxiety [13], and demoralization [14], which could eventually affect the QoL of patients. Therefore, we supposed that stigma may be an adverse influence factor for the QoL of patients with oral cancer. Besides investigating the risk factors of QoL, more attention should be focused on positive resources in order to improve QoL among patients with oral cancer.

Hope is a positive motivational state which is based on an interactively derived sense of successful agency and pathways. [15]. During the treatment, hope could be regarded as one of the most important and effective coping styles when patients face up to the cancer. A systematic review reported that hope was associated with better quality of life and spiritual well-being in Asian patients with cancer [16]. In addition to the positive roles of internal psychological construct, the external social resource has been given increasing attention in research on the coping resources of cancer related distress. Social support is generally defined as perceived assistance, esteem and understood one individual receives from families, friends and others [17]. Higher levels of social support lead the individuals to believing that themselves are concerned and accepted [18], and it have been associated with positive outcomes, such as improved overall health status, fewer psychological problems and higher QoL [19]. A cross-sectional study carried out in Portugal indicates that children with cancer perceived more support form family, they experienced better QoL [20]. Chong et al. also demonstrated the higher level of perceived social support among the breast cancer subjects was associated with better QoL in Malaysian [21]. Thus, we hypothesize that the

presence of hope and supportive interpersonal relationships have the potential to influence the QoL of oral cancer patients in the present study.

However, to the best of our knowledge, extant studies have not yet explored the relationship of patients' QoL with stigma, hope and social support in China. Therefore, in the current study, we aimed to assess the QoL and examined the association between the QoL with stigma, hope and social support in patients with oral cancer.

Methods

Participants

The study was approved by the Committee on Human Experimentation of China Medical University, and the study procedures were in accordance with the ethical standards. All participants were recruited from the department of stomatology of Shengjing Hospital of China Medical University and Stomatology Hospital of China Medical University between May 2016 and October 2017, respectively. Once patients agreed to participate in this cross-sectional study, they were distributed questionnaires and informed content to read and sign. Patients with the following inclusion criteria were included into this study: (1) were at least 18 years old, (2) were diagnosed with oral cancers, (3) were after the surgery, (4) were aware of their own diagnosis, (5) were well enough to answer the questionnaires, (6) and had ability to accurately answer questions fluently. Patients with the following criteria were excluded: (1) had psychiatric history or cognition disorders, (2) were illiterate to complete the survey, (3) and had other oral diseases or other cancers. Investigators were responsible for helping them to read and providing explanation without any inducement questionnaire items. Finally, the completed questionnaires were obtained from 230 individuals, including 135 males and 95 females.

Measurement of demographic and clinical variables

Demographic characteristics consisted of age, gender, marital status, education level, monthly income, work status, residence. Clinical characteristics included reparative therapy, mandibulectomy, distant metastasis, familial inheritance.

Measurement of QoL

In this study, QoL was measured by the Functional Assessment of Cancer Therapy-Head and Neck (FACT-H&N), it is comprised of 39 questions, and consisted of five dimensions: physical well-being, social/familial well-being, emotional well-being, functional well-being and head and neck cancer specific subscales. Each item was rated on a five-point Likert scale from 0 "not at all" to 4 "very much". The total score ranges from 0 to 144, with the higher score indicating the higher levels of QoL. FACT-H&N as a specific instrument, has been translated into many languages and validated in previous researches, including Chinese patients [22-25]. In our study, the Cronbach's alpha coefficients of the scale was 0.931.

Measurement of stigma

The Social Impact Scale (SIS) was developed to assess the level of stigmatization for individuals with cancer or HIV/AIDS [26], and has been applied to different population with good reliability [27]. The 24-item SIS examined 4 domains of stigma: social rejection, financial insecurity, internalized shame, and social isolation. Response to the scale was rated on a 4-point Likert-type scale. Cronbach α coefficients for the scale was 0.947 in this study.

Measurement of hope

The Herth Hope Index (HHI) [28] was used to assess hope in clinical patients, which contained 12 items and each item had 4 response categories from 1 to 4. The total score ranges from 12 to 48, with higher total scores reflected higher level of hope. The Chinese version of HHI has been demonstrated reliability and validity in cancer patients [29]. The Cronbach's α was 0.809 in the sample group.

Measurement of social support

Social support was assessed using the 12-item version the Multidimensional Scale of Perceived Social Support (MSPSS), which developed by Zimet et al [30]. This scale measured perceived social support from three domains: support from family, support from friends and support from significant others. The item is 7-point rating ranging from one "very strongly disagree" to "very strongly agree". The higher total score reflects higher social support. The Chinese version MSPSS was shown to had adequate reliability and validity among other cancer patients [31]. The Cronbach's alpha coefficient was 0.928 in this present research.

Statistical analyses

This study used one-way ANOVA / t-test to describe the mean scores of QoL in different categorical demographic and clinical variables. Pearson's correlation analysis was used to analyze the correlation among QoL, stigma, hope, perceived social support. Hierarchical multiple regression analysis was conducted to investigate the effects of influence factors on QoL. In hierarchical regression analysis, gender, age and potential variables which were associated with QoL in univariate analysis were entered in step 1. Stigma was added in the step 2. And finally, the independent variables hope and social support were entered into step 3. Indicators provided in the regression models included R^2 , adjust R^2 , R^2 -change, F-value and standardization regression coefficient (β). SPSS for Windows (version 22.0) was used to perform the statistical analyses, with a two-tailed P-value of <0.05 considered to be statistically significant.

Results

Descriptive statistics

Demographic and clinical characteristics of the patients and the level of the FACT-H&N scores in different categories of variables were shown in Table 1. There are 230 patients, 135(58.69%) were men and 95(41.31%) were women. The age of patients ranges from 18 to 92 years, and the mean (SD) of age was 56.13(13.54) years old. 89.13% of the participants were married or cohabitation, and 145(63%) who had a household monthly income under 3000 yuan. With regard to clinical variables, only 52(22.6%) of the patients adopted reparative therapy and 182(79.1%) of the patients have used marginal mandibulectomy. Of all the variables, scores of FACT-H&N were found significantly different among different categories of variables including gender($t=7.060, p=0.008$), marital status($t=6.496, p=0.011$), residence($t=5.119, p=0.025$), educational background($F=3.527, p=0.029$), mandibulectomy ($t=2.644, p=0.009$), distant metastasis ($t=2.951, p=0.003$), however, the difference in other variables were not statistically significant.

Correlation between continuous resources and QoL

Results of correlation analyses between continuous variables were presented in Table 2. The mean score of QoL among oral cancer patients was 90.85 ± 20.15 . FACT-H&N were negatively and significantly correlated with stigma ($r = -0.700, p < 0.01$), and positively and significantly correlated with hope ($r = 0.415, p < 0.01$) and perceived social support($r = 0.526, p < 0.01$), respectively.

Hierarchical multiple regression analysis

As shown in Table 3, all the independent variables that were associated with oral cancer patients' QoL in univariate analysis ($p < 0.05$) were entered into the hierarchical multiple regression model. Each step of independent variables made a significant contribution to the variance of QoL. In step 1, demographic characters including gender, marital status, residence area, education level, and clinical variables including distant metastasis and mandibulectomy as a whole accounted for 9.9% variance of QoL. In step 2, after controlling for demographic and clinical characteristics, stigma was found to be significantly and negatively associated with QoL. Stigma exhibited significant effect on QoL of oral cancer patients ($F=26.855, \text{adjusted } R^2=0.504, R^2 - \text{change}=0.393$). In step 3, positive psychological resources including hope and perceived social support were added into the model, they are significant positively associated with QoL. The two independent variables accounted for 8.1% variance of QoL. In addition, all variables in the model could explain 58.5% of the variance in QoL.

Discussion

This relatively large-scale multi-center, cross-sectional study of patients with oral cancer was conducted in the northeastern region of China, which was the first study to examine the effects of stigma, hope and social support on QoL in China. Our findings revealed that a majority of Chinese oral cancer patients was suffering from impaired QoL. Mean score of QoL among Chinese patients with oral cancer was 90.85 ± 20.15 , which is much lower than patients of other countries. Tulio et al. indicated that in Brazil, mean score of FACT-H&N was 96.6 ± 20.5 [32]. In Williams' research, the median of FACT-H&N was 110.20 in America [33]. Dominika et al. reported that in Poland, the mean score of FACT-H&N was 109.19 [34].

Despite the fact that there is continual progress in diagnosis and treatment technology and more convenient to obtain quality care in China, our results found that Chinese patients with oral cancer still suffered from poor QoL. Therefore, it's very important to found out essential influencing factors and targeted solutions to improve their QoL.

Among all the demographic and clinical variables, there are some variables related to QoL including marital status, residence area, educational level, undergone mandibulectomy and distant metastasis. These factors in combination explained 9.9% of the variance in QoL of patients with oral cancer. Findings of our study shows that patients with a college or above educational level had a higher score of QoL, which echoed the findings of Liu's study [35]. On the one hand, individuals with higher education level was proved to be positively related to high resilience [36], resilient patients are always considered to possess stronger capabilities to rebound from frustration and tragedy [37]. On the other hand, patients with higher education have more access to obtain disease-related knowledge and have a better understanding of their condition. This result indicated that more communications between medical workers and patients are essential for improving patient's QoL. Moreover, as the result showed, patients with distant metastasis had the lowest QoL in this study. However, metastasis is one of the main causes of oral cancer patients' death which is the worst negative events of cancer patients [38]. Not only the oral cancer, but metastasis has been confirmed as adverse influential factor in many other cancers in several studies [39-41].

One of the core findings in this study was that stigma alone explained more than one-third of the variance on QoL. Specifically, stigma was found to be significant negatively associated with QoL which was consistent with previous studies [42,43]. Treatment for oral cancer is complex, which can lead to functionality issues such as dysphagia and breathing difficulties, as well as a cosmetic burden with facial disfigurement. However, facial disfigurement always together with the development of shame and a perception of stigma [14]. The sense of inner shame plays a crucial role in these patients' self-evaluation processes. High stigma not only has a negative impact on follow-up treatments including treatment compliance, seeking treatment behaviors, self-esteem and social adaptation, but also harmful to patients' recovery which seriously impairing patients' QoL. Noticeably, the mean score of stigmas of the participants in this study were found to be higher than their counterparts in other countries [44-46], which may partly explain why Chinese patients with oral cancer experienced poor QoL. However, to our knowledge there are no other published clinical interventions addressing stigma in oral cancer patients so far [45]. Therefore, future studies should focus more on positive psychological factors when stigma impacting oral cancer patients' QoL.

In this study, perceived social support and hope were found to be positively associated with QoL of patients with oral cancer. Patients with high level of hope were likely to experience high QoL that is consistent of the previous study [47]. Furthermore, higher level of hope was confirmed to associated with lower rates of alcohol and cigarette abuse, more frequent exercising and better nutrition which were critical factors in preventing cancer recurrence and increasing QoL [48]. Hope is a positive coping resource for people experiencing difficult situations. Reasonably, oral cancer patients with higher level of hope

experienced higher QoL because they are more confident in both daily life and disease conditions. Thus, enhancing the level of hope was one of the important strategies to increase the QoL of patients with oral cancer in China. In addition, we also found that social support was a predictive factor of QoL and positively associated with QoL. Previous study has shown that the absence of social support after diagnosis and during treatment was associated with development of depression and anxiety, and eventually affected the treatment effect ^[50]. However, Li et al. demonstrated that the psychological comfort that cancer patients obtained from family and friends was benefit for clinical treatments and recovery ^[15]. Likewise, Hodges also indicated in their study that social support was positively relate to patients' QoL and promoted well-being, and ultimately improve the QoL ^[51]. Therefore, more social support from family and friends are essential to improve the overall QoL.

The most important value of this study is that we identified the stigma was significant negatively associated with QoL in oral cancer patients. In addition, our study also has added to the evidence that positive resources, hope and social support, were positively associated with QoL in oral cancer patients. Based on our findings, some implications should be mentioned. Firstly, Chinese medical institutions and government should pay more attention to oral cancer patients with low level of QoL. Secondly, it was important for clinicians and nurses to pay more attention to patients with distant metastasis. Thirdly, more attention should be paid to patients with high stigma. There are some studies confirmed that contact with health professionals and the community ^[52], peer counselling ^[53], skill building and empowerment ^[54] were efficient for decrease the stigma. Thus, future research should focus more on longitudinal studies to determine whether reducing stigma is beneficial to improving QoL. Last but not least, some studies have provided the concrete measures and advices to implement psycho-social interventions to enhance QoL in cancer patients. For example, Berg mentioned that hope-based interventions can increase psychological strength, enhance coping with physical symptoms in their research ^[48]. Cramer also indicated in their study that yoga was an effective measure to improving mental health among patients with breast cancer ^[40]. However, up to now, psychological counseling and intervention in clinical setting have not been enough. Overall, health care organizations should realize that the importance of positive psychological strengths for oral cancer patients to combat severe diseases. And more target intervention strategies should be conducted in future researches.

Nonetheless, there were some limitations in our study. First, because of the cross-sectional design and self-reported measures, no causal conclusions could be drawn between psycho-social resources and QoL. Secondly, this study was conducted in one city from a province of the northeastern region of china. Representativeness of sample might be affected. Thirdly, a control group should be included in our study. Thus, the interpretation of the results would be more convincing. Lastly, several potential factors, such as recurrence, pathological stage, may affect QoL of patients with oral cancer, that we didn't included in our study. A lager and longitudinal study should be implied to future researches.

Conclusion

In conclusion, our study shows that patients with oral cancer in northeastern China are suffering from a relatively low level of QoL. Stigma was significantly and negatively associated with QoL, while hope and perceived social support are positively associated with QoL. Thus, in clinical practice, more attention should be paid to patients' psychological status, and more social support from family, friends or clinical workers should be provided to Chinese oral cancer patients. More importantly, more psychological intervention based on positive psychological resources should be introduced to improve their QoL.

Declarations

Ethics approval and consent to participate

All patients provided their informed written consent. This study was approved by the Committee on Human Experimentation of China Medical University.

Consent for publication

No applicable.

Availability of data and materials

The datasets analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

There were no competing interests.

Funding

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Author's contributions

YZ carried out data collection, analysis, interpretation, and wrote the paper. CYC performed data collection, clean the data and revised the paper. YW participated in literature search and data collection. LW organized this investigation and supervised the data collection, statistical analysis and paper writing. All authors read and approved the final manuscript.

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Tables

Table 1 Demographic and clinical characteristics and the score of QoL among oral cancer patients

variables	N (%)	Mean	FACT-H&N			
			SD	F/t	P-value	
Gender					7.060	0.008**
male	135(58.6)	87.93	19.03			
female	95(41.4)	95.01	21.05			
Age					1.289	0.199
<60	139(60.4)	92.42	22.32			
≥60	91(39.6)	88.99	17.13			
Marital status					6.496	0.011**
Single/divorced/ Separated/widow	25(10.8)	99.44	19.07			
Married/cohabitation	205(89.2)	89.68	20.01			
Residence					5.119	0.025*
Rural area	145(63.1)	93.13	19.42			
Urban area	85(36.9)	86.96	20.87			
Educational background					3.597	0.029*
Primary/middle school	101(43.9)	90.40	17.36			
High / secondary/junior school	102(44.3)	88.80	21.41			
College or above	27(11.7)	100.29	22.93			
Household monthly income(yuan)					1.637	0.202
< 3000	145(63.0)	89.93	20.58			
≥3000	85(37.0)	95.62	22.02			
Job status					1.353	0.261
Retirement/unemployed	133(57.8)	91.31	18.71			
Temporary workers	32(13.9)	85.48	20.42			
Regular employee	65(28.2)	93.50	22.69			
Reparative therapy					1.321	0.188
Yes	52(22.6)	87.61	16.92			
No	178(77.4)	91.80	20.94			
Mandibulectomy					2.644	0.009***
Yes	182(79.1)	92.63	19.93			
No	48(20.9)	84.14	19.74			
Distant metastasis					2.951	0.003***
Yes	12(5.2)	74.41	22.08			
No	218(94.8)	91.76	19.69			
Familial inheritance					1.009	0.314
Yes	15(6.5)	95.93	15.07			
No	215(93.5)	90.93	20.43			

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$; SD standard deviations

Table 2 Scores and correlation of FACT-H&N with other variables

	Mean	SD	FACT-H&N	Stigma	Hope	Social support
FACT-H&N	90.85	20.151	1			
Stigma	73.47	12.550	-0.700**	1		
Hope	34.72	3.822	0.418**	-0.311**	1	
Social support	60.20	11.334	0.550**	-0.393**	0.563**	1

** $p < 0.01$; SD standard deviations

Table 3 Hierarchical multiple regression analysis results of QoL

Variables	Step 1		Step 2		Step 3	
	β	<i>P</i> -value	β	<i>P</i> -value	β	<i>P</i> -value
Control variables						
gender	0.068	0.441	0.053	0.414	0.065	0.280
marriage	-0.110	0.090	-0.128**	0.008	-0.086	0.055
residence	-0.176*	0.011	-0.020	0.707	-0.007	0.886
Mandibulectomy	-0.128*	0.048	-0.049	0.312	-0.045	0.315
Distant metastasis	-0.160**	0.007	-0.037	0.445	0.029	0.552
Edu-1	0.052	0.449	-0.076	0.144	-0.059	0.218
Edu-2	0.004	0.954	-0.071	0.183	-0.076	0.116
Stigma			-0.681***	0.000	-0.571***	0.000
hope					0.117*	0.031
Social support					0.261***	0.000
<i>F</i>	4.145***		26.855***		30.327***	
<i>R</i> ²	0.130		0.523		0.605	
Adjusted <i>R</i> ²	0.099		0.504		0.585	
<i>R</i> ² -change	0.130		0.393		0.081	

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Edu-1 means “primary/middle school” vs. “college or above”, Edu-2 means “high/secondary/junior school” vs. “high or secondary school”