

# BMJ Open Influences of facial disfigurement and social support for psychosocial adjustment among patients with oral cancer in Taiwan: a cross-sectional study

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## ABSTRACT

**Objective** To explore the influences of facial disfigurement and social support for psychosocial adjustment in patients with oral cancer.

**Design** A cross-sectional design was used for the study.

**Participants and setting** A convenience sample of 77 patients with oral cancer was recruited from the otolaryngology and oral and maxillofacial surgery outpatient clinics of three general hospitals in Taiwan.

**Measures** Data were collected using the study questionnaires, including the Facial Disfigurement Scale, the Social Support Scale and the Psychosocial Adjustment to Illness Scale.

**Results** The mean score on the Psychosocial Adjustment to Illness Scale was 413.01 (SD=32.32); 71.4% of the participants were maladjusted. Results of multiple regression analysis showed statistically significant main effects of tumour site (beta=0.37), facial disfigurement (beta=0.35) and social support (beta=-1.01), and the interaction effect of facial disfigurement and social support (beta=0.79) (all  $p < 0.05$ ) on psychosocial adjustment after controlling for other sociodemographic and clinical variables. All variables together explained 62% of the variance in psychosocial adjustment ( $F(16, 55)=14.98$ ,  $p < 0.001$ ).

**Conclusions** The level of psychosocial adjustment in patients with oral cancer was suboptimal. Poorer psychosocial adjustment was reported by patients with more severe facial disfigurement and less social support. Patients with cancers in other areas of the oral cavity also reported poorer psychosocial adjustment than patients with cancers in the buccal mucosa. Medical professionals may use these variables to identify higher risk groups for early intensive intervention.

## INTRODUCTION

Oral cancer and its treatments can result in destructive alterations in facial appearance and oral function impairments. Patients with oral cancer often face substantial challenges including problems with speaking, eating, changes in work and restriction of interpersonal relationships, as well as survival uncertainty.<sup>1 2</sup> Adverse psychosocial

## Strengths and limitations of this study

- This is the first known study to explore the inter-relationship among individual characteristics, disfigurement and social support in shaping psychosocial adjustment of patients with oral cancer in Taiwan.
- The study findings present cross-cultural evidence for the importance of financial status, facial disfigurement and social support on the psychosocial adjustment in patients with oral cancer.
- The cross-sectional nature of the study precluded an assessment of the evolution of psychosocial adjustment with disease progression and did not permit us to determine causal relationships among the study variables. The small sample size also limits the generalisability of the study findings.

morbidities such as depression,<sup>3</sup> anxiety,<sup>4</sup> body image disturbances,<sup>5</sup> social isolation<sup>6</sup> and reduced well-being have been well documented and may persist after treatment or even deteriorate over time in some patients.<sup>7 8</sup>

Compared with patients with other types of cancer, those with oral cancer have higher levels of distress and unresolved physical, psychological and social needs.<sup>9</sup> The identification of risk factors for psychosocial maladjustment is important because at-risk persons can then be targeted for earlier assessment and intervention. Explorations of the factors that influence psychosocial adjustment in patients with oral cancer have been limited. Among the variables that have been a focus of interest in oral cancer, two of them may be particularly important in shaping psychosocial adjustment, namely disfigurement and social support.

Disfigurement is defined as an observable and destructive alteration in appearance caused by damage to the skin, soft-tissue or bony structures.<sup>10</sup> Despite the considerable advances in reconstructive surgery, many

patients with oral cancer still endure facial disfigurement and encounter associated social stigmatisation.<sup>11 12</sup> Facial disfigurement resulting from the cancer itself or its surgical treatment has been one of the most stressful aspects of oral cancer.<sup>13</sup> This may be due to the fact that such disfigurement is usually very noticeable and difficult to keep hidden from sight.<sup>14</sup> Moreover, the facial region is important to one's identity, body image, communication and interpersonal relationships.<sup>15 16</sup> Only a few studies have investigated the impacts of disfigurement on psychosocial adjustment in patients with oral cancer. In these studies, the degree of facial disfigurement was negatively associated with psychological and social functioning.<sup>17 18</sup>

Social support is the other factor that may affect the psychosocial adjustment of patients with oral cancer. Social support involves providing psychological and material resources from a social network, with the intention of helping an individual cope with stress.<sup>19</sup> Social support has been studied considerably with regard to the psychosocial well-being in cancer populations. The degree of support was found to be correlated with emotional well-being,<sup>20</sup> psychosocial adjustment<sup>21</sup> and quality of life.<sup>22</sup> Although research has shown the benefits of social support in a number of cancer populations, oral cancer is not the same as other cancer patient populations. As mentioned above, patients with oral cancer often have problems with speech/communication and facial disfigurement after treatment. These issues can lead to social isolation and depression, and more or different support may be required through the disease trajectory. However, few studies exist regarding the influence of social support on psychosocial adjustment in patients with oral cancer, and the findings are equivocal. For example, Katz *et al*<sup>23</sup> reported that social support was associated with positive adjustment. Clarke *et al*<sup>17</sup> found that satisfaction with social support was not a significant predictor of appearance-related adjustment in patients with head and neck cancer. Thus, the purpose of the study was to explore the influence of facial disfigurement and social support on psychosocial adjustment in patients with oral cancer. We hypothesise that psychosocial maladjustment would be associated with more postsurgical disfigurement and less social support after controlling for sociodemographic and clinical variables.

## METHODS

### Study design and setting

This was a cross-sectional study. A convenience sample of patients with oral cancer was recruited from the otolaryngology and the oral and maxillofacial surgery outpatient clinics of three general hospitals in Taipei, Taiwan. A research nurse rated each participant's facial disfigurement and administered the battery of self-reported research instruments. The data collection took place at the waiting areas outside the outpatient clinics during the patients' visits to the clinics.

Volunteers who met the following eligibility criteria were included: (1) diagnosed with stage I to IVA oral cancer, (2) had completed the primary treatment (surgery, chemotherapy or radiation therapy) for at least 1 month, (3) 18 years of age or older and (4) able to speak or read Mandarin. Potential participants were excluded if they were hospitalised within the past month or treated for a psychiatric illness. The desired sample size was estimated using G-Power software (V.3.1).<sup>24</sup> Considering the number of potential predictors ( $n=15$ ) in this study, a sample size of 68 would have 80% power to detect a large effect size of  $f^2=0.35$  with a 0.05 level of significance using a linear multiple regression fixed model.

### Patient and public involvement

The development of the research question and hypothesis was informed by working closely with patients with oral cancer. However, patients and public were not involved in the recruitment to and conduct of the study. An abstract of the study results will be mailed to the study participants.

### Variables and measurements

Sociodemographics including age, gender, education level, marital status, employment status, monthly income and financial hardship were collected from participants. Data on clinical variables, including tumour sites, cancer stages, type of cancer therapies and postsurgical period, were extracted from the participants' medical records. Facial disfigurement was measured both objectively by using the Observer-Rated Facial Disfigurement 9-Point Likert Scale<sup>23</sup> and subjectively by using the Patient-Rated Facial Disfigurement Visual Analogue Scale (VAS).<sup>25</sup> A trained research nurse rated the participants' facial disfigurement on a 9-point observer-rated disfigurement rating scale (1=minimal to 9=severe) with regard to the size and the visibility of the disfigured area, the extent of face/neck shape alteration and the degree of destruction in facial expression.<sup>25</sup> The scale showed good discriminant and convergent validity and inter-rater reliability (intraclass correlation coefficient of 0.91) in previous studies.<sup>23 25</sup> Participants were also administered the two-item Patient-Rated Facial Disfigurement VAS. They were asked to place a mark on a 100 mm horizontal line to represent the extent to which: (1) 'their facial appearance had been altered by surgery' and (2) 'their surgery is apparent to other people'.<sup>25</sup> Each scale is anchored by 'not at all' at the left end of the scale and 'worst possible' at the right end. The scale has shown good reliability and validity in a previous study.<sup>25</sup> The two patient-rated items correlated significantly ( $r=0.76$ ,  $p<0.001$ ) and the patients' self-rated facial disfigurement correlated significantly with surgeon-rated facial disfigurement ( $r=0.45$ ,  $p=0.04$ ).<sup>25</sup>

The Social Support Scale<sup>26</sup> was used to measure perceived social support. The 16-item scale covers four principal areas of social support: emotional, informational, appraisal and instrumental. For each item, the participants indicated how often within the last month they experienced support from their families and friends

on a 4-point Likert scale. The total score of the 16 items represents support from families and friends. A higher score indicates greater support. The scale was developed in Chinese and validated for patients with cancer.<sup>26</sup> In the current study, the Cronbach's  $\alpha$  values were 0.95, indicating good internal consistency.

Psychosocial adjustment to illness was defined as the management of intrapsychic and social demands in response to physical disease.<sup>27</sup> The Chinese version of the Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR)<sup>28</sup> was used to measure psychosocial adjustment. The 46-item scale covers the following seven domains of psychosocial adjustment to illness: healthcare orientation, vocational rehabilitation, domestic environment, sexual relationships, extended family relationships, social environment and psychological distress.<sup>28</sup> The participants indicated how much difficulty they experienced for each item within the last month on a 4-point Likert scale (0—no problem to 3—many difficulties). The total score for each domain represents the level of adjustment difficulty in a specific area. Each raw domain score was converted into a standardised area T-score (0–100) using the norm of mixed cancer patients provided by Derogatis and Derogatis.<sup>29</sup> The total sum of the seven domain T-scores provides a total PAIS-SR score, with a possible range of 0–700. A higher score indicates a greater difficulty experienced by the patient. A cut-off score of 393 (equivalent to a T-score of 62 in mixed cancer patients) and above is positive for clinical levels of maladjustment.<sup>29</sup> The scale has shown an acceptable level of reliability and validity in past studies involving cancer populations.<sup>21 29 30</sup> The internal consistency (Cronbach's  $\alpha$ ) in the current sample ranged from 0.65 to 0.89 for the domain scores and was 0.90 for the total score, indicating good reliability.

### Statistical methods

Hierarchical multiple regression analyses were used to examine the influences of sociodemographic and clinical variables, disfigurement, and social support on psychosocial adjustment. Step 1 involved all sociodemographic and clinical variables. Step 2 included facial disfigurement and social support. Step 3 involved the interaction term of facial disfigurement and social support. Categorical variables were dummy coded prior to analysis. Standardised residual plots and collinearity statistics were used to check normality and independent assumptions of the regression analysis. Neither assumption was violated. Prior to analysis, missing data were examined. There were only two data values missing for each of the tumour site, cancer stage and disease duration variables and one data value missing for the disfigurement variable. Pairwise deletion was used in the correlation analysis and list-wise deletion was used in the regression analysis for handling missing data. All statistical analyses were conducted using the Statistical Package for Social Sciences V.20.0 (IBM). Sensitivity analyses of bivariate relationships between psychosocial adjustment and other study variables were presented in the online supplementary appendix.

### RESULTS

A total of 121 potentially eligible patients with oral cancer were approached; 27 individuals refused to participate and 12 individuals felt too ill to participate. A total of 77 participants were included in the study. Their average age was 53.04 years (range 34–81 years). The majority of participants were male (96.11%), married (76.62%), unemployed (72.73%) and with a monthly income less than NT\$20 000 (71.05%). Most of them had buccal mucosa cancer (67.53%) and had been treated with surgeries and adjuvant therapies (59.74%). The average postsurgical period was 24.84 months (range 1–176 months) (table 1).

The mean score of nurse-rated facial disfigurement was 4.75 (SD=2.07). The mean scores of two patient-rated facial disfigurement were 52.17 (SD=30.62) and 57.59 (SD=33.04) for appearance been altered and surgery apparent to others, respectively. The three disfigurement measures were highly correlated. Separate analyses were performed for them and the results were parallel. Therefore, the inferential analysis results were reported based on patient-rated surgery apparent to others. The mean score on social support was 39.06 (SD=9.40), which indicated a perception of fairly good support from family and friends. The average score on the PAIS-SR was 413.01 (SD=32.32), indicating that these participants were facing great challenges in adjusting to life beyond cancer (table 2). Using a score of 393 as the cut-off point, 55 (71.4%) patients scored positive for clinical levels of psychosocial maladjustment. The mean T-scores for each of the seven PAIS-SR domains ranged from 55.69 to 66.08. The patients reported the most difficulty in extended family relationships, followed by vocational environment, sexual relationships, social environment, healthcare orientation and psychological distress (table 2).

Results of multiple regression analysis showed statistically significant main effects of tumour site (beta=0.37), facial disfigurement (beta=0.35) and social support (beta=-1.01), and the interaction effect of facial disfigurement and social support (beta=0.79) (all  $p<0.05$ ) on psychosocial adjustment after controlling for other sociodemographic and clinical variables. All variables together explained 62% of the variance in psychosocial adjustment ( $F(16, 55)=14.98, p<0.001$ ) (table 3).

### DISCUSSION

In this cross-sectional study, we have examined the inter-relationship among individual characteristics, disfigurement and social support in shaping psychosocial adjustment in patients with oral cancer. Results showed that tumour site, facial disfigurement, social support, as well as the interaction term of facial disfigurement and social support were statistically significant predictors of psychosocial adjustment. Poorer psychosocial adjustment was reported by patients with more severe facial disfigurement and less social support. Patients with cancers in other areas of the oral cavity (tongue, gingiva, mouth

**Table 1** Descriptive data of participants' sociodemographic and clinical variables (n=77)

Variables	Frequency	%	Range
Age (mean; SD)	53.04	9.31	34–81
Gender			
Male	74	96.11	
Female	3	3.89	
Education level			
Primary school and below	19	24.68	
Middle to high school	50	64.93	
College and above	8	10.39	
Marital status			
Single	18	23.38	
Married	59	76.62	
Employment status			
No	56	72.73	
Yes	21	27.27	
Monthly income (NT\$)			
<20000	54	71.05	
20000–39999	10	13.16	
≥40000	12	15.79	
Hospital			
A	7	9.09	
B	23	29.87	
C	47	61.04	
Postsurgical period (mean; SD)	24.84	39.27	1–176
Tumour site			
Buccal mucosa	52	67.53	
Tongue, gingiva, mouth floor, lips	25	32.47	
Cancer stage			
Stage I	13	16.88	
Stage II	22	28.57	
Stage III	11	14.29	
Stage IV	29	37.66	
Adjuvant therapy			
No	31	40.26	
Yes	43	59.74	

floor or lips) also reported poorer psychosocial adjustment than patients with cancers in the buccal mucosa. The associations with psychosocial adjustment for facial disfigurement and social support were independent of sociodemographic and clinical variables. These results suggest that patients with oral cancer with severe facial disfigurement are at particular risk for problems with psychosocial adjustment. Social support has been shown to have a direct supportive effect for psychosocial adjustment and also buffer the detrimental effects of facial disfigurement on psychosocial adjustment. In addition,

**Table 2** Descriptive data of perceived disfigurement, social support, depression and psychosocial adjustment (n=77)

Variables	Mean	SD	Range
Patient-rated facial disfigurement	52.17	30.62	0–100
Social support	39.07	9.40	11–48
Psychosocial adjustment	413.01	32.32	352–499
Healthcare orientation	56.58	10.20	35–76
Vocational environment	62.14	3.52	55–70
Domestic environment	56.13	10.37	34–78
Sexual relationships	58.71	4.89	51–70
Extended family relationships	66.08	3.44	63–73
Social environment	58.44	6.83	45–70
Psychological distress	55.69	8.03	46–72

**Table 3** Hierarchical regression analysis of predictors of psychosocial adjustment (n=77)

Predictive variables	Model 1	Model 2	Model 3
	β	β	β
Age	0.01	–0.04	–0.15
Education level			
Middle to high versus primary and below	–0.01	0.02	0.04
College and above versus primary and below	–0.11	–0.06	–0.09
Marital status (married vs single)	–0.16	–0.00	0.08
Employment status (yes vs no)	–0.22	–0.26	–0.30*
Monthly income			
20000–39999 vs <20000	–0.18	–0.09	–0.01
≥40000 vs <20000	–0.07	0.04	0.06
Tumour site (others vs buccal mucosa)	0.27*	0.32**	0.37**
Cancer stage			
II vs I	–0.08	0.02	0.034
III vs I	–0.16	–0.10	–0.04
IV vs I	–0.04	–0.03	–0.07
Adjuvant therapy (yes vs no)	0.14	0.08	0.09
Postsurgical period	–0.21	–0.23	–0.12
Facial disfigurement	–	0.35**	0.35***
Social support	–	–0.27*	–1.01***
Facial disfigurement * social support	–	–	0.79***
R <sup>2</sup>	0.34*	0.52***	0.62***
F	2.19	3.85	5.48
R <sup>2</sup> change	0.34*	0.18***	0.11***
F change	2.19	10.03	14.98

\*P&lt;0.05, \*\*P&lt;0.01, \*\*\*P&lt;0.001.

the difference in adjustment observed between patients with different tumour sites can also be related to how extensive their surgeries were. For example, patients with cancer of tongue may receive partial or complete glossectomy and patients with gingival cancer may undergo mandibulectomy.

Adequate psychosocial adjustment is crucial for patients with oral cancer to cope with multiple stressors of their disease and to balance their lives within the restrictions imposed by the long-term sequelae of cancer treatments.<sup>231</sup> Maladjustment can result in problems with interpersonal relationships and psychological distress.<sup>32</sup> The results of the study indicate that the psychosocial adjustments after oral cancer vary widely. Overall, the study participants reported a poorer adjustment score than what was reported in a previous study with patients with head and neck cancer.<sup>33</sup> Using PAIS-SR T-score of 62 as the cut-off point for clinical levels of maladjustment suggested by Derogatis and Derogatis<sup>29</sup>, 71% of our participants tested positive.

Facial deformity seriously affects an individual's body image and communication.<sup>7</sup> Postoperative patients with oral cancer often suffer setbacks in interpersonal interactions due to their appearance; resulting in withdrawal, alienation and social isolation.<sup>3435</sup> Only a few studies have investigated the impacts of disfigurement on psychosocial adjustment in patients with oral cancer. In these studies, the level of facial disfigurement was negatively associated with psychological and social functioning.<sup>17 35</sup> Fear of negative evaluation has also been found to be a statistically significant predictor of adjustment.<sup>17</sup> We used both objective and subjective measures of facial disfigurement and yielded similar results, which support the negative impact of facial disfigurement on psychosocial adjustment. This finding is consistent with other reports in the head and neck cancer literature.<sup>5 17 18</sup>

In the current study, 72.73% of participants are unemployed. Although it is hard to know whether this high unemployment rate is due to the disease or the disfigurement, we found a significantly higher level of facial disfigurement in the unemployed participants than in the employed participants. This finding suggests that facial disfigurement may also negatively affect an individual's work status.<sup>36</sup>

Social support is another important factor which may facilitate postoperative psychosocial adjustment in patients with oral cancer. In this study, we found a statistically significant direct effect of social support on psychosocial adjustment. This is consistent with findings in the cancer literature that have shown a positive association between the degree of social support and the extent of psychosocial adjustment.<sup>21 23</sup> We also found a statistically significant interaction effect of social support and facial disfigurement on psychosocial adjustment. These findings indicate that social support benefits occur through both a direct effect and by way of a moderating mechanism shaping the extent to which facial disfigurement affect psychosocial adjustment. Collectively, these results

support the importance of social support for facilitating adaptation to cancer survivorship.

The limitations of this study include the following: it was cross-sectional, involved a small convenience sample and excluded patients without reconstructive surgeries. These factors limit the generalisability of the findings to patients with oral cancer as a whole. Moreover, the cross-sectional nature of the study precluded an assessment of the evolution of psychosocial adjustment with disease progression and did not permit us to determine causal relationships among the study variables. Replication of the findings with a larger sample size, a longitudinal study design and the examinations of other moderating variables are warranted. For example, habits such as smoking, betel nut chewing and alcohol consumption may add additional explanations to the variations of psychosocial adjustment in patients with oral cancer, as these unhealthy habits are strongly related to oral cancers and make a difference on patients' perspectives about their disease (self-blame, self-stigmatised). Gender differences in psychosocial adjustment have been reported in a previous study of head and neck cancer survivors.<sup>23</sup> Females reported higher levels of appearance-related distress than males. However, due to having only three female participants in the current study, we were unable to examine the gender difference in psychosocial adjustment among patients with oral cancer. Nevertheless, the study results present evidence for the importance of facial disfigurement, and social support on the psychosocial adjustment in patients with oral cancer.

The study findings are relevant to the understanding of prerequisites that empower patients with oral cancer to successfully adjust to the diverse consequences of cancer and its treatments. Clinicians who work with patients with oral cancer should engage in an ongoing psychosocial assessment and appropriate referral may be needed. Psychosocial health services can enable patients with oral cancer to manage the psychological and social aspects of their health and thereby promote better adjustment. Future studies exploring the social-cognitive predictors of psychosocial adjustment will further inform the development of effective psychosocial interventions for oral cancer populations.

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**Competing interests** None declared.

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**Data sharing statement** All available data can be obtained by contacting the corresponding author.

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