

Psychological morbidity and health-related quality of life in patients with differing awareness of cancer diagnosis: a cross-sectional study

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Abstract

Objective: Concealment of cancer diagnosis from patients is not rare worldwide and physicians in mainland China are in fact discouraged from disclosing a cancer diagnosis to cancer patients. Preventing worsened psychological morbidity is at the core of the argument for nondisclosure. The purpose of this study was to quantify anxiety, depression, and distress among patients with various degrees of awareness of their cancer diagnosis. Quality of life was also measured.

Methods: Using a cross-sectional and blinded design, the Hospital Anxiety and Depression Scale questionnaire, the Distress Thermometer, and the SF-36 Health Survey were administered to 287 hospitalized patients with oral and maxillofacial tumors. Independently, the patients' awareness of disease was assessed with semistructured interviews.

Results: Hospital Anxiety and Depression Scale, Distress Thermometer, and SF-36 did not identify significant differences in scores among the hospitalized patients with various degrees of awareness of their cancer diagnosis: an awaiting diagnosis group, a concealed diagnosis group, and a disclosed diagnosis group.

Conclusions: Before surgery, inpatients who were hospitalized because of oral and maxillofacial tumors with various degrees of awareness of their cancer diagnosis had similar psychological morbidity and quality of life. Informing hospitalized cancer patients of their diagnosis before surgery may not deteriorate their psychiatric condition or their quality of life.

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Introduction

The last several decades have seen a global trend toward providing more information for cancer patients. Although so-called therapeutic nondisclosure is not very effective [1], concealment of cancer diagnosis from cancer patients is not rare worldwide [2]. The decision not to tell the truth to cancer patients compromises patient autonomy and the reasonable goal of obtaining informed consent, creating confusion and uncertainty in clinical practice.

Fears of causing psychological morbidity to these patients are at the core of arguments for nondisclosure of cancer diagnosis [3]. If this concern was valid and if relevant support was not available and effective, from the perspective of non-maleficence, arguments for nondisclosure might outweigh the arguments for disclosure, including that of autonomy, at least on some occasions. The evidence from research has been very limited, controversial, and inconclusive. Many studies have reported decreased psychological morbidity or better quality of life (QoL) in cancer patients who were unaware of cancer [4–9]. On the contrary, Husson *et al.* in a recent systematic review concluded that there was a positive relation between information provision and mental health [10].

Many factors may contribute to these contrasting results, such as the methods of assessment, cross-cultural differences, variations of anatomic location of cancer, treatment modalities, and the time when the investigations were conducted. There have been considerable efforts to improve the accuracy and completeness of such assessments. Emotional distress has been recognized as a core indicator of a patient's health and well-being. Along with temperature, respiration, heart rate, blood pressure, and pain, it has been designated as the sixth vital sign [11]. Health-Related Quality of Life (HRQoL) assessments have been used as primary outcomes in recent decades. Researching different patient groups by using surveys and cultural descriptions is also important to illuminate potential differences. In turn, cultural considerations should always be weighed in conjunction with the preferences and values of the individual patient and family members.

This study was part of a larger investigation that evaluated disclosure of cancer diagnosis in mainland China, where clinicians are often discouraged from telling the truth to a cancer patient and family members often support nondisclosure, especially when the family members have had experience with a cancer patient who is unaware of

the truth [12]. In addition, we focused on the oral and maxillofacial region, where the disease may cause disfigurement of the face and may be life-threatening.

The main purposes of the study were as follows: first, to study patients' awareness of their disease with semistructured interviews; and second, to evaluate whether there were significant differences in psychological morbidity and HRQoL among patients with varying degrees of awareness of their cancer diagnosis. We hypothesized that most hospitalized cancer patients are not too vulnerable to accept the truth. Family requests to withhold information from patients occur everywhere, including Southern and Eastern Europe, Africa, and Asia [13]. In the USA, requests for nondisclosure are not rare [14,15]. Therefore, findings from this study could provide insight for clinical care around the world. Furthermore, our findings might help clinicians to think about how and when disclosure of diagnosis should occur.

Methods

Prior to the start of the study, approval for the research was obtained from the hospital's Review Board.

Participants and procedure

The survey was conducted in the Department of Oral and Maxillofacial Surgery, School and Hospital of Peking University, in Beijing, China. The department is the largest referral center in Northern China for patients with cancer involving the oral and maxillofacial region. Similar to other oncology centers or hospitals in China, it has no stated policy about the disclosure of cancer diagnoses.

From May 2008 through March 2009, consecutive inpatients with tumors in the oromaxillofacial region were invited. The participants who were younger than 18 years old, or had a history of psychiatric disease, or were too ill to be interviewed were excluded from the study. This was a cross-sectional observational study. To avoid confounding of surgery-related psychological morbidity and HRQoL, we conducted the survey before any major surgical intervention.

First, after providing informed consent, the patients were invited to complete the SF-36 Health Survey, the Hospital Anxiety and Depression Scale (HADS) questionnaire, and the Distress Thermometer (DT). The SF-36 Health Survey Chinese validity and reliability studies were performed in 2003 [16]. The HADS questionnaire [17] is a widely used and well-validated self-report instrument designed to detect anxiety and depression in the medical patient, especially for screening [9]. It has been reported to be a 'gold standard' for evaluation of anxiety and depression in cancer settings. The reliability and validity of the Chinese versions have been established by Ye Weifei and Xu Junmian. It has been reported that

the optimum cutoff points are scores of 9 both in the anxiety subscale score and depression subscale score [18]. Additional use of a self-rating instrument for depression and anxiety, such as the HADS, is recommended when the SF-36 is used for QoL assessment [19]. The DT was developed as a single item indicator of undifferentiated distress [20]. It has been found to have acceptable levels of sensitivity and specificity in detecting psychosocial morbidity [21]. The DT was used according to the National Comprehensive Cancer Network guidelines on distress management. Some patients may be poorly educated, but the DT is very easy to understand. Each patient was asked 'How distressed have you been today and over the last week?' for the DT and to rate their answer on a 0–10 scale (0 = no distress; 10 = extreme distress). A score of 4 was proposed as the most appropriate cutoff for identifying distressed patients, who were defined as having scores of 5 and above [22]. After careful discussion with members of the Department of Psychology at Peking University, the word 'distress' was translated into the Chinese word *yōu lǜ* (忧虑). To be eligible for the present analysis, the patient should have completed all items of the SF-36, HADS, and DT.

Second, we accessed the cancer patient's awareness of disease as reported elsewhere [1]. Because stepwise approaches have been shown to be effective in the delivery of bad news [23], we included potential cancer patients because of their cancer-like clinical manifestation and the waiting period for final histological diagnosis. Some of them may not have been cancer patients ultimately, but all of them shared the same life-threatening prospect of malignant disease, the most significant feature of the cancer experience. The second group comprised histologically verified cancer patients who were unaware of the diagnosis. The third group consisted of patients who knew their confirmed cancer diagnosis. Accordingly, the subgroups were named the awaiting diagnosis group, the concealed diagnosis group, and the disclosed diagnosis group.

Data regarding patient tumor staging were obtained from clinical records. Social demographic variables of interest were the ages of both patients and family participants (categorized as 18–35, 36–60 and 61 years old and older), sex, education, and the number of hospitals or/and clinics the patients had visited. The residential areas were also recorded. Participants were given a detailed explanation regarding the purpose of the study and were free to decline participation in the study. Oral consent was obtained from all the participants.

Data analysis

Data of every patient were independently entered into a computer database by two assistants. If the same data items for the same patient were different, they were

checked and corrected. Data were analyzed using SPSS 16.0 for Windows (SPSS Inc., Chicago, IL, USA). Distribution and frequency analyses were employed to describe the sample. We analyzed whether the patients in the various cancer diagnosis awareness groups in the cancer inpatient setting had different HRQoL and depression, anxiety, and psychiatric status. The results of the SF-36 were analyzed with one-way analysis of variance, and the HAD and the DT with the χ^2 test. A value of $p \leq 0.05$ was considered to be statistically significant.

Results

Sociodemographic and clinical features of the sample

Two hundred and eighty-seven patients were recruited. Eleven patients declined participation and were not asked why. Among those remaining, 252 patients completed all questionnaires (response rate 87.8%). The sociodemographic and clinical data for the 252 patients are summarized in Table 1. Of the 252 patients, 135 (53.6%) were evaluated as being in the awaiting diagnosis group, 39 (15.5%) in the concealing diagnosis group, and 78 (31.0%) in the disclosed diagnosis group.

Table 1. Demographics and disease characteristics

	Number of patients	252
Sex	Male	151 (59.9%)
	Female	101 (40.1)
Age	18–35 years	37 (14.7)
	36–60 years	136 (54)
	>60 years	79 (31.3)
Classification of disease	Benign tumor	73 (29.0)
	Malignant tumor	177 (71.0)
Stage of malignancy	Early stage	81 (45.8)
	Advanced stage	96 (54.2)
Patient awareness of disease	Awaiting diagnosis group	135 (53.6)
	Concealed diagnosis group	39 (15.5)
	Disclosed diagnosis group	78 (31.0)
Educational level	None	50 (19.8)
	Primary school	22 (8.7)
	Middle school	110 (43.7)
	College	70 (27.8)

Table 2. Descriptive statistics for the SF-36 scale

	Physical functioning	Role physical	Bodily pain)	General health	Vitality	Social functioning	Role emotional	Mental health	Total score
Total	88.33± 15.69	66.57± 41.22	67.90± 24.71	60.65± 21.24	70.18± 19.64	75.18± 25.03	61.51± 42.44	76.08± 18.81	115.92 ±16.58
ADG	88.84± 16.52	70.34± 39.28	71.78± 24.96	60.22± 21.25	70.67± 19.84	76.12± 24.32	64.68± 41.03	77.13± 18.36	117.01 ±16.03
CDG	86.88± 14.62	60.00± 40.35	65.05± 21.82	64.00± 19.59	70.00± 18.47	78.61± 25.09	57.50± 42.69	71.20± 18.50	114.68 ±14.96
DDG	88.21± 14.88	63.46± 44.63	62.69± 24.81	59.68± 22.13	69.42± 20.08	71.79± 26.12	58.12± 44.77	76.77± 19.59	114.667 ±18.30
<i>p</i>	0.785	0.305	0.027	0.544	0.919	0.246	0.448	0.296	0.615

ADG, awaiting diagnosis group; CDG, concealed diagnosis group; DDG, disclosed diagnosis group.

The SF-36

The results of the SF-36 are shown in Table 2. We identified a significant difference in the Bodily Pain subscale ($p=0.027$, >0.05) and a post-hoc analysis revealed that the difference was significant between the disclosed group and the awaiting diagnosis group. The total scale and the other subscales of the SF-36 were not significantly different.

The Hospital Anxiety and Depression Scale

According to Zigmond and Snaith [17] and others [24], each patient may subsequently be allocated to one of three 'caseness' categories for anxiety and depression, based on the individual final scores: 0–7, non-case; 8–10, borderline case; and ≥ 11 , definite case. We simplified further by designating non-case as normal and ≥ 8 as abnormal. As shown in Table 3, 33.3% (84/252) of patients had abnormal scores. According to the χ^2 test, there were no differences among the various patient groups ($\chi^2=1.118$, $p=0.572$, >0.05).

The Distress Thermometer

The results of the DT are shown in Table 4. The cutoff point was 4 and 46.4% of the patients were at 5 and above, which indicated that they were distressed. The χ^2 test showed that there were no significant differences among the various patients groups ($\chi^2=0.047$, $p=0.977$, >0.05).

Discussion

It has been reported that psychological distress varies by cancer site [25]. To the best of our knowledge, there have been few published studies conducted in subjects with oral and maxillofacial tumors in which the direct effect of knowing the truth about cancer diagnosis on HRQoL has been examined. Concealment of diagnosis from cancer patients is preferred by some families [3,26,27], with the main justification being the fear of causing psychological morbidity to the patients [12]. These particular

Table 3. Descriptive statistics for the Hospital Anxiety and Depression Scale (HADS)

	HADS normal	HADS abnormal	Total
ADG	89 (65.9%)	46 (34.1%)	135
CDG	29 (74.4%)	10 (25.6%)	39
DDG	51 (65.4%)	27 (34.6%)	78
Total	168 (66.7%)	84 (33.3%)	252

ADG, awaiting diagnosis group; CDG, concealed diagnosis group; DDG, disclosed diagnosis group.

Table 4. Descriptive statistics for the Distress Thermometer (DT) Scale

	DT normal	DT abnormal	Total
ADG	73 (54.1%)	62 (45.9%)	135
CDG	21 (53.6%)	18 (46.2%)	39
DDG	41 (52.6%)	37 (47.4%)	78
Total	135 (53.6%)	117 (46.4%)	252

ADG, awaiting diagnosis group; CDG, concealed diagnosis group; DDG, disclosed diagnosis group.

phenomena may be explained by the affective forecasting theory [28] or the prophylaxis versus treatment perception [12]. These hypotheses have not been supported by empirical research [29].

Concerned about possible methodological flaws, the present report combined the use of the SF-36, HADS and DT. Furthermore, we included the potential cancer patients who shared the same life-threatening prospect of malignant disease. Rather than the aware and unaware cancer patients, we classified the sample into the awaiting diagnosis group, the concealed diagnosis group and the disclosed diagnosis group. The results of the SF-36 indicate that the current sample perceived its general QoL to be moderately good but much poorer than the Chinese norm [30]. With the cut point of ≥ 8 , which gives a sensitivity of 0.82(95%CI, 0.73–0.89) and specificity of 0.74(95%CI, 0.60–0.84) [31], the 33.3% (84/252) overall prevalence of abnormal HADS scores in this sample is a little higher than Mitchell's results (30.8%) of a meta-analysis across 21 original studies [32]. On the DT, 46.4% of the patients were at 5 and above. The prevalence was higher than the 39% reported by Mitchell, who pooled 38 analyses of ultra-short methods of detecting cancer-related mood disorders, including 19 assessing the DT alone, involving a total of 6414 unique patients[33].

These differences between our results and those of others should be analyzed further. The present report focused on psychological morbidity and health-related QoL in patients with differing awareness of cancer diagnosis. The results support our hypothesis that most hospitalized cancer patients are not so vulnerable that they cannot accept the truth. There were no differences in the prevalence and co-morbidity of psychiatric disorders among the various groups of Chinese inpatients suffering from tumors in the oral and maxillofacial region with differing awareness of their cancer diagnosis. The results were in agreement with a few earlier studies, such as by Bozcuk in Turkey [34], Chandra in South India [35], and even those focused on advanced cancer [36] and terminal cancer [37].

The results may be explained as follows. The surveys were performed before oral and maxillofacial operations, which may cause severe complications or sequelae, such as disfigurement, dysphagia, and barylalia. Any concerns about the cancer may have been camouflaged by concerns about the surgery itself. More importantly, the subjects were inpatients who were in a better position to have more time to consult with their physicians and have their needs for information met well. Both prospective and cross-sectional observational studies have found a positive relation between appropriate information provision (satisfaction with the received information, fulfilled informational needs, high quality, and clear information) and mental and global HRQoL and a negative relation between appropriate information provision and depression and anxiety [9]. Talk itself can be therapeutic (e.g., lessening the patient's anxiety and providing comfort) [38].

Our finding that telling the truth to hospitalized cancer patients may not result in worsened psychological problems will help clinicians to think about when disclosure of cancer diagnosis should occur. Some cancer patients may not be informed of the cancer diagnosis when they are admitted to hospital and the bedside may be the best place for the cancer diagnosis to be delivered. Depression and anxiety are less common in patients with cancer than previously thought [39].

However, several studies have reached the opposite conclusion, namely, that cancer patients who were unaware of their cancer had decreased psychological morbidity or/and better QoL [4–9]. These studies were conducted across various cultural backgrounds, such as India [4], Turkey [5], Iran [6,9], France [7], and China [8], with various methods. The sample sizes were too small, ranging from 60 to 173 cases, to support their conclusions strongly.

Possible shortcomings of this research must be acknowledged. The study was conducted in an academic tertiary care hospital where medical care professionals are viewed as omnipotent, and the hopes of patients would not be diminished even by such an adverse diagnosis.

Because of the cross-sectional design, any changes may be subtle and hard to detect. Any psychological effect of the study on either family members' or patients' opinions were unclear. In addition, interviewer bias could have affected the results. Finally, the study employed a limited sample size. Future large scale studies are needed that employ a greater variety of questionnaire surveys.

Conclusion

Before surgery, inpatients who were hospitalized because of oral and maxillofacial tumors with various degrees of awareness of a cancer diagnosis had similar psychological

morbidity and QoL. Informing hospitalized cancer patients of their diagnosis may not worsen either their mental status or their QoL before surgery. The bedside may be the best place to deliver the cancer diagnosis to those patients who are still unaware of it when they are hospitalized.

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Conflict of interest

The authors have declared no conflicts of interest.

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