ORIGINAL ARTICLE

Truth telling for patients with esophageal squamous cell carcinoma in Henan, China

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ABSTRACT   **Objective**: This study aims to investigate the truth-telling status and the relevant factors of esophageal squamous cell carcinoma (ESCC) patients in Henan, China.

Methods: A cross-sectional study from April to June 2015 using questionnaires was given to 301 family members of hospitalized ESCC patients based in three affiliated hospitals of Zhengzhou University (i.e., The First Hospital, The Second Hospital, and Tumor Hospital) and Anyang Tumor Hospital.

Results: Among the 41.9% (126/301) hospitalized ESCC patients who knew of their true diagnoses, only 4.0% patients were informed by their corresponding responsible doctors, 39.7% by their family members, and 56.3% by themselves. Univariate analyses showed that disclosure of confirmed ESCC diagnosis to patients was correlated with gender, family history of cancer (FHC), education level, vocation, hospital administrative level, and attitudes of family members ($P < 0.05$). Furthermore, multivariate analysis indicated that attitude of family members was the most important and an independent factor for diagnosis disclosure. Those patients with a negative FHC, under-education, manual occupation, advanced stages, and hospitalized in municipal hospitals exhibited a low rate of truth telling.

Conclusions: Truth telling for ESCC patients in Henan is not prevalent and may be improved through consultation with family members, particularly for patients with a negative FHC, poor education, manual occupation, and advanced stages.

KEYWORDS   Truth telling; esophageal squamous cell carcinoma; diagnosis

Introduction

Efficient communication between clinicians and patients can release mental stress and improve life quality during medical management of cancer patients. Disclosure of true diagnosis to patients is an essential precondition[1,2]. Truth telling to cancer patients varies in nations with different cultures and traditions[3]. In Western countries, approximately 80%–90% clinicians fully reveal true diagnoses to cancer patients[4,5]. By contrast, truth telling is infrequent in Asian countries[6,7].

Situations of truth telling also vary for malignant cancers

arising from different body parts. For cancers that are exposed or easily touchable, such as breast cancer and craniofacial cancer, diagnosis is inclined to be disclosed[7,8]. For example, as much as 63.2% craniofacial cancer patients are informed about their diagnosis[7]. Esophageal squamous cell carcinoma (ESCC) is one of the most common cancers worldwide and the fourth most frequent cause of cancer-related deaths in China[9,10]. Mortality rate of ESCC varies greatly among different regions and mortality in Henan Province is among the highest in China[10,11]. To date, few investigations have reported the status of truth telling of ESCC patients in Henan. Henan is a region with the highest incidence and mortality for ESCC. In the present study, we aimed to investigate the following: (1) the current situation of truth telling for ESCC patients, (2) the style of truth telling for ESCC patients, and (3) the factors influencing the different attitudes of truth telling for ESCC patients.

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Materials and methods

Study subjects

From April to June 2015, a cross-sectional study using questionnaires was given to family members of 301 in-patients with newly confirmed diagnosis of ESCC recruited from three affiliated hospitals of Zhengzhou University including the First, the Second, and Tumor Hospital and the Fourth Affiliated Hospital of Henan University of Science and Technology (Anyang Tumor Hospital). All family members of patients aged above 18 years showed normal communicative competence. The family members of ESCC patients were personally interviewed at the time of discharge by trained investigators involved in this study. Patient's children were preferentially considered into the investigation if a spouse was not available. Siblings were seldom chosen. No negative emotions were triggered among all participants. This study was approved by the ethics committee of Anyang Tumor Hospital.

Criteria of family history of cancer (FHC), education level, vocation, tumor node metastasis (TNM) stage, and hospital administrative level

People who completed nine years' compulsory education are likely to recognize the Chinese character "Cancer" because its handwriting is not readily recognizable by under-educated people. Thus, nine years' compulsory education was set as our stratification criterion for education level. Manual workers include factory workers, farmers, and unemployed people. Mental workers include teachers, doctors, and civil servants. The criterion of a positive FHC is defined as more than two first-degree family members of malignant cancer victims within three generations. In addition, the patient was directly successive to his/her cancer-bearing relatives. Based on TNM stage of tumors amended by the American Cancer Society in 2002, stages of ESCC are defined as 0, I, IIa, IIb, III, IVa, and IVb. The hospitals located in provincial capitals are directly managed by the provincial Department of Health and the municipal hospital by local municipal health authority in China.

Data collection

All processes were conducted under the informed consent of family members. First, general information including gender, age, address, therapeutic methods, and TNM stage was collected by consulting the medical records. Then, questionnaires were given to family members of ESCC patients to investigate the current situation and style of truth telling for ESCC patients, FHC, education level, vocation, and the attitude of family members to truth telling. The questionnaire took approximately 20 min. This study was in accordance with the ethical standards and the Helsinki Declaration.

Statistical analysis

Two-sided Chi-square test was employed to determine the significant differences in the univariate analyses. The dependent variable was truth telling for ESCC patients. The independent variables included gender, age, FHC, education level, vocation, income, hospital grade, TNM stage, and the attitude of family members to truth telling. In addition, unconditional logistic regression was employed in multifactor analysis to assess which of the independent variables best predicted preference toward the disclosure of ESCC patients among the factors significantly associated in the univariate analyses. SPSS 19.0 for Windows (SPSS Inc., Chicago, IL, USA) was utilized for our data analyses. Odds ratios (ORs) and their corresponding 95% confidence intervals (CIs) were calculated using the maximum likelihood method. A $P<0.05$ was considered statistically significant.

Results

Characteristics of patients

In family members of 330 in-patients with newly diagnosed ESCC patients (within the previous two months), 301 (91.2%) completed questionnaires, whereas 29 (8.8%) refused to complete. Their reasons for refusal had not been inquired with regard to ethics. The distribution of demographic and clinical features is shown in **Table 1**. A total of 65.4% patients were males with a mean age of 63.3 years (standard deviation 8.3). TNM stage of 33 patients without surgery was unavailable.

Current situation and style of truth telling for ESCC patients

In 301 ESCC patients, 175 patients (58.1%) were not informed of their own diagnosis. Among the 126 patients who knew of their cancer diagnoses, only 5 (4.0%, 5/126) were informed of their diagnoses by doctors, 39.7% (50/126) by relatives, and 56.3% (71/126) patients knew the truth on their own either through gaining access to medical test reports, medical records, or bedside card.

Table 1 Univariate analyses for factors affecting truth-telling (*n*=301)

Characteristics	Total	Non truth-telling	Truth-telling	χ²	P
Gender				9.485	0.002
Male	197 (65.4)	102 (51.8)	95 (48.2)		
Female	104 (34.6)	73 (70.2)	31 (29.8)		
Age, years				3.306	0.69
<61	95 (31.6)	48 (50.5)	47 (49.5)		
>60	206 (68.4)	127 (61.7)	79 (38.3)		
Area†				0.013	0.910
HIA	190 (63.1)	110 (57.9)	80 (42.1)		
LIA	111 (36.9)	65 (58.6)	46 (41.4)		
Education level				46.863	0.000
Under-education (less than 9 years)	183 (60.8)	135 (73.8)	48 (26.2)		
Education (more than 9 years)	118 (39.2)	40 (33.9)	78 (66.1)		
Vocation‡				19.132	0.000
Mental workers	27 (9.0)	5 (18.5)	22 (81.5)		
Manual workers	274 (91.0)	170 (62.0)	104 (38.0)		
Family history of cancer				7.804	0.005
Positive	153 (50.8)	98 (66.2)	50 (33.8)		
Negative	148 (49.2)	77 (50.3)	76 (49.7)		
Family's yearly income, RMB				2.082	0.353
0–20,000	120 (39.9)	72 (60.0)	48 (40.0)		
20,000–40,000	143 (47.5)	85 (59.4)	58 (40.6)		
40,000	38 (12.6)	18 (47.4)	20 (52.6)		
Hospital administrative level§				11.066	0.001
Municipal hospital	206 (68.4)	133 (64.6)	73 (35.4)		
Provincial hospital	95 (31.6)	42 (44.2)	53 (55.8)		
Therapy method				0.460	0.498
Operation	268 (89.0)	154 (57.5)	114 (42.5)		
Non-operation	33 (11.0)	21 (63.6)	12 (36.4)		
TNM stage¶				15.742	0.000
Stage 0-I	41 (15.3)	12 (29.3)	29 (70.7)		
Stage IIa-IV	227 (84.7)	142 (62.6)	85 (37.4)		
The attitude of family member				65.419	0.000
Disagreement	159 (52.8)	127 (79.9)	32 (20.1)		
Agreement	142 (47.2)	48 (33.8)	94 (66.2)		

† HIA: high-incidence area; LIA: low-incidence area. ‡ Manual workers include factory workers, farmers and unemployed people and mental workers include teachers, doctors and civil servants. § The provincial hospital is directly managed by the provincial Department of Health in China and the municipal health authority directly manages the municipal hospital. ¶ Thirty three patients treated with no operation can't get clinicopathological TNM stage.

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Univariate analysis for factors affecting truth telling

Univariate analyses were performed to determine the factors affecting truth telling in Henan. Moreover, its results indicated that gender, FCH, education level, vocation, hospital administrative level, TNM stage, and the attitude of family members toward truth telling were statistically significant factors affecting truth-telling rate ($P<0.05$). However, age, region, income, and therapeutic methods showed no statistical significance (**Table 1**).

The attitude of agreement and disagreement for disclosure of true diagnosis was similar. The frequency of truth telling for ESCC patients (66.2%) was strikingly higher in consented family compared with its counterpart (20.1%, $P<0.000$, **Table 1**). Male ESCC patients accounted for approximately two-thirds of total patients (197/104). The frequency of truth telling for ESCC patients was remarkably higher for males than that of females (48.2% *vs.* 29.8%, $P<0.000$, **Table 1**). Most ESCC patients had under-education level (183/301). The percentage of truth telling was notably lower in under-educated patients than others with more than nine years of education (26.2% *vs.* 66.1%, $P<0.05$, **Table 1**). The overwhelming majority of the ESCC patients were manual workers (274/301). The frequency of truth telling for ESCC patients was noticeably lower in manual workers compared with that of mental workers (81.5% *vs.* 38.0%, $P<0.000$, **Table 1**). Approximately half of ESCC patients exhibited FHC (153/301). The percentage of truth telling for patients with a positive FCH was significantly higher than that of patients with a negative FCH (49.7% *vs.* 33.8%, $P=0.005$, **Table 1**). ESCC patients with TNM stages IIa-IV accounted for 84.7% of total patients (227/268). The percentage of truth telling for patients with TNM stages IIa-IV was significantly lower than that of patients with TNM stages 0-I (37.4% *vs.* 70.7%, $P=0.000$, **Table 1**). Most ESCC patients recruited in the present study were hospitalized in a municipal hospital (206/301). The percentage of truth telling for patients hospitalized in municipal hospitals was significantly lower than those in provincial hospitals (35.4% *vs.* 55.8%, $P=0.001$, **Table 1**).

Multivariate analysis of independent factors affecting truth telling

Furthermore, multivariate analysis showed that vocation (OR=3.74, 95% CI 1.19–11.76, $P=0.024$), TNM stage (OR=2.62, 95% CI 1.11–6.20, $P=0.028$), education level (OR=2.46, 95% CI 1.25–4.86, $P=0.009$), hospital administrative level (OR=2.19, 95% CI 1.14–4.19, $P=0.018$), FHC (OR=1.93, 95% CI 1.04–3.57, $P=0.037$), and the attitude of family members (OR=5.97, 95% CI 3.24–11.02, $P=0.000$) remained an independent factor influencing diagnosis disclosure. The attitude of family members was the most important factor for truth telling (**Figure 1**).

Discussion

This study revealed that 41.9% ESCC patients were informed about their true diagnosis in Henan. Nevertheless, the main approaches of informing cancer patients with ESCC of their true diagnosis were not from clinical practitioners but from their family members or learnt on their own. Only 4% of ESCC patients were told by doctors. This result may be due to the following reasons. First, Chinese doctors do not incline to tell the true diagnosis to cancer patients for fear of negative consequences after truth telling[12]. China has a typical Eastern culture, and Chinese medical ethics is mainly influenced by the Confucian culture with an intention of protecting patients from harm by concealing sorrowful information[13]. Sixty-five percent of Chinese oncologists believe that they should not disclose confirmed diagnosis to advanced cancer patients[12]. Second, predicting the response of patients in clinical practice after hearing bad diagnosis is difficult. The doctors-in-charge choose to inform their family members instead of directly telling cancer patients to avoid the responsibility of the negative outcome probably related to true diagnosis telling. In general, this phenomenon is also legal[7]. The majority of patient family members ask the responsible doctors to conceal the true diagnosis because they suppose that a feeling of despair and hopelessness would ensue after hearing sorrowful information[14,15]. In Asia, a
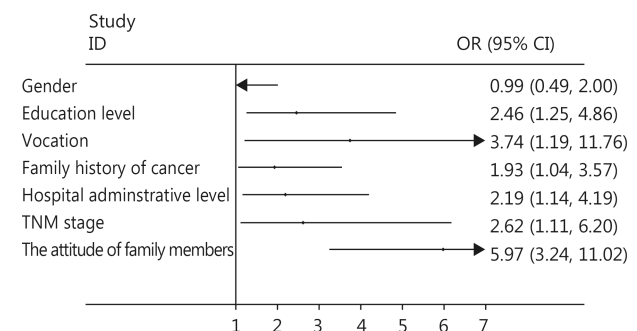
Figure 1 Multiple logistic regression for factors affecting truth telling. Multiple logistic regression revealed that the most important factors for truth telling are vocation, TNM stage, education level, hospital administrative level, FHC, and the attitude of family members.

family generally has an overriding role over an individual in terms of medical management[16,17]. A "family-consent for disclosure" approach is commonly adopted[18]. In China, family members of cancer patients play a decisive role in communication between doctors and patients, which has an important influence on truth telling to cancer patients[14]. Our results showed that 39.7% patients were informed by their family members. The attitude of family members was the most important factor affecting disclosure of true diagnosis to patients. The OR of truth telling for ESCC patients with family agreement increased by a factor of 5.94 compared with those with disagreement. Most family members, however, do not agree with informed diagnosis to cancer patients. They think that informed patients may develop depression. This condition is not conducive to treatment. By contrast, others consider that informed patients are likely to comply with treatment and have good treatment responses (**Table 2**). Obviously, the attitudes of family members were determined by the subsequent consequences after truth telling.

Eighty five percent Chinese cancer patients want to know their diagnoses[15]. In this era of readily available information, patients can obtain access to their diagnostic information through various ways. Therefore, tumor patients have an important influence on truth telling for themselves. In line with several previous investigations[7,19,20], our results indicated that educated patients defined as completion of nine-year compulsory education tend to have high rate of knowing true diagnosis. Obtaining access to information on the diseases by multiple approaches including television, Internet, and medical organizations with advances of current technology is easy for educated patients. Thus, patients with high education level generally have more knowledge about malignant tumors and are willing to know their true diagnosis and to comply with medical treatment compared with under-educated patients[21].

Patients with a positive FHC are more likely to know their true diagnoses than those without FHC. A positive FHC is widely recognized as a risk factor for cancer. Their family background can make them acute to their heritable risk from the symptoms. Therefore, patients with a positive FHC are willing to take physical and genetic examinations for tumors[22-25]. Similarly, women with a positive FHC of breast cancer have sense of breast self-examination[23,24] and people with an FHC of skin cancer pay attention to sun protection[25]. In summary, a positive FHC enables people to know well about prevention and therapy of malignancy.

Patients engaging in mental work are more likely to be informed about their true diagnoses than those engaging in manual occupation. In China, mental workers are usually well educated. Moreover, workmates in the same field may share common information. This finding may possibly explain why mental workers have high disclosure rate. Chinese oncology clinicians tend to inform patients of true diagnosis on the condition that patients have an early-stage cancer. This finding was also the same case for family members evidenced by high percentage of early-stage cancer patients to be informed with their diagnosis.

In addition, this study showed that the high administrative level of hospital generally representing high professional skills (the population viewpoint) in China is likely to disclose true diagnosis. The hospitals located in provincial capitals are directly managed by the provincial Department of Health and the municipal hospital by local municipal health authority in China. Therefore, patients with serious diseases or are rich are frequently referred to the provincial hospital. Our research indicates that physicians in a provincial hospital have a good understanding of truth telling and tend to reveal the truth to the patients. Although few patients were told by doctors, the attitude of doctors for truth telling may hint the next of kins to have the patients informed.

Multivariate analysis showed that gender did not contribute to truth telling although more male patients (48.2%, 95/197) were informed on true diagnosis than female patients (29.8%, 31/104). This difference may correlate with

Table 2 The justifications of family members toward truth telling

Item	n (%)
The reason for 'Yes'	
Disclosure enables patients to cooperate with doctors better in their following medical care	61 (45.9)
Patients will learn about the truth eventually	57 (42.9)
Patients have a right to know the truth about their own condition	15 (11.2)
The reason for 'No'	
Disclosure can make patients feel hopeless and helpless	159 (94.6)
No need to inform	9 (5.4)

education level because the frequency of nine-year education completion for male patients (52.8%, 104/197) was remarkably higher than that of female patients (13.5%, 14/104).

Several limitations in the present study exist. First, we did not consider the attitude of ESCC patients at the meantime, which needs further investigation[7]. Second, we randomly asked one of the first-degree relatives of in-patients without involving all family members. Third, 77.8% patients were farmers from rural areas and may not represent ESCC patients in the city. Lastly, the sample size in this study was relatively small. Large-scale surveys should also be conducted in the future.

Conclusions

Disclosure of true diagnosis to ESCC patients is not prevalent in Henan China with only 41.9% patients informed. The attitude of family members was the most important factor affecting truth telling. The present study suggests that disclosure of ESCC diagnosis may be improved through consultation with family members of ESCC patients, particularly among patients with a negative FHC, poor education, manual occupation, and advanced stages.

Acknowledgments

Conflict of interest statement

No potential conflicts of interest are disclosed.

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