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ORIGINAL ARTICLE

Is therapeutic non-disclosure still possible? A study on the awareness of cancer diagnosis in China

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Abstract
Objective The objectives are to study cancer patients' awareness of their diagnosis and to determine who tends to disclose bad news to cancer patients.
Method A total of 151 consecutive oral and maxillofacial cancer patients and their relatives were surveyed using semi-structured interviews.
Results Of the 151 patients, 64.2% were aware of their cancer diagnosis. Of this group, 20.6% had been told by physicians and 17.5% were informed by relatives, with the remaining 61.9% acquiring the diagnosis on their own. The more educated patients were more likely to be aware they had cancer.
Conclusion Despite efforts by family members to conceal cancer diagnoses from patients, the majority of patients discovered the diagnosis of their own accord. This finding suggests that therapeutic non-disclosure is not very effective at withholding the truth from patients.

Keywords Therapeutic non-disclosure · Family member · Oral and maxillofacial cancer

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Introduction

It is well documented that the last quarter of the twentieth century saw a radical shift of attitudes and practices regarding disclosure of cancer diagnoses to patients [1–3]. In more recent years, progress has been made concerning the best ways to communicate bad news to patients [4–7]. However, whether it is absolutely necessary to tell the truth to cancer patients remains controversial [8–10]. This is partly because the available evidence originates mainly from developed countries with Anglo–American cultures where most cancer patients were aware of their cancer diagnoses.[11] Cultural characteristics may affect the way in which the truth is told in cancer care practice[12]. In Asian countries, therapeutic non-disclosure, referring to a clinician's decision to withhold diagnostic or prognostic information from a patient to protect him or her from perceived harm [13], is widely reported in theoretical scenario-based surveys.

Mainland China, with the world's largest population and most typical eastern culture in the world, is widely viewed as a representative region where therapeutic partial- or non-disclosure still prevails [3, 8]. This makes China one of the best countries to study truth-telling. The practice of disclosing diagnosis and prognosis to cancer patients in more developed countries may be influencing Chinese physicians' attitudes. A recent survey in China indicates that the attitudes of oncologists towards disclosure of cancer diagnosis to patients have changed, especially in the early stage of the disease [14]. However, physicians' attitudes do not correspond directly to their daily clinical practice [15]. According to the People's Republic of

China's Law on Medical Practitioners, doctors should truthfully explain the patients' conditions to the patients and their family members, provided that attention is paid to avoid adverse effects on the patient. Thus, physicians in Mainland China are de facto discouraged to tell the truth to cancer patients, because they must shoulder the legal responsibility of any adverse effects on the patient. The law allows physicians to circumvent direct patient disclosure by telling the relatives. The legal ramifications outweigh the other considerations, such as ethical justification, medical benefits, and deontological argument.

Data about Chinese cancer patients' diagnostic awareness and their sources of information are prerequisite to initiating study in this area but so far no related report has been published. This study investigates both cancer patients' diagnostic awareness and their information sources. We hypothesize that it is difficult to withhold cancer diagnoses from patients in this era of readily available information.

We focused on patients with oral and maxillofacial cancer. Previous studies have shown that different cancer sites have led to different tendencies of disclosure. For example, skin cancer patients were more likely to be told the truth about their cancer diagnosis [16]. Similarly, recent literature indicates that head and neck cancer patients and breast cancer patients are more likely to be told the truth [17]. Most studies focus on patients with breast cancer, prostate cancer, or a mix of different cancers. Research focusing on different patient groups with different cancer sites is needed. Few studies have reported data about patients with oral and maxillofacial cancer.

Participants and methods

Participants

The study was conducted in the Department of Oral and Maxillofacial Surgery, School and Hospital of Peking University, Beijing, which is one of largest treatment centers for patients with cancer involving the oral and maxillofacial region in China. The hospital treats about 300 patients with newly diagnosed cancer yearly. More than two thirds of the patients are referred by doctors in other hospitals outside Beijing city, mostly in Northern China. Similar to other oncology centers or hospitals in China, it had no stated policy about the disclosure of cancer diagnoses. From May 2008 through March 2009, all consecutive new inpatients with a confirmed cancer diagnosis, as well one of their close family members were enrolled as study pairs.

Participants were free to decline participation in the study. Only participants who were older than 18 years old and healthy enough to communicate with the interviewer were included in the study. Patients who could not be interviewed because of their poor physical condition, or who had a history of psychiatric disease were excluded from the study. The family caregivers selected for the study were preferably patients' spouses, and if not available, the parents or the children were asked to participate. Siblings were rarely selected.

We first got the approval from the family members. If the family member of the patient declined to be interviewed or expressed concern about participation by the patient, that led to automatic exclusion of the pair. By this way we would get the family members' understanding and support in case the interviewing harmed the patients through leaking bad news to uninformed patients. Thus we maintained good rapport with the patients and their family members.

Data regarding tumor staging were obtained from clinical records. Socio–demographic variables of interest were age (categorized as 18–35 years, 36–60 years, and 61 years old and older) sex, education, the number of hospitals or/and clinics patients had visited, and the patient's residential area.

Procedure

The study was conducted in two distinct stages. In the first stage, the family members of the patients were asked whether and how the patients had been given the information of cancer diagnosis. We defined patients' awareness of cancer diagnosis as the patient knowing that his or her illness was cancer which was in line with the common definition of diagnosis awareness from other published studies [18]. In the second stage, using a semi-structured interview, the patients were asked to recollect his or her life since the onset of disease. The interviewer's aim was to elicit patients' awareness of their disease. If the patients knew that they had cancer they would be asked to describe how they learned of the diagnosis. If the patient was unaware and the next of kin repeatedly declined to impart the bad news to the patients, the interviewer would withhold the truth from the patient.

All interviews were conducted by one interviewer, lasting 30–90 min.

Statistical analysis

Data was analyzed using SPSS 16.0 for Windows. All tests of statistical significance are two sided Chi-squared tests. The dependent variable is patients' awareness of their diagnosis. The independent variables include patient's gender, age, educational level, disease stage, the number

of hospitals, or clinics patients had visited, and the patient's residential area.

A p value <0.05 was considered significant.

Results

Patient information

One hundred and seventy-two pairs of cancer patients and their family members were invited to participate in the study. Twenty-two patients or family members declined to participate. For ethical reasons they were not asked why they declined. Thus the final sample included 151 patients and family member pairs. The demographic and clinical characteristics of patients are summarized in Table 1. The patients' mean age was 56 years. Of the patients, 57.6% were male. Squamous cell carcinoma constituted the largest histologic-type group, with salivary gland carcinoma ranking second. More than half of the patients had stage III–IV or recurrent cancer.

Patients' awareness of cancer diagnosis and source of diagnostic information

Of the 151 patients, 54 (35.8%) were evaluated as being unaware of the cancer diagnosis. As shown in Fig. 1, among the 97 patients who knew their cancer diagnoses, slightly more than one fifth (20.6%, 20/97) were told the diagnoses by physicians and 17.5% (17/97) were informed by relatives. Approximately two thirds (61.9%,60/97) of patients who knew the truth obtained the cancer diagnosis on their own, either through gaining access to their histo–pathologic reports or medical records or by inferring the truth from subtle changes in their relatives' behavior.

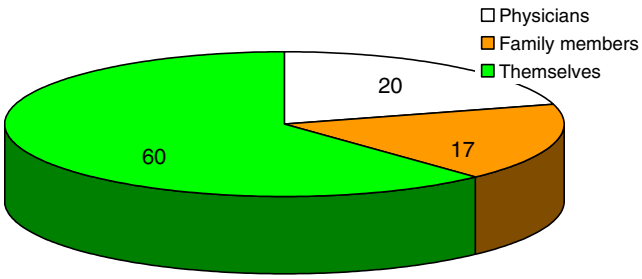

Fig. 1 From whom the patients got the truth (n=97). Of the 97 patients who knew their cancer diagnoses, 20 patients were told by physicians, 17 by the relatives, 60 knew the truth by themselves

Differences in awareness of cancer diagnosis

Those patients with a higher level of education were less likely to have had their cancer diagnosis concealed from them. As shown in Fig. 2, only 18.6% of the patients who were educated to college level were left in the dark about their cancer diagnosis, while 41.1% of the middle school group and 43.5% of the primary school group were unaware (p=0.027). No significant difference was noted between patients' awareness of cancer diagnosis and patients' gender, age, cancer diagnosis, disease stage, the number of hospitals, or clinics patients had visited, and the patient's residential area.

Table 1 Characteristics of the patients (n=151)

	Characteristics	No. (%)
Gender	Male	87 (57.6)
	Female	64 (42.4)
Age (years)	18–35	14 (9.3)
	36–60	72 (47.7)
	>60	65 (43.0)
Cancer diagnosis	Squamous cell carcinoma	104 (68.9)
	Salivary gland malignant carcinoma	30 (19.9)
	Others	17 (11.3)
Tumor staging	Stage I–II	73 (48.3)
	Stage III–IV recurrent cancer	70 (46.4) 8 (5.3)
Awareness of cancer diagnosis	Aware	97 (64.2)
	Unaware	54 (35.8)
Education	Primary school (less than 6 years)	23 (15.2)
	Middle school (6–12 years)	85 (56.3)
	College (more than 12 years)	43 (28.5)

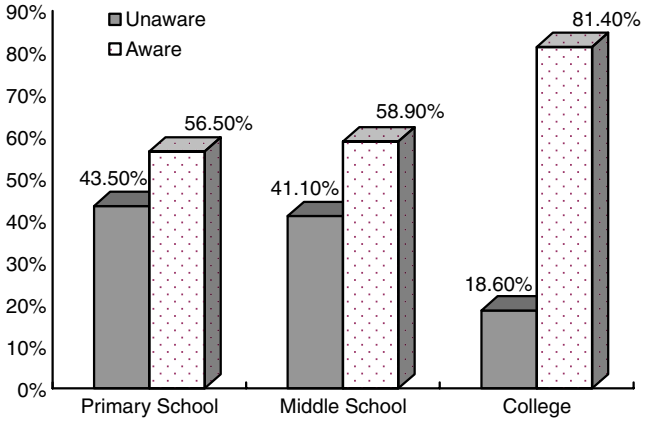

Fig. 2 Patients' educational level and awareness of cancer diagnosis

Discussion

The investigation of cancer patient disease awareness is a challenging task. Some of the patients may not know they have cancer, some of them, knowing the diagnosis, "play along", as if they did not know [19]. So far there is no standardized questionnaire, and using semi-structured clinical interviews is the most common method [20, 21]. We interviewed both patients and their accompanying relatives in order to strengthen the accuracy of the findings. Family members provided us with their perspective on the patients' awareness of their diagnosis, which we then correlated with the patients' own answers. We found that most of the patients (64.2%) were aware of their diagnosis. Only 20.6% of the cancer patients who knew their diagnosis were informed by physicians. This is likely due to several factors, including the possibility that to Chinese physicians, the concealment of a cancer diagnosis from patients is less stressful than its disclosure [22, 23] and secondly, even when physicians have an intention to present the bad news honestly to seriously ill patients, Chinese law mandates that unfavorable consequence to patients be avoided. In China, both the patient and his or her family members are legally qualified to receive the information about cancer diagnosis and prognosis. It is hard for physicians to predict cancer patients' reactions following disclosure and thus easier to avoid disclosure to the patient and sharing the information only with the family members, especially when relatives request non-disclosure.

Only 17% of the family members conveyed the bad news to their sick relatives. Based on these findings we may suggest that the Chinese Mainland could provide a representative example of family members' preference for concealment of cancer diagnoses. The relatives' reluctance to tell the truth to cancer patients can be explained with the theory of affective forecasting. The negative reactions to a future event systematically rivet people, resulting in the other outcomes getting ignored and the duration of the negative emotional reaction to future events being over-predicted [24].

The finding that 64.2% of the patients knew the cancer diagnosis even though only approximately a third of them had been given this information by the physicians or their relatives shows that despite efforts to conceal cancer diagnoses from patients, they are able to obtain the information themselves. Those patients with a higher level of educational were less likely to have had their cancer diagnosis concealed from them. In our study group of 151 cancer patients, only 18.6% of college-educated patents were unaware of their cancer diagnosis compared with 41.1% and 43.5% of patents in the middle school and high school groups, respectively. This is similar to the findings of a recent Iranian study, which revealed a correlation between illiteracy and being unaware of the true diagnosis [25]. As new technologies become more accessible, patients increasingly seek, and obtain medical information outside clinical encounters, generally through mass media or the Internet [26]. This is especially true for those of younger age and higher education [27]. Many patients guessed the diagnosis of cancer from the treatment process or drug adverse effects [28].

It should be pointed out that our survey was conducted before the patients received radical treatments such as surgery or radio-chemotherapy. It is likely that more patients would have become aware of their situation with time passing. In our study the subgroup of patients with recurrent cancer (8/151) shows no significant difference when compared with the other groups, but this is likely due to the small sample size.

Some limitations of our study must be pointed out: (1) We did not collect socio-economic information because most of the patients were comparatively rich. (2) The scope of our study did not include exploration of patients' and relatives' attitudes towards disclosure. This needs further research. (3) This study might not be generalizable to other cancer groups, especially the patients living in the under-developed countryside. (4) The interview may impact patients' diagnosis awareness.

Conclusions

The present study has provided preliminary evidence that a high proportion of patients with oral and maxillofacial cancer in China knew that they had cancer, although only about a third had been given this information by physicians or family members, who are the usual official sources for disclosure. This finding suggests that therapeutic non-disclosure is not very effective at withholding the truth

from patients. More similar research is called for to reinforce our finding.

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References

1. Novack DH, Plumer R, Smith RL et al (1979) Changes in physicians' attitudes toward telling the cancer patient. JAMA 241:897–900
2. Fallowfield L, Jenkins V (2004) Communicating sad, bad, and difficult news in medicine. Lancet 363:312–319
3. Mystakidou K, Parpa E, Tsilika E et al (2004) Cancer information disclosure in different cultural contexts. Support Care Cancer 12:147–154
4. Baile WF, Buckman R, Lenzi R et al (2000) SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 5:302–311
5. Buckman R, Baile W (2007) Truth telling: yes, but how? J Clin Oncol 25:3181
6. Minichiello TA, Ling D, Ucci DK (2007) Breaking bad news: practical approach for the hospitalist. J Hospit Med 2:415–421
7. Leydon GM (2008) Yours is potentially serious but most of these are cured: optimistic communication in UK outpatient oncology consultations. Psycho-Oncol 17:1081–1088
8. Tuckett AG (2004) Truth-telling in clinical practice and the arguments for and against: a review of the literature. Nurs Ethics 11:500–513
9. Surbone A (2004) Persisting differences in truth telling throughout the world. Support Care Cancer 12:143–146
10. Andorno R (2004) The right not to know: an autonomy based approach. J Med Ethics 30:435–439
11. Surbone A (2006) Telling the truth to patients with cancer: what is the truth? Lancet Oncol 7:944–950
12. Baile WF, Lenzi R, Parker PA et al (2002) Oncologists' attitudes toward and practices in giving bad news: an exploratory study. J Clin Oncol 20:2189–2196
13. Wood WA, McCabe MS, Goldberg RM (2009) Commentary: disclosure in oncology—to whom does the truth belong? Oncologist 14:77–82
14. Jiang Y, Li JY, Liu C et al (2006) Different attitudes of oncology clinicians toward truth telling of different stages of cancer. Support Care Cancer 14:1119–1125
15. Grassi L, Giraldi T, Messina EG et al (2000) Physicians' attitudes to and problems with truth-telling to cancer patients. Support Care Cancer 8:40–45
16. Fitts WT, Ravdin IS (1953) What Philadelphia physicians tell patients with cancer. JAMA 153:901–904
17. Costantini M, Morasso G, Montella M et al (2006) Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. Ann Oncol 17: 853–859
18. Tang ST, Liu TW, Lai MS et al (2006) Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally ill cancer patients and their family caregivers in Taiwan. Cancer Invest 24:360–366
19. Hallenbeck J, Arnold R (2007) A request for nondisclosure: don't tell mother. J Clin Oncol 25:5030–5034
20. Andruccioli J, Montesi A, Raffaeli W et al (2007) Illness awareness of patients in hospice: psychological evaluation and perception of family members and medical staff. J Palliat Med 10:741–748
21. Bozcuk H, Erdogan V, Eken C et al (2002) Does awareness of diagnosis make any difference to quality of life? Determinants of emotional functioning in a group of cancer patients in Turkey. Support Care Cancer 10:51–57
22. Panagopoulou E, Mintziori G, Montgomery A et al (2008) Concealment of information in clinical practice: is lying less stressful than telling the truth? J Clin Oncol 26:1175–1177
23. Buckman R (1984) Breaking bad news: why is it still so difficult? Br Med J 288:1597–1599
24. Capozzi JD, Rhodes R (2006) A family's request for deception. J Bone Joint Surg Am 88A:906–908
25. Montazeri A, Tavoli A, Mohagheghi MA et al (2009) Disclosure of cancer diagnosis and quality of life in cancer patients: should it be the same everywhere? BMC Cancer 9:39
26. Surbone A (2008) Information to cancer patients: ready for new challenges? Support Care Cancer 16:865–868
27. Ethan M, Basch HTTWSSYDS (2004) Use of information resources by patients with cancer and their companions. Cancer 100:2476–2483
28. Atesci FC, Baltalarli B, Oguzhanoglu NK et al (2004) Psychiatric morbidity among cancer patients and awareness of illness. Support Care Cancer 12:161–167