

When clinicians telling the truth is de facto discouraged, what is the family's attitude towards disclosing to a relative their cancer diagnosis?

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Abstract

Purpose This study evaluated the attitudes of cancer patients' family members regarding disclosure of a cancer diagnosis to the patient and justifications for their attitudes.

Methods Family members were invited to complete a questionnaire to evaluate their attitudes towards disclosure of a cancer diagnosis to a relative as well as reasons for their point of view. Data were analyzed to evaluate factors influencing attitudes.

Results One hundred eighty-six completed surveys were returned. Of them, 44.1 % (82/186) indicated that the patient should be informed of the diagnosis, and 55.9 % (104/186) stated emphatically that the patient should not be told the truth. The main reason given for concealing the truth was fear that awareness of a cancer diagnosis might cause psychological morbidity. The justifications for disclosing the bad news were as follows: (1) obtaining the patient's cooperation during treatment, (2) the impossibility of concealment, and (3) believing the patient was psychologically strong enough to accept the truth. Patients' educational status and awareness of disease as well as family members' age were the factors that influenced attitudes toward disclosure.

Conclusions Telling the truth to a cancer patient is often de facto discouraged in clinicians. Family members often support nondisclosure, especially when they have experience with a

relative who is unaware of the truth. The education level of family members does not appear to influence decisions regarding disclosure. These findings can be helpful in the development of policies and/or programs to assist medical professionals and family members engage in truthful disclosure to a patient who has cancer.

Keywords Disclosure · Cancer diagnosis · Family · Cancer patient

Introduction

Informed consent and patient autonomy are strongly held ethical principles. However, family requests to withhold vital information from cancer patients are common in various countries [1–3]. Even in the USA, such requests are not rare [2, 4, 5]. Previous studies have reported a high proportion of family members, ranging from 23.1 % to 66.0 %, who preferred to conceal a cancer diagnosis from the patient [6–8]. Family requests to withhold or to mitigate the truth about a cancer diagnosis cannot be ignored [8].

Current practices regarding breaking bad news to cancer patients are not regarded as evidence-based [9], with family members' attitudes often not receiving enough attention. Some researchers have conducted investigations of individuals who may become family members of cancer patients [4–6]. However, there may be differences in findings between hypothetical and real scenarios. More importantly, there are distinct quantitative and qualitative imbalances in the literature. Most of the reports originated in countries where telling patients the truth is well practiced. Literature from nondisclosure-dominant countries is scarce and mostly based on anecdotal reports and

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patronizing remarks. Fujimori and Uchitomi [10] pointed out in their literature review, including 24 studies using interviews or questionnaire surveys, that only five were conducted outside Western countries: three in Japan, one in Taiwan, and the other in Singapore. Similarly, Adams et al. [11] also identified that most studies were conducted with Anglo-American populations. Empirical studies of truth-telling practices have focused on informed patients, inevitably excluding the uninformed ones [12]. Cultural diversity and the paradox that patients benefit have traditionally been considered universal justifications for concealment. However, these assumptions have not been scientifically supported.

In Asian countries, a “family consent for disclosure” approach is commonly adopted based on assertions of filial piety and the relative power attributed to the social world. Families in mainland China usually play a decisive role in disclosing a relative’s cancer diagnosis because physicians are de facto discouraged to tell the truth to cancer patients directly. According to the People’s Republic of China’s Law on Medical Practitioners as well as the Tort Liability Law that went into effect on July 1, 2010, medical professionals are obligated to try to avoid adverse effects on patients when informing them or their families about the disease. The laws impose legal responsibility for any adverse patient effects on the medical professionals. For clinicians, predicting the effect on an individual of receiving news of a fatal disease represents a significant challenge. These laws hint that physicians can legally circumvent direct patient disclosure by telling the truth to the families. The legal ramifications outweigh other considerations, such as ethical justifications, medical benefits, and deontological arguments. Furthermore, compared with concealing a cancer diagnosis from patients, telling them the truth is more stressful to physicians [13] because it involves a risk of losing control [14]. In addition, when a doctor’s personal safety is of concern [15, 16], it makes sense that few doctors and nurses inform patients of a life-threatening disease in the presence of relatives. The family members become the main receivers of bad news, thereafter playing a decisive role in the communication between physician and patient.

This study was conducted in an actual clinical setting in China where families were both legal receivers of vital medical news and legal surrogates for decision making. The purposes were as follows: (1) to investigate family members’ attitudes towards the disclosure of a cancer diagnosis when a relative was either suspected to have cancer or had been previously diagnosed with cancer and was facing surgical treatment, (2) to survey justifications for family members’ attitudes towards disclosure or nondisclosure, and (3) to identify factors affecting the attitudes of family members regarding disclosure of a cancer diagnosis to the patient.

Methods

Participants

The study unit is the largest referral center in northern China for patients suffering from cancer of the oral and maxillofacial region. Similar to other oncological centers and hospitals in China, no mandatory policy about disclosure of a cancer diagnosis exists.

From May 2008 until March 2009, family members of inpatients were enrolled consecutively in the study. All participants and their inpatient relative were older than 18 years of age. Family members of patients with a psychiatric disease were excluded from the study. Those selected for the study were preferably the patient’s spouse. If spouses were not available or it was inconvenient for them, then parents, sons, or daughters were asked to participate. Rarely, siblings were selected if they were the main support for the patient.

Procedure

The study was conducted in two stages. First, through semi-structured clinical interviews [17, 18], patients’ awareness of their disease was separately assessed [19]. Because a stepwise approach has been shown to be effective in the delivery of bad news [20], and the process of truth telling should begin with the diagnostic suspicion of cancer [21], patients with a cancer-like clinical picture were included.

Second, the family members’ attitudes towards disclosure of a cancer diagnosis to the patient were investigated. Based on the pilot interview, we developed a simple questionnaire as a survey tool (Appendix). The family members of patients with suspected cancer were asked “If a cancer diagnosis is confirmed, would you want to disclose the bad news to the patient?” For family members of cancer patients, the question was “What is your attitude towards telling the patient the truth about the diagnosis?”

Data were analyzed using SPSS 16.0 for Windows. All tests of statistical significance were two-sided chi-square tests. The dependent variable was the family members’ attitude towards disclosing a cancer diagnosis to their relative. The independent variables included the family members’ and patients’ gender, age, and educational level as well as patients’ tumor stage, the number of hospitals and/or clinics patients had visited before hospitalization, and patients’ residential area. A value of $p < 0.05$ was considered to be statistically significant.

The study followed the principles outlined in the 6th Declaration of Helsinki and was approved by the review board of the hospital. All participants were given a detailed explanation regarding the purpose of the study and were free to decline participation. Informed consent was obtained from all participants.

Results

Sample characteristics

One hundred eighty-six (81.6 %) of 228 family members of consecutively hospitalized oral and maxillofacial cancer patients completed the questionnaire. Forty-two (18.4 %) chose not to participate. For ethical reasons, they were not asked why they declined. None expressed negative feelings about participating.

The patients were divided into three subgroups according to awareness of the diagnosis. The patients with suspected cancer who were awaiting histological diagnosis comprised the first group. The second group was cancer patients whose diagnosis had been withheld. The third group comprised patients who were aware of their cancer diagnosis. Accordingly, these subgroups were named (1) the awaiting diagnosis group, (2) the concealed diagnosis group, and (3) the disclosed diagnosis group.

Tumor staging and sociodemographic variables such as family members' and patients' age, gender, and education as well as number of hospitals and/or clinics patients had visited before hospitalization and their residential area were retrieved from clinical records. Subsequently, age was allocated to three categories: (1) 18–35 years, (2) 36–60 years, and (3) 61 years and older. Demographic data of family members and clinical characteristics of cancer patients are shown in Table 1.

Family members' attitudes towards disclosure of a cancer diagnosis

More than half of family members preferred to conceal the bad news from their diseased relative. A total of 186 of them, 44.1 % (82/186), agreed that the cancer diagnosis should be disclosed to the patient, whereas 55.9 % (104/186) wanted to conceal the truth.

Family members' justifications for disclosure or nondisclosure

One hundred eighty-four family members (98.9 %) provided justifications regarding their attitude; two participants failed to do so (Table 2). Their utmost concern was the patient's well-being. Among those who wanted to conceal the bad news, 57.7 % expressed fear that awareness of a cancer diagnosis would cause psychological morbidity in the patient. Additionally, 6.7 % were concerned that telling the truth might negatively affect the ongoing treatment and postoperative recovery phase.

In the group who wanted to disclose the bad news to the patient, 25.6 % said that disclosing the diagnosis might lead to better cooperation from the patient during treatment,

Table 1 Characteristics of family members and patients

Characteristics		<i>n</i> (%)
Family members (<i>n</i> =186)		
Age	18–35 years old	43 (23.1)
	36–60 years old	126 (67.7)
	>60 years	17 (9.1)
Relationship with patients	Spouse	95 (51.1)
	Sons or daughters	68 (36.6)
	Parents	8 (4.3)
	Others	15 (8.1)
Education	Primary school	14 (7.5)
	Middle school	81 (43.5)
	University	91 (48.9)
Patients (<i>n</i> =186)		
Gender	Male	111 (59.7)
	Female	75 (40.3)
Age	18–35 years old	20 (10.8)
	36–60 years old	87 (46.8)
	>60 years	79 (42.5)
Type of tumor	Benign tumor	30 (16.1)
	Malignant tumor	156 (83.9)
Stage of the malignancy (<i>n</i> =156)	Early stage	66 (42.3)
	Advanced cancer	90 (57.7)
Awareness of the diagnosis	Waiting diagnosis	63 (33.9)
	Concealing diagnosis	43 (23.1)
	Knowing diagnosis	80 (43.0)
Educational status	Primary school	32 (17.2)
	Middle school	96 (51.6)
	University	58 (31.2)

24.4 % thought that concealment was not possible, and 23.2 % mentioned that their relative was psychologically strong enough to accept the reality. It should be noted that 14.6 % were convinced that the patient had the right to know the diagnosis.

Differences in characteristics of participants related to attitudes towards disclosure

An analysis of family members in favor of disclosure compared with those preferring nondisclosure revealed no significant difference in patients' gender, age, or tumor stage (benign or malignant tumor, early or advanced stage); their relationship to the patient; or family members' educational level. However, statistically significant differences were detected when comparing patients' educational level, their awareness, and age of family members:

1. Patients' educational level

Family members were more likely to tell the truth to a patient with a higher level of education. A total of

Table 2 Family members’ justification for disclosure or nondisclosure of a cancer diagnosis to the patient (*n*=184)

Why disclose the cancer diagnosis to patient? (<i>n</i> =82)	<i>n</i> (%)
1. Need the patient’s cooperation to fight against the cancer	21 (25.6)
2. Concealment of the cancer diagnosis is impossible	20 (24.4)
3. The patient is psychologically strong enough to accept the bad news	19 (23.2)
4. The patient has the right to know the diagnosis	12 (14.6)
5. Other reasons	10 (12.2)
Why not disclose the cancer diagnosis to patient? (<i>n</i> =104)	<i>n</i> (%)
1. Fear of causing psychological morbidity to the patient	60 (57.7)
2. It is unnecessary to tell the truth	21 (20.2)
3. Awareness of the bad news will negatively affect the treatment and recovery	7 (6.7)
4. Other reasons	16 (15.4)

41.4 % of family members of a college-educated patient and 58.3 % of those whose ill relative had a middle school education opposed telling the truth about the cancer. Seventy-five percent of family members did not want to disclose the diagnosis if the patient had an educational level below that of primary school ($p=0.007<0.05$) (Fig. 1).

2. Patients’ awareness of their cancer

Patients’ awareness level was represented by three groups: the awaiting diagnosis group, the concealed diagnosis group, and the disclosed diagnosis group. Family members of patients waiting for the diagnosis were cautious about disclosing the truth. Only 38.1 % of them would tell the patient the truth if the cancer diagnosis was verified. However, nearly two-thirds (62.5 %) of family members of a patient who was aware of the reality would disclose the truth. Only 18.6 % of those

whose relative was unaware would disclose the diagnosis ($p=0.000<0.05$) (Fig. 2).

3. Family members’ age

Younger family members were more likely to conceal the cancer diagnosis from the patient. Family members in the three different age categories revealed different attitudes towards disclosure. In the category of 18–35 years, 37.2 % would disclose the cancer diagnosis, whereas in the categories of 36–60 and >60 years, the proportions were 41.3 and 82.3 %, respectively ($p=0.003<0.05$) (Fig. 3).

Discussion

The main finding of this study conducted in a real clinical setting was that many family members, passively or actively, were prone to withhold pivotal information from a relative with cancer. Furthermore, for those who preferred to tell the truth, cooperation between the patient and their doctor and eventual concealment failure were justifications for their attitudes. In other words, most family members would not intentionally disclose the cancer diagnosis if concealment of bad news was practical or possible. It should be emphasized that the rate of actual disclosure of the diagnosis was low, with 61.9 % of these patients acquiring the diagnosis on their own [19]. A recent survey in China indicated that nondisclosure is generally the default practice when family members are legally both recipients of vital medical news and surrogate decision makers [22].

Studies of truth telling should not exclude uninformed patients [12]. Within groups of patients with differing disease awareness, corresponding family members’ attitudes varied. In the awaiting and concealed diagnosis groups, family members tended to prefer withholding the cancer

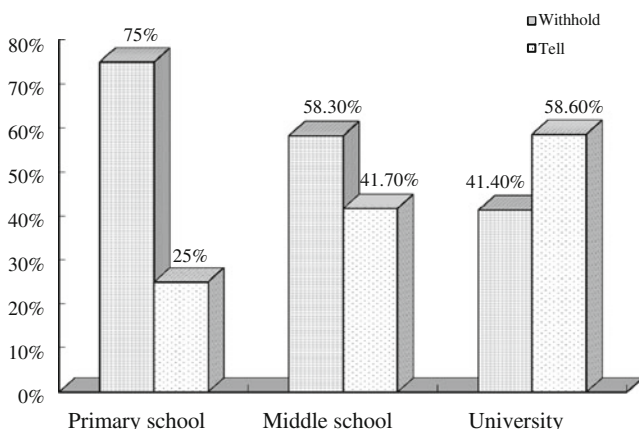


Fig. 1 Influence of patients’ educational level on family members’ attitude toward truth telling

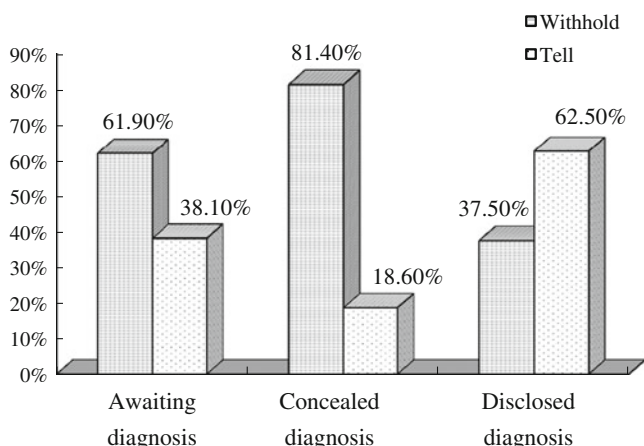


Fig. 2 Variation in family members’ attitude toward truth telling based on the patient’s level of awareness

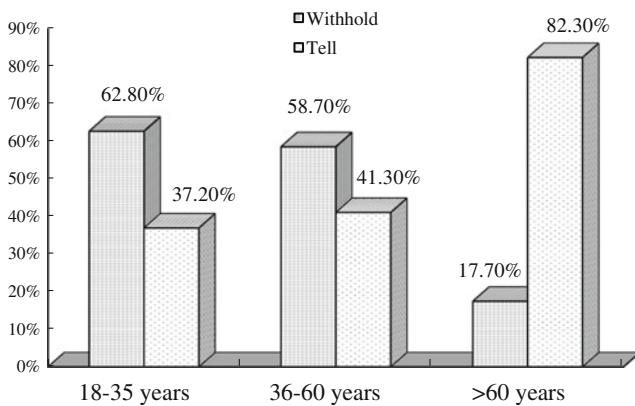


Fig. 3 Influence of family members' age on their attitude toward truth telling

diagnosis, whereas in the disclosed diagnosis group, more than two-thirds of family members agreed with telling the patient the truth.

It might be assumed that in better educated families with less paternalism, more honest disclosure would be preferred. In the literature, this assumption is somewhat controversial [6, 7]. In the present study, family members' educational level did not predict their attitudes towards truth telling. This helps to explain why even in developed countries, such as Japan and some Mediterranean countries with generally better educated people, concealment of vital information from patients still prevails.

Why are requests by family members to withhold information from a relative diagnosed with cancer common? Our study revealed that the family's concern about psychological morbidity in the patient was the first and most important justification for not telling the truth about the diagnosis [23]. This is supported by the following psychological analysis.

First, Capozzi and Rhodes [5] used Wilson and Gilbert's work in cognitive psychology regarding affective forecasting [24, 25] to explain this particular phenomenon. People systematically focus primarily on negative reactions to future events (focalism) while largely ignoring other outcomes and overpredicting the duration of their negative emotional reaction to such events (durability bias), resulting in exaggeration of the psychological impact of bad news. In this study, most family members justified their attitude based on their fear of this phenomenon occurring in the patient. This is also supported by other studies and anecdotal views [26].

Second, the perception that prophylaxis is better than treatment and avoiding harm is better than reducing harm may lead to a tendency to conceal. Disclosure of a cancer diagnosis to a patient is never a pleasant experience for the victim. Keeping the patient uninformed might be

considered a byword for avoiding harm. In countries where full disclosure of a cancer diagnosis is well practiced, reducing harm to the patient is pursued using elaborately developed guidelines such as SPIKES [27] or ABCDE [28]. These guidelines are widely recommended and followed so that telling the truth to the patient has a minimal psychological effect.

Patients' preferences regarding disclosure in Asian populations are similar to those of patients in the West [29]. However, in countries where concealment is dominant, neither training for medical students and health-care providers about how to handle "breaking bad news" [23] nor research regarding this topic has been conducted. More seriously, "hit-and-run" communications of bad news may be widely used, risking harm from cancer awareness [30]. If physicians' expertise and honesty in delivering detailed information are consistently considered of utmost importance for patients in different cultural contexts [29-32], relevant laws are important. According to a 1961 JAMA report, only 10 % of doctors had informed cancer victims of their diagnosis [33]. However, in 1977, 97 % of doctors had disclosed the truth to such patients [34]. The reason for this change in physicians' behavior can probably be attributed to the American Hospital Association Statement on a Patient's Bill of Rights in 1972, suggesting the power of such legislation.

Possible shortcomings of this research must be acknowledged. Any psychological effect of the study on either family members' or patients' opinions was unclear. In addition, interviewer bias could have affected the results. Finally, the study employed a limited sample size. Future studies are needed that employ various large-scale questionnaire surveys.

Conclusions

When clinicians telling the truth to cancer patients is de facto discouraged, the family members' preference is often not to disclose the diagnosis. In this study, this was especially true for participants interviewed who had a relative still unaware of the truth. The educational level of family members does not appear to be an influential factor in this decision. Because of affective forecasting and the perception of prophylaxis, family members' preference for nondisclosure is understandable. Persuading families to accept that concealment of a cancer diagnosis (avoiding harm) is not practical and deliberate disclosure (reducing harm) is a viable option is strongly recommended. However, legislation will be the final word on this issue.

Conflict of interest The authors declare no conflict of interest.

Appendix

Table 3 Survey of family member's attitude towards cancer diagnosis disclosure and justification for their attitude

Patient	
Name _____	ID number _____
Education <input type="checkbox"/> Primary school <input type="checkbox"/> Middle school <input type="checkbox"/> University	
Family member	
Age _____	
Education <input type="checkbox"/> Primary school <input type="checkbox"/> Middle school <input type="checkbox"/> University	
The relationship with the patient <input type="checkbox"/> Spouse <input type="checkbox"/> Son or Daughter <input type="checkbox"/> Parent <input type="checkbox"/> Sibling (other)	
The family's attitudes	
The potential cancer patients	If the patient was confirmed as cancer patient, would you like to disclose the bad news to them? <input type="checkbox"/> TELL <input type="checkbox"/> NOT TELL
Cancer patients	What is your attitude towards telling the truth to cancer patients, tell or not tell? <input type="checkbox"/> TELL <input type="checkbox"/> NOT TELL
The justification of the attitude	
TELL truth: why disclose the cancer diagnosis to patient?	<input type="checkbox"/> 1. Need the patient's cooperation to fight against the cancer <input type="checkbox"/> 2. Concealment of the cancer diagnosis is impossible <input type="checkbox"/> 3. The patient is psychologically strong enough to accept the bad news <input type="checkbox"/> 4. The patient has the right to know the diagnosis <input type="checkbox"/> 5. Other reasons
NOT TELL truth: Why NOT disclose the cancer diagnosis to patient?	<input type="checkbox"/> 1.Fear of causing psychological morbidity to the patient <input type="checkbox"/> 2.It is unnecessary to tell the truth <input type="checkbox"/> 3.Awareness of the bad news will negatively affect the treatment and recovery <input type="checkbox"/> 4.Other reasons

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