

What circumstances lead to non-disclosure of cancer-related information in China? A qualitative study

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Abstract

Background Withholding information from cancer patients is a common practice in many Asian countries, including China, Japan, and Singapore, as well as in some Western countries, such as Spain, Greece, and Italy. Much research has investigated why doctors withhold information from cancer patients generally, both in the West and the East, but little research has been done on specifically why Chinese doctors withhold such information.

Methods Three focus group interviews were conducted with a total of 16 oncologists in China. The interviews were recorded, transcribed, and translated. Qualitative data were analyzed using systematic text condensation.

Results The result of this study revealed numerous circumstances that can lead to non-disclosure of cancer-related information. Many of these circumstances have been described in previous studies about non-disclosure in other countries. We found two additional circumstances that have not been described in previous literature and might therefore expand our current knowledge about this phenomenon; they are *contradiction between laws and fear for personal safety*.

Conclusion Numerous circumstances can lead to non-disclosure of cancer-related information. This study found two additional circumstances that might lead to non-disclosure. The findings of this study suggest further assessment and clarification about the laws that govern doctor-patient communication and that action should be taken to ensure safe working environments for Chinese oncologists.

Keywords Cancer · Non-disclosure · Qualitative study · Cultural differences

Introduction

Non-disclosure of cancer-related information is here defined as the act of withholding information about cancer diagnosis or prognosis. Withholding information about cancer diagnosis or prognosis is a common practice in many Asian countries, including China, Japan, and Singapore [1–4], but also in some Western countries, such as Spain, Greece, and Italy [5–7].

Previous research suggests that doctor's attitude toward cancer diagnosis disclosure is influenced by the way they try to find a balance between the two medical ethical principles *respect for patient's autonomy* and *non-maleficence*. Some countries affirm the importance of truth telling based on the principle of autonomy; while in other countries, the principle of non-maleficence is superior to autonomy. Previous studies suggest that Japanese doctors would consider the negative consequences of disclosing a cancer diagnosis and act accordingly, even if they have to sacrifice autonomy [3].

Many factors can lead to non-disclosure of cancer-related information. They include, but are not limited

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to, fear of causing psychological morbidity to the patient, patients reluctance to be informed, physician's self-interest to conceal the truth, language barrier, lack of time and an appropriate place, psychological distress for the doctor, negative impact on emotional well-being and work satisfaction, family's request of "do not tell," and lack of training, guidelines, and research [8–11].

A previous study using questionnaires that assessed Chinese oncologists' attitude toward truth telling found that 87.5 % of the oncologists believed that patients with early stage cancer should be informed of the diagnosis, while only 40.5 % believed that patients with late stage cancer should know the truth [12]. Another study found different attitudes between Chinese cancer patients and their families. Patients were more likely to favor disclosure of cancer diagnosis than their families, both in the early stage 90.8 vs. 69.9 %, and in terminal stage 60.5 vs. 34.4 % [13]. As far as we know, no published studies in English have explored circumstances that might lead to non-disclosure of cancer-related information among Chinese oncologists.

Despite a global trend toward more disclosure of both cancer diagnosis and prognosis, the discussion on whether patients need to know they are terminally ill is ongoing [14, 15]. In the USA, where some critics claim that autonomy is overemphasized, terminal patients might still not always receive complete information about their prognosis [16]. Additionally, a study from Norway found that 20 % of cancer patients were unaware that they had a cancer diagnosis [17].

A qualitative approach is useful for exploring participants' experiences, attitudes, thoughts, expectations, motives, and interactions [18]. Consequently, and since there is a lack of knowledge about the topic in question, we decided to perform a qualitative study. Further, we have chosen to conduct focus group interviews, as they are suited to produce data about a group's interpretation, interaction, and norms [19].

The authors of this article are from Norway, which practices full-disclosure of cancer-related information. We were aware that this was different in China and wanted to explore possible reasons and circumstances for this difference. The first author is a Chinese born Norwegian citizen who immigrated to Norway at an early age and has training in Western medicine. The second author is trained in, and has conducted research in, traditional Chinese medicine. On his many visits to Chinese hospitals and cancer departments, the issue around non-disclosure of cancer-related information to patients has been present. Hence, we wanted to perform this study to explore and describe circumstances and the rationale a selected group of Chinese oncologists gave for disclosing or withholding cancer diagnosis to their patients.

Design, material, and methods

We chose a focus group design because it allows sharing of experiences, interaction, and communication between the participants on the difficult questions that were the focus of our study. To allow for differences, we invited oncologists, from three different hospitals in Beijing, China, to participate. Hence, we arranged for three focus group interviews, with participants in each group knowing each other well from their shared clinical work. Because of time-related issues and lack of funding, we ended up with a combination of purposive and convenience sample. The first author scheduled appointments through a gate keeper with oncologists from three oncology wards and visited the oncology wards to present the study to the oncologists. Those who were interested were asked to write down their names and title. We included all the participants that were interested in participation. Our sample consists of 16 doctors working in oncology wards, 12 females and 4 male doctors who were aged 26 to 48. Years of work experience related to cancer patients ranged from 1 to 23, with an average of 10.3 years. There were five participants in each of the two focus groups and six participants in the third focus group. The study was approved by the Regional Committee for Medical and Health Related Research Ethics in Norway.

All three interviews were audio-recorded with the first author as moderator (fluent in Chinese). Interviews took place in different hospital rooms, each lasting for about 1 1/2 h. The moderator used an interview guide with pre-specified questions that was tested and modified after a pilot focus group interview with Chinese medical students. The interview guide was based on a *funnel approach*, with general and open-ended questions in the beginning for free discussion to more specific questions towards the end [19]. All participants were promised anonymity in the published article; hence, quotations used in this text are anonymous. The transcripts were transcribed and then translated into English by a certified medical and legal court interpreter. Both authors cooperated on the analysis. This was accomplished by systematic text condensation [20–22]: (1) reading all the material to obtain an overall impression and bracketing previous preconceptions, (2) identifying units of meaning, representing different aspects of the doctor's experiences with withholding medical information, (3) condensing the contents of each of the coded groups, and (4) summarizing the contents of each code group to describe circumstances that might lead to non-disclosure of cancer-related information in a hospital setting.

Results

Our analysis revealed numerous circumstances that could lead to non-disclosure of cancer-related information. These include, but are not limited to fear of causing psychological

morbidity, family's request of "do not tell," lack of training, time, and environment. However, two of our findings have not been described in previous literature. They are *fear for personal safety* and *contradiction between laws*, and they are therefore further described in the following.

Fear for personal safety

Most of the oncologists agreed that the most common reason they would hold back information related to cancer diagnosis or prognosis is by request from the patient's family. The patient's family plays an important role both during and after the patient's visit to the hospital and is almost always present and participates in the consultation with the oncologists. The diagnosis would usually be disclosed to the family first without the patient present. All of our participants agreed that it is important to cooperate with the patient's family, and this might be different from overseas. One senior oncologist explained that "I think in China seeing a doctor is like [seeing] a network of families. You are completely wrapped in it. Maybe families very rarely have such big impact on a patient's treatment in foreign countries as they do in China. No matter it is the emotional support, or the financial support. It is such a gigantic system, that it is very hard to be separated. It indeed plays a very big role during the treatment."

Most of our participants further agreed that following the family's request is an unwritten rule. They further explained that they would object to withholding information about a cancer diagnosis if they felt that it is not in the patient's best interest. One oncologist expressed a different attitude, believing that it is not a decision that the patient's family has the right to make. Even if the family insists he would still tell the patient if asked directly by the patient.

One oncologist described her routines in the outpatient clinic: "for instance if I have this question in outpatient clinic, the patient asks what do I have, I will first look at the patient's family member. Look at the person behind him first. If this person gives me a signal in his glance, then I know he does not know. Then I will tell him right away there is no big problem, it is probably a small cyst or something, and purposefully withhold the conditions from him. Because if I tell him right there, the family will probably throw his fist at me. So I must first protect myself. Then after the patient gets out, I will talk to the family. Maybe I will tell the family that you should let him know, even if you cannot tell him right away, you should tell him gradually."

All of the groups believed that by not following the norm of consulting the family before disclosing cancer-related information might result in malpractice suits, being blamed for the deterioration of the patient's condition after disclosure, disputes with the family, risk of verbal assault, and even the risk of physical violence. Most of our participants believe that the patient's family would know the patient better, and that it is

wise to consult the family before disclosing any cancer-related information in order to assess how the patient might react. Several participants explained that early communication with the family and letting the family understand the doctor's actions might reduce the risk of potential misunderstandings.

A senior oncologist explained: "what is weighted the most nowadays is probably the family's opinion... the family force is the most important force in the society, we need to consider the family's opinion. If we do not consider the family's opinion, the consequences can be very serious; we may be beaten or scolded, or involved in law suits in many cases. So no matter from a cultural perspective, or from a practical point of view, we need to respect the family's opinion. So this is the first thing laid in front of us. The second is about the patient's strength. Who knows about his strength? The family knows, but the doctor doesn't know. Because in the beginning when [the patient] is sick,... we recommend [the family] to tell [the patient], which is, to protect [the patient's] right to informed consent. But in the end, we need to [know] how [the patient's] emotional strength is, how [the patient] handles things, then we let the family exercise their discretion. [We will] ask the family's advice whether I may tell [the patient] or not. If the family says no, don't tell [the patient], then we cannot insist on telling the patient, which will for sure lead to disputes."

Contradiction between laws

A central theme that all of the groups brought up without prompting the issue is the contradiction of the laws concerning patient's rights to information in China. One law states that patients have the right to know about their condition. A second law states that it is inappropriate for the healthcare providers to inform the patient if it would cause adverse events. A third law grant doctors the right to withhold information with good intent. In such case, the doctor should inform the patient's family in order to avert adverse consequences.

One oncologist explained: "The 62nd section of the Specifics in Regulation of Management of Medical Institutions also points out that "if it is inappropriate for the healthcare providers to inform the patient during protective medical procedures, they should inform the patient's family of the relevant conditions"... The same oncologist further explained: "the healthcare providers have a special right to intervene,... which includes the healthcare providers' right to withhold information with good intentions. This is granted by the nation, the patient has the right to learn the diagnosis and prognosis of [his/her] disease, the doctor should tell the patient the truth, but if the diagnosis or prognosis is serious, it may affect the treatment or even cause serious consequences once the patient knows about it. At this time the doctor should use his right to intervene, not to inform or to temporarily withhold information, but they should tell the patient's family the truth."

Another oncologist summarized the issue: “First, the law grants patients the right to informed consent. [The patient] should know. Secondly, we need to avoid adverse consequences. Thirdly, we as doctors have the, the right to intervene. The three types of rights put together, generate an ambiguous, oh, a random thing. Then how do you decide to inform or not to inform...”

Several oncologists added that this contradiction is solved differently at different hospitals. Some hospitals have *surrogation agreement* which relieves doctors from their obligations to inform the patient.

One oncologist explained: “...it seems almost every patient needs to sign a surrogation agreement,... upon admission, in particular for in-patients, we have this for almost every patient, which states that I entrust [the patient’s family] with my affairs. With this statement, we doctors are protected by law. We can talk to the surrogate about his conditions; we are no longer obligated to inform the patient himself...”

A senior oncologist expresses discontent with the current situation in his/her hospital: “There is one line in our informed consent [form], which says that the doctor has the right to inform the patient, assuming that it does not cause any harm to the patient’s health and interest. How do I know under what circumstances a patient’s interest will be harmed?”

Discussion

The aim of this study was to explore circumstances that might lead to non-disclosure of cancer-related information. Non-disclosure of cancer-related information is in this article referred to the conscious act of withholding information regarding cancer diagnosis or prognosis. Withholding cancer-related information is common in many Asian and some Western countries. Our findings suggest that the practice of non-disclosure of cancer-related information in China is assessed individually for each patient. Our findings further suggest that this practice is similar to those in cultures centered on family values [23]. The role and importance of the patient’s family, as suggested by our participants, are crucial in the understanding of why Chinese doctors withhold the cancer diagnosis. Contradictions between laws make it difficult for doctors to disclose information even when they believe it to be right.

But where previous literature suggests family and the doctor jointly agree to assume a protective role by not disclosing the diagnosis, our findings suggests the decision is not solely based on the doctors’ discretion. While the doctors can try to persuade the family from withholding the diagnosis, the final decision seems to lie within

the patient’s family. This shift of power might be caused by the contradictions within Chinese laws, and perhaps also by doctors’ fear for personal safety. Numerous reports of violence against doctors in China have been reported in Chinese media and international medical journals [24].

A qualitative study on cancer disclosure in Japan found that Japanese doctors can be divided into *tellers*, defined as those who would usually but not always disclose, and *non-tellers*, defined as those who usually would not tell but in some circumstances may disclose [3]. Japanese *tellers* would also avoid consulting the family first and reportedly experience very few problems from the family despite such an approach. The results of our study do not suggest such a distinction, and none of our participants described following the approach by Japanese *tellers*.

Nevertheless, a distinction between those who would resist the family’s request to withhold and those who would follow the family’s advice and wishes can be found in our material. Several of our oncologists described how they would continue to persuade the family to disclose the diagnosis if they believed it to be wrong to withhold. One oncologist stated that he/she would reveal the diagnosis if asked by the patient directly. These attitudes and approaches were only expressed by senior doctors. One junior doctor explains that this approach is easier to pull off because patients’ families have more respect for senior doctors. “Don’t waste your money on a young doctor” is a saying in China. One oncologist hypothesized that the deterioration of doctor-patient/family relationship is also partly caused by the commercialization of health care in China. Some medical treatment is so expensive that it can cause catastrophic medical expenses and lead to unrealistic expectations of treatment results. Since most actions are taken by the patient’s family, such as law suits, it is important to include and listen to the family from an early stage.

A recent study [25] suggests change in Japanese legislation may have increased the incidence of a cancer diagnosis being disclosed. But a review article of court decisions and characteristics of Japanese culture suggests that the current Japanese legal norms regarding informed consent and information disclosure still raise concerns, and that these concerns might be related to aspects of Japanese culture [26].

We chose focus group interviews as the method for data collection. The advantages of using focus group interviews are that it allows us to collect data about a group’s opinions and perceptions and observe how the group interacts. It is an effective method for collecting large amount of data in a short period of time compared to in-depth interviews. Because much research has already been conducted in this area, we wanted to compare and see if our data could expand or challenge existing knowledge through our participants’

spontaneous interactions with each other. The disadvantages of using focus group interviews is that it can be difficult to encourage everyone in the group to participate, especially if there is a hierarchy in the group and there are disagreements. Focus group interviews may also produce a large amount of information that can be difficult to analyze.

Because this topic has been researched in many other countries, data collection and analysis were focused on finding circumstances that have not been previously described. After analysis, we emerged with two findings that as far as we know have not been described in previous research. They are fear for personal safety and contradiction between laws. Two researchers with different backgrounds, both professionally and culturally, have been involved in the interpretation of the data.

This study is limited to a sample of oncologists working in hospitals in a major city. Different medical specialists such as radiologists might approach this question differently. The situation might also be different outside a hospital setting or in other parts in China. The results of this study are limited to oncologists' perspective. A study of nurses' experience of caring for cancer patients not told of their diagnosis suggest nurses believe the rights of the patient should override those of the relatives [27]. This suggests other health professions might have different attitudes towards cancer disclosure practice.

It is beyond the scope of this study to provide a complete overview of circumstances that might lead to non-disclosure of cancer-related information in China or to reveal the mechanism in which these clinical decisions are made. We welcome studies that seek to elucidate these questions. In-depth interview studies can explore the views, experiences, beliefs, and motivations of individuals and can reveal and explore sensitive topics where participants may not want to talk about such issues in a group. More research is needed about the patient's family's role in patient-doctor relationships in China, and whether other life threatening diagnose, such as end-stage renal failure or severe heart failure, would also be associated with non-disclosure. The findings of this study suggest an assessment and clarification about the laws that govern doctor-patient communication and it would also be interesting to know if doctors in other countries are affected by similar laws. Action should be taken to ensure a safe working environment for Chinese oncologists.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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