



## Information needs

## The discordance of information needs between cancer patients and their families in China



Ting-wu Yi, Yao-tiao Deng, Hui-ping Chen, Jie Zhang, Jie Liu, Bo-yan Huang, Yu-qing Wang, Yu Jiang\*

Institutions Department of Medical Oncology, Cancer Center State Key Laboratory of Biotherapy, West China Hospital, Sichuan University, Chengdu, People's Republic of China

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## ABSTRACT

**Objective:** We aimed at studying information needs of patients and their families, and their attitude towards the counterparts' information needs. Factors influencing psychological status of patients were investigated.

**Methods:** Self-designed questionnaires for information needs and attitude were delivered to participants. Patient Health Questionnaire 9-item and Generalized Anxiety Disorder 7-item scale were used to evaluate psychological status of patients.

**Results:** 183 eligible pairs of patients and families were involved. Except for the patients' expected life span, most patients and families needed information for all other subscales of disease-related information. Most patients wished families know more information; however, caregivers tended to prevent this. The occurrence of patients' psychiatric disorders was related to their needs for expected life span (OR 3.06 95%CI 1.36–6.93), as well as the attitude of caregivers about whether to provide more information about treatment outcomes (OR 0.24 95% CI 0.10–0.63).

**Conclusions:** Information discordance between cancer patients and their families tended to happen when it came to patients' prognostic information. The psychological status of cancer patients was found in association with their information needs and families' attitude towards it.

**Practice Implications:** To guide oncology professionals and cancer patients' families for information provision.

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## 1. Introduction

The Chinese medical model of doctor–family–patient relationship is quite different from that in Western countries [1]. Chinese clinical practices, influenced by Confucianism, center on family, especially in the field of information provision [2]. The medical profession is one of the most important sources of information [3]. Law of the Peoples Republic of China on Medical Practitioners (1999) gives patients the right to know what they want. However, it also requires doctors who disclose bad news to avoid an adverse impact on the patients. In addition, Tort Law of the People's

Republic of China (2010) states that doctors should inform patients of their conditions and the treatment programs. It was also written into the Tort Law that if it is inappropriate to disclose the patient's condition, it should be explained to the patient's close relatives and their written consent should be obtained. Therefore, Chinese doctors tend to supply the key information to cancer patients' family first, and patients' family has the final authority to decide whether or not to tell the patient [4]. Chinese families are more likely to want the patient to know less, which blocks the fulfillment of patients' information needs [5].

Information needs of cancer patients mainly focus on that related to treatment and prognosis [3]. Studies in Taiwan and Hong Kong revealed unmet information needs in cancer patients [6,7]. According to an Italian study, one-third of cancer patients thought that their family withheld disease-related information to protect them [8], which may account for unmet information needs of cancer patients. According to a cross-sectional survey in the United Kingdom, cancer patients who were dissatisfied with disease-related information were much more likely to be depressed and

\* Corresponding author at: Department of Medical Oncology, Cancer Center, State Key Laboratory of Biotherapy, West China Hospital, Sichuan University, Chengdu 610041, People's Republic of China. Fax: +86 28 85423609.

E-mail addresses: [21201800@qq.com](mailto:21201800@qq.com) (T.-w. Yi), [575942837@qq.com](mailto:575942837@qq.com) (Y.-t. Deng), [308672439@qq.com](mailto:308672439@qq.com) (H.-p. Chen), [156515494@qq.com](mailto:156515494@qq.com) (J. Zhang), [382486310@qq.com](mailto:382486310@qq.com) (J. Liu), [35247965@qq.com](mailto:35247965@qq.com) (B.-y. Huang), [295763835@qq.com](mailto:295763835@qq.com) (Y.-q. Wang), [jiangyu1973@hotmail.com](mailto:jiangyu1973@hotmail.com) (Y. Jiang).

anxious [9]. A study in Hong Kong also reported that cancer patients with higher health system information needs were much more likely to suffer from higher global distress [10]. To the best of our knowledge, there has been limited research in the Chinese mainland about the relationship between information needs of cancer patients and their psychiatric status.

Few studies in China have evaluated the attitude of family members towards the information needs of patients. Family members of cancer patients also have strong needs for disease-related information [11]. According to a survey from Shanghai, high unmet information needs were found in family caregivers of patients with advanced cancer [12]. These investigators also studied the factors associated with needs of caregivers [12], but they did not examine the attitude of patients towards the information needs of their families. Previous studies in Chinese populations mainly have focused on the attitudes towards the disclosure of cancer diagnosis; few have paid attention to comprehensive information needs of cancer patients and their families [13,14].

Above all, it is necessary to study comprehensive information needs, as well as their attitude, of cancer patients and their caregivers in China, and we assumed that they would be in some association with the psychological status of cancer patients. Moreover, we assumed that there would be discordance between the information need of cancer patients and the attitude of caregivers towards the information needs of patients (or vice versa). To test the hypothesis, in the study we aimed at investigating whether or not the information discordance existed, and how the psychological status of cancer patients was associated with their information needs and those of their families, as well as their information attitude towards the other party

## 2. Methods

### 2.1. Participants and procedure

Patients and their families were recruited during May and October 2014 from the inpatient unit of the oncology center, of the West China Hospital. To be eligible for this study, patients were required to be over 18 years of age, know their cancer diagnosis and could read and write Chinese. Patients with a history of schizophrenia, bipolar disorder, or psychoactive substance abuse were excluded. The eligible caregivers were required to be over 18 years of age, could read and write Chinese. This study was approved by the Institutional Review Board of West China Hospital and carried out according to the provisions of the Declaration of Helsinki.

The study was conducted face-to-face by oncologists trained to deliver questionnaires. Initially, the oncologists explained the purpose of the study to patients and their caregivers. Both patients and their families signed the consent forms after they agreed to participate in the study. If there were more than one caregiver attending the patient, questionnaires would be administered to the family member sitting nearest the patient when the oncologist entered the ward [15,16]. Then the oncologist instructed the patients and caregivers to finish the questionnaire independently in the ward within 20 min. The patients' medical data was collected from electronic records. Then data was entered into a database and analyzed by another independent researcher.

### 2.2. Measures

The questionnaire package for the patient was made up of the demographic form (age, gender, level of education and information sources and so on), information needs questionnaire for cancer patient, PHQ-9 and GAD-7. The one for the family member

included the demographic form (age, gender, relationship with the patient, level of education, employment and information source) and information needs questionnaire for the caregiver.

For the information needs questionnaire for the patients and the family, potential items were generated from the review of literatures [3,13,17–19]. The collected items were reviewed by 10 oncology specialists and 3 clinical nurse specialists, and 2 psychiatric specialists, and 10 of them had the experience in survey item development. The items were revised according to their critiques. Next, a pilot study with 30 patients and 30 caregivers was performed to confirmed clarity and ease of comprehension. According to the feedback of participants, some ambiguous and misleading items were excluded and some revision of the wording was made. The final version of the patients' questionnaire included 14 questions. Patients were required to choose one answer for each question. Seven questions were as follows: 'How much do you need more information about your current disease status/treatment-related information/how to get more available medical education/the likelihood of recurrence or metastasis after treatment/the chance of cure/your expected life span/self care or home care issue'. The other 7 questions were as follows: 'How much do you wish your family to know more information about your current disease status/treatment-related information/how to get more available medical education/the likelihood of recurrence or metastasis after treatment/the chance of cure/your expected life span/self care or home care issue'. Answer for these 14 questions was one of the followings: 'I don't need (wish) that at all'/'I don't need (wish) that'/'I need (wish) that'/'I need (wish) that very much'. No matter the content or structure, the information needs questionnaire for the caregivers was similar, with some modifications in expression, and was intended to study the caregivers' information needs and attitude—whether caregivers wished the patient to know more.

To assess the psychological status of patients, PHQ-9 was used to evaluate the symptom of depression, and GAD-7 was for the symptom of anxiety. These two scales had been well validated to screen severe depression and generalized anxiety of patients with malignant tumor, including Chinese patients [20]. The PHQ-9, consisting of nine items, has the possible answers—'not at all', 'on single days', 'on more than half of the days', and 'almost every day' scored as 0, 1, 2, and 3, respectively, and its cut-off for moderate/severe depression is ten point [21]. The answers and score system of GAD-7, consisting of seven items, is similar to PHQ-9, and its cut-off point for moderate/severe anxiety is also ten [22].

### 2.3. Statistical analyses

Demographic and clinical data was analyzed to provide descriptive statistics on patients and caregivers. The results of information needs questionnaires for the patients and caregivers were dichotomized. Comparisons were conducted using the McNemar test in order to study the difference between the information needs of patients and caregivers, as well as the information attitude within the dyads. We also tried to elicit the discordance between the information needs of patients and the information attitudes of caregivers, as well as the discordance between the information needs of caregivers and the information attitudes of patients, using the McNemar test.

Multivariate logistic regression analysis was performed to identify the factors, proven significant in univariate analysis, that were associated with the information needs or attitude of patients and caregivers and the psychological status of patients. Statistical analysis was performed using SPSS 17.0 (SPSS, Chicago, IL, USA). The significance level was set at 0.05.

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