

## RESEARCH ARTICLE

# Staged Improvement in Awareness of Disease for Elderly Cancer Patients in Southern China

Xing Li<sup>1&</sup>, Min Dong<sup>1&</sup>, Jing-Yun Wen<sup>1&</sup>, Li Wei<sup>1</sup>, Xiao-Kun Ma<sup>1</sup>, Yan-Fang Xing<sup>2&</sup>, Yun Deng<sup>3</sup>, Zhan-Hong Chen<sup>1</sup>, Jie Chen<sup>1</sup>, Dan-Yun Ruan<sup>1</sup>, Ze-Xiao Lin<sup>1</sup>, Tian-Tian Wang<sup>1</sup>, Dong-Hao Wu<sup>1</sup>, Xu Liu<sup>4</sup>, Hai-Tao Hu<sup>5</sup>, Jia-Yu Lin<sup>6</sup>, Zhuang-Hua Li<sup>7</sup>, Yuan-Chao Liu<sup>8</sup>, Qing Xia<sup>9</sup>, Chang-Chang Jia<sup>10</sup>, Xiang-Yuan Wu<sup>1\*</sup>, Qu Lin<sup>1\*</sup>

### Abstract

**Background:** In mainland China, awareness of disease of elderly cancer patients largely relies on the patients' families. We developed a staged procedure to improve their awareness of disease. **Materials and Methods:** Participants were 224 elderly cancer patients from 9 leading hospitals across Southern China. A questionnaire was given to the oncologists in charge of each patient to evaluate the interaction between family and patients, patient awareness of their disease and participation in medical decision-making. After first cycles of treatment, increased information of disease was given to patients with cooperation of the family. Then patient awareness of their disease and participation in medical decision-making was documented. **Results:** Among the 224 cancer elderly patients, 26 (11.6%) made decisions by themselves and 125 (55.8%) delegated their rights of decision-making to their family. Subordinate family members tended to play a passive role in decision-making significantly. Patients participating more in medical decision-making tended to know more about their disease. However, in contrast to the awareness of disease, patient awareness of violation of medical recommendations was reversely associated with their participation in medical decision-making. Improvement in awareness of diagnosis, stages and prognosis was achieved in about 20% elderly cancer patients. About 5% participated more actively in medical decision-making. **Conclusions:** Chinese elderly cancer patient awareness of disease and participation in medical decision-making is limited and relies on their family status. The staged procedure we developed to improve patient awareness of disease proved effective.

**Keywords:** Decision making - cancer - Confucian philosophy - patient relationships - family - disease awareness

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### Introduction

Medical decision-making in western countries is largely individual-based. However, this decision-making mode is not prevalent in China (Chan et al., 2013; Li et al., 2013; Goss et al., 2014), especially for elderly cancer patients. In mainland China, medical decision-making for elder patients with malignant disease largely relies on the patients' families (Fan, 2011). This mode has been always criticized for the latent moral risks that the interests of vulnerable patients might not be fully met or, even worse, might be violated by their family members (Li and Wen, 2010; Fan, 2011; Cheng et al., 2012). However, few efforts have been made and evaluated to improve patient awareness of disease for these patients.

The common excuses for separating elder patients from the truth of their disease were prevention of their mental breakdown, relieving their worry about financial burden and making reasonable choice on treatment (Chen and Fan, 2010; Chan et al., 2013). Nowadays, tension has been raised between doctors and patients (Li and Dong, 2011; Yang et al., 2013). In order to avoid conflicts with patients and their family members, Chinese doctors have to obey the demand of patients' family on how much truth shall be told to patients. However, exclusion of elder patients from medical decision-making might lead to violation of the will of elder patients (Say et al., 2006; Tariman et al., 2010). Thus, in clinical practice we developed a staged way to give patients increased information about their disease with cooperation of patients' family members.

<sup>1</sup>Department of Medical Oncology, the Third Affiliated Hospital of Sun Yat-Sen University, <sup>2</sup>Department of Nephrology, the Third Affiliated Hospital of Guangzhou Medical University, <sup>4</sup>State Key Laboratory of Oncology in Southern China, Department of Radiation Oncology, Cancer Center of Sun Yat-sen University, <sup>5</sup>Department of General Surgery, the Second Affiliated Hospital of Guangdong Pharmaceutical University, <sup>6</sup>Department of Medical Oncology, the Sixth Affiliated Hospital of Sun Yat-sen University, <sup>10</sup>Cell-gene therapy Translational Medicine Research Center, Guangdong Provincial Key Laboratory of Liver Disease Research, Guangzhou, <sup>3</sup>Department of Radiation Oncology, the Fifth Affiliated Hospital of Sun Yat-sen University, Zhuhai, <sup>7</sup>Department of Medical Oncology, Dongguan People's Hospital, Dongguan, <sup>8</sup>Department of Oncology, the First Hospital of Yueyang, Yueyang, <sup>9</sup>Department of Oncology, the First Hospital of Shanghai, Shanghai, China <sup>&</sup>Equal contributors \*For correspondence: wuxiangy@mail.sysu.edu.cn; Linqu@mail.sysu.edu.cn

Previous studies on medical decision-making were mainly focused on the patients, which could not give a full view of the family-based mode (Lam et al., 2003). Thus, in this multicenter study we aimed to systematically illustrate our staged procedure to increase elder patients' awareness of disease and participation in their medical decision-making with cooperation of family members. Furthermore, the obstacles were discussed.

## Materials and Methods

### *Patient selection*

A total of 224 consecutive elder (age > 60 years) cancer patients were included in this study between September 1st 2013 and December 31st 2013 from 9 departments of oncology in local leading general hospitals or cancer centers from 5 big cities across Southern China, including the Third Affiliated Hospital, Cancer Center, and the Sixth Affiliated Hospital of Sun Yat-sen University, as well as the Third Affiliated Hospital of Guangzhou Medical University, and the Second Affiliated Hospital of Guangdong Pharmaceutical University in Guangzhou, together with the Fifth Affiliated Hospital of Sun Yat-sen University in Zhuhai, Dongguan People's Hospital in Dongguan, the First Hospital of Yueyang in Yueyang, and the First Hospital of Shanghai in Shanghai. Patients were excluded in the following condition: those whose lives was directly threatened by acute disease other than cancer and associated complications; cancer diagnosed without pathological proof; those who were incompetent in making medical decision; patients with acute leukemia. Additionally, 15 patients were excluded due to a lack of substantial information needed. This study was approved by the Clinical Ethics Review Board at all the hospitals included in this study. Informed consent was obtained at the time of admission.

### *Procedure of staged information*

The major misunderstanding of elder patients to cancer was that they thought cancer would cause instant death and treatments including chemotherapy were extremely painful, expensive and useless. Thus, the major aim of staged information was set to correct these misunderstanding. Patients would not believe the doctor's introduction to the treatment and the optimistic side of their condition in the first place. Consequently, patients' participation in decision-making and information of disease given to the patients was according to the demand of family members before initial anti-cancer treatment. After first cycles (mainly 1-2) of treatment, increased information including diagnosis, prognosis and stages was given to patients after discussion with the family members. The information was given in an optimistic way always indicating a great chance to control the cancer. With practical experience of anti-cancer treatment, patients were easily to accept the concept that cancer was a chronic disease with effective, safe and economic remedy. Then, their participation in decision-making would be promoted with permission of the family members.

### *Procedure of information collection*

Three research assistants (Oncologists) helped with the data collection. Training for research assistants was given to maintain the consistency and guarantee the reliability of the data collection process. The three research assistants visited the above hospitals and met with the participant oncologists on a one-to-one basis. The information on included patients was provided by their oncologist in charge. Each oncologist was given an explanation of the purpose of this study and the protocol. They were also informed that there was no right or wrong answers to the questions, because its purpose was to explore attitudes and not to promote any particular concept. All oncologists were informed and assured of their right to refuse or withdraw from the study at any time. A closed-ended questionnaire was given to the oncologists in charge to evaluate each patient under the guidance of research assistants.

### *Data Collection*

Data that were considered to be associated with decision-making by all the oncologists involved in this study were collected as follows. Medical insurance types were classified into 4 categories: state-funded public medical system (medical reimbursement covered most of the medical expense), local medical insurance (medical reimbursement covered more than half of the medical expense), nonlocal medical insurance (medical reimbursement covered less than half of the medical expense) and no insurance. Education levels were categorized into following levels: intellectual (received at least undergraduate education), ordinary people (received high school education), and functional illiterate (received primary education or less). Family statuses were ranked as superordinate (the major decision maker in the family), equality (discussed important issues with family members and made decision with consensus of family members), and subordinate (usually don't be involved in significant family issues). The main Living environment of patients was defined as the place where the patients had grown up and work for most of their lives; this was dichotomized into city and countryside. The above information about the patients was determined by their doctor in charge.

### *Endpoints and statistical analysis*

Patients' awareness of their diagnosis, stages and prognosis before commence of treatment were endpoints, as well as their improvement of awareness during treatment thereafter. Decision-making modes were classified into 3 conditions: patient unilateralism (oncologists discussed planned treatments with patients and patients made decision themselves), bilateralism (oncologists discussed planned treatments with patients and their family members, and final decision was made by consensus of patients and family members) and family unilateralism (oncologists discussed planned treatments with family members and patients were not involved in final decision-making). Critical medical recommendations were defined strategy of anticancer therapy, including regimes of chemotherapy, administration of target agents, radiotherapy, surgery, and termination of anti-cancer therapy. Violation of optimal medical recommendations meant patients or their family finally rejected the

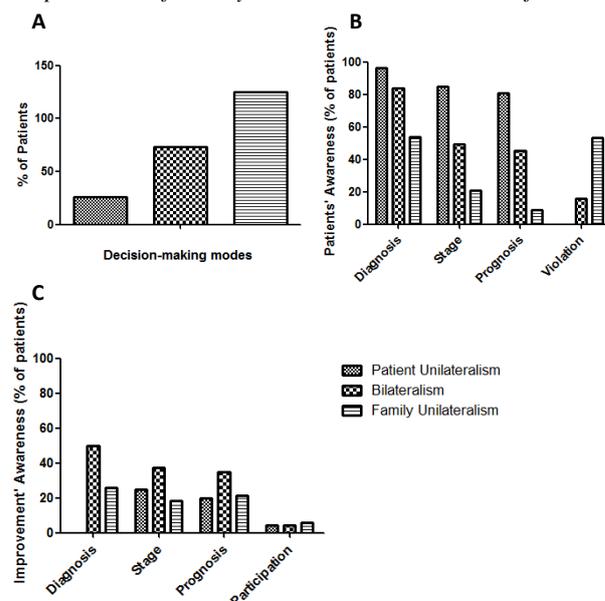
suggestions of doctors and patients received less optimal treatments. In China, this less optimal decision sometimes was not discussed or told the patients. Thus, the major moral end point of this study was the patients' ignorance of violation of critical medical recommendations from oncologists (Li and Wen, 2010; Koerner and Shirai, 2012).

We compared the variables in different groups using a chi-square analysis. Multivariate analysis using a Logistic proportional hazards model was used to test for independent significance of the explanatory variables. The criterion for statistical significance was set at a  $\alpha$  of .05 and all  $P$  values were based on 2-sided tests. SPSS (version 20.0; SPSS Inc, Chicago, IL) was used for all statistical analyses.

## Results

### *Patients' family status significantly predicted their participation in medical decision-making*

Among the 224 elder cancer patients, only 26 (11.6%) patients made decision by themselves. As high as 125 (55.8%) patients delegated their rights of decision-making to their family members. The rest of 73 (32.6%) patients involved in the medical decision-making and final treatment were chosen by the consensus of patients, family members and oncologists. (Figure 1A) Chi-square analysis revealed that patients with following characteristics tended to give up their rights in treatment decision:



**Figure 1. A) Distribution of elder cancer patients among different medical decision-making modes. B) Elder cancer patients' awareness of their disease according to medical decision-making modes. C) Improvement of awareness of their disease of the elder cancer patients who did not know the information of their condition according to medical decision-making modes**

**Table 1. Patients' Characteristic Using Different Medical Decision-Making Modes**

Characteristics	Patients unilateralism n=26	Bilateralism n=73	Family unilateralism n=125	$P$
Age	66.8 (60.0-78.0)	65.7 (60.0-87.0)	66.9 (60.0-85.0)	0.343
Sex				0.132
Female	12 (46.2%)	20 (27.4%)	49 (39.2%)	
Male	14 (53.6%)	53 (72.6%)	76 (60.8%)	
Initial stage				0.037
I	3 (11.5%)	3 (4.1%)	7 (5.6%)	
II	8 (30.8%)	10 (13.7%)	15 (12.0%)	
III	8 (30.8%)	14 (19.2%)	25 (20.0%)	
IV	7 (26.9%)	46 (63.0%)	78 (62.4%)	
Insurance				0.018
State-funded	6 (23.1%)	13 (17.8%)	10 (8.0%)	
Local	11 (42.3%)	22 (30.1%)	30 (24.0%)	
No insurance	0 (0.0%)	8 (11.0%)	21 (16.8%)	
Nonlocal	9 (34.6%)	30 (41.1%)	64 (51.2%)	
Main living environment				0.007
Village	5 (19.2%)	27 (37.0%)	63 (50.4%)	
City	21 (80.8%)	46 (63.0%)	62 (49.6%)	
Patient education level				0
Intellectual	13 (50.0%)	21 (28.8%)	14 (11.2%)	
Ordinary	11 (42.3%)	33 (45.2%)	50 (40.0%)	
Illiterate	2 (7.7%)	19 (26.0%)	61 (48.8%)	
Family status of patients				0
Superordinate	13 (50.0%)	26 (35.6%)	14 (11.2%)	
Equality	11 (42.3%)	31 (42.5%)	18 (14.4%)	
Subordinate	2 (7.7%)	16 (21.9%)	93 (74.4%)	
Family education level				0.013
Intellectual	NA	34 (46.6%)	35 (28.0%)	
Ordinary	NA	37 (50.7%)	89 (71.2%)	
Illiterate	NA	2 (2.7%)	1 (0.8%)	

Abbreviations: NA, not applicable

advanced stages at diagnosis of cancer, aided by nonlocal insurance, villagers, functionally illiterate, subordinate in family status and better family member education level. (Table 1) Multinomial logistic regression illustrated that patients' family status independently correlated with medical decision-making modes (Table 2). Patients' family status significantly determined their participation in medical decision-making. Patients, as superordinate family members, tended to play a positive role in medical decision-making. By contrast, patients with subordinate role in family continued to play a passive role in medical decision-making.

*Violation of optimal treatment tended to be hid from patients, especially for those participating actively in medical decision-making*

Elder cancer patients participating more in medical decision-making tended to know more about their

**Table 2. Determinants of Decision modes**

Characteristics	P	HR (95%CI)
Initial stage		
I	0.571	1.612 (0.309-8.143)
II	0.541	1.395 (0.480-4.051)
III	0.307	1.617 (0.644-4.065)
IV		
Insurance		
State-funded	0.422	0.601 (0.173-2.084)
Local	0.067	0.426 (0.171-1.062)
No insurance	0.734	1.215 (0.395-3.738)
Nonlocal		
Main living environment	0.209	0.545 (0.211-1.404)
Patient education		
Intellectual	0.805	1.194 (0.292-4.875)
Ordinary	0.984	1.010 (0.372-2.746)
Illiterate		
Family status		
Superordinate	0	0.076 (0.027-0.216)
Equality	0	0.088 (0.035-0.222)
Subordinate		
Family education		
Intellectual	0.99	0.980 (0.042-22.937)
Ordinary	0.656	2.003 (0.094-42.764)
Illiterate		

Abbreviations: HR, hazard ratio; 95% CI, 95% confidence interval

diseases including diagnosis, stages and prognosis. Interestingly, awareness of their less optimal treatment decreased for the patients participating more in medical decision-making. Contrast to the awareness of diagnosis, stages and prognosis, the violation of optimal treatment tended to be hid from patients participating actively in medical decision-making. (Table3 and Figure 1B) Notably, violation of medical recommendation was not associated with fundamental decision-making modes, which indicated that decision-making mode was not a cause for potential hazard to elder cancer patients' medical interests. (Table 3)

*Efficacy of staged procedure to increase patients' awareness of disease and participation in their medical decision*

Improvement in awareness of diagnosis, stages and prognosis was achieved in about 20% elder cancer patients. For patients who didn't know the truth of their disease, 0.0%, 50.0% and 25.9% elder cancer patients were told about their real diagnosis after anti-cancer therapy in patient unilateralism group, bilateralism group and family unilateralism group, respectively; 25.0%, 37.5% and 18.2% elder cancer patients were told about their stages of disease after anti-cancer therapy in above 3 groups, respectively. As to the prognosis, the incidences of awareness were 20.0%, 35.0% and 21.1% for the 3 groups. However, improvement of participation in medical decision-making was not that successful. Only 4.2%, 4.1% and 5.6% elder cancer patients acted more actively in medical decision-making in patient unilateralism group, bilateralism group and family unilateralism group, respectively. (Table3 and Figure 1C)

## Discussion

Information given to cancer patients at the time of diagnosis is based on culture, education and age (Chen and Fan, 2010). In the past three decades, the medical culture of China has changed greatly (Fan and Yu, 2011; Goss et al., 2014); education level has been greatly improved for new generations; individualism is accepted by young people; tension has been raised between doctors and patients (Li and Dong, 2011; Li et al., 2014) which leads

**Table 3. Patients' Awareness of Disease and Participation in Medical Decision-Making**

Characteristics	Patients unilateralism n=26	Bilateralism n=73	Family unilateralism n=125	P
Awareness				
Diagnosis	25 (96.2%)	61 (83.6%)	67 (53.6%)	0
Improvement	0 (0.0%)	6 (50.0%)	15 (25.9%)	0.201
Stage	22 (84.6%)	36 (49.3%)	26 (20.8%)	0
Improvement	1 (25.0%)	14 (37.5%)	18 (18.2%)	0.056
Prognosis	21 (80.8%)	33 (45.2%)	11 (8.8%)	0
Improvement	1 (20.0%)	14 (35.0%)	24 (21.1%)	0.205
Participation in decision-making				0
Improvement	1 (4.2%)	3 (4.1%)	7 (5.6%)	0.881
Violation†	10 (38.5%)	25 (34.2%)	58 (46.4%)	0.233
Awareness of Violation	0 (0.0%)	4 (16.0%)	31 (53.4%)	0.002

†Violation of critical medical recommendation of patients

to disappearance of physicians' paternalistic behavior to patients. The obstacle for elder cancer patients' awareness of disease was their shortage of education about cancer (Goss et al., 2014). In present study, the majority of elder cancer patients were functionally illiterate, which strictly limited their decision-making capability. Consequently, the elder could not adapt themselves to the modern society adequately and demand help from their offspring in medical situation. Thus, family based decision-making for important issues still acts prevalently (Fan, 2011). For them, relying on educated family members as surrogate was a practical way to make reasonable decisions and to balance their medical interests and the financial situation of their families. In the preset study, we illustrated that education levels of decision makers were higher than patients' levels. Our results showed that the majority of elder Chinese cancer patients did not participated in medical decision-making. Patients' family status significantly determined their participation in medical decision-making. Patients with superordinate role in family continued to play an active role in medical decision-making. Notably, medical decision-making styles did not influence the treatment choice, which indicated that family base medical decision-making was an acceptable choice for elder cancer patients.

The fundamental aims of medical decision-making were to provide the patients with reasonable treatment and to realize personal goals (Chen and Fan, 2010). However, these aims were difficult to be realized and evaluated due to complicated causes including culture context (Chan et al., 2013; Aydogan et al., 2015), medical decision-making capacity (Sessums et al., 2011), education background, personality, financial situation, medical insurance, family status (Li and Wen, 2010), gender, age (Ahmad and Al-Gamal, 2014), prognosis of disease, relation between family members (Koerner and Shirai, 2012), physical and mental status, trust between doctors and patients (Li and Dong, 2011), and other potential factors (Tariman et al., 2010). Furthermore, Medical decision-making style determined patients' awareness of disease (Chen and Fan, 2010; Li et al., 2013). In our study, elder cancer patients' awareness of diseases was parallel with their participation. Interestingly, contrast to the awareness of diseases, the violation of optimal treatment tended to be hided from patients participating actively in medical decision-making. They latent causes were based on current dilemma in China medical system and Confucian culture. The expenses of medical service was not fully covered by insurance, which was a critical burden the families of cancer patients. This was the substantial reason for the violation of optimal medical recommendation. There was a common worry that elder cancer patients might think their families reluctant to pay for their treatment and of no filial piety if they knew their therapy was not as good as others. Thus, in order to keep the mental health of elder patients, Chinese family members always protected the patients from the message of their sub-optimal therapy, especially for those who cared their treatment a lot.

Laws recognizing the primacy of the patient's common law right to self-determination do not act as efficiently as expected (Chan et al., 2013). Elder patients tended to

believe that cancer was their fate to end their life and were reluctant to fight against disease, which critically hazarded their health interests. Secondly, deceptive information in social life promoted their fear to chemotherapy (Li et al., 2014). Furthermore, shortage of death education in traditional Chinese culture and present education system caused excessive fear of death. For Chinese patients, the coming death was among the most terrible news, which might lead to their mental breakdown and misjudgment in medical decision-making. Thus, unawareness of terminally ill condition became a general method to protect the mental health of elder cancer patients. However, the real will of elder cancer patients might be ignored. Thus, it is imperative to improve their awareness of disease and promote their participation in medical decision-making. Targeting on above obstacles for elder cancer patients, we developed our staged procedure to improve their understanding of their disease, which was giving more information after first cycles of anti-cancer therapy and help them to understand it in an optimistic way. Their practical experience of anti-cancer therapy and relief of the symptoms made elder cancer patients easier to accept the views of the oncologists. As a result, we improved awareness of disease in nearly 1/5 elder cancer patients and participation of medical decision-making in 5% patients.

Above all, the family-based medical decision-making mode limited elder cancer patients' awareness of disease and their participation in medical decision-making. And our results probably reflected the profile of the increasing emigrants Chinese worldwide. Furthermore, awareness of violation of critical medical advice was related the decision-making styles, which was the major risk of this non-self-determination mode. However, this study did not document the hidden conflicts between family members, which could be a latent cause for financial shortage. Besides, patients who refused to be hospitalized due to false believe in traditional Chinese medicine, or who mainly live outside of mainland China were not included.

In summary, through systematically analysis of the interaction between family and cancer patients, we illustrated that Chinese elder cancer patients' awareness of disease and participation in medical decision-making was limited and relied on their family status. The staged procedure we developed to improve patients' awareness of disease was effective.

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