



Original Article

Patient preferences and shared decision making for the traditional Chinese medicine treatment of lung cancer: A discrete choice experiment study

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ABSTRACT

Background: Traditional Chinese Medicine (TCM), integrating patient preferences into decision-making process, has been widely used in the multimodality therapy of lung cancer. This study aimed to estimate patient preferences for treatment and shared decision-making (SDM) modes concerning inpatient TCM treatment of lung cancer in Shanghai in order to provide a basis for clinical decision-making process on TCM therapy for lung cancer.

Methods: This study was conducted among patients ($n = 347$) from nine tertiary hospitals in Shanghai by discrete-choice experiment (DCE) survey and Shared Decision-Making Questionnaire-patient version (SDM-Q-9) survey. The DCE was developed with the inclusion of the most relevant attributes at appropriate levels for the TCM treatment of lung cancer. The empirical data analyses of patients were performed using mixed logit models. Additionally, subgroup analysis was conducted.

Results: In total, 347 respondents completed the questionnaire. All attributes' coefficients were statistically significant for patients' preferences. Patients showed strong preferences for increasing disease control rate, relieving nausea and vomiting, reducing the risk of side effects, and were concerned about monthly out-of-pocket costs. Subgroup analysis indicated that patients with a lower SDM-Q-9 score and those who were satisfied with medical services emphasized more importance of higher disease control rate. Furthermore, most of the patients (90.20%) self-reported a high willingness to use SDM during the decision-making process.

Conclusion: In Shanghai, patients mainly preferred SDM and considered disease control rate as the most essential attribute in the TCM treatment of lung cancer. The study findings could underscore the importance of considering patients' preferences and promote SDM.

1. Introduction

Lung cancer is a multi-step and multi-factorial neoplasia composed of a variety of histological subtypes. Worldwide, with an estimated 2.2 million new cases and 1.8 million deaths in 2020, lung cancer remains one of the most commonly diagnosed cancer and the leading cause of cancer-related mortality, posing a serious threat to global health.¹ It is worth mentioning that China accounts for more than one-third of all newly diagnosed cancer cases and approximately 40% of total deaths universally.² In recent years, lung cancer has become an increasingly prevalent cancer in China, resulting in the subsequent socioeconomic burden to both the government and the public.³

Greater patient involvement in treatment decisions is associated with less decisional conflict, which can be viewed as a moderator for patient satisfaction. Based on the ideal of patient-centered care, shared decision

making (SDM), where we move away from paternalistic approach to patient involvement in treatment preferences, has been widely accepted in clinical practice, especially in the field of oncology.⁴ SDM involves at least one patient and one health care provider. Both parties take steps to actively participate in the process of decision-making, share information and personal values, and together arrive at a treatment decision with shared responsibility.⁵ Charles et al.⁶ defined SDM as a two-way exchange of information between patient and physician, medically and personally. In the context of consensus, the ultimate treatment option is chosen after discussions on multiple possible alternatives and uncertain outcomes.⁷ Patient-clinician communication, including SDM, can not only improve health outcomes directly but also affect health outcomes indirectly through affective-cognitive and behavioral outcomes, where preference plays an essential role.⁸⁻¹¹ Since one imperative domain of SDM is preference-related discussion, representing a vital connection

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between preference and decision-making mode, realization of such an indispensable linkage is necessary for better patient and clinician engagement in medical decision-making.

The integration of patient preferences into decision-making process is becoming progressively more prevalent throughout the medical product life cycle.¹² Patient preferences are qualitative or quantitative assessments of the relative desirability or acceptability to patients of specified alternatives or choices among outcomes or other attributes that differ among alternative health interventions.¹³ Patient participation in prioritizing their treatment preferences has an impact on the curative effect. Thus, understanding of patients' treatment preferences and preferred SDM mode is crucial to inform the regimens selection, as well as promote patient-centered health care.¹⁴ However, in China, few published studies focusing on the preference and SDM mode of patients in the treatment of lung cancer have been conducted, let alone TCM therapies. Selection preferences exist in TCM technology of lung cancer in terms of curative effects, potential risks of toxicity, and medical expenditures,¹⁵⁻¹⁸ physicians and patients need to jointly weigh all the aspects and accomplish the optimal clinical decision-making. SDM is such a patient-centered approach in which clinicians and patients work together to find and choose (by taking into account the best available evidence, as well as the patients' problems, values, preferences, and contexts) the best course of action for each patient's particular situation,¹⁹ an approach that is pertinent to the care of patients with chronic conditions.²⁰ The objective of this study aims to identify patients' preferences and their SDM modes when it comes to TCM treatment decision-making of lung cancer.

2. Methods

2.1. Study participants

A multi-center survey among patients at nine tertiary hospitals from Shanghai, China was conducted from September 16, 2020 to January 12, 2021. A total of 347 eligible respondents were enrolled in this study, based on the following inclusion criteria: (1) participants were required to be at least 18 years old with a physician diagnosis of lung cancer; (2) participants have or had received TCM treatment (in-hospital patients who had been used or were currently in the use of anti-tumor TCM injections); (3) patients were informed of the purpose and their rights to refuse to be involved. Patients were excluded from the study if they did not complete the questionnaire. These patients were investigated in-person by 9-item Shared Decision-Making Questionnaire for Patients (SDM-Q-9) and Discrete Choice Experiment Questionnaire (DCE).

The study protocol and questionnaires were approved by the Human Research Ethics Committee of School of Public Health, Fudan University, Shanghai, China (IRB00002408&FWA00002399), in accordance with the Declaration of Helsinki alongside relevant rules and regulations domestically. Patients received copies of written informed consent and were informed about their rights to refuse.

2.2. Shared decision making survey

The SDM-Q-9 is a 9-item measure of the decisional process in medical encounters from patients' perspective, based on Elwyn's model of competences for involving patients, as well as the Ottawa Decision Support Framework.²¹ It has good acceptance, feasibility, and reliability.²² The SDM-Q-9 was developed on the basis of nine practical steps of the SDM process, which include (1) disclosure that a decision needs to be made; (2) formulation of equality of partners; (3) presentation of treatment options; (4) informing on the benefits and risks of the options; (5) investigation of patients' understanding and expectations; (6) identification of both parties' preferences; (7) negotiation; (8) reaching a shared decision; and (9) arrangement of follow-up.²³ The SDM-Q-9, displayed in Supplement 1, was adopted to conduct the SDM survey on patients in Shanghai so as to measure patients' participation in the long-term

decision-making process of TCM therapy for lung cancer. Patients' responses could be rated on a five-point scale from "completely disagree" (1) to "completely agree" (5). A higher score represented greater satisfaction with the information provided, indicating a higher level of perceived SDM. Descriptive analyses were carried out for each item's score of SDM-Q-9. A raw total score could be calculated by summing up the scores of all items.

2.3. Discrete choice experiment survey

2.3.1. Methodology

DCE, a stated preference method, which means that study participants are presented hypothetical scenarios, characterized by attributes and their associated levels, has been extensively used to assess patient preferences and marginal rates of substitution (e.g. marginal willingness to pay) in health care.²⁴ DCEs are mainly based on the random utility theoretic framework. Under this framework, an individual respondent is assumed to choose the alternative for which he or she holds the highest utility.²⁵ A DCE survey was conducted in this study, following the guidance from a report by the ISPOR Conjoint Analysis Good Research Practices Task Force.²⁶ Respondents were required to make trade-offs between their preferred and less preferred attribute level for each choice set. A DCE has four main stages: (1) identifying and defining attributes and levels; (2) the experimental design; (3) the data collection survey; and (4) the analysis and interpretation of results.²⁷

2.3.2. Identify attributes and their levels

To determine the key attributes of TCM treatment in this study, we performed a literature search of Chinese journal literature databases, including CNKI, CBM, and Wanfang along with global databases, such as PubMed, EMBASE, and MEDLINE. The key words included "lung cancer", "preference", "main safety indicators", "safety", "effectiveness", "efficacy", "toxicity", "adverse effect" and "Traditional Chinese Medicine".

Based on the results of the literature search, eight attributes, including disease control rate, quality of life, nausea and vomiting, thrombocytopenia, leukopenia, peripheral nerve damage, liver function abnormalities, joint pain, were initially gathered. In addition, we consulted lung cancer physicians and related experts from the oncology, TCM, and integrated Traditional Chinese and Western Medicine departments by means of semi-structured interviews, which was conducive to clarify the suitable attributes, their exact meanings and corresponding levels. The interview outline comprised three main parts: (1) treatment methods, costs, efficacy indicators, and adverse effects of TCM therapy for lung cancer; (2) advantages and disadvantages of TCM therapy for lung cancer; and (3) design of DCE choice set.

Therefore, we identified and summarized four attributes of TCM therapy for measuring patients' preferences, namely disease control rate, nausea and vomiting, risk of side effects, and out-of-pocket costs to patients. Among these attributes, disease control rate, nausea and vomiting, and risk of side effects were categorical variables assigned three or four levels, whereas out-of-pocket costs to patients was a continuous variable. The list of these attributes and their levels is shown in Supplement 2.

2.3.3. Construction of the DCE questionnaire

The four attributes and their corresponding levels (three attributes with three levels and one attribute with four levels) resulted in 108 hypothetical scenarios, which obviously could not be impractical in a questionnaire. Therefore, in order to guarantee statistical efficiency and relieve respondents of further burden when completing the questionnaire, we applied the D-optimal designs using the SAS software, version 9.4 (SAS Institute, Cary, NC, USA) to generate optimal scenarios.²⁸ The ultimate DCE design consisted of 18 choice sets were divided into two blocks, that is to say, each patient respondent needed to answer nine

trade-off questions. Supplement 3 illustrates an example of a DCE survey choice set. The survey instrument included an introduction to choice pairs with a description of the attributes and their levels so as to help reduce the cognitive burden of respondents.

Besides the DCE survey, questions on the demographic characteristics of patients and other factors that may influence patients' preferences for TCM therapy in terms of lung cancer were included in the survey instrument. A single-center pilot survey ($n = 20$) was conducted before formal survey to improve and modify the questionnaire and study (The data from these 20 patients were not included in the data analysis of the formal investigation).

2.4. Statistical analysis

A mixed logit model was used to estimate preference weights for the involved attributes, obtaining the main effects of the model on patients. The coefficients of the mixed logit model represented estimates of the probability of choosing a TCM therapy for lung cancer.

Afterwards, according to the split-sample analysis methods, we conducted a subgroup analysis to estimate potential differences in preference of patient subgroups with different SDM-Q-9 scores, patients' satisfaction and several key demographic characteristics. The general characteristics of the patients were summarized as means and standard deviations or frequencies and percentages.

In the analysis, random effects were included to explain the fact that each patient was answering multiple questions and may have systematic preferences. All DCE responses were analyzed with multiple logistic regression models by STATA version 16 (StataCorp LP, College Station, TX, USA).

The out-of-pocket cost was regarded as a continuous variable in the models, whereas other attributes were encoded as dummy variables, according to their assigned levels. All coefficients of the model were assumed to be normally distributed. In estimating parameters, $p < 0.05$ was considered statistically significant.

3. Results

3.1. Demographics

In this study, 347 eligible patient respondents from nine sample hospitals in Shanghai participated the questionnaire survey on preferences and SDM mode of TCM therapy for lung cancer. The social demographic characteristics of the respondents are reported in Table 1. Among 347 respondents, 187 (53.89%) were male. The average age of the participants was 66 years, spanning a range of 40 to 87 years. The majority of the patients were local residents (80.12%), had medical insurance (98.85%), and received senior high school education (55.04%). Most patients were diagnosed as NSCLC (82.42%). As for lung cancer treatment practice, 170 (48.99%) patients were treated with TCM combined with conventional therapeutic methods, 167 (48.13%) adopted TCM as monotherapy.

3.2. SDM-Q-9 results

A survey on the respondents' shared decision making was conducted using the SDM-Q-9 instrument. The mean SDM-Q-9 score of 347 participants was 39.42 ± 6.62 and the median SDM-Q-9 score was 41. The average score of each of the nine items was above four. Most of the patients (90.20%) self-reported a high willingness to participate in the decision-making process on TCM therapy for lung cancer. Table 2 shows the SDM-Q-9 scores of the respondents in this study.

3.3. Patient preferences on TCM therapy for lung cancer

The main effects of the mixed logit model results are presented in Table 3. The parameter of the discrete choice model for each attribute

level can be explained as regression coefficients, which reflect the extent to which each attribute influences treatment choice intention. In this study, the coefficients were statistically significant for all attributes, including disease control rate, nausea and vomiting, risk of side effects and monthly out-of-pocket costs. As shown in the results, patients considered disease control rate to be about quintupling as important to the risk of side effects, and almost twice as much as nausea and vomiting. Evidently, patients showed a strong preference for a higher disease control rate (level, 80%), which was their most valued attribute when making TCM therapeutic decisions. Successively, patients also had positive preferences for fewer episodes of nausea and vomiting (level, mild) and lower risk of side effects (level, low).

3.4. Subgroup analysis

Additionally, we conducted a subgroup analysis to estimate the preferences of patients with different key socio-demographic characteristics. Based on the analysis of the main effect model, taking into account the possible factors of patient's preferences, the following indexes were comprised in the subgroup analysis, including therapeutic modalities, insurance types, family members' highest academic qualifications, annual per capita household income, preferred SDM modes, SDM-Q-9 scores and satisfaction with medical services. Apart from the SDM-Q-9 score and service satisfaction, the preferences for all attributes between different subgroups with other socio-demographic characteristics were relatively similar. Supplement 4 and Supplement 5 reveal the results of the mixed logit models among different patient subgroups according to the SDM-Q-9 score (median score, 41) and service satisfaction. Patients with a lower SDM-Q-9 score emphasized more importance of higher disease control rate and cared about monthly out-of-pocket costs to a greater extent. Those who were satisfied with medical services put more weight on the improvement of disease control rate, while the dissatisfied patients indicated higher focus on monthly costs. Patient preferences were different according to the SDM-Q-9 score and service satisfaction.

4. Discussion

In this study with a multi-center sample of patients, we applied a DCE framework to investigate patient preferences for TCM therapy of lung cancer, and an SDM-Q-9 survey to estimate their perspectives of the shared decision-making process in clinical encounters. To the best of our knowledge, this study is the first to tentatively associate discrete choice experiment with shared decision making in the context of TCM therapy of lung cancer in China. According to our findings, most of the patients showed a relatively high willingness to be engaged in a shared decision-making process during the TCM treatment for lung cancer. Besides, the results indicated that the patients preferred TCM therapy for lung cancer with higher disease control rate, fewer nausea and vomiting episodes, and lower risk of side effects. Meanwhile, most patients paid close attention to treatment costs. Additionally, preferences for these attributes were similar among patients with various socio-demographic characteristics, while differences in preference existed among patients based on SDM-Q-9 score and service satisfaction.

The findings of the current study were consistent with some previous studies. With regard to disease control rate, qualitative studies have shown that survival benefits seem to be critical in clinical decision-making process.²⁹ Tang et al.³⁰ reported that longer survival was the main reason for choosing a particular treatment regimen. With respect to treatment-related adverse effects, both Osoba et al.³¹ and Dubey et al.³² found that nausea and vomiting were the side effects that contributed the most to the patients' selection regarding various treatment options. Additionally, Liu et al.³³ indicated that not only efficacy factors such as disease control rate but also other factors including side effects and treatment costs were considered to be important for patient preferences. Hence, the findings of our study were basically in accordance with those of earlier studies on patient preferences for the treatment of lung cancer.

Table 1
Demographic Characteristics of the Patient Respondents.

Characteristic	Subjects (n = 347)	Proportion (%)
<i>Gender</i>		
Male	187	53.89
Female	160	46.11
<i>Age</i>		
40–49	17	4.90
50–59	72	20.75
60–69	150	43.23
>69	108	31.12
<i>Local residents</i>		
Yes	278	80.12
No	69	19.88
<i>Patients' education level*</i>		
Primary school and below	32	9.22
Junior high school	122	35.16
Senior high school (technical secondary school)	124	35.73
College and above	67	19.31
Missing value	2	0.58
<i>Major diagnosed disease</i>		
NSCLC	286	82.42
SCLC	27	7.78
Others	34	9.80
<i>Tumor stage*</i>		
I	91	26.22
II	48	13.83
III	66	19.02
IV	139	40.06
Missing value	3	0.86
<i>Medical insurance</i>		
No medical insurance	4	1.15
Urban employee medical insurance	187	53.89
Urban and rural residents medical insurance	59	17.00
Other medical insurance	97	27.95
<i>Therapy*</i>		
TCM as monotherapy	167	48.13
Mainly western medicine, supplemented by TCM	170	48.99
Western medicine was ineffective, then TCM was adopted	9	2.59
Missing value	1	
<i>Preferred decision-making mode</i>		0.30
Decision made by patient	2	0.6
Decision made by both patient and physician	313	90.2
Decision made by physician	31	8.9
Others	1	0.3

* missing values in the sample.

Table 2
SDM-Q-9 Scores of the Respondents in This Study (n = 347).

Item	Completely Disagree (%)	Strongly Disagree (%)	Mediate (%)	Strongly Agree (%)	Completely Agree (%)	Mean Score (n = 347)
1	5 (1.44)	6 (1.73)	28 (8.07)	108 (31.12)	200 (57.64)	4.42±0.82
2	6 (1.73)	7 (2.02)	30 (8.65)	98 (28.24)	206 (59.36)	4.41±0.86
3	6 (1.73)	4 (1.15)	21 (6.05)	107 (30.84)	209 (60.23)	4.47±0.80
4	5 (1.44)	6 (1.73)	30 (8.65)	96 (27.66)	210 (60.52)	4.44±0.83
5	6 (1.73)	8 (2.30)	35 (10.09)	112 (32.28)	186 (53.60)	4.34±0.88
6	19 (5.48)	11 (3.17)	34 (9.80)	92 (26.51)	191 (55.04)	4.22±1.10
7	14 (4.04)	10 (2.88)	37 (10.66)	93 (26.80)	193 (55.62)	4.27±1.03
8	6 (1.73)	7 (2.02)	24 (6.91)	95 (27.38)	215 (61.96)	4.46±0.84
9	11 (3.17)	8 (2.31)	32 (9.22)	81 (23.34)	215 (61.96)	4.39±0.97
Total SDM-Q-9 score						39.42±6.62

Unlike Western medicine which adopts the standard disease-targeted approach, studies have shown that TCM, with the concept of holism, focuses on improving disease control rate, as well as alleviating clinical symptoms, reducing side effects, and improving the health-related quality of life of patients by strengthening their immunity and removing pathogenic factors.³⁴ Accordingly, when it comes to TCM therapy for lung cancer, the holistic care has become an increasingly momentous trend permeating in various occasions throughout the entire process of cancer treatment. Therefore, it takes more time for both physicians and patients to be engaged in health care decisions. However,

generally, physicians are the main source of information on therapeutic options.^{35,36} Discussions between patients and physicians on therapy and its potential side effects play an essential role in the treatment of lung cancer, where shared decision making has been proved to be an optimal decision-making mode in cancer treatment in order to improve informed consent and decrease uncertainty about clinical decision-making.³⁷ With advances in treatments among patients with lung cancer, it is increasingly important to understand patients' preferences to facilitate shared decision making, especially for treating lung cancer with high mortality in China.^{38,39} Surprisingly, most of the

Table 3
Main Effects of the Mixed Logit Model Results: Patient Preferences for TCM Therapy of Lung Cancer.

Attributes and Levels	Coefficient	SE	SD	SE
<i>Disease control rate</i> (Ref: 30%)				
55%	1.220***	0.086	0.017	0.132
80%	2.585***	0.168	1.790***	0.163
<i>Nausea & vomiting</i> (Ref: Strongly Severe)				
Severe	0.651***	0.106	0.035	0.204
Moderate	1.086***	0.109	0.316	0.327
Mild	1.525***	0.126	0.719***	0.163
<i>Risk of side effects</i> (Ref: High)				
Medium	0.380***	0.079	0.001	0.112
Low	0.575***	0.086	0.118	0.440
Monthly out-of-pocket costs	-0.000038*	0.0000172	0.0002142***	0.0000241
Sample size	347			
Observation value	6246			
LR chi2(8)	222.07			
Log likelihood	-1470.003			
AIC	2972.01			
BIC	3079.84			

Notes: * p < 0.05, ** p < 0.01, *** p < 0.001.

Abbreviations: SE, standard error; SD, standard deviation; Ref, reference; AIC, Akaike information criterion; BIC, Bayesian information criterion.

participants had a strong willingness to be positively involved in the decision-making process on TCM therapy for lung cancer.

A key component to shared decision making is acknowledging patient preferences and values.⁴⁰ The objectives of SDM are achieved when the trade-offs between risks and benefits of treatment options are discussed with the patients.⁴¹ Based on the results of the subgroup analysis, patient preferences seemed to be diverse according to the SDM-Q-9 score and service satisfaction, which was probably due to different measurement tools. Specifically, the service satisfaction was self-reported by patient respondents, most of whom were satisfied with the decision-making process, especially those who indicated being more involved in SDM; whereas the SDM-Q-9 was used in this study to assess patients' perspective on the shared decision-making process in clinical practice, which could reflect the real SDM engagement of patients. Furthermore, although the definition and implementation steps of shared decision making were explained clearly in the process of collecting data, yet, due to individual differences in cognition, some patients might simply equate informed consent with shared decision making, which possibly led to a higher SDM score than the actual data from the perspective of patients. Thus, more studies are needed to further demonstrate this potential difference.

This study had few limitations. First, due to COVID-19, the investigation sites and sizes were limited, the enrolled samples of this study were lung cancer patients from the tertiary hospitals in Shanghai, China, directly resulting in an important limitation, that is, it limited the generalizability of these data, which may not be representative of patients with other diseases, from extended regions or hospitals of additional levels. Therefore, a large-sample survey needs to be carried out in the future to corroborate the findings in this study. Second, due to the limitations of discrete choice experiment method itself, it is impossible to cover all clinical decision-making attributes. However, the attributes included in our study were determined by literature review and expert consultation. Third, given that clinical decision-making is complex and dynamic, particularly with respect to TCM therapy for lung cancer, the SDM-Q-9 instrument could probably not comprehensively reflect the preferred decision-making mode of patients in the real world. In the meantime, the selection sets in discrete choice experiments were hypothetical scenes and whether the collected preference information is consistent with the actual choices clinically still needs to be further verified on that account. Therefore, further researches are required to prove the real clinical decision and preferred decision-making mode of patients.

In conclusion, this study was the first to associate discrete choice experiment with shared decision making for TCM therapy of lung cancer patients in Shanghai. Patients placed a relatively high value on improvement of disease control rate and relief of nausea and vomiting. Besides, the risk of toxic-side-effects and monthly out-of-pocket expenses were the key factors to be considered in TCM treatment of lung cancer. In clinical practice, patient preferences were supposed to be fully reckoned to promote SDM. Remarkably, most patients in Shanghai preferred SDM during the decision-making process. In Addition, patient preferences for TCM therapy were different in the light of SDM-Q-9 scores and service satisfaction. This study provided some insights to improve TCM treatment implementation of lung cancer in terms of patient-centered care and SDM in Shanghai.

Conflict of interests

The authors declare that they have no conflicts of interest.

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Ethical statement

This research was reviewed and approved by the Human Research Ethics Committee of School of Public Health, Fudan University, Shanghai, China (registration number IRB00002408&FWA00002399). Informed consent was obtained from all participants.

Data availability

The data that support the findings of this study are available from the corresponding authors upon reasonable request.

CRediT authorship contribution statement

Yue Teng: Conceptualization, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing. **Yan Wei:** Formal analysis, Supervision, Project administration, Funding acquisition,

Writing – review & editing. **Yingyao Chen**: Supervision, Project administration, Funding acquisition, Writing – review & editing. **Juntao Yan**: Software, Validation, Visualization. **Shimeng Liu**: Methodology, Writing – review & editing. **Fuming Li**: Software, Visualization, Formal analysis. **Shiyi Bao**: Software, Data curation. **Yanfeng Ren**: Software, Data curation. **Liu Liu**: Software, Validation. **Yi Yang**: Investigation, Writing – review & editing.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.imr.2023.100969](https://doi.org/10.1016/j.imr.2023.100969).

Supplement 1. Patients' Shared Decision Making Mode Study (SDM-Q-9)

Supplement 2. Attributes and Their Levels in the DCE Questionnaire

Supplement 3. Example of DCE choice set

Supplement 4. Results of Mixed Logit Models by Different Subgroups in SDM-Q-9 Score

Supplement 5. Results of Mixed Logit Models by Different Subgroups in Patient Satisfaction

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