

Preferences of Gastric Cancer Survivors for Follow-up Care—A Multicenter Discrete Choice Experiment Study

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Abstract

Purposes: The purposes of this discrete choice experiment are as follows:

- 1.To investigate the preference of gastric cancer survivors for follow-up care.
- 2.To quantify the importance of follow-up care-related characteristics that may affect the gastric cancer survivors' choices of their follow-up, so as to provide references for development of the follow-up strategy of gastric cancer survivors.

Methods: Discrete choice experimental design principles was applied to develop the survey instrument. All questionnaires were filled out by the respondents and collected on site. A mixed logit model was used to estimate gastric cancer survivors' preferences. Willingness to pay estimates and simulations of follow-up uptake rates were calculated.

Results: All six attributes are significant important for the follow-up care of gastric cancer survivors ($p \leq 0.05$). Achieving very thorough follow-up contents was the most valued attribute level (coefficient=1.995). Specialist doctors are the most preferred providers, followed by specialist nurses and gastric cancer survivors were willing to pay more for these attribute levels. Changes in attribute levels affected uptake rate of follow-up. When the multiple attribute levels were changed at the same time, a very thorough follow-up contents provided by the same specialist doctor (specialist nurse), the probability of receiving follow-up increases by 95.82% (94.90%).

Conclusions: The characteristics of follow-up care in our study reflect the health management services expectations of gastric cancer survivors. A dedicated specialist nurse involved in follow-up care should be developed to contributes to solve the complex and multifaceted personal needs of gastric cancer survivors.

Introduction

Gastric cancer is the fourth most common malignant tumor in the world[1,2]. With the development of radiotherapy, surgery, and chemotherapy, the survival rate of patients with gastric cancer has been significantly improved[3]. According to the data from Surveillance, Epidemiology, and End Results (SEER) Program, the survival rate of gastric cancer patients rose from 4% in 1973 to 30% in 2010 <https://seer.cancer.gov/>. And in Asian countries, the survival rate of gastric cancer is higher, up to 45.4% [4]. Patients with cancer who completed the treatment and are still alive after a period of time are called cancer survivors[5,6].The overall quality of life is poor for gastric cancer survivors[7] who fear the cancer will return and suffer from complications such as gastrointestinal discomfort, osteoporosis and anemia[8,9]. Studies have confirmed that regular follow-up of gastric cancer survivors can monitor the recurrence and early metastasis of gastric cancer[10,11], reduce complications after gastrectomy[12,13], and provide psychological support for gastric cancer survivors to improve their negative mental state [14,15]. Therefore, regular follow-up of gastric cancer survivors is very necessary.

At present, researches on follow-up of postoperative gastric cancer survivors mainly focus on the impact of various follow-up strategies on the clinical outcome and quality of life of patients. However, the study

showed that gastric cancer survivors have low compliance with follow-up care[16]. In addition, one very recent study explored that during the follow-up, many needs of gastric cancer survivors were not met, such as information needs, care acquisition needs and emotional needs [17].Currently, the development of follow-up strategies for postoperative gastric cancer patients in many medical institutions is usually based on staff experience[18].The staff experience oriented clinical decision-making inevitably pays more attention to the clinical outcome of patients, such as the incidence of complications and tumor recurrence, which ignores the gastric cancer survivors' needs and preferences[19-21]. In the context of patient-centered medicine, patient participation in clinical decision-making can not only increase patient satisfaction, but also can achieve better patient outcomes[22,23]. Furthermore, patients' needs and preferences can provide information for clinical decision-making and increase satisfaction and adherence of patients to health programs[24]. Therefore, clarifying the needs and preferences of gastric cancer survivors will help formulate targeted follow-up strategies to meet the health management needs of gastric cancer patients and improve the quality of life of patients.

Although some factors influencing on the participation of gastric cancer survivors in follow-up care have been analyzed, to date there has been no research to compare and validate the importance of these factors in gastric cancer survivors. Therefore, the reference value for the formulation of follow-up strategies for gastric cancer survivors is limited.

Discrete Choice Experiments (DCEs) are often used in the health field. It evaluates the intensity of preferences to achieve the following meanings: 1. Optimize resource allocation; 2. Provide reference for the formulation of medical policies (project), thereby improving individual compliance with policies (projects); 3. Provide data for economic evaluation and decision-making[25-27].The purposes of implementing our study are as follows:

1. To investigate the preference of gastric cancer survivors for follow-up care.
2. To quantify the importance of follow-up care-related characteristics that may affect the gastric cancer survivors' choices of their follow-up, so as to provide references for development of the follow-up strategy of gastric cancer survivors.

Methods

2.1. Survey design

We determined attributes and levels based on methods recommended[28, 27].First, we reviewed the relevant literatures in the electronic databases,such as EMBASE, PubMed, China National Knowledge Infrastructure (CNKI) and WANFANG DATA, and identified factors affecting the participation of gastric cancer survivors in follow-up and their concerns during the follow-up process and their existing needs. Subsequently, the researchers developed a topic form and used it to conduct semi-structured qualitative interviews with 15 gastric cancer survivors from different regions, then the possible attributes and levels were identified. The topic form includes the following topics:1. Factors influencing cancer survivors' participation in follow-up; 2. Concerns of gastric cancer survivors; 3. Opinions and suggestions of gastric cancer survivors on current follow-up; 4. Existing and unmet needs of gastric cancer survivors. In addition, detailed discussions,

combined with current different region policies, were held with three experts who currently provide cancer follow-up care for gastric cancer survivors to explore current policy considerations and supplement and revise possible attributes and levels. Then, four focus groups (each group including four gastric cancer survivors) were invited to evaluate and determine the level of the all attributes and to vote on the attributes to determine the priority of attributes. Data were refined into six attributes which were considered as the optimal number of attributes in DCE[29], each with two to three levels. Details of attributes and levels were reported in Table 1.

Table 1
List of attribute and levels

Attribute	Level	Description
Thoroughness of follow-up contents	Very thorough	The service provider answers your questions very clearly and completely. Not only to solve the problems associated with the disease, but also to answer the questions related to social psychology, quality of life and so on.
	General thorough	Service providers clearly explain the problems associated with disease, but pay less attention to the questions related to social psychology, quality of life and so on.
Provider	Specialist doctor	They have received specialized training in the diagnosis and treatment of gastrointestinal surgery and/or Oncology.
	Primary care physician	They provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities. This is patients own local doctor whom patients normally see when they get sick (e.g., coughs and colds, blood pressure, diabetes, infections etc.)
	Specialist nurse	A registered nurse who has completed extra study in the specialty of gastrointestinal nursing or its equivalent.
Cost(I)	100	Each follow-up costs is 100 yuan.
	300	Each follow-up costs is 300 yuan.
	500	Each follow-up costs is 500 yuan.
Method	Face to face	You will be face-to-face with the service provider.
	Telephone or We-chat	You will communicate with the service provider by telephone or We-chat.
	Alternate between face-to-face & telephone/ We-chat	If you communicate with the service provider by telephone/We-chat this time, next time is face-to-face communication, and so on.
Continuity	Yes	Each follow-up services was performed by the same person.
	No	Each follow-up service may be performed by different people.
Supplementary services*	Treatment of complications	The main supplementary service is the treatment of complications.
	Psychosocial support	The main supplementary service is psychosocial support.
	Health behavior suggestions	The staff will give you health advice**.

2.2. Choice sets

A full factorial design consisting of four attributes with three-level and two attributes with two levels would have generated 324 possible hypothetical scenarios ($3^4 * 2^2=324$). It is very difficult to provide participants with too many hypothetical scenarios, which will cause high cognitive burden on the respondents. Thus, in Ngene, 36 scenarios were generated by using a fractional factorial design developed by Burgess and Street[30]. Furthermore, the 36 scenarios were randomly divided into 4 blocks to further reduce the cognitive burden of respondents, with 9 scenarios in each block. In order to test the consistency of the respondents' choices, the second scenario of each block was repeated as the tenth scenarios (the scenario was not included in the data analysis). Ultimately, four versions (v1, v2, v3 and v4) of the questionnaire were produced, each consisting of ten DCE scenarios, and each scenario consisting of two profiles and an exit option (not willing to participate in follow-up) that reflects the follow-up compliance of gastric cancer survivors. For each choice set, in addition to the DCE scenarios, the sociodemographic characteristics of the participants was included to support investigation of how preferences might differ according to participants characteristics such as gender, age, level of education, monthly income, place of residence, primary caregiver and tumor stage. The survey instrument (versions 1–4) was pilot-tested in an face to face manner with a convenience sample of 17 participants who were from different hospitals to revise the wording of the questionnaires to improve the clarity of the questionnaires, refine the language, test construct and content validity. An example of scenario from a final questionnaire is shown in Supplement 1.

2.3. Survey sample and method

Taking into account the differences in regional and economic development, we recruited gastric cancer survivors at different economic zones and different regions. In order to accurately obtain the views of gastric cancer survivors without being affected by other major diseases, the exclusion and inclusion criteria of this study are as follows: The inclusion criteria: (1) patients with a history of gastric cancer; (2) patients were 18 years old and/or older; (3) patients had completed main treatment (surgery, radiotherapy, and chemotherapy). Exclusion criteria: (1) patients gastric cancer patients with other malignant tumors; (2) with severe cardiovascular disease; (3) with cognitive impairment; (4) with hearing impairment; (5) unwilling to participate in this study. Respondents were recruited by the people who are responsible for cancer follow-up of participants. Questionnaire survey was performed by trained researchers. The trained researchers provided the hard-copy questionnaires to the respondents face-to-face. All questionnaires were filled out by the respondents and collected on site. The two researchers cross-checked the returned questionnaires to ensure the quality of our study. The questionnaires that meet the one of the following criteria were defined as invalid questionnaires: (1) the questionnaire was not completed; (2) the consistency test was not passed; (3) all the options in a questionnaire checked by a respondent were the same; (4) the checked options selected by a respondent were regular, such as 3, 2, 1, 3, 2, 1. This study was approved by the Ethics Committee of the School of Nursing of Jilin University [Ethics Number:2019051101].

Data analysis

Data were double-entered into Epidata 3.1 and transferred to Stata 15.0 for processing and analysis. Descriptive statistics were summarized (percentages) on the participants' sociodemographic characteristics.

A mixed logit model was used to evaluate the preferences of participants for the different levels of the follow-up attributes. The mixed logit model makes it achievable to explore the preference heterogeneity of

respondents and allows for multiple observations from each respondent who was presented with 10 choice sets. All models included main effects, without interaction terms.

Except for the attribute "cost" which was specified as a continuous variable to calculate of willingness to pay (WTP) that was estimated as the ratio of the value of a specific attribute level to the negative of the cost attribute, all other attributes were dummy code. The nlcom command was used to simulate the uptake rate, which is when the levels of one or more attributes change compared with the baseline follow-up program, changes in the probability of a participant receiving a follow-up program. Models were stratified by demographic variables to explore differences in the preferences of gastric cancer survivors with different demographic characteristics. For all calculations, statistical significance was determined at the $p < 0.05$ level.

Results

Characteristics of respondents

A total of 440 gastric cancer survivors from Sichuan province, Chongqing Municipality, Gansu Province, Hainan Province, Beijing, Jilin Province and Guangdong Province participated in the study. After excluding invalid questionnaires, 376 respondents were included in the analysis. Of the 376 respondents, there are more men than women, and fewer are over 18–40 and 70 years old, accounting for 6.12% and 13.83% respectively. Respondents with education level below primary school were less, accounting for 8.24%, while respondents with education level at senior high school for were the most, accounting for 39.36%. The respondents with monthly income between 2000–6000 are mostly, accounting for 44.95%, while the respondents with monthly income less than 2000 and more than 10,000 are fewer, accounting for 6.91% and 15.69% respectively. The proportion of respondents living in cities is relatively large, at 48.67%. Most respondents are cared for by their spouses, accounting for 56.91%. There are most respondents whose tumor is stage II gastric cancer, accounting for 51.06%. More detailed characteristics are reported in Supplement 2.

Discrete choice experiment results

In Table 2, the mixed logit estimates for the total sample are reported. The results confirmed that all six attributes are important for the follow-up care of gastric cancer survivors, and the coefficient of all levels of each attribute are significant ($p \leq 0.05$). Achieving very thorough follow-up contents, versus achieving general thorough follow-up contents, was the most valued attribute level (coefficient = 1.995, 95%CI 1.652–2.338). The specialist doctor and specialist nurses considered as the providers in follow-up care, versus the primary care physician, were also highly valued (coefficient = 1.111, 95%CI 0.805–1.419 and coefficient = 0.909, 95%CI 0.592–1.226, respectively). The continuity (follow-up was conducted by the same person) (coefficient = 0.740, 95%CI 0.476–1.004), treatment of complications (coefficient = 0.726, 95%CI 0.476–0.976), and alternate between face-to-face & telephone/ We-chat (coefficient = 0.664, 95%CI 0.360–0.968) were also highly valued. The cost also had a significant effect on the follow-up care preferences of gastric cancer survivors (coefficient = -0.0014019, 95%CI -0.0022122 – -0.0005917), but not as important as other attribute levels. Furthermore, significant standard deviations (SD) were found across all attribute levels except that the main supplementary service is health behavior suggestions, suggesting heterogeneity among the respondents.

Table 2
Mixed logit estimates for total sample(n = 376)

Attribute levels	Mean		SD			
	Coefficient (se)	95% CI		coefficient (se)	95% CI	
Cost	-0.0014019** (0.0004134)	-0.0022122	-0.0005917	-	-	-
Thoroughness of follow-up contents (relative to General thorough)						
Very thorough	1.995** (0.175)	1.652351	2.338355	2.108** (0.195)	1.726211	2.489665
Provider (relative to Primary care physician)						
Specialized nurse	0.909** (0.162)	0.5917919	1.225981	0.651** (0.177)	0.3036522	0.9982409
Specialist doctor	1.111** (0.157)	0.8049118	1.418858	1.205308**	0.9041152	1.5065
Method (relative to Telephone or We-chat)						
Alternate between face- to-face & telephone/ We- chat	0.664** (0.155)	0.3600249	0.9679347	0.671** (0.158)	0.3623664	0.9805605
Face to face	0.322** (0.099)	0.1275092	0.5167208	0.530* (0.187)	0.1645484	0.8963858
Continuity (relative to No)						
Yes	0.740** (0.135)	0.4755201	1.003947	1.400** (0.132)	1.142065	1.65771

*P < 0.05, **P < 0.01

Attribute levels	Mean			SD		
	Coefficient (se)	95% CI		coefficient (se)	95% CI	
Supplementary services (relative to Psychosocial support)						
Treatment of complications	0.726** (0.128)	0.4760592	0.9761819	0.744** (0.167)	0.4163536	1.071087
Health behavior suggestions	0.528** (0.121)	0.2907214	0.765518	0.234 (0.256)	-0.2680045	0.7366853
*P < 0.05, **P < 0.01						

Table 3 reports the results of the willingness to pay calculations, which measures how much money an individual would be willing to spend to improve follow-up care characteristics, or would need to be compensated for undesired follow-up care characteristics. Respondents were willing to pay 1423.2837 CNY (95%CI 546.57363-2299.9937) for very thorough follow-up contents, 793.10676 CNY (95%CI 359.09048–1227.123) for follow-up by specialist doctors, and 648.3079 CNY (95%CI 384.33175-912.28405) for follow-up by specialist nurses. In comparison, the face-to-face follow-up method was the lowest, at 229.76437 yuan (95%CI 64.447727–395.08101). Comparatively speaking, willing to pay for the face-to-face follow-up is the lowest, which was 229.76437 CNY (95%CI 64.447727–395.08101).

Table 3
willing to pay for attribute levels

Attribute levels	WTP	95%CI	
Very thorough	1423.2837	546.57363	2299.9937
Specialized nurse	648.3079	384.33175	912.28405
Specialist Physician	793.10676	359.09048	1227.123
Alternate between face-to-face & telephone/ We-chat	473.61627	265.12726	682.10527
Face to face	229.76437	64.447727	395.08101
Yes	527.65145	173.20017	882.10272
Treatment of complications	517.94124	156.81784	879.06464
Health behavior suggestions	376.70738	96.800281	656.61447

Simulated preferences for follow-up care with changes in follow-up program characteristics

Probabilities of acceptance of a baseline follow-up program after a change in the level of one or more of the follow-up attributes were simulated, with the most significant findings reported in Fig. 1. In terms of individual attribute level change, the thoroughness of follow-up contents changed from general thorough to very thorough had the greatest influence on preferences, and the probability of receiving follow-up increases by 76.01%. When the follow-up provider changed from a primary care physician to a specialist doctor and from a primary care physician to a specialist nurse, the probability of receiving follow-up increased by 50.50% and 42.55%, respectively. When multiple attribute levels change at the same time, the optimal follow-up program increases the probability of receiving follow-up by 99.08%. The optimal program needs to meet the following points at the same time: 1. Each follow-up costs 100 CNY; 2. The providers are specialist doctors; 3. Each follow-up care is provided by the same person; 4. Thoroughness of follow-up contents are very thorough; 5. Method of follow-up is alternate between face-to-face & telephone/ We-chat; 6. The main supplementary service is the treatment of complications. However, the changes of attribute levels were less, such as a very thorough follow-up contents provided by the same specialist doctor (specialist nurse), the probability of receiving follow-up increases by 95.82% (94.90%), which was close to the optimal follow-up program.

Discussion

To the best of our knowledge, this is the first study to explore the preferences of gastric cancer survivors for follow-up care and to analyze follow-up-related characteristics that motivate gastric cancer survivors to receive follow-up care. We found that gastric cancer survivors attach great importance to the comprehensiveness and completeness of the information obtained from follow-up care, and they are willing to spend more money for very thorough communication. Specialist doctors are the most preferred providers for gastric cancer survivors, followed by specialist nurses and gastric cancer survivors were willing to pay more for these attribute levels. Changes in attribute levels affected uptake rate of follow-up. Thoroughness of follow-up contents changed from general thorough to very thorough was the single factor that has the greatest impact on the uptake rate, followed by the follow-up provider from primary care physician to specialist doctor and from primary care physician to specialist nurse. When the multiple attribute levels were changed at the same time, the optimal follow-up program had the greatest impact on the uptake rate. It is worth noting that approximate effect can be achieved by changing fewer attribute levels with higher weights at the same time. For example, the probability that gastric cancer survivors receive the very thorough follow-up care provided by the same specialist doctor (specialist nurse) was close to the optimal follow-up program.

The characteristics of follow-up care identified as important to gastric cancer survivors in our study reflect the health management services expectations of gastric cancer survivors. While some of our attributes were similar to previously reported DCEs addressing follow-up care choice for cancer survivors, such as participants preferred specialist doctors and specialist nurses as follow-up providers[31, 32]and prefer that each follow-up care is provided by the same person[32], others were not. Our study adds to the international literature by highlighting gastric cancer survivors' follow-up care preferences, and by identifying highly valued

follow-up care characteristics that can be modified at the hospital or health system level. Some of our attributes are both novel and timely, reflecting changing follow-up contents and follow-up method. For example, the very thorough follow-up contents attribute responds to the increasing emphasis on psychological intervention in follow-up care, while effective intervention for cancer patients can improve their long-term survival results and improve their quality of life [33, 34]. Similarly, follow-up methods respond to the changing expectations of tumor survivors based on new communication equipment and communication methods[35].

The follow-up care choice is influenced by the hospital or health system -related factors, and also by an individual's personal, family, social and financial circumstances, as well as experiences that patient's experience in dealing with the disease[35–38]. It is clear that the combined improvement of multiple measures is needed to effectively improve the compliance of gastric cancer patients to follow-up care[16]. Studies have confirmed that it is necessary to develop a set of interventions based on the preferences and expectations of the specific group of cancer survivors[37, 39]. Our study provides the development of follow-up strategy with preliminary information on which follow-up characteristics matter most to gastric cancer survivors under the patient-centered medical background.

Cancer survivors are unlikely to believe that primary care physicians have extensive knowledge of appropriate cancer follow-up care, and diagnosis and treatment of cancer or cancer treatment-related symptoms[40]. This may be the reason why gastric cancer survivors prefer specialist doctors or specialist nurses as follow-up care providers in our research and are willing to pay more for this. Although specialists as follow-up providers are preferred by gastric cancer survivors, specialist nurses seem to be the best providers of follow-up care. The specialist nurses with a larger role can improve medical services and control costs[41]. In addition, more and more studies have shown specialist nurses can provide effective cancer follow-up care[42–46]. The information provided by nurses in follow-up care is easier to understand[47] and nurse-led primary care can achieve higher patient satisfaction and cause slightly higher quality of life for patients[48]. Therefore, it is very important to provide nurses with specialized training so that they can play an important role in cancer follow-up care.

Gastric cancer survivors are willing to pay the most for very thorough follow-up contents. People are increasingly aware of the unmet needs of different cancer survivors[49]. More and more documents have revealed a series of complex practical, physical, psychological and emotional needs[50–53]. Meeting these needs better may be the reason why gastric cancer survivors are willing to spend more money to obtain very thorough follow-up care.

When multiple attribute levels were changed simultaneously, the change of fewer attribute levels had a significant impact on respondents' choice of follow-up care. With other characteristics unchanged, the very thorough follow-up care provided by the same specialist doctor (specialist nurse) can increase the probability of choice for follow-up care by 95.66% (94.90%). Each follow-up is carried out by the same person, which is conducive to establish a trust relationship between doctors/nurses and patients and can understand the patient's situation more clearly. Although it is considered important for specialist doctors to be the providers of follow-up care, in terms of cost, developing a dedicated team of cancer follow-up nurses may offer a more economical choice for the future follow-up care of cancer survivors. In summary, follow-up care provided by a

dedicated specialist nurse with whom a gastric cancer survivor can build a personal and continuous relationship over several years to solve the complex and multifaceted personal needs of gastric cancer survivors, which may be the way forward for more effective cancer survivor follow-up services in the future.

Our research has some limitations. First, DCE explores the declarative preferences of the interviewees, and the degree of consistency between declarative preferences and preferences in real life cannot be verified. In addition, although our previous exploratory work confirmed that the attributes included in this study are the most important for gastric cancer survivors, it should be recognized that the excluded attributes may also be important, which limits our discussion of the results. The views of non-responders and those who provided invalid responders may be different from those of the participants included in this article, and future research should try to obtain these views.

Conclusion

The characteristics of follow-up care identified as important to gastric cancer survivors in our study reflect the health management services expectations of gastric cancer survivors. A dedicated specialist nurse involved in follow-up care should be developed to contribute to solve the complex and multifaceted personal needs of gastric cancer survivors.

Declarations

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Conflict of Interest

The all authors declare no conflict of interest.

Data availability

The data used to support the findings of this study are included within the article, and all data included in this study are available upon request by contact with the corresponding authors.

Ethics approval and consent to participate

This study was performed in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of School of nursing, Jilin university. We introduced the study to all participants and obtained

their consent.

Consent for publication

The manuscript contains any individual person's data in any form (including individual details, images or videos), consent for publication was obtained from that person.

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Figures

Figure 1. Simulated follow-up program preferences with changes in program characteristics

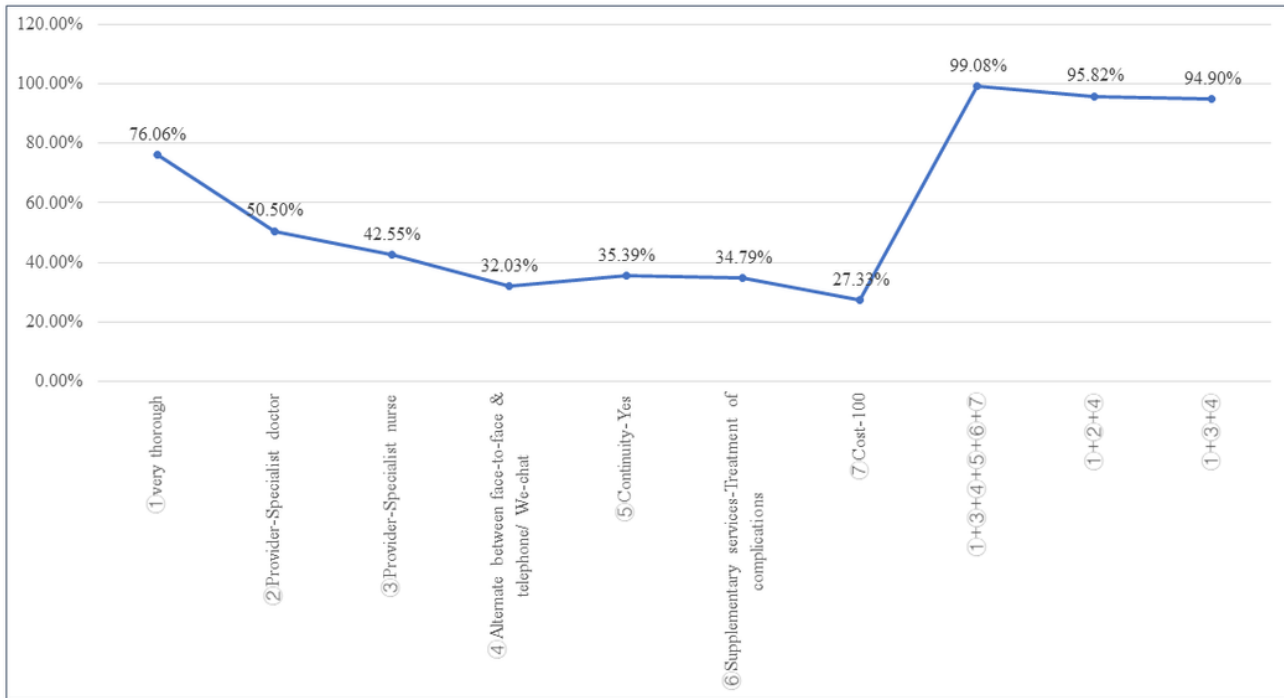


Figure 1

Probabilities of acceptance of a baseline follow-up program after a change in the level of one or more of the follow-up attributes were simulated, with the most significant findings reported in Figure 1.

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