

Towards Informed Decisions on Breast Cancer Treatment: Development Process and Pilot Testing of a Decision Aid for Chinese Women

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Received Date: October 15, 2024 | Accepted Date: November 08, 2024 | Published Date: December 18, 2024

Citation: Jinping Gao, (2024), Towards Informed Decisions on Breast Cancer Treatment: Development Process and Pilot Testing of a Decision Aid for Chinese Women, *Dermatology and Dermatitis*, 9(8); DOI: 10.31579/2578-8949/180

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Abstract:

Background: in order to develop a patient decision aid that could support patients with breast cancer in making an informed decision about breast cancer treatment.

Design: Using the Qualitative interview, the modified Delphi and pilot testing to confirm the contents of the breast cancer decision aid.

Materials and Methods: The development included four stages: (i) Establishment of a multidisciplinary team; (ii) Needs assessment consisting of semi-structured interviews in patients; (iii) Creation of content, design and technical system; and (iv) Acceptability and usability was measured using the System Usability Scale (SUS).

Results: From the needs assessment, five sub-themes were identified, captured by the two general themes of acceptability and feasibility. The decision aid that was developed contained three parts:(i) about breast cancer, (ii) surgical treatment options for breast cancer, (iii) Health popularization (including questions and tips for making sure patients obtained their desired disease knowledge in the decision), (iv) your preferences, (v) Extended care (including videos of patients entering and leaving, diet, exercise, etc.), and (vi) Background management. The decision aid was perceived to be informative, helpful and easy to use by patients.

Conclusion: The content of decision aid was scientific and feasible, and most participants indicated that the decision aid was acceptable and comprehensive.

Practice implications: Women want to be informed about breast cancer and the present decision aid is an acceptable and feasible form of decision support to facilitate discussions with doctors.

Impacts: To solve the practical difficulties of breast cancer patients participating in treatment decision-making information needs, in the case of limited medical resources, to meet the diversified information needs of breast cancer patients participating in treatment decision-making, and to achieve timely, professional and personalized decision-making auxiliary information supply.

Key words: breast cancer; patient decision aid; delphi technique; information needs; wechat mini program

Introduction

Breast cancer is one of the most common malignant tumors in women, with the highest incidence [1]. Breast cancer is the sixth cause of cancer-related death among women in China, with about 169,000 cases and 45,000 deaths due to breast cancer each year [2]. The peak age of breast cancer patients in China is 45-55 years old, and the age of the incidence group is younger, accounting for 19.9% of all new cancer cases in Chinese

women [3]. With the continuous progress of medical technology, there is a trend of diversification of breast cancer treatment, and the benefits and risks of different treatment methods are different, which seriously affects the quality of life of breast cancer patients [4, 5]. In conclusion Patients face an increasingly complex clinical decision-making process, and they need to weigh the risks and benefits of different treatment options, quality

of life and their own economic conditions, and it is not easy to find the right treatment plan for their own.

With the change of the medical model, the role of the patient in the treatment decision-making process has become increasingly important, and the degree of patient participation in the treatment decision-making has become an important indicator to judge the quality of medical care [6]. Shared decision-making (SDM) involves the joint participation of patients and health care professionals in making health care decisions based on the best available evidence and patient preferences [7]. Patient decision aids (DA) are an effective knowledge translation tool in supporting SDM and achieving patient-centered care. Matsen conducted a study on attitudes toward SDM in young breast cancer patients, showed that most young women tend to take an active role in decision-making [8]. Fang conducted a questionnaire survey on 480 breast cancer patients with nursing decision participation, and the study showed that 57.3% of the patients believed that their nursing decision participation attitude was positive, 40.2% of the patients believed that their nursing decision participation was actually high [9]. Yamauchi reported 87% of patients who were diagnosed with breast cancer preferred to play active or collaborative roles and 78% of the patients actually played such decisional roles [10]. Peng revealed 64.8% of breast cancer patients preferred to play collaborative decision-making role [11]. These data suggest that patients with breast cancer are likely to perform affirmative involvement in the treatment decision-making process. While, China's medical staff have heavy workload and busy work, lack of time to communicate with patients, and difficulty to explain to patients the uncertain prognosis of disease treatment and other information, resulting in information asymmetry between doctors and patients, and patients are difficult to participate in treatment decision-making. Moreover, doctors do not recognize patients' preference to participate in treatment decision-making, and rarely encourage patients to participate in treatment decision-making

and obtain patients' ideas [12], Thus affecting patients' participation in treatment decisions. Therefore, how to communicate effectively is a challenge for doctors, and how to make the most appropriate decision based on their preferences and values while fully understanding the pros and cons of various treatment options.

There is evidence to support the use of das by breast cancer patients. we conducted a systematic review of DA for patients making a decision with respect to multiple treatment modalities. which included 22 studies revealed that Ads are helpful to breast cancer patients by decreasing decisional conflict (Gao, Jin, Yu, Wu, & Han, 2021). Given the advantage, we decided to develop breast cancer DA and conduct pilot study, we therefore conducted a pilot testing to develop and evaluate a WeChat mini program-based breast cancer decision aid.

Materials and Methods

We formed a scientific team of surgeons, oncologists, statisticians, epidemiologists, and patient advocates. The research team meets as a group to review the first version of Decision Aid and regularly consults on changes and improvements to decision aid.

The ethical review of this study has been approved.

stage 1: Qualitative Interview---assessing patient needs

Using purpose sampling, the sample is saturated when the interviewee's information is repeated and no new topic appears. From October to December 2022, 12 breast cancer patients who visited a tertiary hospital in Xiamen for cardiothoracic surgery were selected for qualitative interviews on the information needs of breast cancer decision-making assistance platform. The interview outline is shown in Table 1. The inclusion and exclusion criteria of the research object and the interview outline are as follows.

No	Contents
1	What difficulties did you encounter in participating in the treatment decision-making process?
2	What factors do you think currently affect your participation in the treatment plan selection?
3	What information do you need to participate in the treatment decision-making process ?
4	What channels do you turn to for help when you encounter decision-making confusion (e.g., doctor/nurse/Internet/fellow patients/reading related books) ?
5	If we want to develop a small program that can help patients choose treatment options, what do you think should be added?

Table 1: The Interview Outline

Inclusion criteria: ① Inpatients initially diagnosed as breast cancer in the first diagnosis; ② Age>18; ③ the patient voluntarily participated in the study with informed consent; ④ the patient has no cognitive impairment and can communicate; ⑤ the patient's spirit and memory are normal.

Exclusion criteria: ① patients with other serious diseases besides breast cancer; ② the patient is critically ill and in danger of life; ③ Mental illness, unable to communicate normally.

Stage 2: Delphi Technique--- Determine the content of DA

We used a modified Delphi design for this study. The improved Delphi is the change of consultation form, reincarnation, expert selection and so on according to the actual situation, there is no need to adopt the four-round model, as long as the opinions of the experts tend to be consistent and highly coordinated, the consultation can be ended, which can reduce the number of consultations rounds and shorten the time needed [13].

Based on the previous evidence-based research [14], this study searched the relevant guidelines for breast cancer treatment, including Cochrane Library, JBI Evidence based Health Care Center Library, OVID Evidence based Database, PubMed, Canada Clinical Practice Guidelines Database,

China Biomedical Literature Database, Wanfang, VIP and other databases, and developed the auxiliary manual for early breast cancer patients to participate in treatment decisions.

On this basis, qualitative interviews were conducted with 10 breast cancer patients to understand their information needs for participating in treatment decisions and their acceptance and preference for applications, and the first draft of "mobile medical treatment decision support scheme for breast cancer patients" was constructed. Through a round of expert meetings, experts in medical, nursing, evidence-based medicine, software engineering and other fields were included, and from their professional and experience perspectives, the content, process Supplement and improve the effectiveness evaluation. Through two rounds of Delphi expert consultation, the first is to review and proofread all the text, pictures, and videos in the content of the plan, and the second is to provide suggestions for the revised decision support path, ultimately determining the decision support path and the final draft of the plan.

The WeChat mini program-based tool was designed with the following core characteristics:

- WeChat mini program -based platform, providing an easily accessible platform for both patients and clinicians that can be updated rapidly and disseminated broadly.
- applicability to the breast cancer patients: providing knowledge of breast cancer diseases such as the occurrence and development of breast cancer, treatment methods, examination items, etc.
- Setting up a decision path: help patients make the best treatment plan for their individual needs
- Provide continuous care for patients after discharge, including postoperative follow-up items, frequency, online expert consultation, etc.

Stage 3: Pilot Testing

Usability was measured using the System Usability Scale (SUS). Interviews were conducted with participants to collect open-ended feedback questions.

The System Usability Scale (SUS), developed by Brooke, had a great success among usability practitioners since it is a quick and easy to use measure for collecting users' usability evaluation of a system [15]. Wang translated this scale into Chinese version in 2020(Wang, Lei, & Liu, 2020). The SUS consists 10 questions, using Likert five-point scale; questions 1, 3, 5, 7, and 9 are positive and questions 2, 4, 6, 8, and 10 are negative. The higher the score, the better the product usability. The overall internal consistency and content validity of the scale were 0.840, 0.879, and high reliability and validity, which has been widely used in product usability evaluation [3, 16].

Results

Qualitative Findings

A total of 12 women who met initial criteria were invited to participate. five sub-themes were identified, captured by the two general themes of acceptability and feasibility. The general characteristics of the participants are shown in Table 2.

NO.	Age	Education	marriage status	Number of children	Disease Staging
P1	32	Bachelor	married	1	II
P2	43	Bachelor	married	2	III
P3	53	Senior high school	married	2	II
P4	46	PhD	married	1	II
P5	37	Master	married	2	II
P6	46	junior high school	divorce	1	III
P7	57	Under primary school	divorce	2	III
P8	38	Bachelor	married	2	II
P9	43	Senior high school	widowed	3	II
P10	29	junior high school	divorce	Nil	III
P11	58	Master	married	2	II
P12	47	Senior high school	married	3	III

Table 2: The general characteristics of the participants (n=12)

1. Acceptability

a. Information

The information needs of treatment decision-making are varied and different for different patients

In the face of many treatment methods, I feel confused and urgently want to know the advantages and disadvantages of different treatment options. (P4)

I started with a vague lump in my left breast that didn't hurt or itch. It was found to be breast cancer during my physical examination. If I had known the symptoms of different stages of breast cancer earlier, I would have been able to notice it and treat it earlier. (P10)

The Doctor had better tell me in detail why he did all these tests. The doctors know all about them, but I don't know what they're talking about. (P6)

b. Neutral information

most patients felt the DA would have empowered them to make an informed decision about breast cancer.

Often the 'right' decision would be different for everyone, which is closely related to personal preferences, cultural level, economic factors, etc., our goal in developing breast cancer decision support tools is not to encourage or discourage patients from making or not making a decision, but to help them make the decision that best suits their needs. Most

participants were willing to accept the breast cancer decision aid tool and felt the DA was 'neutral'.

I don't think its saying, you should do this, or you shouldn't do this. I feel like it's saying, you've got to think about what's important to you and make the decision on that basis" (P10).

c. Individuality and professionalization

Most patients say there is a lot of information available online about breast cancer decision-making, but it is hard to tell if it is real or not, so patients indicated that they hoped to have standardized and personalized decision-support.

Let me choose my own treatment, I think it is very difficult for me, the main thing is that I do not understand, I need professional help to help us participate

I think it is difficult for me to choose my own treatment, the main thing is i don't understand, I need professional tools to help us participate in decision-making (P8).

2. Feasibility

a. Need: The information of treatment decision-making is in great demand

We need to have all the information on the treatment, otherwise we don't have a choice, and everything else, anything related to the disease, I'm interested in, I want to know (P2).

b. Implementation: most patients had positive attitude towards the DA for breast cancer. Almost all patients believe that the DA can assist them to participate in treatment decision-making. They also think that the DA was feasible and would be used to compliment.

If the hospital can make this platform, that's great, there's a lot of information about breast cancer on the internet, but it's

hard for us to tell if it's true or not, if the authoritative hospital can do it, then the credibility is much higher, we will all use it. (P3)

3.2. Delphi Technique

The two rounds of expert consultation included a total of 18 experts, including 9 medical experts and 9 nursing experts each. The basic characteristics of the experts who were involved in the full study are shown in Table 3.

	项目	医生 (n=9)	护士(n=9)	占比 (%)
年龄	30-40	3	4	38.89
	41-50	4	3	38.89
	>50	2	2	22.22
学历	本科	2	6	44.44
	研究生	4	3	38.89
	博士	2	0	11.11
工作年限	10-15	3	5	44.44
	16-20	4	2	33.33
	>20	2	1	16.67
职称	中级	2	5	38.89
	副高	4	2	33.33
	正高	3	1	22.22

Table 3: The general characteristics of the experts (n=18)

In both rounds, 18 questionnaires were distributed and 18 were retrieved, with an effective recovery rate of 100%. The coefficient of expert judgment for two rounds is 0.89, the coefficient of familiarity is 0.91, and the degree of authority is 0.90. The expert review coordination coefficient (Kendall's W) has a significance of $P < 0.05$ and a coefficient of variation of 0.25.

In the first round of expert consultation, two secondary indicators were modified after discussion by the research group;

(i). In the information support part for classified decision-making, similar questions should be combined, and reducing items can reduce patients' reading difficulties. Modified content such as: breast cancer risk factors and breast cancer risk groups combined; The anatomy of breast cancer is associated with the occurrence and development of breast cancer.

(ii). The target group of this program is breast cancer patients, who are already under great psychological pressure. Therefore, in the presentation of the content of the scheme, it is suggested that the combination of text and pictures should be used more often, and the text should be mild, and too radical and sensitive words should be used less.

In the second round of expert consultation, a total of two secondary indicators were modified:

(i). Some experts suggested that the DAs is for patients, and professional terms should be avoided as much as possible.

(ii). Some experts suggest adding treatment cost and medical insurance information during breast cancer treatment, so add "Breast cancer treatment cost and medical insurance information".

3.3. DA contents

The following sections were offered: (1) about breast cancer, (2) surgical treatment options for breast cancer, (3) Health popularization (including questions and tips for making sure patients obtained their desired disease knowledge in the decision), (4) your preferences, (5) Extended care (including videos of patients entering and leaving, diet, exercise, etc.), and (6) Background management (including User data storage, collection,

statistics (general information and decision information), decision path output, knowledge base management, health education video management, etc.

Users are encouraged to proceed through the program in the sequence provided, but are also free to navigate the program in any order they wish.

That said, certain sections must be completed before the program can generate a final advance directive.

3.4 Pilot study

Five patients and three family members were invited to participate in the decision aid test, and their SUS scores were 86.5, 88, 92, 90, 94, 87, 89, 90, respectively. Which indicates that the usability of this platform is good.

The feedback after the test version of breast cancer patient trial platform is as follows:

All response platforms provide them with very comprehensive breast cancer treatment options related information support.

This is completely developed for our patients, there is no commercial use, the most critical is authority, the first part of breast cancer disease knowledge content is really comprehensive and professional, thank the hospital can think so thoughtful for our patients(P1).

The patient feedback the DAs can help them clarify their preferences.

This is the first time for me to use the decision aid tool, which is a novel way to assist decision-making. Through comparison and rating, I am clearer about my own ideas. Moreover, it is convenient for me to share the link with my family and friends, and they can also give me suggestions(P3).

Discussion

The breast cancer DAs is scientific and feasible

The development of breast cancer decision aid tool is based on the Ottawa Decision Support Framework. The latest breast cancer treatment

guidelines, expert consensus, clinical health education materials and professional books are consulted to ensure the scientific and accuracy of the program, and the real information needs of breast cancer patients participating in treatment decision-making are deeply explored through qualitative interviews, so as to establish the first draft of the decision aid tool. Through the Delphi method to determine the final draft of decision aid tools, the experts demonstrated are intermediate or above titles, bachelor's degree or above, 10 years or more work experience, rich clinical work experience, can be better combined with clinical practice to solve the problems of patient concern; The effective recovery rate of the two rounds of questionnaires was 100.00%, indicating that the experts had high enthusiasm. The expert judgment basis of the two rounds is 0.85, the familiarity is 0.79 and 0.77, and the expert authority coefficient is 0.83 and 0.85, respectively, indicating that the experts are familiar with the content of the argument, and can demonstrate the content and form of the program in an all-round and multi-angle manner to improve the treatment decision-making experience of patients.

DA content

Most participants expressed a desire to obtain more comprehensive and true information about the disease, especially practical issues such as surgical cost and postoperative recovery time, because these can greatly determine the treatment decisions of some people, and because cost is an important factor affecting patients' health and treatment decisions, we also used surgical cost as a comparison item when comparing different treatment options. In addition, some patients mentioned that it would be better to add risk comparison, but unfortunately, the decision aid tool we are currently developing does not have this function. If patients want to conduct personalized risk assessment, they need to be assisted by doctors.

DA Form

As we know, the form of decision aids included a variety of print products, computer learning modules and web-based intervention, Diverse forms of decision aids serve different target groups. With the improvement of the global mobile information level, the public has more and more diversified ways to obtain health information, and m-Health brings hope to solve the above problems with its unique advantages of "convenient, efficient, low cost and easy to use". Compared with mobile App, WeChat mini program has greater application potential and value. It is simple to operate and can be used without downloading or installing, which can greatly improve the user's sense of experience. At the same time, mini program does not take up memory, and users can exit anytime and anywhere when they run out. It has better use experience and application value, and can also save cost economically.

Limitation

There are still shortcomings in this paper. Patient decision AIDS should provide patients with clear and personalized decision-making guidance on the basis of a powerful database. However, breast cancer decision AIDS still lack sufficient sexualized data, so it is difficult to provide digital and accurate individualized benefit risk assessment.

Conclusion

Through literature review, qualitative interview and Delphi technique, the breast cancer decision aid was finally determined. The content was scientific and feasible, and most participants indicated that the decision aid was acceptable and comprehensive. Some participants reported they wanted access to information about breast cancer personalized risk estimates, Unfortunately, we haven't developed this function yet, and we will develop it in the future.

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