# Developing "Information Assistant": A Smartphone Application to Meet the Personalized Information Needs of Women with Breast Cancer

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## Abstract

*Breast cancer presents specific challenges both physically and psychologically to women. Women living with breast cancer frequently do not receive adequate information support and they urgently need professional assistance that help them to cope and adjust to challenges. This paper documents the process of developing a smartphone application (app) "Information Assistant" for women with breast cancer in China. First, individual interviews were used to explore and understand the real experience of breast cancer patients and their diverse information needs during different stages of diagnosis and treatment. Next, expert working group discussions and the Delphi technique, including breast cancer care physicians, nurses and software engineers, were used to draft the structure and contents of the m-health based information support program. Then, these feedbacks were used to develop "Information Assistant" app. This app has five modules: personalized information recommendation, category knowledge center, headline information browsing, newest information browsing and information searching.*

*Keywords:*

Breast Cancer; Information Management; Smartphone

## Introduction

Breast cancer is the most common cancer among women worldwide [1-2]. According to the Chinese National Central Cancer Registry, breast cancer is the most common cancer among urban women and the fourth most common cancer in rural areas [3], cases in China account for 12.2% of all newly diagnosed breast cancers and 9.6% of all deaths from breast cancer worldwide [4].

Women with breast cancer have a higher relative survival rate than other cancers which makes it possible for patients to live a prolonged life [5]. Breast cancer poses specific challenges both physiologically and psychologically to women. A significant proportion of women experienced physical and emotional difficulties within the first year following diagnosis and years later after treatment [6]. Under these circumstances, information support has been identified as being vital to helping women to cope their challenges [7]. Information support not only increases the client's involvement in the decision-making process which induces greater satisfaction with treatment choices, but also reduces the feeling of uncertainty and helps decrease emotional anxiety [7-9]. Thus, with adequate information support, women could feel empowered to fight their cancer and improve their quality of life [10].

However, the information needs of women with breast cancer have become increasingly difficult to meet as the number of survivors grows and the workforce of breast cancer care physicians and nurses faces personnel shortages. Since there is limited availability of time and resources by clinicians, there is a need to identify a new method to provide adequate information support and improve the quality and efficiency of follow-up care for breast cancer survivors.

Recently, the rapid expansion of health information technology provides such an opportunity. It has been shown that health information technology can play an important role in helping cancer patients to get high-quality information and become active participants in their care [11-12]. Smartphones with variety functionality such as touch screen technology, audio, video, internet access have become a ubiquitous technology in both the developed and developing world [13]. With the increasing usage and acceptance of smartphones, the smartphone applications (apps) have shown great potential to provide clients with information specific to their needs [14]. Our project is to develop a smartphone app to meet the personalized information needs of women with breast cancer in China. The purpose of this paper is to document the process of developing the smartphone app.

## Methods

This is a multidisciplinary research program, our research team included three postgraduate students (Ying Liu, Zhaohui Geng and Fulei Wu) majored in Chronic Disease Caring & Cancer Nursing, nursing educationist (Changrong Yuan), breast cancer care physicians, breast cancer caring nurses and software engineers. The research team members worked collaboratively to design and conduct the research. The workflow of the multidisciplinary research and developing of the app is presented in Figure 1.

Data collection spanned from March 2015 to December 2016. First, interviews and follow-up study with 12 breast cancer patients were used to explore and understand the real experience of breast cancer patients and their diverse information needs during different stages of diagnosis and treatment. Next, the expert working group discussion including 7 experts from medical, nursing and software engineering was conducted. Experts added some information need contents of breast cancer patients from their professional point of view, and gave suggestions for developing an m-health based information support program. Then, a Delphi expert consultation was conducted, in which 20 clinical nursing experts participated and gave their opinions on the core part of the mobile information support program. Finally, expert consultations including 5 clinical medical and nursing experts and 3 software engineers were conducted. A researcher organized the multi-disciplinary cooperation of the experts to revise and finalize the mobile information support program, and then work with software engineers to develop the software.

The study was approved by the National Natural Science Foundation of China and the Second Military Medical

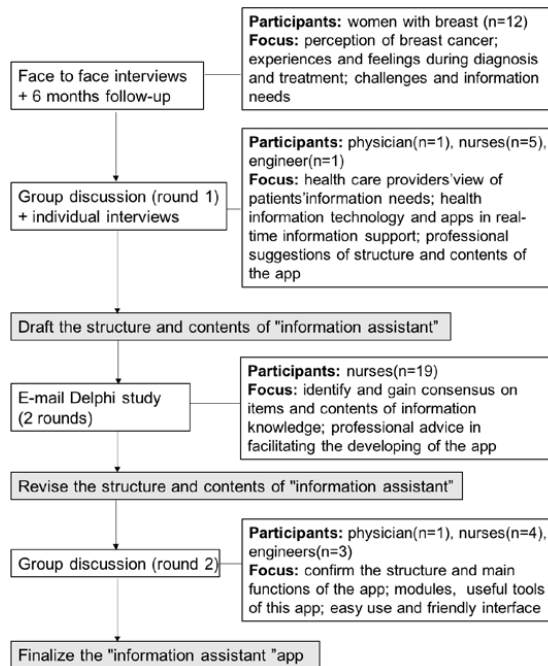University. All participating patients provided written informed consent to participate in the study.



*Figure 1 – Workflow of Developing "Information Assistant".*

### Interviews with Breast Cancer Patients

First, a qualitative approach was used to collect data about the information needs of women with breast cancer during diagnosis and treatment process. Twelve women who were diagnosed with breast cancer between March to April 2015 were selected to be interviewees. Eligibility for participating in this key informant interview included: (a) participants were diagnosed with breast cancer for first time, and receiving treatments; (b) participants were above 18 years old and they were able to communicate fluently in Chinese; (c) participants knew about their diagnosis and they were willing to talk about it; (d) participants were interested and willing to use smartphone apps to facilitate their breast cancer care. Informed consent was obtained from those participants.

We conducted at least two interviews with each patient and also had a 6 months follow-up to get the whole picture of patients' heterogenous information needs during the different diagnosis and treatment process. The first interview for each woman was conducted during her diagnosis stage before the surgery, and the second interview was conducted about 2-4 days after her surgery. Some patients even had a third time interview just before they discharged from the hospital. The follow-up was started when the patient discharged from the hospital and went to his/her home or community for further rehabilitation, and all follow-up lasted for about 6 months.

All face to face interviews were conducted in conference rooms of several different hospitals in the east provinces of China and each interview lasted for 30-45 mins. The follow-up was conducted by telephone calls, short messages and the WeChat (a communication software).

Topics and questions related to patients' possible information needs were derived from the literature review and physicians'

and nurses' clinical experience. During the interviews and follow-up, participants were asked to describe: (a) their perception of breast cancer; (b) their experiences and feelings during breast cancer diagnosis and treatment process; (c) challenges they may face and information needs in living with breast cancer.

The individual interviews were audio-recorded with participants' consent and continued until data saturation was reached, meaning that no new information of value was obtained from the interviewees. Interviews were transcribed verbatim within two days of the interview.

A qualitative content analysis aimed at finding manifest and latent meanings of data was applied to analyze the information manually[15]. Firstly, the transcripts were read several times by the researcher, then segmentation of information was done and significant information related to research questions was extracted. Finally, data were coded and grouped into categories and abstracted into sub-themes and the main theme.

### Groups Discussion Round One: Physicians, Nurses and Software Engineers

The group discussion with breast cancer care physicians, nurses and software engineers was conducted to draft the structure and contents of the "information assitant" app. The physicians and nurses had at least ten years working experience with breast cancer patients, and they were qualified with a masters degree or above, with the exception of one nurse who was qualified with a bachelor degree.

The discussions were conducted in a conference room at School of Nursing, the Second Military Medical University in China and lasted 120-150 mins. After the first round of group discussion, one-on-one interviews ranging from 20-45 minutes were conducted in a private room with those who were relatively active in the group discussion, to gain more suggestions.

The group discussion focused on: (a) what's the breast cancer patients' diverse information needs during the diagnosis and treatment process from health care providers' point of view; (b) what questions or problems patients consulted most in the follow-up caring of breast cancer; (c) how can health information technology and the app help in meeting patients' information needs and give real-time feedback?; (d) professional suggestions of structure and contents of the app.

### Electronic Mail Delphi Study: Nurses

In order to identify and gain consensus on items and contents of information knowledge for addition into the app to support patients, and have more professional advice in facilitating the development of the app, we conducted an electronic mail Delphi study. The e-Delphi was more efficient and less time consuming. Nurses from all over China, who were not able to attend a face-to-face consensus conference or take part in nominal groups, were invited to participate in this study.

According to Keeney [16-17], Delphi does not use a random sample which is representative of the target population, rather, it employs 'experts' in the area in which the researcher is interested. As for this study, our research team defined and chose nurses who had more than five years working experience with breast cancer patients.

An introduction to the study and specific goals to reach were given to the participants in the first round consulting. The first round questionnaire consisted of two sections: the first section was the demographic information about the experts, including education background and working experiences. The second section was the main part. In this section experts were asked to give their opinions whether to accept or refuse or suggest for

revising about each item within the "eight information banks". Some open-ended questions also included that experts can add more details on each information bank and give advice on revising the "information assistant" app.

**Group Discussions Round Two: Physicians, Nurses and Software Engineers**

We held the second round group discussion to finalize the "information assistant" app. Five experts in medical and nursing field who had already participated the first round group discussion were included, and the second round discussion also included three engineers. The discussion was conducted in the same conference room as previous and lasted between 120-150 minutes. We presented participants a protocol with revised structure and contents of the "information assistant" app. The discussion was focused on: (a) confirming the structure and main functions of the app; (b) modules, main functions and useful tools of this app; (c) easy to use and user-friendly interface; (d) the web-based administration portal.

# Results

**Draft the Structure and Contents of the "Information Assistant" App**

*Individual Interviews*

In total, 12 women with breast cancer participated in the interview. The age of the participants ranged from 36 to 67 years, with a medium of 47 years. Half of them had a full-time job, eleven of them were married, and four had an education level above high school. As for their treatment, three of them had surgery only, seven had a combination of surgery and chemotherapy, and two had a combination of surgery and other adjustive therapy.

Five major categories of information needs are identified as:(a) psychosocial support needs; (b) information about the treatment choosing and planning; (c) surgery process and related adverse reactions; (e) side effects of chemotherapy and coping strategy; (f) instructions of self-care at home. This part was reported in our previous work [18].

*Group Discussion Round 1 and Individual Interviews*

There were one physician (with 15 years working experience with breast cancer patients), five nurses (with an average of 18.8 years working experience with breast cancer patients) and one senior software engineer participated in the discussion.

During the discussion, we developed a draft of information support protocol. First, we provided the expert with the results of the qualitative study of the patients' true information needs, as well as our previous literature review findings in the group discussion.

Next, considering all patients' needs, professionals opinions and the breast cancer treatment guidelines [19], we identified eight key phrases in breast cancer caring, and these key phrases represented eight different stages in breast cancer care (see Table 1).

We assumed that patients in each stage can receive personalized information support through the app. Then we identified the concrete information contents in each stage; a total of 62 information items were identified. We called the overall stages and information items as "eight information banks", and our next step would be to build the eight information banks.

Besides this, the group discussion also identified three more contents of the app as: (a) a category knowledge centre including all information; (b) a headline information browsing part for patients to get the most helpful information; (c) the

newest information browsing part for patients to get the latest information about breast cancer treatment and caring.

**Revise the Structure and Contents of the "information Assistant" App**

There are 20 (a response rate of 91%) nursing experts participated in the round 1 e-mail Delphi study and they all completed the round 2 study. They came from five provinces (Shanghai, Zhejiang, Jiangsu, Hubei and Guangdong) and seven Grade Ⅲ Class A hospitals in China. The age of the participants ranged from 29 to 54 years, with a mean of 38.9 years. The average working time was 17.0 years, ranging from 7 to 36 years. As for the education level, 15 of them had a bachelor degree or above.

The essential objective of this e-Delphi study was to access the suitability of each item and to identify any additional valuable information items in the eight information banks.

The overall original items of the eight information banks were 62. After the 2-round e-Delphi process, the experts reached consensus on 84-items information banks. According to the experts' suggestion, we added some useful information items in each bank so as to develop a more helpful app, enabling patients with breast cancer to get the maximum benefit.

The process of identifying information items during the 2-round Delphi study is shown in Table 1, and in Table 2 we present the contents of "adjuvant chemotherapy stage" as one example of the eight information banks.

*Table 1 – Revised Information Items of Eight Information Banks.*

| Eight information banks | Original items | Delphi 1 round | Delphi 2 round |
|---|---|---|---|
| Diagnosis stage | 13 | 13 | 15 |
| Adjuvant chemotherapy stage | 3 | 6 | 8 |
| Operation stage | 13 | 16 | 17 |
| Chemotherapy stage | 8 | 10 | 11 |
| Radiation therapy stage | 4 | 5 | 5 |
| Endocrine therapy stage | 6 | 7 | 7 |
| Targeted therapy stage | 3 | 6 | 6 |
| Rehabilitation stage | 12 | 13 | 15 |
| Total | 62 | 76 | 84 |

*Table 2 – Information Items of Adjuvant Chemotherapy Stage.*

| Item | Content of adjuvant chemotherapy stage |
|---|---|
| 1 | What's the meaning of adjuvant chemotherapy |
| 2 | What kind of people need adjuvant chemotherapy |
| 3 | Medications of adjuvant chemotherapy and it's indication |
| 4 | Choosing transfusion methods of chemotherapy |
| 5 | Caring of the peripherally inserted central catheter(PICC) |
| 6 | Caring of the implantable venous access port |
| 7 | Coping with the adverse effects of chemotherapy |
| 8 | Dietary and nutrition instruction during chemotherapy |

**Finalize the "Information Assistant"**

In group discussion round 2, we went through our previous results, revised our contents and structure about the app and then finalized the app.

We did some modification of the app, for example, experts suggested that a searching bottom should be added to the interface of the app, to make it more user-friendly and easy use. Since most of our information support items were text materials, it may be difficult for some patients to catch up the

meaning. To facilitate the patients' understanding we added photo and video materials in the eight information banks, e.g., for breast self-examination and post-operation exercise.

Finally, an app with five main function modules was developed, as presented below:

### Module One: Personalized Information Recommendation

This module is the major function of the app. In this module, we match the patients' present medical status, treatment planning and information preference with the "eight information banks". Based on this, we analyse and extract relevant information items from the bank, and then we deliver personalized information support to the patients.

### Module Two: Category Knowledge Center

This module presents all the credible information that patients may want to know about breast cancer caring, including diagnosis, different tests, treatment regimens, medication management, dietary and nutrition instruction, and rehabilitation exercises instruction. Patients can find useful information in this module as complementary to the personalized information recommendation.

### Module Three: Headline Information Browsing

This module is to provide the headline information which patients browse most. Patients best know what they want to learn. The top ten information items identified by real-time page views through our web-based administration portal could best represent issues that patients are concerned with.

### Module Four: Newest Information Browsing

Both personalized information recommendation module and category knowledge center modules are based on the fixed eight information banks. This module is reserved to display latest research findings, new technologies and new methods about breast cancer caring, thereby helping patients get the most updated information.

### Module five: Information searching

This module is also complementary to the personalized information recommendation. Patients who may have problems to find the information they need they can search in this module. Just like searching in google, patients can search by typing in the keywords and all credible information related within the eight information banks will be displayed on the screen.

Two screenshots are given as examples to visualize the smartphone app in Appendix (labeled as Appendix Figure 1 and Appendix Figure 2). The software is in the debugging process currently, the practical application and effectiveness test of the software will be carried out in our future study.

## Discussion

Hearing of the diagnosis of breast cancer or just suspected of breast cancer, can put heavy pressure on patients, let alone enormous challenges they may face related to the various of treatments or rehabilitation strategies. Information support plays a vital role in helping patients to cope with their condition, as proved in many studies [7-10], and the effectiveness of web-based information systems has also been reported [20-21]. So, our focus in this work was not whether the information support would be useful for breast cancer patients, but how to adopt a more efficient and effective way to provie them with optimal information support. Inspired by the idea of m-health [13], a smartphone app which has huge advantages over the traditional ways [22] was developed based on a scientific method.

The primary goal of this "information assistant" is to meet the personalized information need of breast cancer patients, and provide each patient with personalized information support

according to their different medical status, treatment process and special needs. Based on interviews with breast cancer patients, group discussion with physicians, nurses and engineers, and e-Delphi study, the protocol of this "information assistant" app was developed. A qualitative study is a credible way to explore patients' true needs, and an e-Delphi study is an efficient way to gain consensus by experts. Besides, multidisciplinary group discussion promotes better communication and understanding between experts. These all contribute a lot to develop the app and deliver high-quality information support for the patients.

There were also some limitations of this study; first of all, the participating patients in interviews and experts in group discussions were relatively few and the findings may not cover all patients' information needs in various conditions; secondly, although e-health technologies have thrived in health care industry, there is no guideline or generally accepted principles for our health provider to develop a smartphone app. Finally, future research is needed to examine the usability and effectiveness of the "information assistant" app, and to optimize the app accordingly.

## Conclusion

In this study, we tried a new method (smartphone app) to provide personalized information support for patients with breast cancer. By combining the results with patients' interviews, experts group discussion, and e-Delphi studies, we developed the "eight information banks" and developed the "information assistant" app. This app has five modules; personalized information recommendation, category knowledge center, headline information browsing, newest information browsing and information searching. Each module has a unique function to support patients optimally. Meanwhile, this process also gives a good example for future studies focusing on the design of e-health smartphone apps.

## Acknowledgements

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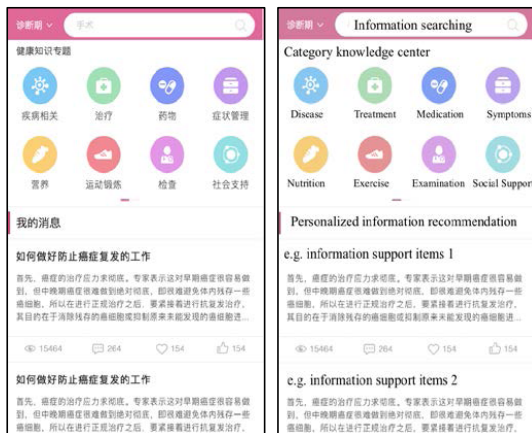
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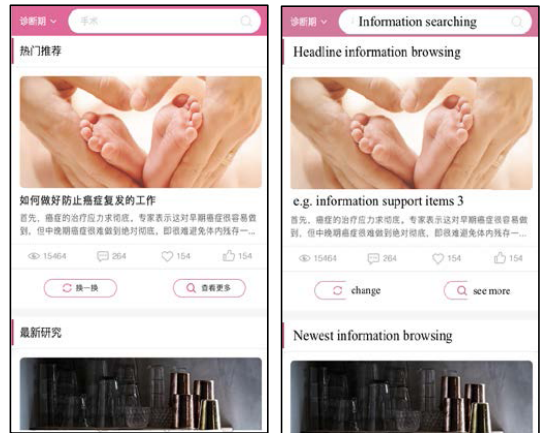
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*Appendix figure 2 – Left: main interface（Module three & four）; right: english translation of main interface.*

**Appendix: Screenshots of "information assistant"**



*Appendix figure 1 – Left: main interface（Module one，two & five）; right: english translation of main interface.*