Development and Usability Testing of a Decision Support App for Women Considering Breast Reconstruction Surgery



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Abstract

Women with breast cancer have difficulty deciding whether to undergo breast reconstruction when mastectomy is necessary. A computer-based decision aid that can be individualized to provide both surgery information and value clarification may be helpful for women considering breast reconstruction surgery. The objectives of this study are to program a prototype of an application (app) with a value clarification exercise and to evaluate the pilot usability, feasibility, and efficacy of the app. In phase 1, a prototype app called *Pink Journey* for use on the iPhone OS (IOS) platform was created following the framework of shared decision making. In phase 2, 11 women who were given the option of reconstruction by a breast surgeon were recruited from July 2017 to December 2017. A pretest-posttest design was adopted to test the usability and feasibility of the app. The results showed that the women who used the app reported significantly less decisional conflict after intervention on each subscale of the Decision Conflict scale, i.e., "being informed", "uncertainty", "social support", "effective decision", and "value clarification". This research provides preliminary data indicating that *Pink Journey* holds promise for decreasing decision conflict. Most women felt that the app was both helpful and user-friendly. The app increased their participation in decision making, helped them obtain more accurate risk perceptions, and clarified their values. It also helped the women make decisions regarding breast reconstruction more confidently.

Keywords Shared decision making · Decision aid · Breast reconstruction

Introduction

Surgery is the main treatment for women with breast cancer. Approximately 30% to 40% of women with breast cancer must undergo mastectomy, and the resulting change in appearance can lead to various types of psychosocial distress [1]. Breast reconstruction is an option for women after mastectomy that uses medical technology to rebuild the breast. Different options, including implant-based breast reconstruction and autologous breast reconstruction, are available.

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However, the effects of breast reconstruction are inconsistent. Some studies indicate that breast reconstruction can improve body image and quality of life [2, 3], while other studies have found no differences between individuals who undergo breast reconstruction and those who do not [4–7]. One study revealed that some women who are satisfied with their body shape may still perceive defects in their body [8]. In general, women have difficulty making the decision to undergo the surgery.

Breast reconstruction decisions are usually made under stressful situations. Nearly 50% of women experience decisional conflict when facing breast reconstruction decisions. Approximately 11% and 50% of women were unsatisfied with and regretful about their breast reconstruction decisions, respectively [6, 9]. Recent studies have revealed that women with difficulties making treatment decisions experienced chronic psychological distress [10], and insufficient knowledge, poor communication with professionals, and less involvement in decision making contributed to these difficulties [9, 11, 12]. Thus, providing education and facilitating effective communication to ensure women are involved in the decision-making process are important.



A decision aid is a tool that provides information and value clarification during the process of treatment decision-making. Various decision aids, including paper-based educational resources and computer-based interactive devices, have been developed [13–16]. A recent systematic review revealed that computer-based decision aids, such as compact disk read-only memory (CD-ROM) aids, computerized multimedia programs, and websites, perform better than paper-based decision aids due to their potential for wide use by patients [13]. However, these decision aids rely on either computer hardware or software. Given that smartphone devices and downloaded applications (apps) are more convenient than using other devices with or without an Internet connection [17], this study aims to develop an app as a decision aid and examine the feasibility and usability of such an interactive app among women newly diagnosed with breast cancer.

Methods

There were two phases of the development process: (1) prototype design and (2) feasibility and usability testing. Detailed information is provided below.

Phase 1 Development of **Pink Journey** as a Decision Aid

The prototype of the decision support app has a user-centered design based on the Ottawa Decision Support Framework [18]. The app was developed according to literature reviews and related websites [11, 13, 19, 20] and then refined by multidisciplinary team members, including a software engineer, a breast surgeon, breast care nurses, an informaticist, and a researcher specializing in breast cancer. This decision aid contains information regarding surgical options, including breast reconstruction and mastectomy, such as the advantages and disadvantages, the complication probabilities of each option, a value clarification exercise for the patient's self-evaluation, and a summary of the participant's decision-making process.

The name of the app, *Pink Journey*, suggests that women embrace and travel through their cancer journey (Fig. 1). In color psychology, pink represents a sign of hope, has a positive connotation, and inspires warm and comforting feelings. Pink symbolizes that women with breast cancer can break through the stigma and embrace their bodies with confidence [21]. The star in the logo symbolizes guidance through the cancer journey. The app is run on the iPhone OS (IOS) version 11.0 platform. The user interface consists of sliders, switches, and buttons.

Framework of Pink Journey as a Decision Aid

The framework of the decision aid is based on the Ottawa Decision Support Framework [18]. This framework emphasizes the shared decision making (SDM) concept and consists of five steps that guide the decision-making process. The development of *Pink Journey* from steps 1 to 5 is shown in Fig. 2.

Step 1): Clarify the decision and needs

The aim of this step is to ensure that the patients are aware of the options available to them. The research team designed an introduction with empathetic instructions to help women understand the problems they face and think about their next steps.

Step 2): Provide facts and probabilities

The purpose of this step is to provide detailed information regarding each option. We devised an educational brochure to present the advantages and disadvantages of each breast surgery option, including mastectomy and various types of breast reconstruction. We provided the probabilities of each complication based on a literature review. To make the information easier to understand, pictures were used to illustrate and explain the processes of the different breast surgeries, and tables were designed to help the women compare the different surgeries in terms of benefits and complications. A breast surgeon and breast care specialist validated the content of the information.

Step 3): Clarify values

The aim of the value clarification exercise is to help the women assess, explore, and determine their personal values and encourage thoughts regarding how their values influence their decision making [22]. To design an attractive and effective value clarification exercise, the research team listed ten issues related to breast reconstruction that may be of concern to women, including appearance, texture, scarring, self-perception clothing, cost, complications, recovery time, expectations regarding their relationship with their partner, and impact on their everyday lives [23, 24]. The women choose their specific concerns.

Step 4): Guidance in deliberation and communication

The aim of this step is to guide the patients to become aware of their choices and determine what matters to them the most. Following the previous step, information regarding the possible effects of each type of surgery (mastectomy



Fig. 1 The logo of Pink Journey



alone, implant-based breast reconstruction, and autologous breast reconstruction) is presented in terms of their concerns.

Women are guided in deliberating between each option according to their concerns. The selected factors with which

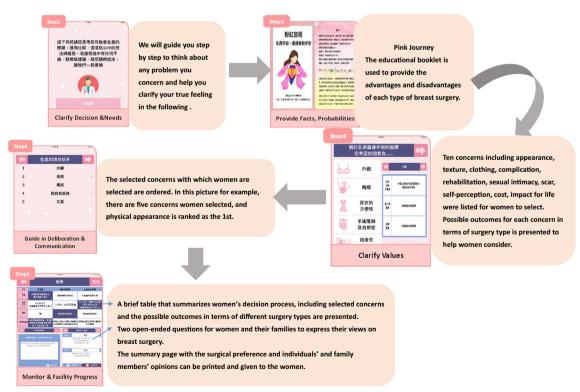


Fig. 2 Pink journey process-steps 1-5



each woman is concerned are then ordered. Women are also encouraged to think about the opinions of their significant others.

Step 5): Monitor and facilitate progress

The purpose of this step is to help women proceed with their final decision. To facilitate the decision progress, our app presents a brief table that summarizes the women's decision process, including the selected factors and the possible harms or benefits of each option. The women's preference is highlighted by a dark blue color. This information lists preferences according to each concern. Following the brief summary page, we designed two open-ended questions allowing women and their families to express their views on breast surgery because family members serve as advocates and care coordinators in the decision-making process [23].

Finally, a summary page recording the results of the above five steps is connected to a wireless Wi-Fi printer, and the page is printed and given to the woman. The tailored printout pages help patients initiate a discussion with their families or physicians regarding their concerns and options. Then, women make their final decision in a follow-up visit with their surgeon.

Phase 2 Feasibility and Usability Testing

A quasi-experimental pre-posttest design was used at a single medical center to pilot test the usability and feasibility of the app. The participants were recruited between July 2017 and December 2017. Eligible patients had to meet the following criteria: (1) age of at least 20 years or under 20 years but married, (2) females newly diagnosed with breast cancer who are candidates for mastectomy, and (3) ability to read and speak Taiwanese or Mandarin. Women with cancer recurrence or poor cognitive function and those who were diagnosed with psychiatric disease were excluded.

Measurements

Sociodemographic Information

Sociodemographic information was collected from the sample to obtain the covariates according to the literature [25]. Some disease-related information, including the cancer stage, surgery type, comorbidities, and postoperative complications, was retrieved from the medical records after surgery. Physical satisfaction was also evaluated before and after surgery using a 10-point visual analogue scale.

Decisional Conflict Scale (DCS)

The DCS was used to pilot test the preliminary effects and usability of this app. This instrument contains 16 items and was developed by O'Connor. The items were summed, divided by 16, and multiplied by 25 [26]. The Cronbach's alpha coefficients were over .78 among the women with breast cancer [27]. This scale was also validated for surgery decisions in Chinese women with breast cancer [28]. The Cronbach's alpha coefficients of the Chinese version were .51–.87.

Acceptability of and Satisfaction with the App

The acceptability of and satisfaction with the app were measured using a self-developed qualitative questionnaire designed to obtain feedback from the participants using seven open questions (Table 1).

Procedures

After approval was obtained from the Institutional Review Board, the eligible women were first invited by their physician and then referred to the first author to provide permission to participate in this study. After the written informed consent form was signed, the demographic data were collected, and the Decisional Conflict Scale (DCS) was administered. Then, the participants received information about the surgery through educational brochures. After this education, the first author guided the women in the use of the app for assistance in performing a value clarification exercise. Finally, the DCS and a self-developed qualitative questionnaire were administered.

Results

Patient Characteristics

In total, 13 patients were approached, and 11 patients were recruited for this pilot study. Two patients were excluded due to refusal to participate (n = 1) and cognitive

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|----------|------|---------|----------|----|
|----------|------|---------|----------|----|

- (1) What is the most important thing you learned from this app?
- (2) What did you like most about this app?
- (3) What did you dislike most about the app?
- (4) If you had a chance to revise the app, which part would you like to change?
- (5) Was there any missing information in this app?
- (6) How do you feel about this app?
- (7) Do you have any suggestions or ideas about the app?



impairment (n = 1). The detailed demographic and treatment-related information is shown in Table 2.

Decisional Conflict

A Wilcoxon's signed-rank test was conducted to determine the difference in the DCS scores before and after the intervention. The overall decisional conflict score significantly decreased after the use of our app intervention (p < .05), especially in the "being informed", "uncertainty", and "value clarification" domains (Table 3). Spearman's rank correlation coefficient was also used to examine the relationship between decisional conflict and satisfaction with physical appearance (Table 4). The

Table 2 Participants' characteristics (N = 11)

| | Number | % |
|--|--------|---------------|
| Age | | |
| Mean (range) | 11 | 54.18 (40-70) |
| Partner | | |
| No | 2 | 18.2 |
| Yes | 8 | 72.7 |
| Missing | 1 | 9.1 |
| Marital status | | |
| Married or partnered | 6 | 45.5 |
| Without partner | 5 | 54.5 |
| Education | | |
| Middle school | 3 | 27.3 |
| High school | 3 | 27.3 |
| College | 2 | 18.2 |
| Graduate degree | 3 | 27.3 |
| Occupation status | | |
| Unemployed or retired | 4 | 36.4 |
| Full-time | 5 | 45.5 |
| Part-time | 2 | 18.2 |
| Private health insurance status | | |
| No | 1 | 9.1 |
| Yes | 10 | 90.9 |
| Monthly income (NTD/month) | | |
| \$10,000–30,000 | 5 | 45.5 |
| \$30,000-50,000 | 3 | 27.3 |
| \$50,000-100,000 | 3 | 27.3 |
| Grade of breast cancer | | |
| DCIS | 7 | 63.6 |
| Stage 1 | 2 | 18.2 |
| Stage 2 | 2 | 18.2 |
| Surgery type | | |
| Mastectomy alone (age: 40–70, mean: 49) | 8 | 72.7 |
| Breast reconstruction (age: 41–49, mean: 46) | | |
| Implant breast reconstruction | 2 | 18.2 |
| TRAM | 1 | 9.1 |

results revealed that the more satisfied the women were with their physical appearance, the less decisional conflict they reported before the app intervention (p < .01). However, this relationship became nonsignificant after the app intervention.

Acceptability of and Satisfaction with the App

Qualitative interviews were used to obtain considerable feedback regarding the use of the app, including its function, user interface, and content.

The app prototype worked sufficiently with stable function during the time period of the pilot study. Regarding the function of our app, none of the participants experienced technical difficulties. However, regarding the user interface of our app, 4 women had difficulties switching the screen pages. They suggested highlighting the button so that users could easily recognize it. In addition, half of the women recommended increasing the text size on the screen to make it easier to read. Five women suggested simplifying the color scheme to present a peaceful image on the screen.

Most of the participants considered the app helpful and felt reassured. They were stimulated to think about their concerns and identify and clarify their personal values. Additionally, they found that the printed-out pages were useful for family members who were not able to attend the surgery consultation. The majority of the women reported that their postintervention decisions were consistent with their values. Regarding the content of our app, half of the women expected someone to provide more educational information about breast surgery when they saw the brochure. They suggested that the app could deliver breast surgery information.

Discussion

Decisional Conflict After the App Intervention

This pilot study evaluated the effect of an app as a decision aid on women's decision-making regarding breast reconstruction surgery. The results showed that the women who used the app reported significantly less decisional conflict immediately after the intervention on all subscales of the DCS. This result is consistent with recent studies that used a website and computer program as decision aids [19, 20]. However, some women still felt less support and could not make a final decision, as shown by the items in the "social support" and "effective decision" subscales. Women with breast cancer value their family members' opinions and often need to balance gender role expectations, which emphasize modesty and family responsibilities in Asian cultures [29]. In our study, seven participants completed the app intervention alone, and it was difficult for them to make a final surgery decision without their family members' advice. Additionally, compared to



 Table 3
 Decision Conflict scores between pre- and post-intervention

| Decisional Conflict Scale | $Pre\text{-test (mean} \pm SD)$ | Post-test (mean \pm SD) | p value |
|---|---------------------------------|---------------------------|---------|
| Being informed | 10.27 ± 4.40 | 3.36 ± 0.67 | .003** |
| 1. I know which options are available to me. | 3.18 ± 1.66 | 1.09 ± 0.30 | .007** |
| 2. I know the benefits of each option. | 3.55 ± 1.51 | 1.09 ± 0.30 | .005** |
| 3. I know the risks and side effects of each option. | 3.55 ± 1.29 | 1.18 ± 0.41 | .003** |
| Value clarification | 12.18 ± 2.96 | 3.45 ± 0.93 | .003** |
| 4. I am clear about which benefits matter most to me. | 4.09 ± 1.04 | 1.09 ± 0.30 | .003** |
| 5. I am clear about which risks and side effects matter most to me. | 4.00 ± 1.00 | 1.18 ± 0.41 | .003** |
| 6. I am clear about which is more important to me (the benefits or the risks and side effects). | 4.09 ± 1.14 | 1.18 ± 0.41 | .003** |
| Support | 6.90 ± 2.50 | 3.82 ± 1.66 | .008** |
| 7. I have enough support from others to make a choice. | 1.73 ± 1.01 | 1.27 ± 0.47 | .102 |
| 8. I am choosing without pressure from others. | 2.45 ± 1.57 | 1.45 ± 1.21 | .071 |
| 9. I have enough advice to make a choice. | 2.73 ± 1.49 | 1.09 ± 0.30 | .011* |
| Uncertainty | 4.00 ± 3.07 | 2.63 ± 2.50 | .005** |
| 10. I am clear about the best choice for me. | 3.36 ± 1.12 | 1.45 ± 0.69 | .007** |
| 11. I feel sure about what to choose. | 2.27 ± 1.27 | 1.55 ± 0.52 | .071 |
| 12. This decision is easy for me to make. | 4.27 ± 1.10 | 2.91 ± 1.76 | .061 |
| Effective decision | 8.09 ± 2.95 | 5.45 ± 1.92 | .011* |
| 13. I feel I have made an informed choice. | 2.64 ± 1.50 | 1.18 ± 0.41 | .011* |
| 14. My decision shows what is important to me. | 1.82 ± 0.88 | 1.09 ± 0.30 | .038* |
| 15. I expect to stick with my decision. | 1.64 ± 0.81 | 1.45 ± 0.69 | .414 |
| 16. I am satisfied with my decision. | 2.00 ± 0.89 | 1.73 ± 0.79 | .257 |
| Total score | 2.96 ± 0.79 | 1.38 ± 0.42 | .003** |

DCS decision conflict score

studies conducted by Jibaja-Weiss et al. [20] and Sherman et al. [19], who measured decisional conflict before surgery and 1 month after intervention, respectively, our time interval between the pretest and posttest was shorter. As a result, the items in the "social support" and "effective decision" domains in our pilot study failed to reach significance. A follow-up period before surgery is recommended to confirm the effect on the decisional conflict subdomain [12, 20].

Satisfaction with Physical Appearance and Decisional Conflict

Our results revealed a significant correlation between physical appearance satisfaction and decisional conflict before the intervention. However, this correlation did not exist after

our app intervention. In our pilot study, the women who were satisfied with their bodily appearance stated that they did not think too much about the surgery decision because limited surgical information was provided. A recent qualitative study conducted by de Boer et al. [30] indicated that women with breast cancer had unrealistic expectations about their physical appearance after breast reconstruction when they did not have sufficient surgery information. Preoperative consultation and the use of decision aids could reduce such unrealistic expectations by increasing the patients' knowledge about the surgery [31, 32]. The women who were satisfied with their bodily appearance were stimulated and encouraged to think about the benefits and risks of the options after our app intervention.

 Table 4
 The correlation between the DCS and the perception of physical appearance

| Physical appearance perception | Pre-test DCS | Post-test DCS |
|---|--------------|---------------|
| 1. The gap of the perception of physical appearance between the reality and the ideal | .442 | .095 |
| 2. The importance of physical appearance | 191 | 546 |
| 3. Satisfaction with physical appearance | 746** | .095 |

DCS decision conflict score



^{*}*p* < .05; ***p* < .01; ****p* < .001

p < .05; **p < .01; ***p < .001

Modification of the App

The women in our study perceived that they participated in decision making more actively, had more accurate risk perceptions, and had better clarified their values after they used the app. However, they offered advice regarding certain aspects of the app, including the function, user interface, and content. Based on a recent literature review summarizing and analyzing the features of computer-based decision aids, a good content design that considers aspects such as the navigability and clarity of information on the app could significantly improve the quality of decision making and patient engagement [13]. Additionally, a user-friendly interface that allows consumers to use the app more easily is important, as is well-designed functionality, including the creation of reminders for the app [33]. Consequently, modification of the app's content, touch controls, text size, and color scheme is recommended. One study involving women with breast cancer and low health literacy levels in America suggested that using interactive learning modules and navigational instructions could help inform women with low health literacy about breast cancer surgery options [20]. Therefore, creating a video providing information, including the advantages and disadvantages of different breast reconstruction surgeries, in both the official language and regional dialects could be useful in clinical practice. In addition, nearly 30% of the women in our pilot study opted to undergo breast reconstruction, and the women chose implant-based breast reconstruction more than autologous breast reconstruction. This trend is similar to that observed in recent studies conducted in Australia and North America [34, 35] due to the lower cost of the surgery and less complex procedure used for implants compared to those the procedure involved in using an autologous flap [36, 37]. In a recent study focusing on postmastectomy long-term patientreported outcomes, women who underwent autologous reconstruction were more satisfied with their breasts and had greater psychosocial and sexual well-being than those who underwent implant-based reconstruction [34]. We may integrate this information into the content of the app.

Study Limitations and Future Research Directions

An app installed on a smartphone or tablet may be more convenient for patients due to the high usage of smartphones and tablets [17]. The results of our study revealed that our offline app *Pink Journey* is easy for women to use. However, some limitations need to be overcome in future research. First, the findings cannot be generalized because the participants were limited; they were predominately from Southern Taiwan and had some degree of literacy. Future research should make the suggested revisions to the app and use a randomized control trial (RCT) to examine the long-term and other psychological effects.



Conclusion

The *Pink Journey* app was useful for women making breast reconstruction decisions. This app reduced the decision conflict in women facing breast reconstruction decisions.

Practical Implications

The women appreciated the app. As a decision aid, the app is an acceptable and feasible tool that increased the women's participation in decision making, helped them attain more accurate risk perceptions and facilitated value clarification.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Ethical Approval Ethical approval was obtained from the committee of National Cheng Kung University Hospital (Taiwan) (IRB number B-ER-106-072). All procedures involving human participants were performed in accordance with the ethical standards of the institutional and/or national research committee and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The authors have full control of all primary data and agree to allow the journal to review their data if requested.

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