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Physicians and Patients Perspectives about a Patient Decision Aid Tool for Breast-Conserving Surgery in the Cancer Institute of Iran

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A B S T R A C T

22

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Background: We aimed to explore opinions of breast cancer patients and clinicians in Iran about a patient decision aid (PDA) for breast-conserving surgery.

Methods: We conducted a qualitative study and evaluated the opinions of breast cancer patients and clinicians about a PDA for breast-conserving surgery in the Cancer Institute of Iran. We applied Barun and Clarke's thematic analysis approach for data analysis. We categorized the results into three themes including "perceived advantages", "perceived disadvantages", and "suggested strategy" and seven subthemes.

Results: Both patients and clinicians believed that PDA was useful for improvement of breast cancer conserving surgery and quality of care among Iranian patients. In contrast to the clinicians, the patients were interested in knowing more about surgery techniques. Both groups believed that considering the cultural issues in the adaptation process is essential and families (i.e. husband) should be involved in the decision-making process in Iran.

Conclusion: PDA is a useful tool for implementation of breast cancer conserving surgery in Iran and other low and middle-income countries. However, it should be adapted based on the context and cultural issues in each country. We recommend implementing PADs in the routine practice for increasing breast-conserving surgery in Iran. However, further research is needed to reach an optimal PDA for Iranian patients.

Keywords: Breast cancer, Breast conserving, Patient decision aid, Qualitative study



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INTRODUCTION:

Breast cancer is the most common cancer in Iran, and more than 10,000 patients are diagnosed with breast cancer in Iran each year^{1,2}. The incidence and prevalence rate of breast cancer is increasing in Iran and other low and middle-income countries³. The treatment of breast cancer has been changing a lot in recent decades. Surgical treatment of breast cancer has shifted from radical mastectomy, which causes deformity and severe disability, to modified radical mastectomy and breast-conserving surgery for early-stage breast cancer⁴.

Breast-conserving surgery can enhance the patient's body image and quality of life⁵⁻⁷. However, patients may regret to accept breast-conserving surgery due to inadequate information about treatment choices and misunderstanding about the risk of recurrence in this method⁸⁻¹¹. Lee and colleagues studied 440 breast cancer patients and reported that many of them did not have enough information about treatment options, and the women who had mastectomy did not receive appropriate treatments¹². Existing evidence highlight the importance of education in the decision-making process for patients and physician. Therefore, several education materials and methods, including patient decision aid tools (PDA) have been developed to help the patients and provides to decide about breast-conserving surgery. PDAs provide information about existing evidence on treatment benefits and risks for patients^{13,14}, and help the patient select a treatment based on his/her values¹⁵ and enhance their involvements in the decision-making process^{15,16}. In fact, PADs not only give the patients a more realistic view about diseases and their probable harms and side effects but also increase assurance of the patient about their decision. A Meta-analysis has shown that patient decision tools lead to 25 percent

increase in choosing breast-conserving surgery¹¹. Following the information patients receive about the pros and cons of each treatment type, they may choose either breast-conserving surgery or mastectomy for their treatment¹⁷⁻¹⁹. The PDAs are usually used in high-income countries including the United States, Canada, and England, and their application is not common in the low and middle-income countries²⁰. Because of cultural variation in different populations, PDAs should be adapted for application in each country²¹. We have reported the opinions of physicians and patients about a PDA developed for breast-conserving surgery in the cancer institute of Iran.

METHODS:

Development of PDA:

We evaluate several PDA developed for breast-conserving surgery among early-stage breast cancer patients and selected a PDA from Ottawa Hospital²². Two physicians who were fluent in English translated it to Farsi language. The inconsistencies were discussed and reached a consensus on the final version of the PDA. Subsequently, ten oncologists from different disciplines like surgery, radiotherapy, and hematology-oncology discussed the translated version and provided some suggestions for further clarity and improvement, such as simplifying the statements, avoiding medical terminology, and providing further information about breast cancer.

Validation of the PDA:

To assess patient and physician's viewpoints on breast-conserving PDA, we conducted semi-structured interviews with ten physicians and ten breast cancer patients in 2015 in the Cancer Institute of Iran, Tehran, Iran. We selected the physicians and patients through purposeful and maximum variation sampling. Sam-

pling continued up to data saturation. Patients were breast cancer women who were preparing to undergo breast surgery and were visiting the clinic for their follow-up. Physicians had different specialties that could use PDAs.

The interviewers used open questions to explore the opinions of physicians about the compatibility of tools with Iranian culture, the applicability of this tool among Iranian population, the advantages and disadvantages of using this tool, and the changes considered necessary for making the tools compatible for Iran. Patient interviews began with a presentation and explanation of the Persian PDA tool. Afterward, we asked questions concerning patients' rights, general opinions about their advantages and disadvantages, appropriateness of content and construct of the tool, and recommendations for upgrading the tool.

Data analysis:

An inductive thematic analysis was conducted to analyze the data. We extracted the codes and categories from the text of the transcripts. We assumed each interview's text as a whole and described the meanings or its general context in one or a couple of paragraphs. Primary codes and categories were determined. Following several analyses, we merged the repeated categories and codes. A note-taker was also present during the interviews. After obtaining permission, we recorded the interviews by audio-taped and subsequently transcribed verbatim. Data management was conducted by Nvivo software (ver 10).

Rigor

For member checking, primary results of the qualitative analysis were returned to the ten physicians to confirm that we presented their real perceptions and asked if the findings from our analysis made sense to them. For the confirmatory issue, We also reviewed the findings

with two patients and asked if they confirmed the findings from our analyses. Regarding the reliability, the inter-rater agreement between the two analyzers was higher than 90% for all the interviews.

Ethical Considerations

We obtained Ethical approval for this study from the Ethics Committee of Tehran University of Medical Sciences (TUMS) (Code: 28535510194) and obtained written informed consents from all patients and physicians who participated in this study.

RESULTS:

From 144 primary codes, we extracted 21 codes, 7 sub-themes, and three themes from the interviews (**Table 1**). Each of the themes and codes has been explained and the exact phrases expressed by some participants were quoted in *Italic font*. The type of participant was parenthesized at the end of the quote in abbreviated form; e.g. woman from upper socioeconomic status has been represented by 'W-USES'. Moreover, specialists have been represented by the first few letters of each specialty, e.g. general surgeons by 'GS' and Health educator by 'HE'.

Applicable content of PDA

For all patients, the information content of the PDA was helpful to know all about both types of breast surgery. With all patients, they were interested in using the PDA that was confirmed by a specialist. Participants reported that the PDA is feasible to understand the content based on literacy, self-experience and patient-doctor education.

"It was helpful, and understandable, I found there is two types of operation, particularly when both compared in one table it was easy to find" HSEP8

Based on all participant viewpoints, the present PDA has rationality and relevancy of its information. Participants particularly emphasized their understanding of

Table 1. the relationship between themes and codes

Theme: Perceived Advantages	Codes
<u>Applicable content</u>	Brief but Comprehensive Credible The rationale and relevant information Understandable feasible
<u>User-friendly Format</u>	Compositional Illustrated Potable (size) Printable
<u>Reciprocal impact of patient and physician</u>	Cooperative treatment Increasing patient Awareness Decrease probable worries about surgery Training Aid for Physician Time-saving for Physicians
Theme: Perceived Disadvantages	Codes
<u>Inappropriate Content</u>	Lack of sufficient information (Abstractness) Pitiful and a few images
<u>Limited application</u>	Low coverage and limited usage in low literacy level
<u>Ambiguity and indecision</u>	Bias in transferring messages Causes patient feels uncertainty and doubt
Theme: Suggested strategy	Codes
<u>Culturally based adaption</u>	Feedback from patients and piloting Fine tuning Taking into account patient culture

information by comparing both types of breast surgery in one separate table.

“Well, I found in there everything I should know, although it was brief but had everything” HSEP2

User-friendly Format

The participants were asked what aspects of this PDA facilitated their accomplishments. Almost all patients and physicians acknowledged that the PDA was in a proper structure. All of them mentioned that information in the PDA such as images, tables, and texts were interrelated. Moreover, they believed that using the printable format of a PDA, as well as a small size booklet or pamphlet is preferred.

“Since the content of this tool is not too much, the patient will be interested in using it more” HP

Reciprocal impact of patient and physician

In this theme, participants, in particularly the physicians, mentioned various benefits of the breast-conserving PDA. Likewise, with one exception, all physicians expressed that providing the patient with more information and education affect the treatment process positively. They also mentioned that patient-education materials like this PDA not only increase patient's awareness about breast conserving-surgery but also make patients ready for surgery psychologically. Moreover, most of them believed that a well-constructed PDA helps both patient and surgeons in the treatment process.

Inappropriate Content

Since the content of the PDA addresses patients who are volunteering for breast cancer surgeries, viewpoints of both patients and physicians expressed some insufficiencies in PDA content. Physicians believed that the

present PDA is too summarized to understand fully and the patient is required to know more details. According to patients, they are interested in knowing more about surgery details with illustration and explanation.

“It brought me some questions in my mind; I wanted to know whether after radiotherapy the color change in breast skin is temporary or permanent not?. I want to know more details.” HSEP1

“It was brief; I want to know more explanation about the operation even in pictures” HSEp5

From another perspective, most of the physicians believed that post-surgery information is not sufficient. They expressed that a patient should know more about breast cancer definition, breast cancer risk factors and side effects of each surgery type for breast cancer. Although the distinction between the content of the book and booklet was pointed out, insufficient content of the booklet is considered a flaw.

“There is not enough explanation of problems and complications of breast reconstruction, in this PDA and the patient might think that reconstruction is an easy operation and can always be performed simultaneously with mastectomy. It should be mentioned that reconstruction might be unsuccessful and complications can happen. In addition, reconstruction is a staged operation and second or third corrective surgeries might be needed. In addition, the financial costs (issues) and recovery period of reconstructive surgery should be discussed.” GS2

There are two different extracted comments from physician and patients regarding the images used in the text. Although both emphasized the essential role of using pictures to transfer more information, the number of pictures and the perceived impressions from the pictures were challenged. According to patient perspec-

tives, the pictures were informative, but the more picture, the better. However, physicians believed that fewer distressing pictures would produce a better outcome.

“I would prefer to see more color photos. For example, I like a cancer cell was shown in this guide, more understandable.” HSE p7

“Although the used images in the PDA may be a little pathetic for the patient, this manual is going to help the patient in decision making, so she needs to know more about surgery details.” BS1

Limited application

Physicians, based on their experience, believed that publishing media with scientific issues covers a limited population. They supposed that explaining technical details regardless of medical terminology to the patients with low literacy is very difficult. Otherwise, a patient with low and limited literacy in this study believed that the physician is the only acceptable source of information. She believed that the verbal explanation by her doctors would be more efficient than any aid material.

“Well, I prefer to take information from my doctor I am illiterate... the doctor is with more information until I admit his experience. So his decision is correct.” LSEp8

“Maybe due to low levels of literacy and awareness, and lack of understanding patient may be with more confusion in these cases need to be a doctor oral.” BS3

Ambiguity and indecision

Based on physicians' opinions about current PDA, information tendencies emphasize the mastectomy as dominant breast-conserving cancer. Most physicians acknowledged that the patient decision aid should provide the patient with clear, complete, correct, and im-

partial information.

“It is biased in favor of mastectomy, while a booklet for the patient should be neutral so that the patient can choose for herself.” GS3

“I am not sure if the patient has bilateral breast cancer, total mastectomy is better, you can conserve both and radiate both easily (I have at least five patients with bilateral breast cancer, now they are happy, thankful and had normal life after bilateral breast cancer treatment.”. Bilateral reconstruction surgery is more complicated.” BS2

In considering whether the breast-conserving PDA provides patients with the essential information to choose a specific operation, after reading the PDA certain patients believed that they had become confused. Although they confessed that their knowledge about the types of breast cancer surgery was not sufficient, they reported that receiving more knowledge held them in doubt and indecision.

“In fact, I decided to keep my breast, but I read the booklet I was a bit of doubt and hesitation.” HSEP8

Culturally based adaption

According to physicians in this study, receiving feedback from patients is one of the most important ways for adapting. They revealed that the patients experienced with breast cancer surgery are the best source for adaption process.

“It is essential to know that whether if the patient can understand the contents or not.” GS4

“We should let a patient with experience of breast cancer operation PDA and send us her feedback” BS4

“This decision guide should be piloted in the all size, then to be advised it as a routine practice.” BS4

Taking into account the views of patients experienced with breast surgery helps to extract probable cognitive difficulties of the PDA. In other words, getting feedback not only facilitates the process of adaption, but feedback also prevents cost wasting for publishing and distribution when piloting the PDA in small sample size. Moreover, both participants pointed at requiring fine-tuning in the text and title of PDA.

“I think it would be better if to underline the important statements... it helps me to understand more.” HSE P2

“To explain things in simple Sentences and vocabulary used to be for patients to understand.” GS5

“The title used for this PDA is not attractive, it can be changed to an attractive title: as mastectomy or lumpectomy which one?” GS1

“The cancer is the word that no one wants to hear so maybe it can be replaced by tumor.” GS3
Both participants had believed that ignoring family factor in the context of PDA was a perceived gap.

“In Iranian culture, the role of family and husband in making decisions is very crucial... Since breast surgery is associated with sexual quality of life of the patient, it is important to take the role of the husband into account for such a decision and also the marital status in developing questions in the PDA” HE

DISCUSSION:

The purpose of this study was to explore patient and physician perspective about PDA in breast-conserving. Our findings reveal that both physicians and patients approved cooperated decision-making. The

main contribution of the present study is that although breast-conserving PDA facilitates patient decision process, it has certain disadvantages that should be taken into account in the Farsi version of the PDA.

Likewise, other scientific literature that has explored viewpoints from the present study reveals that patient awareness is a useful enabling factor in the decision-making process. Therefore, raising patient's awareness of decision-making principles and active participation is one probable enabling strategy. Literature also shows that raising awareness programs have been suggested for primary levels at different classes because primary health care services include the most referrals across different socio-cultural levels²³.

PDA as a useful raising awareness tool that includes informative content that is directed towards an end-user or an audience. As we know, the action or process of completing or finishing a concept, particularly in textual media, establishes comprehensive cognition, so any negligence in expression does not lead to a comprehensive understanding²⁴. Individuals with low or limited literacy may experience difficulties in reading, writing, computation, and information processing skills to everyday life situations. Hence, developing informative messages and patient choice orientation weights the PDA as a useful developed material.

Lack of sufficient information, being pitiful and using too few images, low coverage and limited usage in patients with low literacy levels, bias in transferring messages, causes for uncertainty in patients, and doubt was the most perceived disadvantage of the breast-conserving PDA for both physicians and patients. Evidence shows that patient decision-making is a cooperative process involved in content development, raising awareness and patient-oriented aid material. This em-

phasizes the importance of paying more attention to patient education as one of the leading participatory approaches. Moreover, decision-aided consultations smoothed the service of strategies associated with more active choices^{25,26}.

While physicians considered this PDA helpful, patients were more concern about the uncertainty they felt after reading the PDA. This lack of explicitness could explain why certain patients were not eager to receive any guide from doctor consultation exclusively. Moreover, most physicians believed that this ambiguity and indecision was due to insufficient information in the PDA that created bias in transferring messages. Likewise, with one exception, patients expressed that the PDA raised more questions about lower side effects of the breast-conserving operation and the numbers of operations needed after lumpectomy. This resulted in experiencing a state by patients in which the mind remains suspended between two contradictory propositions and unable to make a strong decision.

This confirms the view that doubt, a status between belief and disbelief, involves uncertainty and distrust, as well as a lack of assurance of an alleged fact, action, motive, or decision. Thus, after making a choice, a patient is likely to maintain the belief that the chosen option was better than the options rejected. Every choice has an upside and a downside. The process of making a decision mostly relies on previous experiences. Therefore, a patient will remember not only the decision made but also the reasoning behind making that decision. A bias-free message gave the patient the freedom they needed to decide these types of surgeries. Results from Rashidian et al. study also confirm these findings^{20,27}. While the findings of the present study do not support those studies, the studies are similar in that

they found patient education, educational material and bridging knowledge and decision in the patient decision-making process^{6,11,28}.

Being brief but comprehensive, credible, the rationale and providing relevant information, being understandable, feasible to use, compositional, being illustrated, portable (size), printable, creating cooperative treatment, increasing patient awareness, decreasing probable worries about surgery, being training aid for physician, and time-saving for physician were the most perceived advantages of using PDA of breast-conserving surgery which mentioned by both physicians and patients.

According to participants, the current PDA requires revision. Moreover, they emphasized rewriting, simplification, and use of Farsi culture in the content. It seems that the editing process in both linguistic and cultural adaptation is needed to make the PDA more understandable. In a content adaption process, fine-tuning refers to circumstances when the elements or aspects of a structure must adjust very precisely to agree with observations. Feasibility and application of minimum criteria for development of patient-oriented aid material are consistent with previous studies^{29,30}.

Although we have focused on the hindrance and benefits of applying the PDA, we also explored certain participants concerns about their authority for decisions about operation types and their marital quality of life. Apparently, both types of breast surgeries including lumpectomy and mastectomy affect patient body image and her quality life subsequently. Therefore, the husband's involvement in the decision process is as significant as a woman right.

Family factors are crucial in the decision-making process. Since the decision for Iranian woman is related to

husband's viewpoint, considering the husband's role in this process has been an effective part of adaptation. Overall, cultural adaptation is the process of ensuring that the message, whether translated into another language, is presented using cultural references and role models that the intended to be identified by the audience.

The present study is a qualitative study and suffers from its inherent limitation. It is hard to generalize the results to all Iranian patients and findings of this study should be interpreted cautiously. Another limitation of this study was that cancer patients were reluctant to talk about their problems. Overall, it seems that the majority of Iranian patients and physicians under this study have acknowledged the present PDA. The applicability of this tool may increase by laying greater emphasis on the adapting process regarding patient culture and level of knowledge. Additional research is needed to evaluate the application of this PDA among Iranian population and implement in the clinical practice. As a further step, we recommend evaluating physicians' opinions about revising PDA designed based on an adaptive process with larger and more generalizable sample size. However, maximum variation sampling should be considered for both participants. Despite the fact that the breast-conserving PDA had not been used in the country before, after conducting the interviews, we realized that the responses given by various specialties and patients from different socioeconomic classes did not fluctuate significantly.

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AUTHORS CONTRIBUTION:

FZ was the principal investigator, designed the project,

collected the data, performed the statistical analysis, and wrote the first draft of the manuscript. KZ, HR, and MN contributed to the study design and interpretation of the results. All authors critically appraised the results and the first draft of the paper and approved the final version of the manuscript.

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