



## Development of Culturally Sensitive Questionnaire Assessing Factors Affecting Engagement of Egyptian Female Patients in the Decision Making of Breast Cancer Surgeries

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**Abstract:** **Background:** Shared decision-making is advocated as the hallmark model in treatment journey. In Egypt, there is no existing psychometric tool assessing factors affecting engagement of Egyptian female patients in the decision making of breast cancer surgeries. **Objective:** to develop culturally sensitive questionnaire assessing factors affecting engagement of Egyptian female patients in the decision-making of breast cancer surgeries that will be utilized in a larger study. **Interventions/ Methods** of developing this questionnaire involved: conceptualization stage, development of patients' and doctor related items, and testing and piloting phases. Target group of this questionnaire was women diagnosed with breast cancer and admitted to Oncology Centre Mansoura University for breast cancer surgeries, aged 18-70 years, and show willingness to participate. **Results:** Kappa coefficient ranged from 0.54 to 0.82 that means moderate to almost perfect inter-rater agreement. The overall Content validity index was 0.83 which reflects adequate agreement between panellists. **Conclusion:** this is the first context specific questionnaire assessing factor affecting engagement of Egyptian female patients in breast cancer surgeries. Results and the psychometric properties suggest applicability and feasibility of the questionnaire in larger studies. **Implications for practice:** This study is part of larger study assessing factors affecting engagement of Egyptian female patients in the decision making of breast cancer surgeries. Consequently, designing and implementing interventions targeting maximizing patients' engagement in the decision making of breast cancer surgeries in culturally sensitive way.

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**Keywords:** Development; Culturally; Sensitive; Questionnaire; Assessing; Factor; Female Patient; Breast Cancer Surgeries

### Introduction

Surgical options for women diagnosed with breast cancer are variable ranging from simple breast conservative or oncoplastic surgeries to more aggressive modified radical mastectomy. When two or more medically justified treatment options exist, preference sensitive care inheres which refers to incorporating sensitively patients' preference to multiple treatment options <sup>1</sup>.

In medical encounters, shared decision-making (SDM) is advocated as the hallmark model during treatment journey. However, clear understanding of the conceptualization of shared decision-making is needed before evaluating its merits and drawbacks. In the

shared decision model of decision-making, treatment preferences and information are exchanged among health care providers, patients, and their family members through an interactive process in order to enable a shared process to happen <sup>2</sup>.

Decision making for breast cancer surgeries involves an interaction between surgeon, patients, and family members. Clinical presentation, patients' perspectives and preferences have to be taken into account in the decision making process <sup>3</sup>. Nowadays, patients can build and participate knowledgeably in the decision of breast cancer surgeries particularly those enjoying greater access to information <sup>4</sup>.

A systematic review by <sup>5</sup> was investigating the impact of shared decision on patient satisfaction, treatment adherence, and health status. Results of this systematic review reported that shared decision-making is particularly beneficial in the context of chronic illness and long-term decision and reaching treatment agreement.

Due to the uniqueness of the Egyptian cultural context and after reviewing the literature and up to our knowledge, no psychometric tool assessing factors affecting the role of Egyptian female patient in the decision making of breast cancer surgeries was found. Therefore, this paper aims to develop culturally sensitive psychometric tool assessing factors affecting the role of Egyptian patient in breast cancer surgeries.

This work aims to develop culturally sensitive psychometric questionnaire assessing factors affecting engagement of Egyptian female patient in the decision making of breast cancer surgeries. This questionnaire will be utilized in a larger study assessing factors affecting engagement of Egyptian female patient in the decision making of breast cancer surgeries.

## Methods

### *Target group of this questionnaire*

Women fulfilling the following criteria were considered suitable for this questionnaire:

- 1- Women diagnosed with breast cancer and admitted at Oncology Centre Mansoura University for breast cancer surgeries
- 2- Aged 18-70 years
- 3- Showed willingness, mental capacity, and gave informed consent to participate
- 4- Both literate and illiterate participants were included

### *Stages of questionnaire development*

#### I-Conceptualization phase:

The aim of this stage is to establish domains of the construct, the development of the questionnaire began with reading published literature and studies about patients' engagement in the decision making of breast cancer surgeries. Additionally, interviewing sample of women admitted at Oncology Centre Mansoura University (OCMU) diagnosed with breast cancer and about to undergo breast cancer surgeries, and consultation with surgeons at (OCMU) had been undertaken.

#### II-Development phase

Authors generated items that are particularly relevant to the Egyptian culture context; two main dimensions were generated; patient related factors that contain fourteen items and surgeon related factors that contain eight items. At this stage, a first draft of the questionnaire was formulated and further interviewing with women had been conducted to assess patient's feedback on this questionnaire, some items were

reworded after patients' interviews. During women interview at the conceptualization phase, women emphasized that marital status of the woman and husband's opinion might affect their choice of surgical type. Moreover, they mentioned talking to women who had undergone breast cancer surgeries could affect their choice. Additionally, women mentioned the age of surgeon who will introduce information about breast cancer surgeries could matter; therefore, these factors were integrated and considered in questionnaire development. Final draft of patients' related items included thirteen items after deletion of one item.

Items under doctor related dimensions had been sent to oncologists at Oncology centre, Mansoura University for feedback and four more items were added based on their suggestions resulting in eleven items under doctor related factors' dimension. On both dimensions, all questions are closed ended on three-response styles (yes, no, and I do not know) except four open-ended questions; three in patient related dimension and one in doctor related dimension.

III-Determination of the sample size of the pilot sample size of the pilot study, <sup>9</sup> suggested that pilot study can be carried out on 10% of the sample projected for the larger parent study. <sup>10</sup> reported that pilot sample of 10 to 30 participants for survey research brings practical advantages to the study including feasibility. Moreover, <sup>11</sup> recommended a pilot sample as 25 to 40 for instrument development.

The current study is part of a larger study assessing factors affecting role of Egyptian female patients in the decision making of breast cancer surgeries. Sample size of the larger study was determined to be 240 patients. Size of the pilot was determined to be thirty-three patients; all women who matched the study inclusion criteria were included. Coordination between authors of the study and department surgeons' was established in order to interview women for data collection after informative meetings with surgeons about surgical treatment options.

For surgeon related items of the questionnaire, pilot testing was performed on 15 surgeons, as the total number of breast oncologists at OCMU is nearly 40 surgeons.

### *Administration of the questionnaire*

Patients' related items of the questionnaire were administered through face-to-face interviews with author (NI) as many participants were illiterate. Surgeon related items of the questionnaire were self-reported.

## Results

### *I- Judgement and testing of the questionnaire by panel experts in breast surgeries*

Cohen's Kappa was run for patients' related items in SPSS to determine the level of agreement for each item of the questionnaire between two assessors. Kappa ranged from 0.54 to 0.82 which means moderate to almost perfect agreement<sup>12</sup>. Table shows inter-rater agreement of individual items of patient's and doctor related items of the questionnaire.

#### **Please insert table here**

Six experts in breast cancer surgeries at OCMU were invited to participate in judging the questionnaire. Experts rated each item along four point scale continuum (1 not relevant, 2 somewhat relevant, 3 quite relevant, 4 highly relevant). Items have been dichotomized in the analysis into relevant and irrelevant. Four of the experts rated two items as irrelevant, therefore it were deleted. 20 out of the remaining 24 items (patients and doctor related) were rated as highly relevant by experts. The overall CVI prior to elimination of irrelevant items was 0.83 which reflects adequate and acceptable agreement between experts.

#### *II-Results of patients' related items of the questionnaire*

During face-to-face interviews with patients, no vague or unclear items of the questionnaire were reported by them. Descriptive statistics of patients' related items of the questionnaire were as follow; the mean age of participants in the pilot testing was 50 years (SD=10.1). All participants were married except one single, one-divorced, and five widow participants. 57.6 % of the pilot was illiterate and only two participants had university degree. All participants are housewives and are not employed. 90.0% of the pilot was aware of their medical condition and being diagnosed with breast cancer, additionally 66.7 % of the pilot accidentally detected breast mass. 66.7% of the pilot were informed about surgical options available for them. More than half of the pilot (54.5%) reported preferring breast conserving surgeries if it is among surgical options.

About one third of the pilot sample reported that age of the surgeon particularly if it is less than 40 years matters when they choose between surgical options. Patients' marital status from perspective of 57.6% of the pilot does not affect their surgical choice. 34.0% of the pilot had talked to women who had undergone breast cancer surgeries possibly to relieve their anxiety and gain more information and 10% of them have been influenced by talking to them in their surgical decision making process. 40.0% of the pilot reported that their surgical decision would be affected if surgeries at OCMU were paid (N.B OCMU offers free services to Egyptian patients). This could be correlated with the

social, economic, and educational background of patients in the pilot.

#### *III-Results of surgeon related items of the questionnaire*

Surgeon related items of the questionnaire were collected through self-report. All items were answered by surgeons and no items were reported as vague.

All surgeons in the pilot reported that they engage patients in surgical decision-making process. However, 93.3 % of them reported difficulty in the engagement process. 46.7 % of the surgeons in the pilot reported that they engage family members of the patients when they find difficulty in engagement process. The other half of the surgeons reported that they simplify information of surgical options as possible to gain patients' engagement.

Regarding factors that affect engagement process; 53.3% of the surgeons reported that patients' social level affects engagement process. 60.0% of the surgeons in the pilot reported that age of patients and stage of illness affect engagement. 66.7% of the pilot reported that patients' comorbidity profile affects their engagement of patients in surgical decision-making process.

73.3% of surgeons in the pilot reported the need of audio-visual and simplified explanatory aids and materials for patients to facilitate their informative understanding of surgical options as the majority of patients admitted at OCMU are illiterate or are not highly educated (this correlates with the characteristics of patients in the pilot).

#### **Discussion**

To our knowledge, there is no Egyptian questionnaire assessing factors affecting engagement of Egyptian female patients in the decision making of breast cancer surgeries. Based on the results of the larger study that will utilize this questionnaire, an intervention will be developed aiming to facilitate engagement of Egyptian female patients in the decision making of breast cancer surgeries.

The total content validity index was computed after the six panellists have rated items into relevant or irrelevant. In this manuscript the total CVI was 0.83 and that is considered acceptable<sup>13</sup>. In the prospective larger study assessing factors affecting engagement of Egyptian female patient in the decision making of breast cancer surgeries, more than one researcher will be collecting data, therefore Cohen's kappa was used in the stage of questionnaire development to ensure consistency among researchers in the interpretation of phenomena of interest. Kappa coefficient ranged from 0.54 to 0.82 that means moderate to almost perfect inter-rater agreement.

After implementing the pilot study with surgeons, authors thought about adding socio demographic, postgraduate academic qualifications, and years of experience in breast cancer surgeries to surgeon related items of the questionnaire to be implemented in the prospective bigger study.

In this first context specific questionnaire assessing factors affecting engagement of Egyptian

female patients in the decision making of breast cancer surgeries, the adequate content validity, moderate to almost perfect reliability and clarity of the questionnaire items for both patients and surgeons during pilot testing suggests further use of this questionnaire in the bigger study.

Table: Inter-Rater Agreement Regarding Individual Items of Patients' and doctor Related Items of the Questionnaire.

Individual items	Kappa
<b>Patients' related items</b>	
1- Do you know what your diagnosis is?	0.69
2-how did you detect your illness?	0.76
3- What was the speciality of your first consulting doctor?	0.82
4-Did the surgeon inform you about possible treatments for your case?	0.79
5- Did the surgeon inform you about possible surgeries for your case?	0.81
6- Does the age of the oncology surgeon matters when it comes to deciding the possible surgery for your case?	0.79
7- Would you go for partial mastectomy if it is advisable in your case?	0.61
8- Would you go for breast conservative surgeries if it is advisable in your case?	0.67
9- Does marital status matters when it comes to choosing among different surgical options?	0.76
10- Does husband's point of view matters to you when it comes to choosing among different surgical options?	0.54
11- Have you talked to women who underwent breast cancer surgeries? If yes, have you been affected by their experience?	0.79
12-if surgical interventions in Oncology Centre, Mansoura University were paid, would that affect your surgical choice?	0.81
<b>Doctor related items</b>	
1- Does patient's level of education affects engagement process?	0.70
2- Do you find difficulty in explaining surgical options to patients?	0.76
3- Does patient's socio-economic level affects engagement process?	0.75
4- Does patients' age affects engagement process?	0.76
5- Does the presence of patients' companions affects engagement process?	0.64
6- Does previous chemotherapy affects engagement process?	0.72
7- Does the stage of illness affect engagement process?	0.73
8- Do comorbidities affect engagement process?	0.70

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