

Are Patients with Breast Cancer Satisfied with Their Decision Making?: A Pilot Study

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Breast cancer is a topic of concern for all women, regardless of family history. One in eight women in the United States develop breast cancer; this translates to a 12.6% lifetime probability (Ries et al., 2005). The Surveillance, Epidemiology, and End-Results (SEER, 2011) group of the National Cancer Institute (NCI) collects cancer information from nine different geographic locations throughout the United States and has provided accurate demographics on cancer every year since 1973. The group estimated 207,090 women would be diagnosed with and 39,840 would die of breast cancer in the United States in 2009 (SEER, 2011). (See Table 1 for the incidence rate of breast cancer by race/ethnicity.)

Based on the scientific evidence published by the Agency for Healthcare Research and Quality and the initiatives of the National Guideline Clearinghouse (2009), surgical management of early-stage breast cancer (stages I and II) and ductal carcinoma in situ (stage 0) for eligible candidates should be based on patient preference. The choice between breast conservation therapy (lumpectomy and radiation) with a total mastectomy should not be based on surgeon's preference. When possible, surgical treatment for stage 0, I, or II ductal or lobular breast cancer should be based on the patient's preference. Implementing a tool or process to assist with shared decision making may improve patient satisfaction (Lacovara, Arzouman, Kim, Degan, & Horner, 2011).

This pilot study measured participants' comfort with their decision making to have a lumpectomy and radiation or total mastectomy to treat their breast cancer. Findings showed 87% of the patients believed they had made an informed choice and were satisfied with their decision making regarding their surgical procedure selection.

TABLE 1.
Incidence of Breast Cancer
per 100,000 Women

Race/Ethnicity	
All races	124
White	127.3
Black	119
Asian/Pacific Islander	93.7
American Indian/ Alaska Native	77.9
Hispanic	78.1

Source: SEER, 2011.

Literature Review

The impetus for the pilot study came from a Dutch study by Koedoot and colleagues (2001). Participants in this original study were women diagnosed with early-stage breast cancer

who were given the choice between mastectomy or lumpectomy followed by radiation. From three different hospitals, 155 participants were given a questionnaire to assess their decision making. In the Dutch study, the questionnaire's internal consistency and construct validity were examined and supported. The results of the Dutch study showed uncertainty in the patient's decision making. The authors suggested the questionnaire be more thoroughly investigated and expanded for use in patient decision making in other populations (Koedoot et al., 2001).

In validation of a decisional conflict scale, O'Connor (1995) used a telephone survey of 360 women ages 50-69 to question the participants' knowledge, attitudes, and practices regarding breast cancer screening. The tool was a questionnaire designed to study the decision-making

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TABLE 2.
Review of Literature on Decision Making in Breast Cancer Treatment

Author	Sample	Method	Findings
O'Conner (1995)	909	Survey	Construct validity was tested on the survey instrument.
Koedoot et al. (2001)	170	Survey	Respondents were uncertain of their decision between mastectomy or lumpectomy.
Sepucha et al. (2003)	Case study and three clinical trials (n=24)	Survey	Templates were developed to improve the quality of breast cancer treatment decisions.
Janz et al. (2004)	101	Patient interviews	Study showed the need for better communication between patient and clinician. Higher education was associated with patient's preferred level of control of decision making.
Whelan et al. (2004)	201	Decision board	Patients who received the decision board had higher knowledge scores about their treatment options and were more satisfied with their decisions.
Hawley et al. (2007)	1,101	Survey	Patients had variations in the actual surgical decision involvement and match between the actual and preferred involvement.
Lally (2009)	18	Interviews	Patients associated treatment options with a better prognosis.

process in breast cancer screening patients by measuring the level of decisional conflict. The decisional conflict scale was correlated to a knowledge test about the risks of breast cancer. The author concluded the decisional conflict scale met acceptable standards of reliability and validity, with a test-retest reliability coefficient of 0.81 and internal consistency coefficients ranging from 0.778-0.92.

In the study by Sepucha, Belkora, Aviv, Mutchnick, and Esserman (2003), two different templates were used to improve the quality of breast cancer treatment decisions. Authors cited the large amount of information patients get at the time of surgery. They developed a consultation recording template (CRT) that outlined process issues, diagnosis and prognosis, treatment choices, treatment implications, values and preferences, and next steps for patients to take. The CRT was tested in a pilot study and then later in three clinical trials involving different settings. The authors concluded the CRT, which helps to improve treatment decision making for the patient, can be adapted for different clinical settings.

Janz and co-authors (2004) inter-

viewed 101 women with stage I or II breast cancer to identify their preferences for involvement in the breast cancer treatment decision. They also evaluated the effect of demographic and psychosocial characteristics on the patients' decisions. Results showed the need for better communication between patients and clinicians. In addition, 47% of women reported a preference for shared decision making.

In a cluster randomized trial with 20 different participating surgeons and 208 women with newly diagnosed early breast cancer (Whelan et al., 2004), patients received the standard surgical education or were assigned to a decision board to allow them to articulate their preference for treatment. The researchers reviewed all prior studies from the early 1980s that demonstrated breast conservation therapy (lumpectomy and radiation) resulted in equivalent survival to mastectomy for patients with early-stage breast cancer. Results showed the group of patients that received the decision board had higher knowledge scores and less decisional conflict, and were more satisfied with their decisions.

Hawley and colleagues (2007)

studied the characteristics of patients with breast cancer among 277 surgeons in the Detroit and Los Angeles metropolitan areas. They compared the actual decisional involvement of these patients with their preferred decisional involvement, and determined decision tools are needed to assist patients. They also noted younger women and more educated women were more likely to prefer more involvement in the surgical decision making.

In a qualitative study of 18 women, open, semi-structured interviews were conducted after surgical consultation but prior to the patient's decision (Lally, 2009). The author found more-educated and younger women desired more information from their surgeons and also participated more in decision making than older and less-educated women. The researcher found women associated having a surgical option with a better prognosis for their breast cancer. See Table 2 for a comparison of the literature on decision making in breast cancer surgery.

Conceptual Framework

The conceptual framework for this pilot study was decisional conflict. In decisional conflict, a person is unable to decide which route to take. The patient may experience hesitation or may vacillate between choices. In some situations, the decisional conflict may be so intense the person is not able to make a decision at all and would like someone else to make the decision (Janis & Mann, 1981). In those cases, the person may want the surgeon who will be performing the procedure (either the lumpectomy with radiation or the mastectomy) to make the decision. Decisional conflict theory suggests the person's stress level may be so high, it actually will affect the quality of the decision making. Authors of this pilot study gave the patients information about the 20-year survival rate of patients with stage 0, I, or II ductal or lobular carcinoma; it is the same for patients treated with lumpectomy and radiation, or with mastectomy (National Guideline Clearinghouse, 2009). By giving patients this information, researchers hoped patients would feel more confident in making their decisions for surgical treatment.

Purpose

The purpose of the pilot study was to test the clarity of the nine-item survey as an adequate assessment tool for a full parent study in the future. The pilot study also allowed the researchers to assess the feasibility of a full study and identify appropriate recruitment methods (Connelly, 2008). The pilot study received approval by the University of Arizona Institutional Review Board (IRB). The IRB required a copy of an informed consent for the participants as well as a signed Health Insurance Portability and Accountability Act form.

Sample Selection and Characteristics

Convenience sampling was used to recruit participants. Study participants were English-speaking females

age 18 or older who had been diagnosed with stage 0, I, or II ductal or lobular carcinoma of the breast. Patients with inflammatory breast cancer were excluded. Patients were referred for participation in the study by their surgeon during a pre-operative clinic visit at the Arizona Cancer Center, a NCI-designated facility and a division of University Medical Center North (Tucson, AZ).

The surgeon described the risks and benefits of both procedures to the patients, as was her current practice.

Potential risks to the participants included psychological stress related to participation in the research. Some participants felt the need to be involved in a decision rather than just being told what procedure to undergo. This psychological stress may be separate from the psycholog-

FIGURE 1.
Patient Questionnaire

How Satisfied Are You With Your Decision?				
Coding number: _____ Initial Survey _____				
This questionnaire is entirely optional and will not affect your treatment if you decide not to participate in this study. The questionnaire will take approximately 3-5 minutes. We would like you to indicate what your current treatment preference is. Your answer is not binding. <u>It concerns the treatment you prefer at this moment.</u>				
1. My preference will certainly be a total mastectomy.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
2. My preference will probably be a total mastectomy.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
3. I am in doubt and still thinking.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
4. My preference will probably be a lumpectomy + radiation.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
5. My preference will certainly be a lumpectomy + radiation.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
6. I have no preference for one or the other treatment.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
7. This decision is hard for me to make.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
8. I feel I have made an informed choice.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree
9. I am satisfied with my decision.				
1. Strongly Agree	2. Agree	3. Neither Agree nor Disagree	4. Disagree	5. Strongly Disagree

Sources: Koedoot et al., 2001; O'Connor, 1995. Reprinted with permission.

ical stress related to the diagnosis of breast cancer. Potential benefits to the participants included the acquisition of useful health information that may have assisted in decision making. Another potential benefit may have been increased comfort with the surgical treatment decision. If the patients agreed verbally to participate in the pilot study, they were given the nine-item survey (see Figure 1) to complete at the time of the surgical consent and pre-operative informational session.

Method and Design

The tool was developed originally by O'Connor (1995) for use in studying the decision-making process in patients undergoing breast cancer screening and it measures the level of decisional conflict. The tool had acceptable standards of reliability and validity, with a test-retest reliability coefficient of 0.81 and internal consistency coefficients ranging from 0.778 to 0.92. O'Connor's tool was further studied by the Dutch scientists (Koedoot et al., 2001), and the authors suggested the questionnaire be more thoroughly investigated and expanded for use in patient decision making in other populations.

This pilot study measured the participants' comfort with their decision making to have a lumpectomy and radiation or a total mastectomy to treat their breast cancer. The questionnaire was given to the patients who agreed to participate. Completed questionnaires were put in sealed envelopes and collected by the principal investigator. They were coded numerically so the patient's name never appeared on the actual survey. The sealed envelope contained a list with an arbitrary number assigned to each participant. The list recorded the name, address, age, phone number, and planned procedure for each participant.

Findings

The mean age of the participants was 60.7 (range 31-82). Of the original 30 participants, 18 chose to have a lumpectomy with radiation and 10 chose to have a mastectomy. Two of

the participants were undecided at the time of the survey. Of the two participants who chose lumpectomy, one was later advised to have a mastectomy after further work-up by the surgeon; the second was found to have metastatic disease and was no longer a surgical candidate (Lacovara

& Arzouman, 2006). Findings showed 87% of patients believed they had made an informed choice and were satisfied with their decision making regarding their surgical procedure selection. See Table 3 for survey results.

TABLE 3.
Results of Survey Findings

Response Option	Phase 1	n
Statement 1: My preference will certainly be a total mastectomy.		
Strongly Agree	16.7%	5
Agree	10.0%	3
Neither Agree nor Disagree	16.7%	5
Disagree	10.0%	3
Strongly Disagree	46.7%	14
Total	100.1%	30
Statement 2: My preference will probably be a total mastectomy.		
Strongly Agree	10.0%	3
Agree	13.3%	4
Neither Agree nor Disagree	13.3%	4
Disagree	10.0%	3
Strongly Disagree	53.3%	16
Total	99.9%	30
Statement 3: I am in doubt and still thinking.		
Strongly Agree	10.0%	3
Agree	3.3%	1
Neither Agree nor Disagree	6.7%	2
Disagree	30.0%	9
Strongly Disagree	50.0%	15
Total	100.0%	30
Statement 4: My preference will probably be a lumpectomy with radiation.		
Strongly Agree	26.7%	8
Agree	20.0%	6
Neither Agree nor Disagree	6.7%	2
Disagree	6.7%	2
Strongly Disagree	36.7%	11
Total	96.8%	29
Statement 5: My preference will certainly be a lumpectomy with radiation.		
Strongly Agree	36.7%	11
Agree	13.3%	4
Neither Agree nor Disagree	6.7%	2
Disagree	10.0%	3
Strongly Disagree	30.0%	9
Total	96.7%	29

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TABLE 3. (continued)
Results of Survey Findings

Response Option	Phase 1	n
Statement 6: I have no preference for one treatment or the other.		
Strongly Agree	3.3%	1
Agree	3.3%	1
Neither Agree nor Disagree	13.3%	4
Disagree	30.0%	9
Strongly Disagree	46.7%	14
Total	96.6%	29
Statement 7: The decision is hard for me to make.		
Strongly Agree	16.7%	5
Agree	3.3%	1
Neither Agree nor Disagree	10.0%	3
Disagree	36.7%	11
Strongly Disagree	33.3%	10
Total	100.0%	30
Statement 8: I feel I have made an informed choice.		
Strongly Agree	56.7%	17
Agree	30.0%	9
Neither Agree nor Disagree	3.3%	1
Disagree	6.7%	2
Strongly Disagree	3.3%	1
Total	100.0%	30
Statement 9: I am satisfied with my decision.		
Strongly Agree	53.3%	16
Agree	33.3%	10
Neither Agree nor Disagree	6.7%	2
Disagree	6.7%	2
Strongly Disagree	0	0
Total	100.0%	30

Nursing Implication

Nurses play an important role in educating patients about their surgical choices and supporting their decisions. The evidence shows the survival rate is the same for mastectomy and radiation, and lumpectomy in early-stage breast cancer. Thus nurses can act confidently as advocates for patient involvement in treatment decision making.

Conclusion

Results of this pilot study encouraged the researchers to use the ques-

tionnaire with the existing patient population by surveying them again 6 months after their surgical procedure to assess if their decision satisfaction changed over time. **MSN**

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