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TITLE: Increasing Adherence to Follow-up of Breast Abnormalities in Low-Income Korean American Women: A Randomized Controlled Trial

PRINCIPAL INVESTIGATOR: Annette Maxwell, M.D. Ph.D.

CONTRACTING ORGANIZATION: University of California, Los Angeles Los Angeles, CA 90095-6900

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Table of Contents

Cover
SF 2982
Table of Contents3
Introduction4
Body4
Key Research Accomplishments8
Reportable Outcomes8
Conclusions9
References9
Appendices9

INTRODUCTION:

The purpose of this study is to design and test an intervention to assist Korean American women who have been identified with a potential breast abnormality through the Breast Cancer Early Detection Program (BCEDP) and who have missed their first follow-up appointment (at-risk women). The intervention takes place in the form of peer navigation which includes reminder phone calls or home visits by a trained peer counselor to explain the importance of follow-up procedures, emotional support, help with transportation to follow-up appointments, translations, organizing care for children or grandchildren during medical appointments, and other assistance to overcome barriers to follow-up identified during the initial phase of the study.

As reported previously, phase I of the study informed us that a peer navigator intervention may greatly facilitate adherence to follow-up of breast abnormalities by Korean American at-risk women. We have therefore designed an intervention that utilizes a peer navigator model and are testing this intervention. Since our last report, we have hired and trained our peer navigator, pilot tested our study materials, and are currently conducting a randomized controlled trial to assess the effectiveness of our intervention. We have thus far recruited 72 subjects into our protocol. We have also collected extensive process measures including number and type of intervention activities requested and delivered in order to estimate the feasibility for institutionalizing intervention activities.

BODY:

Following activities as listed in the Statement of Work have been completed:

Task 1: Setup and Formative Research

Tasks **a-d** and **f** have been completed and have been addressed in our previous reports.

e. Hire and train 3 mature, English-Korean bilingual Korean American peer counselors

After receipt of the DOD Human Subject approval in August 2005, we hired and trained 3 mature, English-Korean bilingual bicultural Korean American peer counselors. They received training on research ethics, the study protocol, interviewing techniques, and clinic policies and procedures pertaining to BCEDP. During the initial months (August – October) one navigator was assigned to each of the three clinics. However, we realized that the workload per navigator was often less than 20% per given week. As a result, two of the navigators left our study to find work with longer hours. Also during this time, KHEIR (Korean Health Education, Information, and Research Center) withdrew from

participation. Due to financial constraints, KHEIR was experiencing an agency-wide restructuring which resulting in staffing problems unrelated to this study. Although both partners had agreed on the scope of work and on the budget, the study became a burden to KHEIR. Thus, we decided to have the remaining navigator cover both of the remaining clinics. This navigator has since been averaging 12 - 20 hours of work per week.

g. Pretest intervention in 6-10 Korean American women, revise and finalize

During the month of August, we pretested the intervention in 8 Korean American women. We paid special attention to the order and flow of the questionnaire and the content of the intervention. Survey questionnaire and the content of the intervention did not require changes but we modified the log forms that are used by the navigators to keep track of their activities and subject's needs and activities.

h. Establish randomization procedure

We are using a random number table to randomly assign subjects into control or intervention arm. Each women who is identified by the BCEDP case manager through BCEDP records is given a random number (odd = intervention arm, even=control arm). Per BCEDP protocol, BCEDP case managers are obligated to track and follow-up women, including those requiring follow-up procedures. The subjects include all women who become eligible during the recruitment phase and who agree to participate.

Task 2: Enrolling Subjects into Randomized Trial

a. Identify eligible subjects during the 2 year recruitment, randomize into the study and administer verbal informed consent to intervention subjects (choice of English or Korean).

Since August 2005, based on the BCEDP clinic logs at the two clinics, we have identified 81 eligible subjects. We were successful in contacting all but one of these subjects and enrolling 72 of them into our study. Two subjects could not be contacted neither through phone nor through mail. Eight subjects refused participation. Thirty-seven of the enrolled subjects were assigned to the intervention arm and 35 were assigned to the control arm.

Task 3: Conducting Intervention

a. Conduct telephone needs assessment and counseling for each newly enrolled intervention subject (N=86). Contact each intervention subject at least once every other week until completion of diagnostic follow-up/treatment. Offer intervention components as appropriate. Document all contacts, responses to needs assessment questions, intervention requests and activities.

Each woman in the intervention arm has been contacted through telephone or in-person by our peer navigator for needs assessment using our Initial Assessment and Intervention Survey Questionnaire. Once the initial assessment has been made, our peer navigator follows up with each patient to address their identified need (i.e. reminder call prior to appointment, provide transportation, provide translation, fill out paper work at the hospital, provide emotional support, answer questions, etc.). In order to keep track of how much time and how much effort are given to each woman, we are logging all of these activities.

b. Conduct alternative protocol for intervention subjects who cannot be reached by telephone.

All but one of the subjects has been contacted through telephone. Initial contacts are made through telephone using the numbers given to us by the clinic. Clinics gave us one or two telephone numbers for each woman. If we weren't successful with given numbers (i.e. disconnected or no longer residing at such location), we contacted the clinic for accuracy of numbers, any other alternate numbers, and addresses. This process has thus far been successful and we have been able to reach all but one patient through telephone. For this woman, we sent an inquiry through mail but the letter was returned undeliverable by the post office.

c. After completion of the follow-up survey, provide intervention to women in the control group who did not complete follow-up procedures.

Many of the women in the control arm eventually complete their follow-up of abnormalities. We are keeping track of how long it took for them to complete their follow-up to assess whether our intervention could shorten this length of time. For those that did not complete their follow-up, we will offer the identical intervention after we complete the 6 month follow-up survey questionnaire. Of the 19 women in the control arm who have completed the six month follow-up survey to date, 16 have completed their follow-up of abnormalities based on self-report.

Task 4: Collecting Data

a. Collect and compile log sheets from contacts with intervention subjects (process measures) into a data base (months 7-35)

As mentioned above, we are collecting and compiling log sheets. A database has been created and we are currently entering this information.

b. Develop (draft, translate, back translate, pretest, revise) follow-up survey based on the Adherence Model (months 3-12)

A follow-up survey questionnaire, based on the Adherence Model, has been developed and pretested. This survey questionnaire has been already reviewed and approved by both the UCLA and DOD Institutional Review Boards. We have attached a copy to this report.

c. Hire and train interviewer(s) to conduct follow-up survey (months 12-13)

Our peer navigator, who received training in survey procedure and IRB protocols has been conducting follow-up survey through telephone interviews until recently. We felt that this may be sufficient since we will be double checking with medical record review to confirm follow-up. However, thus far, only about a third of the women have agreed to sign medical record release forms. Therefore, in order to minimize bias, a study staff other than our peer navigator (i.e. Dr. Jo) will conduct the follow-up surveys from now on to reduce social desirability bias.

d. Conduct post-intervention survey with all subjects (N=160) 6 months after referral for diagnostic follow-up. Administer verbal consent prior to conducting survey to subjects in the control group (months 13-40)

We are currently conducting post-intervention survey with subjects in both intervention and control arms. Thus far, we have completed 30 interviews (19 control, 11 intervention).

e. Conduct chart reviews for all subjects (N=160) 6 months after referral for diagnostic follow-up (months 13-40)

We have not started this task at this time.

Task 5: Data Management and Analysis

Tasks **a** and **b** have been addressed in our previous report.

c. Set up data entry programs and enter information from intervention log sheets, needs assessments, intervention requests and activities (process measures)

As mentioned in Task 4 a, we have created a database using Microsoft Excel for the intervention log sheets, needs assessments, intervention requests and activities, and peer navigator activities Data from Microsoft Excel is easily transferable to statistical softwares such as SPSS and STATA.

d. Set up data entry program and enter information from 6 month follow-up survey

We have also created a database using Microsoft Excel for the follow-up survey and are entering information at regular intervals. We are entering data at least twice a month.

e. Set up data entry program and enter information from chart reviews

We have not completed this task at this time. Once we begin chart reviews, we will set up data entry program and begin entering this information.

f. Data management and cleaning will be ongoing

Data management and cleaning is ongoing. Additionally, all written data and information storage devices are kept secure in locked filing cabinet. We are also using log-in and password protected computers in order to ensure confidentiality of study subjects.

g. Data analysis, preparation of annual reports and manuscripts.

At this time, we have only prepared the annual reports required by the DOD.

KEY RESEARCH ACCOMPLISHMENTS:

The previous phase (Exploratory Phase) informed us that that a peer navigator intervention may greatly facilitate adherence to follow-up of breast abnormalities by Korean American at-risk women. Thus we have designed an intervention that utilizes a peer navigator model in the previous phase. Since our last report, we have pilot tested this intervention and our study materials and are currently testing this intervention in a randomized controlled trial. Thus far, we have identified 81 eligible women, enrolled 72 of them into our study, and have conducted 6 month follow-up interviews with 30 women.

REPORTABLE OUTCOMES:

At this time, 30 women have completed follow-up interviews, 19 women in the control group and 11 women in the intervention group. Based on self-reports, 16 of the 19 women in the control group and all 11 women in the intervention group have completed all follow-up diagnostics. The peer navigator has assisted women in the intervention group in the following ways: among the 11 women in the intervention group, 6 have received help at the hospital with filling out forms and translations, another 5 have received phone calls only. None of the 11 women has requested or received transportation. The peer navigator has contacted women between 2 and 6 times (mean 3.7, mode 4). Our impression to date is that the peer navigator intervention is well accepted and appreciated by the women. One woman who was very reluctant to adhere to followup recommendation by her physician also showed reluctance to receiving our peer navigator's help initially but after having completed her follow-up, she was very thankful and glad for the navigator's persistence. Several of the women assigned to the intervention arm expressed how glad and relieved they were to have a real live person help them accompany them and translate and help fill out forms at a facility that is often intimidating to them. We also have the impression that this intervention is accepted and appreciated by the clinics as well. Koryo Health Foundation, who screens women for

cervical cancer, also asked whether we could do the same for women who need follow-up of abnormal screening pap smears.

The types of assistance that at-risk women seek that we are able to provide have thus far been: rescheduling follow-up appointments, calling to remind them of their appointment, providing directions, providing translation, answering questions about breast cancer and follow-up process, and providing emotional support.

CONCLUSION:

Since our last report, we have designed an intervention that utilizes a peer navigator model and we have started to test this intervention in a randomized trial. We have thus far recruited 72 subjects into our protocol. We have also collected extensive process measures including number and type of intervention activities requested and delivered in order to estimate the feasibility for institutionalizing intervention activities. Thus far, we can see that this peer navigator intervention is well accepted and appreciated by the women and the participating clinics.

Due to the fact that it took us a little over 2 years to obtain Human Subject approval from the DOD (3/2003 to 6/2005), we are about 2 years behind our timeline. Funding of this study started 9/2003 for activities not involving human subjects. However, phase II of the study only started in 8/2005. Although this is our third annual report, the deliverables are those that were planned for the 2nd Annual Report, since we are only 1 year into phase II of our study. We have projected a 2 year recruitment period for phase II of the study. After the first year of recruiting for phase II, we have recruited 64 subjects, slightly less than half of the 160 subjects that we need for the study. This is due to the fact that one of our study sites, KHEIR, dropped out. We have planned to reassess the situation together with the KHEIR leadership at the end of summer to see if they can rejoin the study at that time. We are also looking into the possibility of adding another clinic that is serving Korean American women to speed up recruitment.

REFERENCES:

N/A

APPENDICES:

- 1. Revised Statement of Work
- 2. 6-month follow-up survey questionnaire

Statement of Work (Revised)

Task 1: Setup and Formative Research (Months 01-06)

- a. Develop discussion guides for semi-structured interviews (English and Korean, using standard translation procedures including back translations)
- b. Identify women who received a referral for follow-up procedures in the past 12 months from BCEDP logs. Conduct telephone interviews (N=20) with these women (Angela Jo, Kim Young)
- c. Identify 5 health care professionals through participating sites and conduct semi-structured interviews (Maxwell, Jo, Young)
- d. Draft intervention components (strategies, scripts, materials) and assessment forms (intervention activity logs, needs assessment questions) all materials in English and Korean language
- e. Hire and train 3 mature, English-Korean bilingual Korean American peer counselors
- f. Establish procedures to identify women who missed follow-up appointments on a daily basis
- g. Pretest intervention in 6-10 KA women, revise and finalize
- h. Establish randomization procedure

Task 2:Enroll subjects into randomized trial (Months 07-30)

a. Identify eligible subjects (N=253 during the 2 year recruitment), randomize into the study and administer verbal informed consent to intervention subjects (choice of English or Korean).

Task 3:Conduct Intervention (Months 07-33)

- a. Conduct telephone needs assessment and counseling for each newly enrolled intervention subject (N=86). Contact each intervention subject at least once every other week until completion of diagnostic follow-up/treatment. Offer intervention components as appropriate.
 - b. Document all contacts, responses to needs assessment questions, intervention requests and activities.
 - c. Conduct alternative protocol for intervention subjects who cannot be reached by telephone.
 - d. After completion of the follow-up survey, provide intervention to women in the control group who did not complete follow-up procedures.

Task 4:Data Collection (Months 3-40)

- a. Collect and compile log sheets from contacts with intervention subjects (process measures) into a data base (months 7-35)
- b. Develop (draft, translate, back translate, pretest, revise) follow-up survey based on the Adherence Model (months 3-12)
- c. Hire and train interviewer(s) to conduct follow-up survey (months 12-13)
- d. Conduct post-intervention survey with all subjects (N=160) 6 months after referral for diagnostic follow-up. Administer verbal consent prior to conducting survey to subjects in the control group (months 13-40)
- e. Conduct chart reviews for all subjects (N=160) 6 months after referral for diagnostic follow-up (months 13-40)

Task 5:Data Management and Analysis (Months 1-42)

- a. Transcribe and translate into English audiotapes from semi-structured interviews.
- b. Analyze qualitative and quantitative data from Task 1.
 - For qualitative data analysis, summarize transcripts from semi-structured interviews, including key points and notable quotes (in English and Korean language) using standard procedures (Krueger 1994); compare and consolidate summaries prepared independently by two Korean speaking investigators (Drs. Jo and Kim); sort findings by the domains of the Adherence Model.
 - For quantitative analysis, tabulate findings from semi-structured interviews, including specific needs expressed, services requested and barriers and concerns voiced about follow-up procedures. Tabulate findings from chart reviews by adherence status.
- c. Set up data entry programs and enter information from intervention log sheets, needs assessments, intervention requests and activities (process measures)
- d. Set up data entry program and enter information from 6 month follow-up survey
- e. Set up data entry program and enter information from chart reviews
- f. Data management and cleaning will be ongoing
- g. Data analysis, preparation of annual reports and manuscripts.

Deliverables

1st Annual Report

- a. Summary of findings from semi-structured interviews and chart reviews
- b. Intervention protocol, including questions for needs assessment, scripts for barrier counseling, fact sheets to answer frequently asked questions, and intervention strategies (English and Korean)
- c. Training curriculum and materials for KA peer counselors (English and Korean)
- d. Process measures: number of women enrolled; frequency with which intervention strategies are requested, offered, and implemented
- e. Preliminary results of ongoing individual needs assessment

2nd Annual Report

- f. Finalized chart review form and follow-up survey (English and Korean)
- g. Updates on process measures and needs assessment

3rd Annual Report

- h. Preliminary results of 6 month follow-up assessments (chart reviews, surveys)
- i. Updates on process measures and needs assessment

Final Report

- j. Final study protocol including all materials developed for training peer counselors and for delivering the individualized intervention (English and Korean)
- k. Final report on process and outcome measures
- 1. Summary of findings for distribution to BCEDP sites (English and Korean)

ADHERENCE TO FOLLOW-UP OF BREAST ABNORMALITIES IN LOW-INCOME KOREAN AMERICAN WOMEN: A RANDOMIZED CONTROLLED TRIAL P.I.: Annette E. Maxwell
Case ID No.:
Interview Date (mo/day/yr): _ / / Interviewer:
Address:
Telephone Number(s):
EXPLAIN THE STUDY, ADMINISTER INFORMED CONSENT, ANSWER QUESTIONS

TELEPHONE SURVEY

<u>OUESTIONS ON THE FOLLOW-UP EXAM</u>

First, I would like to ask you a few questions about the follow-up exam that was recommended to you when you had a mammogram at (clinic site) about 6 months ago.

1. Our records show that the doctor or nurse has recommended that you get a follow-up breast exam. Can you tell me what exam was recommended to you?

9. DK

10. RF

If patient does not know what her follow-up exam is, inform her of her follow-up exam based on the BCEDP records.

- 2. Have you completed this follow-up exam?
 - 1. YES
 - NO (Go to Question No. 6)
 DK (Go to Question No. 6)
 RF (Go to Question No. 6)
- 3. When did you complete this exam? (mo/day/yr) |_|_|/|_||/|_|
 9. DK
 10. RF
- 4. Where did you have it done?
 9. DK
 10. RF
- 5. What was the result? (Check all that apply)
 - 1. CYST (FLUID-FILLED LUMP)
 - 2. FIBROADENOMA (BENIGN MASS, NO CANCER)
 - 3. MICROCALCIFICATIONS
 - 4. HAVE TO COME BACK FOR ANOTHER TEST
 - 5. CANCER
 - 6. OTHER (SPECIFY)
 - 9. DK
 - 10. RF

- 6. Do you know what a(n) (specify recommended exam) is?
 1. YES (Go to Question No. 7)
 2. NO (Read appropriate definition in the box below after Question No.7)
 10. RF
- 7. Can you explain to me what a(n) (specify recommended exam) is?

If answer is somewhat correct, say: **That's right.** Then read appropriate definition in the box below based on the patient's recommended follow-up exam.

DEFINITIONS:

• A **Diagnostic Mammogram** is given if there are unusual breast changes such as lumps. Diagnostic mammography takes longer than screening mammography because more x-rays are usually taken of each breast.

An Ultrasound is a painless method for producing images of the breast on a computer screen.
Cyst Aspiration: In this procedure, the doctor will use a small needle to extract the liquid contents of the lump in a woman's breast. The patient is injected with a local anesthesia and should not feel the procedure at all. Most women feel fine after the procedure and return to their normal routine right away.

• Needle Breast Biopsy: In this procedure the doctor will obtain a sample of the abnormal tissue from a woman's breast by inserting a small biopsy needle and removing a tiny amount of tissue. The patient is injected with a local anesthesia and should not feel the procedure at all. Most women feel fine after the procedure and return to their normal routine right away.

• **Surgical Biopsy**: This is also called open biopsy, which is the most accurate method of confirming whether a breast change is cancerous. During this procedure, the doctor removes all or part of a lump for examination under a microscope. The surgery may leave a small scar but should have little effect on the shape of the breast. Most surgical biopsies are performed in the hospital on an outpatient basis.

If answer to Question No. 2 is <u>YES</u>, then <u>Go To Question No. 8</u> and Skip Question No. 9. <i>Otherwise, Go To Question No. 9.

8. What is (are) the reason(s) why you had your follow-up exam? (Probe. Do not read. Check all that apply.)
1. DOCTOR/NURSE RECOMMENDED IT
2. I KNOW IT'S GOOD FOR ME
3. I WANT TO KNOW IF I HAVE CANCER
4. I WANT TO BE TREATED EARLY IF I HAVE CANCER
5. OTHER REASON, SPECIFY:

9. DK 10. RF (*Go to Question No.10*)

- 9. What is (are) the reason(s) why you did not get your follow-up exam? (*Probe. Do not read. Check all that apply.*)
 - 1. I DON'T NEED THE EXAM
 - 2. I'M TOO BUSY TO TAKE THE EXAM
 - 3. I'M EMBARRASSED TO TAKE THE EXAM
 - 4. I'M WORRIED ABOUT THE PAIN
 - 5. I'M WORRIED ABOUT FINDING CANCER
 - 6. OTHER REASON, SPECIFY: _____
 - 9. DK
 - 10. RF
- 10. How well do you understand why your doctor or nurse recommended that you get a follow-up exam? Would you say ...
 - 1. Very well
 - 2. Pretty well
 - 3. Not well at all
 - 9. DK
 - 10. RF
- 11. How important is it for you to get your follow-up exam? Would you say ...
 - 1. Very important
 - 2. Somewhat important
 - 3. Not important
 - 9. DK
 - 10. RF

BARRIERS TO ADHERENCE

- 12. How embarrassed would you be when getting your follow-up exam? Would you say -
 - 1. Very embarrassed
 - 2. Somewhat embarrassed
 - 3. Not embarrassed
 - 4. IF MD/TECHNICIAN MALE EMBARASSED, IF FEMALE NOT
 - 9. DK
 - 10. RF
- 13. How uncomfortable is it for you to get your follow-up exam? Would you say -
 - 1. VERY UNCOMFORTABLE
 - 2. SOMEWHAT UNCOMFORTABLE
 - 3. NOT UNCOMFORTABLE
 - 4. DK
 - 5. RF
- 14. How worried are you about the pain from your follow-up exam? Would you say ...
 - 1. Very worried
 - 2. Somewhat worried
 - 3. Not worried at all
 - 9. DK
 - 10. RF

- 15. How difficult would it be for you to get to the clinic for your follow-up exam?
 - 1. Very difficult
 - 2. Somewhat difficult
 - 3. Not difficult
 - 9. DK
 - 10. RF

16. How concerned are you about the cost of your follow-up exam?

- 1. Very concerned
- 2. Somewhat concerned
- 3. Not concerned at all
- 9. DK
- 10. RF
- Next, I would like to ask you about some things that Korean women are concerned about when they have to have a follow-up exam. What do you think are the reasons why some Korean women do not get a follow-up exam?

Would it be because:

STRONGI Y	-		STRONGLY		
AGREE	AGREE	DISAGREE	DISAGREE	DK/NS	RF
1	2	3	4	9	10
1	2	3	4	9	10
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BELIEF IN THE EFFICACY OF THE FOLLOW-UP EXAM

The next questions are about the follow-up exam that your doctor recommended to you.

29. Do you believe that this follow-up exam can find the cancer if it is there?

- 1. YES
- 2. NO
- 9. DK
- 10. RF

30. Do you think that the benefits of getting this follow-up exam are greater than any inconvenience?

- 1. YES
- 2. NO
- 9. DK
- 10. RF

SOCIAL SUPPORT VARIABLES

- 31. How supportive would your family and friends be in getting your follow-up exam? Would you say...
 - 1. Very supportive
 - 2. Somewhat supportive
 - 3. Not supportive
 - 9. DK
 - 10. RF
- 32. Do you feel a need to have someone help you decide whether to get this follow-up exam or not, or do you feel you could make this decision alone?
 - 1. NEEDED HELP
 - 2. COULD MAKE THE DECISION ALONE
 - 9. DK
 - 10. RF
- 33. Would you agree or disagree with the following statement: "With regards to getting my follow-up exam, I want to do what my friends think I should do."?
 - 1. AGREE
 - 2. DISAGREE
 - 9. DK
 - 10. RF
- 34. Would you agree or disagree with the following statement: "Getting the recommended follow-up exam gives peace of mind".-
 - 1. STRONGLY AGREE
 - 2. AGREE
 - 3. DISAGREE
 - 4. STRONGLY DISAGREE
 - 9. DK
 - 10. RF
- 35. Most women who are recommended a follow-up exam do not have cancer, although a small percentage do. How worried were you that your follow-up exam may show that you have cancer? Would you say ...
 - 1. Very worried
 - 2. Somewhat worried
 - 3. Not worried at all *(Skip Question No. 37 if not worried and not nervous in next question)*
 - 9. DK
 - 10. RF

- 36. Would you say you were very nervous, somewhat nervous, or not nervous that you may get breast cancer?
 - 1. VERY NERVOUS
 - 2. SOMEWHAT NERVOUS
 - 3. NOT NERVOUS (Skip Question No. 37 if not nervous and not worried in previous question)
 - 9. DK
 - 10. RF
- 37. How did your worry or nervousness affect your decision in getting a follow-up exam? Would you say it 1. made you get the follow-up exam
 - 1. made you get the follow-up exam
 - 2. made you avoid the follow-up exam
 - 3. did not affect your decision to get a follow-up exam
 - 9. DK
 - 10. RF

QUALITY OF LIFE CONCERNS

38. How much do you think breast cancer follow-up tests interfere with your family life?

- 1. Very much
- 2. Quite a bit
- 3. A little
- 4. Not at all
- 9. DK
- 10. RF
- 39. How much do you think breast cancer follow-up tests affect harmony among you and your family members?
 - 1. Having follow-up tests improves the harmony
 - 2. Having follow-up tests is bad for the harmony
 - 3. Having follow-up tests does not affect the harmony
 - 9. DK
 - 10. RF
- 40. How much do you think breast cancer follow-up tests interfere with your social activities?
 - 1. Very much
 - 2. Quite a bit
 - 3. A little
 - 4. Not at all
 - 9. DK
 - 10. RF

41. How much do you think breast cancer follow-up tests cause you financial difficulties?

- 1. Very much
- 2. Quite a bit
- 3. A little
- 4. Not at all
- 9. DK
- 10. RF

When you think of having quality of life, which of the following items are most important?

	VERY	SOMEWHAT	NOT	Γ	
	IMPT	IMPT	IMP	T DK	RF
42. Being healthy without illness	1	2	3	9	10
43. Being able to live without stress	1	2	3	9	10
44. Having family members that are successful	1	2	3	9	10
45. Having satisfactory family relationships	1	2	3	9	10
46. Being successful in work	1	2	3	9	10
47. Living an honorable life	1	2	3	9	10
48. Leading a religious life	1	2	3	9	10
49. Not having financial difficulties	1	2	3	9	10
50. Having a good social network/relationships	1	2	3	9	10
51. Being able to engage in activities you like to do	1	2	3	9	10
52. What else does it mean for you to have quality of	life? (specify	y)			

53. How much do you think breast cancer follow-up tests improve your quality of life?

- 1. Very much
- 2. Quite a bit
- 3. A little
- 4. Not at all
- 9. DK
- 10. RF

54. How much would you rate your overall quality of life right now?

1	2	3	4	5	6	7	8	9	10	11	12
Very									Excellent	DK	RF
poor											

55. How much would you rate your overall <u>quality of life</u> at the time when you were waiting for the result of your follow-up test?

1	2	3	4	5	6	7	8	9	10	11	12
Very									Excellent	DK	RF
poor											

GENERAL HEALTH

The following questions are about your physical health and daily activities.

56. In general, would you say your health is –

- 1. Excellent
- 2. Very Good
- 3. Good
- 4. Fair
- 5. Poor
- 9. DK
- 10. RF

MEDICAL HISTORY

Has your doctor ever told you that you have -

57. Heart problems	2. NO	1. YES
58. Stroke	2. NO	1. YES
59. Hypertension (high blood pressure)	2. NO	1. YES
60. Diabetes (blood sugar problems)	2. NO	1. YES
61. Cancer	2. NO	1. YES, specify:
62. Any other health problem?	2. NO	1. YES, specify:
63. Do you have a family history of cancer	2. NO	1. YES, specify:

COMMUNICATION WITH HEALTH CARE PROVIDER

The next questions are about your health care provider.

- 64. How comfortable are you discussing your health care with your physician?
 - 1. VERY COMFORTABLE
 - 2. SOMEWHAT COMFORTABLE
 - 3. NOT COMFORTABLE AT ALL
 - 9. DK
 - 10. RF

65. When your doctor recommended that you get a follow-up exam, how worried were you about your health in the future?

- 1. Very much worried
- 2. Quite a bit worried
- 3. A little worried
- 4. Not at all worried
- 9. DK
- 10. RF

I have only a few more questions now and then we will be done. These questions are for general statistical purposes only.

HEALTH CARE INFORMATION

- 66. Do you have health insurance?
 - 1. YES
 - 2. NO (Go to Question No. 69)
 - 9. DK (Go to Question No. 69)
 - 10. RF (Go to Question No. 69)
- 67. What kind of health insurance do you have (CIRCLE ALL THAT APPLY)?
 - 1. PRIVATE INSURANCE (e.g. Prudential)
 - 2. HMO (e.g. Kaiser, CIGNA, Maxicare, Healthnet)

3. MEDI-CAL 4. MEDICARE 5. OTHER, specify: 9. DK 10. RF

DEMOGRAPHIC INFORMATION

68. When is your birthday (mm/day/yr)? |____//___//___/

- 69. What is your marital status?
 - 1. NEVER BEEN MARRIED
 - 2. MARRIED
 - **3. LIVING WITH A PARTNER**
 - 4. DIVORCED
 - 5. WIDOWED
 - 6. SEPARATED
 - 10. RF
- 70. Which of the following best describes your annual household income from all sources?
 - 1. < \$10,000 per vear
 - 2. 10,000 less than 20,000 per year
 - 3. 20,000 1 less than 30,000 per year
 - 4. \$30,000 less than \$50,000 per year
 - 5. More than \$50,000 per year
 - 9. DK
 - 10. RF
- 71. What is the highest level of education that you completed?
 1. LESS THAN 8TH GRADE
 2. 8TH GRADE TO 11TH GRADE

 - 3. HIGH SCHOOL GRADUATE
 - 4. POST HIGH SCHOOL, TRADE OR TECHNICAL SCHOOL
 - 5.1 TO 3 YEARS OF COLLEGE
 - 6. COLLEGE GRADUATE
 - 7. SOME GRADUATE WORK OR GRADUATE DEGREE
 - 9. DK
 - 10. RF

72. In what country were you born?

73. How long have you been living in the U.S.? months years

ACCULTURATION

- 74. What language do you usually use with most of your friends?
 - 1. Only English
 - 2. Mostly English
 - 3. Korean and English
 - 4. Mostly Korean
 - 5. Only Korean
 - 9. DK
 - 10. RF

- 75. When you read newspapers or magazines, are they:
 - 1. Only in English
 - 2. Mostly in English
 - 3. About half in English and half in Korean
 - 4. Mostly in Korean
 - 5. Only in Korean
 - 9. DK
 - 10. RF

76. When you watch television, do you watch programs that are:

- 1. Only in English
- 2. Mostly in English
- 3. About half in English and half in Korean
- 4. Mostly in Korean
- 5. Only in Korean
- 9. DK
- 10. RF

77. Do you consider yourself -

- 1. More Korean
- 2. More American
- 3. An equal blend of both
- 9. DK
- 10. RF

This concludes the survey.

IF WOMAN DID NOT COMPLETE FOLLOW-UP EXAM: ENCOURAGE HER TO COMPLETE EXAM.

OFFER TO RESCHEDULE EXAM AND CALL HER BACK WITH HER NEW APPOINTMENT.

OFFER TO REFER HER TO PEER NAVIGATOR. EXPLAIN THAT THE PEER NAVIGATOR CAN HELP WITH TRANSPORTATION TO THE CLINIC, TRANSLATION, ETC.

As a way to thank you for your time and contribution to this research, we would like to send you \$20.

VERIFY MAILING ADDRESS ON PAGE 1

Thanks again and remember to continue to get mammograms every year.

Good bye

ADHERENCE TO FOLLOW-UP OF BREAST ABNORMALITIES IN LOW-INCOME KOREAN AMERICAN WOMEN: A RANDOMIZED CONTROLLED TRIAL P.I.: Annette E. Marwell
Case ID No.:
Interview Date (mo/day/yr):///// Interviewer:
Address:
Telephone Number(s):
EXPLAIN THE STUDY. ADMINISTER INFORMED CONSENT. ANSWER OUESTIONS

TELEPHONE SURVEY

QUESTIONS ON THE FOLLOW-UP EXAM

우선 6 개월 전 (clinic site)에서 유방암 X 선 검사(mammogram)를 했을때 권유받았던 추가 검사에 대해 몇가지 질문하도록 하겠습니다.

 기록에 의하면 의사(혹은 간호사)가 당신에게 추가 검사를 받아보라고 권유했습니다. 어떤 검사를 권고받으신지 말씀해주시겠습니까?

9. DK 10. RF

If patient does not know what her follow-up exam is, inform her of her follow-up exam based on the BCEDP records.

- 이 추가검사를 마치셨습니까?
 예
 아니요 (Go to Question No. 6)
 DK (Go to Question No. 6)
 RF (Go to Question No. 6)
- 3. 검사를 마치신 건 언제입니까? (mo/day/yr) |_|_//_| |/|_| 9. DK 10. RF
- 검사는 어디서 받으셨습니까? 9. DK 10. RF
- 5. 결과는 어떠했습니까? (Check all that apply)
 - 1. 포낭(액체로 가득찬 흑)
 - 2. FIBROADENOMA (BENIGN MASS, NO CANCER)
 - 3. MICROCALCIFICATIONS
 - 4. 다른 검사를 받기 위해 병원으로 돌아올 것
 - 5. 암
 - 6. 기타(SPECIFY)_
 - 9. DK
 - 10. RF

- 6. (specify recommended exam)은 무엇안지 아십니까? 1. 예 (Go to Question No. 7) 2. 아니요 (Read appropriate definition in the box below after Question No.7) 10. RF
- 7. (specify recommended exam) 은 무엇인지 저에게 설명할 수 있습니까?

If answer is somewhat correct, say: 맞숩니다. Then read appropriate definition in the box below based on the patient's recommended follow-up exam.

정의:

• '진단을 내리기 위한 유방암 X 레이검사'(Diagnostic Mammogram)는 유방에 혹 이나 멍울같은 이상 칭후가 있을 때 실시합니다. 진단을 내리기 위한 유방암 X 레이 검사는 '초기 검사 단계의 유방암 X 레이검사'(screening mammogram)보다 오랜 시간이 소요됩니다. 각각의 젖가슴별로 더 많은 X 레이를 촬영하기 때문입니다.

•초음파검사(Ultrasound)는 유방의 영상을 컴퓨터 화면에 담을 때 사용하는 방법으로 통증이 없습니다.

•물**흑 추출 검사(Cyst Aspiration):** 의사는 작은 침을 사용해 유방에 있는 물혹을 추출하게 됩니다. 이때 환자는 부분 마취를 해 검사가 진행되는 걸 느끼지 못합니다. 대부분은 검사 후 곧바로 일상생활로 돌아갈 수 있습니다.

•주사 바늘을 이용한 유방 조직 검사(Needle Breast Biopsy): 의사는 생체 조직 검사용 작은 침을 이용해 유방의 이상 조직 일부를 추출합니다. 이때 환자는 부분 마취를 해 검사가 진행되는 걸 느끼지 못합니다. 대부분의 경우 검사 후 곧바로 일상 생활을 할 수 있습니다.

•수술을 통한 조직검사(Surgical Biopsy): 수술을 통한 조직검사는 개봉조직검사(open biopsy)라고도 불리며 유방암 발생 여부를 가장 정확하게 알 수 있는 방법입니다. 의사는 현미경율 통해 관찰하면서 혹의 일부나 전체를 떼내게 됩니다. 수술 뒤 작은 자국이 남을 수도 있습니다. 하지만 가슴 모양은 거의 변화지 않습니다. 수술을 통한 조직검사는 주로 수술실이 아닌 진찰실에서 간단한 방법으로 이뤄집니다.

If answer to Question No. 2 is <u>YES</u>, then <u>Go To Question No. 8</u> and Skip Question No. 9. Otherwise, Go To Question No. 9.

 당신이 추가 검사를 받은 이유(들)은 무엇입니까? (Probe. Do not read. Check all that apply.)
 1. 의사/간호사가 추천했다 DOCTOR/NURSE RECOMMENDED IT
 2. 추가검사를 받는 것이 좋은 걸을 알고 있다 I KNOW IT'S GOOD FOR ME
 3. 암이 있는지 알고 싶다 I WANT TO KNOW IF I HAVE CANCER
 4. 암이 있으면 조기에 치료받고 싶다 I WANT TO BE TREATED EARLY IF I HAVE CANCER
 5. 기타 OTHER REASON, SPECIFY:

9. DK 10. RF (Go to Ouestion No.10)

 추가 검사를 받지 않은 이유(들)은 무엇입니까? (Probe. Do not read. Check all that apply.) 1. 나는 검사가 필요하지 않다 I DON'T NEED THE EXAM 2. 너무 바빠 검사 받을 시간이 없다 I'M TOO BUSY TO TAKE THE EXAM 3. 검사 받는 것이 당황스럽다 I'M EMBARRASSED TO TAKE THE EXAM 4. 고통이 걱정된다.I'M WORRIED ABOUT THE PAIN 5. 암을 발견하게 될까봐 걱정된다 I'M WORRIED ABOUT FINDING CANCER 6. 기타 OTHER REASON, SPECIFY: 9. DK 10. RF 10. 의사나 간호사가 추가 검사를 받으라고 하는 이유를 얼마나 잘 이해하고 있습니까? 1.아주 잘 2. 어느정도 3. 잘 이해못함 9. DK 10. RF 11. 추가검사를 받는 것이 당신에게 어느정도 중요합니까? 1. 매우 중요하다 2. 약간 중요하다 3. 중요하지 않다 9. DK 10. RF BARRIERS TO ADHERENCE 12. 추가 검사를 받을 때 어느 정도 당황스러울까요? 1. 매우 당황스럽다 2. 약간 당황스럽다 3. 당황스럽지 않다 4. 의사나 검사자가 남자라면 당황스럽다, 여자라면 괜찮다 9. DK 10. RF 13. 추가 검사를 받는 것은 어느 정도 불편하십니까? 1. 매우 불편하다 2. 어느 정도 불편하다 3. 불편하지 않다 4. DK 5. RF 14. 추가 검사 때의 고통이 어느 정도 걱정되십니까? 1. 매우 걱정된다 2. 어느 정도 걱정된다 3. 전혀 걱정되지 않는다 9. DK 10. RF

15. 추가 검사를 받기 위해 병원에 가는 것이 어느 정도 어렵습니까?

- 1. 매우 어렵다 2. 어느 정도 어렵다
- 3. 어렵지 않다
- 9. DK
- 10. RF

16. 추가 검사 비용이 어느 정도 걱정되십니까?

1, 매우 걱정된다

- 2. 어느 정도 걱정된다
- 3. 전혀 걱정되지 않는다
- 9. DK
- 10. RF
- 다음으로는 한인 여성들이 추가 검사를 받는 것에 대해 걱정하는 것들에 관해 질문하도록 하겠습니다. 다음 중 일부 한인 여성들이 추가 검사를 받지 않는 이유는 무엇이라고 생각하십니까?

강력	ठ <u>)</u>			강력히		
-	동의	동의	동의 않음	동의 않음	DK/NS	RF
17. 검사가 고통스럽기 때문에?						
18. 검사 받는것이 불편해서?	1	2	3	4	9	10
19. 검사 받는다는 사실이 당황스러워?	1	2	3	4	9	10
20. 암을 발견하게 될까봐 걱정돼서?	1	2	3	4	9	10
21. 아무런 증상이 없는데 검사받는 것은	- 1	2	3	4	9	10
불필요하다고 생각해서 ?						
22, 검사 비용이 격정돼서?	1	2	3	4	9	10
23. 검사 약속을 잊어버려서?	1	2	3	4	9	10
24. 검사 받을 시간이 없어서?	1	2	3	4	9	10
25. 주변사람들의 격려가 부족해서?	1	2	3	4	9	10
26. 검사 일정을 조정하기 힘들어서?	1	2	3	4	9	10
27. 병원에서 기다리는 시간이 길어서?	1	2	3	4	9	10
28. 언어 장벽 때문에?	1	2	3	4	9	10

BELIEF IN THE EFFICACY OF THE FOLLOW-UP EXAM

다음 질문들은 의사가 당신께 추천한 추가 검사에 관한 것들입니다.

29. 단약 암이 있다면 이 검사가 암을 발견할 수 있다고 믿으십니까?

1. 예

2. 아니요

9. DK

10. **RF**

30. 추가 검사를 받는 것의 이점이 추가검사를 받기 때문에 생기는 어떤 불편함보다 더 크다고 생각하십니까?

1.예

2. 아니요

9. DK

10. RF

SOCIAL SUPPORT VARIABLES

31. 추가 검사를 받는 데 대해 가족이나 친구들은 어느 정도 협조적(supportive)일까요?
1. 매우 협조적이다
2. 어느 정도 협조적이다

3. 협조적이지 않다

9. DK

10. RF

32. 추가 검사를 받을 지 여부를 결정하는 데 있어 누군가의 도움이 필요하다고 느끼십니까 아니면 혼자서 결정할 수 있다고 느끼십니까?

- 1. 도움이 필요하다

- 2. 혼자서 결정할 수 있다
- 9. DK
- 10. RF

33. 다음 의견에 동의하시겠습니까?: "추가 검사를 받을 지 결정함에 있어 친구들이 어떻게 생각하느냐를 고려해서 결정하고 싶다."
1. 동의한다
2. 동의하지 않는다

- 9. DK
- 10. **R**F

34. 다음 의견에 동의하시겠습니까?: "권고받은 추가 검사를 받으면 마음이 편안해진다."

1. 강력히 동의한다

- 2. 동의한다
- 3. 동의하지 않는다

4. 강력히 동의하지 않는다

- 9. DK
- 10. RF
- 35. 추가 검사를 권고받은 대부분의 여성들은 암이 없는 것으로 판정됩니다. 추가 검사 결과 당신이 암에 걸렸을 거라고 얼마나 걱정하셨습니까?

1. 매우 걱정했다

- 2. 어느정도 걱정했다.
- 3. 전혀 격정하지 않았다 (Skip Question No. 37 if not worried and not nervous in next question) 9. DK

10. RF

36. 유방암을 갖고 있을 지도 모른다고 어느 정도 불안(nervous)하셨습니까?

- 1. 매우 불안했다
- 2, 어느 정도 불안했다
- 3. 불안하지 않았다 (Skip Question No. 37 if not nervous and not worried in previous question) 9. DK
- 10. RF
- 37. 추가 검사에 대한 걱정이나 불안이 검사 받는 것을 결정하는 데 어떻게 영향을 미쳤습니까? 그런 걱정이나 불안이...
 - 1. 추가 검사를 받게 했다
 - 2. 추가 검사를 피하도록 했다
 - 3. 결정에 영향을 미치지 않았다
 - 9. DK
 - 10. RF

OUALITY OF LIFE CONCERNS

38. 유방암 추가 검사가 당신의 가족의 생활에 어느 정도 방해될 것 같습니까?

- 1. 매우 많이
- 2. 꽤 많이
- 3. 약간
- 4. 전혀 방해되지 않는다
- 9. DK
- 10. RF
- 39. 유방암 추가 검사가 당신과 가족 사이의 조화(hannony)에 어느 정도 영향을 미칠 것 같습니까?
 1. 추가 검사를 받으면 조화가 개선된다
 2. 추가 검사는 받는 것은 조화에 좋지 않다
 3. 조화에 영향을 미치지 않는다
 9. DK
 - 10. **RF**

40. 유방암 추가 검사가 당신의 사회 생활에 어느 정도 방해될 것으로 생각하십니까?

- 1. 아주 많이
- 2. 꽤 많이
- 3. 약간
- 4. 전혀 방해되지 않는다
- 9. DK
- 10. RF
- 41. 유방암 추가 검사가 당신에게 어느 정도의 재정적 어려움을 줄 것으로 생각하십니까?
 1. 아주 많이
 - 2. 꽤 많이
 - 3. 약간
 - 4. 전혀 어려움을 주지 않는다
 - 9. DK
 - 10. RF

<u>삶의 질(quality of life)</u>을 생각할 때, 다음 중 어떤 것이 가장 중요합니까?

	1 A	.1	× + -> ->		
	매우 로 수	어느 정도	중요하지		
	<u>दृष</u> ्	중요		DK	RF
1이 건강한 것 	1	2	3	9	10
스 없이 살 수 있는 것	1	2	3	9	10
·가족 구성원을 갖는 것	1	2	3	9	10
·과 만족스런 관계를 맺는 것	1	2	3	9	10
성공하는 것	1	2	3	9	10
런 삶을 사는 것	1	2	3	9	10
인 일생을 보내는 것	1	2	3	9	10
어려움이 없는 것	1	2	3	9	10
·회적 네트워크/관계를 갖는 것	I	2	3	9	10
는 활동에 참여할 수 있는 것	1	2	3	9	10
다른 어떤 것이 <u>삶의 질</u> 에 의미있습니	까?(specify)				
개선하지 않는다					
·신의 <u>삶의 질</u> 을 어느 수준으로 평가하 2 3 4 5 6 7	시겠습니까 8 9		11 DK	12 RF	
사결과를기다릴때의 <u>삶의 질</u> 온 어느 2 3 4 5 6 7	정도로 평기 8 9		? 11 DK	1	

- 1. 우수하다
- 2. 매우 좋다
- 3.좋다
- 4. 적당하다
- 5.나쁘다
- 9. DK
- 10. RF

MEDICAL HISTORY

당신 주치의가 당신온 ---질병이 있다고 말한 적이 있다.

57. 심장 문제	2. 아니요	1. 예
58. 뇌졸중	2.아니요	1. 여
59. 고혈압	2,아니요	1. 예
60. 당뇨	2, 아니요	1. 여
61. 암	2.아니요	1. 예, specify:
62. 다른 건강상 문제?	2.아니요	1. 예, specify:

63. 가족 중에 암을 앓은 사람이 있습니까? 2. 아니요 1. 예, specify: ____

COMMUNICATION WITH HEALTH CARE PROVIDER

다음은 건강 관리자 **(health care provider)에 관한 질문입니다.

64. 얼마나 편안하게 주치의와 건강 관리에 대해 논의하십니까? 1. 매우 편안하다 2. 어느 정도 편안하다 3. 전혀 편안하지 않다 9. DK 10. RF

65. 의사가 추가 검사를 받으라고 권유했을 때, 장래 건강에 대해 얼마나 걱정 됐습니까?
1. 매우 많이
2. 많이

- 3. 약간
- 4. 전혀 걱정되지 않았다
- 9. DK
- 10. RF

이제 일반적인 통계 작성을 위한 몇가지 질문만 남아있습니다.

HEALTH CARE INFORMATION

66. 건강 보험이 있습니까? 1. 예 2. 아니요 (Go to Question No. 69) 9. DK (Go to Question No. 69) 10. RF (Go to Question No. 69)

67. 당신이 갖고 있는 건강 보험은 어떤 것입니까?(CIRCLE ALL THAT APPLY)? 1. 개인 보험(예, 프루텐셜) 2. HMO (e.g. Kaiser, CIGNA, Maxicare, Healthnet) 3. 메디칼(MEDI-CAL) 4. 매디케어(MEDICARE) 5. 기타, specify: _________ 9. DK 10. RF DEMOGRAPHIC INFORMATION

68. 생년월일이 언제입니까?(mm/day/yr)|_'_//___

69. 결혼 하셨습니까?
1. 결혼한 적 없다
2. 결혼했다
3. 동거중이다
4. 이혼했다
5. 사별했다
6. 별거중이다

10. RF

70. 연간 가구 소득은 얼마입니까?

1.1만달러 이하 2.1만-2만달러 이하 3.2만-3만달러 이하 4.3만-5만달러 이하 5.5만달러 이상 9.DK 10.RF

71. 최종 학력은 무엇입니까?

- 1.8 학년 이하
- 2.8-11 학년
- 3. 고졸
- 4. 고졸, 무역 혹은 기술 학교
- 5. 대학 1-3 학년
- 6. 대학졸업
- 7. 대학원
- 9. DK
- 10. RF

72. 어느 나라에서 태어났슙니까? _____

73. 미국 체류 기간은 얼마입니까? _____ months _____ years

ACCULTURATION

74. 친구들과 대화할 때 주로 사용하는 언어는 무엇입니까?
1. 영어만
2. 주로 영어
3. 한국어와 영어
4. 주로 한국어
5. 한국어만
9. DK
10. RF

75. 신문이나 잡지를 읽을 때 주로 사용하는 언어는 무엇인가요? 1. 영어만 2. 주로 영어 3. 한국어와 영어 반반 4. 주로 한국어 5. 한국어만 9. DK 10. RF 76. TV 를 시청할 때 사용하는 언어는 무엇입니까? 1.영어단 2. 주로 영어 3. 한국어와 영어 반반 4. 주로 한국어 5. 한국어만 9. DK 10. RF 77. 당신은 당신 자신을 어떻게 생각합니까? 1. 한국인에 가깝다 2. 미국인에 가깝다 3. 반반 9. DK

10. RF

이것으로 조사를 마치겠습니다.

IF WOMAN DID NOT COMPLETE FOLLOW-UP EXAM: ENCOURAGE HER TO COMPLETE EXAM.

OFFER TO RESCHEDULE EXAM AND CALL HER BACK WITH HER NEW APPOINTMENT.

OFFER TO REFER HER TO PEER NAVIGATOR. EXPLAIN THAT THE PEER NAVIGATOR CAN HELP WITH TRANSPORTATION TO THE CLINIC, TRANSLATION, ETC.

조사에 옹해준 감사의 표시로 20 달러를 보내드리겠습니다.

VERIFY MAILING ADDRESS ON PAGE 1

다시 한번 감사드립니다. 해마다 유방암 X 선 검사를 계속하십시요.

안녕히 가십시요.