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14. ABSTRACT During the past first year of this study, the research team has made significant progress in obtaining approvals from multiple IRBs; designing, refining through feedback from Community Advisory members, and translating into 2 languages the study instruments for the first phase of the study (qualitative and focus group interviews); establishing the study fieldwork protocol; and beginning to successfully recruit breast cancer patients.					
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INTRODUCTION

The objective of this study is to measure the prevalence and impacts of discrimination at the institutional- and individual- level to identify the underlying factors contributing to disparities in breast cancer diagnosis, treatment, and quality of life. The specific aims are to: 1) develop a survey tool tailored towards cancer patients for assessing discrimination in health care settings; 2) quantify the prevalence of individual- and contextual-level discrimination across racial/ethnic groups; and 3) assess the effects of individual- and contextual-level discrimination on disparities in: a) late stage diagnosis, b) cancer treatment (including BCS and adjuvant radiation), and c) QOL. This study comprises two components: developmental (Aim 1) and application (Aims 2-3). The developmental component uses qualitative research to develop an instrument tailored for breast cancer patients. Because tools have not been developed for cancer patients nor for different races/ethnicities, we will conduct focus groups and qualitative (one-on-one) interviews to discern relevant discrimination topics. The topics, together with existing instruments, will be used to develop an instrument to be cognitive-tested in a small sample of patients. We will then conduct a pilot test, including a reliability test-retest, of the instrument and field methodology to optimize its reliability. In the application component, we will conduct a cross-sectional epidemiologic study using a multilevel approach by incorporating individual- and neighborhood-level information including: 1) previously collected geographic information systems (GIS) data about the social and built environment; and 2) telephone interviews (~14 months after diagnosis) with a population-based cohort of breast cancer patients.

BODY

The Statement of Work for the first year of the study is as follows:

- Task 1* Obtain IRB approvals, design and obtain approvals on focus group and qualitative interview instruments, translate and back-translate instruments, develop study tracking system and training materials, Months 1-6
- Prepare and submit IRB applications for DOD and NCCC.
 - Apply for cancer registry data from the Greater Bay Area Cancer Registry (GBACR).
 - Develop MS Access tracking system.
 - Develop interviewer training manual.
 - Translate, back-translate, convene meeting(s) to decenter instruments.
 - Hire staff.
 - Obtain first case listing data from the GBACR, download into tracking system.
 - Organize community advisory committee meeting to introduce study and obtain feedback about general research strategy.
- Deliverables: IRB approvals, finalized instruments for focus group and qualitative interviews, community advisory committee feedback
- Task 2* Conduct focus group and qualitative interviews, Months 7-12
- Select breast cancer patients for contacting regarding focus group and qualitative interviews.
 - Recruit breast cancer patients for fulfilling the numbers of required focus group and qualitative participants for each racial/ethnic group.
 - Conduct focus group and qualitative interviews.
 - Transcribe interviews.
- Deliverables: completed focus group and qualitative interviews, transcripts of completed interviews

Progress

Over the past 12 months, we have completed most of the tasks outlined in the Statement of Work. Obtaining Institutional Review Board (IRB) approvals proved to take considerably more time than expected. During the course of this study, the California Cancer Registry changed its requirements for disclosure of cancer registry data, requiring investigators to additionally seek approval from the California Protection of Human Subjects

IRB Committee. Coordinating the submission of applications and instrument changes among three IRBs consumed quite a large proportion of staff time as well as the overall timeline. Also during this time, we have designed all of the instruments for the focus group and qualitative interviews; assembled a 7-member Community Advisory Committee, which met on March 7, 2008 and provided critical feedback on the topics guides for the focus group and qualitative interviews; revised the instruments according to the Committee's feedback as well as received IRB approvals on the instruments; and translated and back-translated all of the instruments into Mandarin and Cantonese Chinese, and Spanish.

We have also designed the subject tracking system, developed the field study and interviewer manuals; hired and trained the four interviewers who will be conducting all of the interviews for this study; obtained the necessary registry approvals and received cases from the registry; so far completed 5 qualitative interviews and expect to complete all of the qualitative interviews by the end of August all of the focus groups by the end of September.

We have also recently presented our study as a poster at the DOD Era of Hope meeting, and was selected (although was not able to attend) for a podium presentation.

In the upcoming year, we plan to complete the qualitative and focus group interviews, conduct the qualitative data analysis, design the epidemiologic survey instrument, conduct the cognitive interviews, and finalize the epidemiologic instrument for pilot testing.

KEY RESEARCH ACCOMPLISHMENTS

- Successfully coordinated and received IRB approval from 3 separate IRBs
- Designed all of the instruments (cover letters, study brochure, telephone scripts, consent forms, topics guides, etc.) for the focus group and qualitative interviews
- Assembled a Community Advisory Committee, with representatives from all target population groups of interest, and received valuable feedback on the topic guides
- Translated and back-translated all of the instruments into Mandarin and Cantonese Chinese, and Spanish
- Developed a study protocol that provides a model for other future studies

REPORTABLE OUTCOMES

None.

CONCLUSIONS

Despite unexpected delays in obtaining IRB approvals, we have made good progress and overall, the study has been largely successful thus far.

REFERENCES

None.

APPENDICES

Appendix A:

Mini-Demographic Questionnaire (used for collecting basic sociodemographic information in focus groups and qualitative interviews)

Equality in Breast Cancer Care Study

Date: ____/____/____

1. Were you born in the United States? (circle one response)

A. Yes

B. No → if NO, in what year did you first come to the United States to live? ____

2. When were you born? (mm/dd/yyyy) ____/____/____

3. What is your marital status? (circle one response)

A. Currently married or living with a partner as married

B. Separated or divorced

C. Widowed

D. Never married

E. Other (please specify): _____

F. Don't know

4. What is the highest grade or year of school you have completed? (circle one number or category)

Did not attend school

1 2 3 4 5 6 7 8 9 10 11 12/GED

Vocational school / technical school

Some college

College graduate

Post-college graduate

Don't know

5. What is your current employment status? (circle one response)

A. Employed

B. Unemployed (includes being on welfare, disability)

C. Homemaker

D. Student

E. Retired

F. Other (please specify): _____

G. Don't know

6. In total, including yourself, how many people live in your household? _____ persons

7. It may be hard to estimate your household income, but please do your best. This information will be strictly CONFIDENTIAL. Taking the income of all of the members of your household, which of these categories best fits your total household income for the past year (2007)? This includes wages, social security, pensions, unemployment benefits and disability. (circle one response)

A. Less than \$10,000

B. \$10,000 to \$19,999

C. \$20,000 to \$29,999

D. \$30,000 to \$39,999

E. \$40,000 to \$49,999

F. \$50,000 to \$59,999

G. \$60,000 to \$69,999

H. \$70,000 to \$79,999

I. \$80,000 to \$89,999

J. \$90,000 to \$99,999

K. \$100,000 or more

L. Don't know

8. What type of health insurance do you have now? (circle all that apply)

A. Medicare

B. Medi-Cal

C. Private insurance (please specify): _____

D. No insurance

E. Don't know

THANK YOU!

Appendix B:
Qualitative (one-on-one) interview topics guide

Qualitative (one-on-one) Interview Topics Guide

Equality in Breast Cancer Care Study

[These questions do not have to be read verbatim. They are topics to be used as a guide for steering the conversation. It is okay to go out of order, but be sure that all of the topics are covered. Questions indicated by asterisk (*) are of highest priority and should be covered first should there be not enough time to cover all of the questions]

Thank you once again for participating in our research study. Again, the goal of our study is to learn more about how women from diverse cultural and ethnic backgrounds go through the experience of being diagnosed and treated for breast cancer. In particular, we are interested in hearing about the challenges that you may have faced during this experience. We will also be asking some questions about challenges that you may have faced as part of your daily life.

WARM-UP QUESTIONS

[These are warm up questions so that participants can focus to the time and experience of their diagnosis and treatment for breast cancer.]

How long has it been since you first learned that you had breast cancer?

How did you find out you had breast cancer?

PROBE: Through a routine mammogram? Did you notice any symptoms? Did you feel a lump? Did your doctor feel a lump? Did you experience any pain?

When you found out that you had breast cancer, how did you feel and what did you do?

[Participants may express their feelings or what was happening to them at the time. Give them time to express their feelings, and then transition to the next questions.]

PROBE: Did you act on it right away? Did you wait? (If yes) Why?

II. DIAGNOSIS

* Where were you diagnosed?

PROBE: What was the name of the medical facility?

How was this process for you?

PROBE: Did you feel that there were problems with understanding your doctors or nurses? Did you get printed materials in a language that you could understand? What kind of information were you given? Did you find it helpful? Would you have wanted more?

* Did you feel that the doctors gave you the information you needed to understand what you needed to do?

PROBE: What to expect? What treatment you needed?

* Did you feel respected by your doctors and nurses? Why or why not?

Did you trust your doctors and nurses? Why or why not?

Looking back at the experience, would you have liked things to happen differently?

Did you have medical health insurance at the time of your diagnosis?

What was your medical insurance at the time?

PROBE: Did you have private insurance? Were you on MediCaid or MediCal? Were you on Medicare?

Did you experience any difficulties with your insurance?

PROBE: Did you lose your insurance?

III. TREATMENT

I would like to now focus on your treatment experience.

* Where were you treated?

PROBE: What was the name of the medical facility?

* What did your doctors tell you to do?

PROBE: What did the doctors tell you about treatment?

* Did you do what the doctors said?

PROBE: What treatments did you receive?

* Did you do anything else?

PROBE: Did you have other treatments?

* Did your doctor tell you you had a choice about which treatment to go with?

Did you have unexpected side effects from the treatment? (If yes) Did you feel that your providers helped you in the best way that they could with these side effects?

PROBE: Did you have pain that you weren't expecting? Did you have nausea? Weight loss? Weight gain?

Did you go to other sources or talk to other people to get more information? What sources?

PROBE: Did you look up information on the Internet? If yes, where and what sites did you find to be most helpful.

* Do you think that your doctor listened to your opinions when discussing and making decisions about your treatment? Did you feel like you were heard by your doctors?

* Are you satisfied with the communication between yourself and your doctors?

PROBE: Did you like the way your doctors and the other medical staff talked to you? Did you feel like you were part of a team? Would you recommend your doctors?

IV. DISCRIMINATION – MEDICAL SETTING

* We know that not all people are treated the same way when they are diagnosed with breast cancer. An important part of what we're doing is to try to understand the reasons for this.

Do you know of people who have been treated poorly by their doctors, or did not receive the treatment that they should have?

* What about you? How do you feel about the medical care that you got for your breast cancer?

**[if participant reports that she basically received good medical care, the remaining questions in this Section may be more appropriate with the lead]: I understand you received good [basically good, pretty good] medical care.*

[NOTE: If participant raves about the care she got such that it seems she feels she could not have possibly gotten any better care, skip to Section V. This will be a judgment call by the interviewer].

Do you feel that you would have gotten [even] better medical care if you had belonged to a different race or ethnic group?

** Do you feel that you would have gotten [even] better medical care if you had a different skin color?*

Do you feel that you would have gotten [even] better medical care if you were a different age?

[For non-English speakers]

** Do you feel that you would have gotten [even] better medical care if you spoke a different language?*

Do you feel that you would have gotten [even] better medical care if you were of a different height or weight?

** Do you feel that you would have gotten [even] better medical care if you had more education?*

** Do you feel that you would have gotten [even] better medical care if you had more money?*

[Participants may report biases/discriminatory practices in certain medical settings, but not others. Try to elucidate, as specifically as possible, the settings in which such biases were experienced. For each question, if the response is “yes”, probe as to how they felt their care was sub-optimal, and what type of people do they perceive receive the most optimal care.]

V. DISCRIMINATION – OTHER SETTINGS

** What is your race/ ethnicity?*

[For Latinas: Where are you from?]

How often do you think about your race or ethnicity?

** Often in our society, people are treated unfairly because of their race or ethnicity. What about you? Have you ever experienced any physical symptoms, for example a headache, an upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race or ethnicity? How often do you have these symptoms?*

** Have you ever felt emotionally upset – sad, frustrated, angry – as a result of how you were treated based on your race or ethnicity? How often have you felt this way?*

[Encourage participants to describe specific discriminatory experiences.] How did you react to this experience?

PROBE: Did you verbally or physically respond to the offender? Took it as a fact of life? Told yourself that it didn't matter as long as you remain good and strong? Told other people about it?

Do you feel that certain groups of people in this country have more opportunities for success than others? Who are these groups of people? Can you give examples?

VI. COPING & SOCIAL SUPPORT

Do you know about cancer support groups? [If no, explain]

Did your doctors or other medical staff offer information about joining a support group? Were any of the support groups offered in your language?

Did you participate in a cancer support group?

[If yes] Did you find it to be helpful?

[If no] Why not?

* How well do you think you coped or dealt with your breast cancer diagnosis and treatment experience?

* Did you discuss or share your experiences with anyone? Who?

PROBE: Did you tell your family? What was their response? Did you tell any friends? What was their response?

* Did you find it helpful to discuss or share your experiences? In what ways did you find it helpful?

Overall, are you satisfied with how close you are with your family With your friends?

Do they give you emotional support?

* Now I'd like to ask some questions about your neighborhood and community.

* How long have you lived in your neighborhood? Do you feel that most people in your neighborhood know each other? Do you feel a sense of "community" in your neighborhood?

PROBE: Why or why not?

* Do you feel that people in your neighborhood are willing to help each other out?

PROBE: Why or why not?

* Do you feel that people in your neighborhood generally get along with each other?

PROBE: Why or why not?

* Do you feel that people in your neighborhood share the same values?

PROBE: Why or why not?

* Do you feel that people in your neighborhood would come to the aid of a stranger in need in the neighborhood?

PROBE: Why or why not?

* Can children play safely in your neighborhood?

PROBE: Why or why not?

* Do you ever travel outside of your neighborhood? How often?

Did you ever hear about any informational meetings in your neighborhood or community to help you learn about some medical illness(es)? For example, did you ever see flyers posted around or other advertisements for talks being given?

If yes: What were they? Did you ever attend? Were you told what to look out for for certain medical illnesses? Did any educational resources in your community ever tell you about mammograms or where to get screened for breast cancer?

VII. IMMIGRANT STRESS

[This section is only asked in interviews with immigrants.]

*** *Please tell me where you were born?***

[If outside of US, then proceed, if born in US, then GOTO Section VIII]

*** When did you come to this country to live? Why did you come to this country?**

*** Some people who emigrate from other countries find that living in the US is stressful. Have you ever felt stressed because you are living far away from your family, relatives, and friends?**

*** Have you ever felt stressed because you are unable to do the things you used to enjoy in the home country?**

*** Do you have people here to confide in and talk to in times of stress?**

*** Have you ever felt mistreated because of where you come from?**

PROBE: Have you ever felt that you were treated as an outsider, stranger or alien by other Americans? Can you give some examples?

*** Are you currently working? What do you do [for work]?**

*** Do you feel that you have a job that is below your experience and qualifications?**

PROBE: Do you feel that the job experience you had in (place of birth) is not recognized in the US?

*** Have you ever felt disappointed that your standard of living is not what you had hoped for when you first came to the US?**

VIII. OTHER CONCERNS

Do you have other suggestions that we have not covered?

IX. CONCLUSION

That's all. Thank you for your time and for your participation.

Appendix C:
Focus group topics guide

Focus Group Interview Topics Guide

Equality in Breast Cancer Care Study

[These questions do not have to be read verbatim. They are topics to be used as a guide for steering the conversation. It is okay to go out of order, but be sure that all of the topics are covered. Questions indicated by asterisk (*) are of highest priority and should be covered first should there be not enough time to cover all of the questions.]

Thank you once again for participating in our research study. Again, the goal of our study is to learn more about how women from diverse cultural and ethnic backgrounds go through the experience of being diagnosed and treated for breast cancer. In particular, we are interested in hearing about the challenges that you may have faced during this experience. We will also be asking some questions about challenges that you may have faced as part of your daily life.

WARM-UP QUESTIONS

[These are warm up questions so that participants can focus to the time and experience of their diagnosis and treatment for breast cancer.]

1. How long has it been since you first learned that you had breast cancer?
2. How did you find out you had breast cancer?
PROBE: Through a routine mammogram? Did you notice any symptoms? Did you feel a lump? Did your doctor feel a lump? Did you experience any pain?

3. When you found out that you had breast cancer, how did you feel and what did you do?

[Participants may express their feelings or what was happening to them at the time. Give them time to express their feelings, and then transition to the next questions.]

PROBE: Did you act on it right away? Did you wait? (If yes) Why?

II. DIAGNOSIS

- * 4. Where were you diagnosed?
PROBE: What was the name of the medical facility?
5. How was this process for you?
PROBE: Did you feel that there were problems with understanding your doctors or nurses? Did you get printed materials in a language that you could understand? What kind of information were you given? Did you find it helpful? Would you have wanted more?
- * 6. Did you feel that the doctors gave you the information you needed to understand what you needed to do?
PROBE: What to expect? What treatment you needed?
- * 7. Did you feel respected by your doctors and nurses? Why or why not?
8. Did you trust your doctors and nurses? Why or why not?

9. Looking back at the experience, would you have liked things to happen differently?
10. Did you have medical health insurance at the time of your diagnosis?
11. What was your medical insurance at the time?
PROBE: Did you have private insurance? Were you on MediCaid or MediCal? Were you on Medicare?
12. Did you experience any difficulties with your insurance?
PROBE: Did you lose your insurance?

III. TREATMENT

I would like to now focus on your treatment experience.

- * 13. Where were you treated?
PROBE: What was the name of the medical facility?
- * 14. What did your doctors tell you to do?
PROBE: What did the doctors tell you about treatment?
- * 15. Did you do what the doctors said?
PROBE: What treatments did you receive?
- * 16. Did you do anything else?
PROBE: Did you have other treatments?
- * 17. Did your doctor tell you you had a choice about which treatment to go with
- 18. Did you have unexpected side effects from the treatment? [If yes] Did you feel that your providers helped you in the best way that they could with these side effects?
PROBE: Did you have pain that you weren't expecting? Did you have nausea? Weight loss? Weight gain?
- 19. Did you go to other sources or talk to other people to get more information? What sources?
PROBE: Did you look up information on the Internet? If yes, where and what sites did you find to be most helpful.
- 20. Do you think that your doctor listened to your opinions when discussing and making decisions about your treatment? Did you feel like you were heard by your doctors?
- 21. Are you satisfied with the communication between yourself and your doctors?
PROBE: Did you like the way your doctors and the other medical staff talked to you? Did you feel like you were part of a team? Would you recommend your doctors?

IV. DISCRIMINATION – MEDICAL SETTING

- * 22. We know that not all people receive are treated the same way when they are diagnosed with breast cancer. An important part of what we're doing is to try to understand the reasons for this.

23. Do you know of people who have been treated poorly by their doctors, or did not receive the treatment that they should have?

* 24. What about you? How do you feel about the medical care that you got for your breast cancer?

[if all group members report that they basically received good medical care, the remaining questions in this Section may be more appropriate with the lead]:

I understand you received good [basically good, pretty good] medical care.

For those of you who feel they did not get the best possible medical care for their breast cancer

[For non-English speakers]:

* 25. ***Do you feel that you would have gotten better medical care if you spoke a different language?***

* 26. Do you feel that you would have gotten better medical care if you had belonged to a different race, ethnic group or had different skin color?

27. ***Do you feel that you would have gotten better medical care if you were a different age?***

28. ***Do you feel that you would have gotten better medical care if you were a different height or weight?***

* 29. ***Do you feel that you would have gotten better medical care if you had more education?***

* 30. ***Do you feel that you would have gotten better medical care if you had more money?***

[Participants may report biases/discriminatory practices in certain medical settings, but not others. Try to elucidate, as specifically as possible, the settings in which such biases were experienced. For each question, if the response is “yes”, probe as to how they felt their care was sub-optimal, and what type of people do they perceive receive the most optimal care.]

V. DISCRIMINATION – OTHER SETTINGS

31. ***What is your race/ ethnicity?***

[For Latinas: Where are you from?]

32. How often do you think about your race or ethnicity?

* 33. Often in our society, people are treated unfairly because of their race or ethnicity. What about you? Have you ever experienced any physical symptoms, for example a headache, an upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race or ethnicity? How often do you have these symptoms?

* 34. Have you ever felt emotionally upset – sad, frustrated, angry – as a result of how you were treated based on your race or ethnicity? How often have you felt this way?

VI. COPING & SOCIAL SUPPORT

- 35. Do you know about cancer support groups? [If no explain]
- 36. Did your doctors or other medical staff offer information about joining a support group? Were any of the support groups offered in your language?
- 37. Did you participate in a cancer support group?
[If yes] Did you find it to be helpful?
[If no] Why not?
- * 38. How well do you think you coped or dealt with your breast cancer diagnosis and treatment experience?
- * 39. Did you discuss or share your experiences with anyone? Who?
PROBE: Did you tell your family? What was their response? Did you tell any friends? What was their response?
- * 40. Did you find it helpful to discuss or share your experiences? In what ways did you find it helpful?
- * Now I'd like to ask some questions about your neighborhood and community.
- * 41. Do you feel that people in your neighborhood are willing to help each other out?
Do you feel a sense of "community" in your neighborhood?
PROBE: Why or why not?
- * 42. Do you feel that people in your neighborhood would come to the aid of a stranger in need in the neighborhood?
PROBE: Why or why not?
- * 43. Can children play safely in your neighborhood?
PROBE: Why or why not?
- 44. Did you ever hear about any informational meetings in your neighborhood or community to help you learn about some medical illness(es)? For example, did you ever see flyers posted around or other advertisements for talks being given??
[If yes]: What were they? Did you ever attend? Were you told what to look out for for certain medical illnesses? Did any educational resources in your community ever tell you about mammograms or where to get screened for breast cancer?

VII. IMMIGRANT STRESS

[This section is only asked in interviews with immigrants.]

- * 45. Please tell me where you were born?
- * 46. ***[If not born in the United States]: When did you come to this country to live? Why did you come to this country?***

[If everyone in the group was born in the United States, GOTO Section VIII].

- * 47. Some people who emigrate from other countries find that living in the US is stressful. For those of you who emigrated, have you ever felt stressed because you are living far away from your family, relatives, and friends?
- * 48. Have you ever felt stressed because you are unable to do the things you used to enjoy in the home country?

49. Have you ever felt mistreated because of where you come from?
PROBE: Have you ever felt that you were treated as an outsider, stranger, or alien by other Americans? Can you give some examples?

* 50. Have you ever felt disappointed that your standard of living is not what you had hoped for when you first came to the US?

VIII. OTHER CONCERNS

51. Do you have other suggestions that we have not covered?

IX. CONCLUSION

That's all. Thank you for your time and for your participation.