

# **Bucksbaum Institute for Clinical Excellence**

## **2012 Pilot Grant Final Report**

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### **Endometrial Cancer Survivorship: A qualitative approach to understanding healthy lifestyle change in African American endometrial cancer survivors and their support network**

#### **Introduction/Background**

Each year, 43,000 women in the United States are diagnosed with endometrial cancer making it the most common gynecologic malignancy. Obesity is the leading cause of this cancer. Approximately, 60 - 80% of women are obese at diagnosis. Most women will have early-stage, curable disease. Nevertheless, these women are at higher risk of death due to the complications of obesity e.g., diabetes and cardiovascular disease than the cancer or treatment.

Endometrial cancer is an important health disparity possibly due to factors such as delays in care, differences in surgery utilization, and more aggressive tumor types. African American women are more likely to die from their disease; they represent 7% of all new cases, but 14% of deaths. According to national data, the 5-year survival for African American women is 70% compared to 90+% for white women. African American women with advanced stage disease have a 31% 5-year survival compared to 58% for white women. Specifics on how obesity related illnesses and performance status shape patient choices about their own care are poorly understood and represent a research gap to be addressed.

Having an obesity-related cancer can be a “wake up call” for women and families. However, physicians often focus on evaluating only disease recurrence rather than also counseling about health maintenance, obesity and the link between obesity and cancer. Thus, due to lack of time, skills and failure to understand patient needs, clinicians are missing a critical opportunity. Further, clinicians may also be missing an opportunity to influence the behaviors of women’s social networks. Social networks can influence behavior including weight gain and set expectations and norms regarding obesity. Public health efforts have demonstrated the importance of peer support in interventions around smoking, alcohol, and weight loss. The power of such social and familial influences among African American women in community health care settings has been articulated and validated in social models and studied in breast and cervical cancer but not specifically in endometrial cancer. This research will use qualitative research methods to provide critical, patient-derived information for clinicians about the ways in which they can address obesity, the most critical contributor to morbidity and mortality among women with endometrial cancer and their families.

#### **Methods**

We are conducting focus groups with women diagnosed with endometrial cancer and their social networks. The purpose of these groups is to gain data to help guide clinicians and better enable

them to address these issues among women with endometrial cancer and to inform future community-based obesity reduction interventions for African American women.

**Recruitment:** African American women above age 40 years with a diagnosis of endometrial cancer will be asked to participate in a focus group about endometrial cancer and obesity. Eligibility criteria will include obesity (BMI >25), English speaking, and completion of cancer treatment. These women will be asked to list 1-5 female relatives or peers who would be interested in participating in a focus group. Women from this cohort will be recruited. Participants will sign IRB approved informed consent for participation and collection of baseline information via a confidential survey.

**Focus Group Logistics:** Four focus group sessions had originally be planned. The sessions are led by experienced African American female moderators. A focus group note taker will observe group dynamics, body language, and non-verbal communications. Mentors with prior experience in qualitative research and multidisciplinary methods will assist in the training and preparation for focus group sessions. The focus group guide will include structured questions with set probes to promote discussion and ensure that desired topics are explored.

**Focus group topic guide:** The goal of the sessions will be to better understand barriers and facilitators to lifestyle change in general and in particular to participation in a structured weight management programs. We will also seek to understand whether an endometrial cancer diagnosis (in oneself or a loved one) is a teachable moment for weight loss by assessing readiness to change. The focus group guide will be based on a series of structured questions with set probes to promote discussion and ensure that desired domains are explored. We will ask participants to identify attitudes, facilitators and barriers that might be unique to women who might be similar to them. The focus group structured script (seen below) will be used. We will focus on identifying those themes that participants endorse as views held strongly by members of their community. These sessions will fill a research gap and inform future recruitment efforts. Information and knowledge gained from this aim will be used to better understand the specific self-defined needs of this cohort.

**Domain 1: Defining healthy lifestyle**

*First, I would like to talk about healthy lifestyle choices. These are commonly used words, but I would like to hear what that would mean for you.*

*What do you think a healthy lifestyle should include?*

- Diet and what kinds of food you eat?
- How much food you eat?
- Exercise or physical activity?

**Domain 2: Weight loss and weight management/Competing priorities**

*Now let's talk about weight loss in general. Is weight management a realistic goal? Are there more pressing priorities or issues in your life that make focusing on weight loss difficult?*

- Is being overweight a problem among women who are in your family or friends?
- Tell me about your experience with losing or gaining weight.
- Why is it so difficult for people to lose weight and keep it off?

**Domain 3: Making change in eating habits or activity level.**

*What comes to mind when you think about making changes in your current diet or activity level?*

- What are challenges in improving your diet?
- What are challenges in increasing your daily activity level?
- What would make things easier for you to do these things?

**Domain 4: Best approaches to a learning about and maintaining healthy weight or making lifestyle change**

*What ways would you want to learn about how to maintain a healthy weight or make changes in your diet or physical activity?*

- Would you like classes or written material or online information or individual sessions?
- Where, when and how often could they take place?

*Are there cultural issues specific to African American women to be considered in a program?*

**Domain 5: Participating in a formal weight loss or weight management program**

*There are many types of weight loss or weight management programs that are advertised. What are the challenges in joining or sticking to a weight loss program?*

- What would make you want to attend a class or program on weight management or healthy lifestyles?
- What would motivate you to continue in the program?

*Would having friends and or family have the same goals be helpful?*

**Domain 6A: Specific for endometrial cancer survivors' focus group**

*How does your past diagnosis of endometrial cancer affect how you view your health now?*

- Does it make you want to make changes for yourself in your life or learn more?

**Domain 6B: Specific for social support network members' focus group**

*How does having a friend or family member diagnosed with cancer affect you and your thinking about your health?*

- Does it make you want to make changes for yourself in your life or learn more?

**Final summary and conclusion:**

*Are there any other comments that anyone would like to make?*

*What other questions should we have asked? Did we forget anything?*

*Are there things you want more information about?*

**Qualitative Data Collection and Analysis**

All qualitative data will be audio recorded during each of the focus groups and transcribed verbatim by transcription services. The PI and project coordinator at the University of Chicago will code the data and enter it into ATLAS/ti 5.0 ® (a qualitative data analysis software program that allows for coding, text retrieval, and data management and analysis). The data will be stored by the PI and the research team and will be kept secure in password protected files or locked office. We will use a content analysis approach to create a structured codebook based on focus group questions. Then, the transcribed focus group data will be studied line-by-line in a grounded theory approach in order to identify salient themes related to endometrial cancer and facilitators/ barriers to weight loss and lifestyle changes we will supplement the codebook with new themes that we identify.

**Discussion**

The research focuses on endometrial cancer survivorship as a critical intersection for improving health care by addressing cancer care, health disparities and obesity. Initial motivation for this proposal was driven by clinical experiences in gynecologic oncology in treating women with endometrial cancer. Conversations with women and families prompted a growing sense of needs

of this understudied population of African American women. Our speciality and many others in oncology acknowledge the importance of issues of obesity and promotion of healthier lifestyles and the critical need for research on how best to address this in practice. Information generated from this project can be used better understand women's perspective on their health and may foster better communication between providers and patients. Patient generated themes could ideally guide interventions and reveal priorities that have not been addressed. Acknowledgement of concrete barriers and facilitators can allow focus on modes of delivery of information/ intervention that are most suitable. Novel interventions could be developed to target both cancer survivors and their social support network. This research creates an important interdisciplinary collaboration between oncology, primary care, and social sciences.

## **Results**

As an update of our research project, we have completed our planning and design of the focus group topic guide and qualitative research methods, recruitment of subjects and enrollment of subjects. We have IRB approval and have begun our research focus groups in Dec 2012.

We have completed 2 of the planned 4 focus group sessions and have had 3-7 women present for each session. We have additional sessions which will take place in March.

We have transcribed the 1.5-2 hour sessions and are currently in the process of data analysis and construction of code dictionaries. We plan to use the Atlas program for management of the data.

