

“That was menopause, but I didn't know that”

Understanding Family Systems of Menopause Knowledge among African American Women with Endometrial Cancer

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Abstract

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Understanding Family Systems of Menopause Knowledge among
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Objectives: Little is known regarding how African American families acquire and disseminate menopause knowledge. The objectives of this study were to describe how knowledge, attitudes, and beliefs about menopause are shaped by family knowledge systems for African American women of postmenopausal age with endometrial cancer and identify opportunities to further shape menopause-related education throughout the reproductive life course for African American women.

Methods: This was a secondary analysis of qualitative data from a larger study seeking to characterize the experiences of symptom onset and diagnosis of African American women who have been diagnosed with endometrial cancer. In-depth, qualitative interviews from thirteen African American women who received a diagnosis of endometrial cancer were examined using thematic analysis.

Results: Three themes emerged from the data: family as an insufficient source of menopause knowledge, menopause knowledge gaps and resultant experiences, and confusion regarding early signs of endometrial cancer. When considering family systems of menopause knowledge among African American women with endometrial cancer, our results support that although family was a primary source of menopause knowledge, this knowledge was insufficient in quality. This resulted in a mismatch between menopause expectations and experiences and subsequent vulnerability to misinterpretation of early endometrial cancer symptoms.

Discussion: African American families need greater access to comprehensive and culturally relevant education to successfully navigate menopause. To address the full spectrum of needs that arose in this study, our recommendations include creating menopause learning opportunities at the premenopausal, menopausal and postmenopausal stages of a woman's life coupled with opportunities to increase awareness of gynecologic cancer risk.

Menopause, often viewed as a universal female transition, occurs once the ovaries stop producing estrogen and progesterone. Menopause consists of four stages: pre-menopause, early transition, late transition and post-menopause (Gracia et al., 2005), and is reached once a woman has not had any bleeding for twelve consecutive months (Centers for Disease Control and Prevention, 2017). In the United States, the median age of menopause is 51 years old. Symptoms of menopause vary but include weight gain, irritability, sleeplessness, headaches, hot flashes (Huffman, Myers, Tingle & Bond, 2005; E.W. Freeman et al., 2007), vaginal dryness, flooding, and tender breast (Holmes-Rovner et al., 1996).

While viewed as a universal and significant transition, literature highlights that there is no universality in how menopause is experienced. In addition to symptoms, the experience of menopause is shaped by the social determinants of health - the personal, social, economic and environmental factors that reach beyond the boundaries of traditional healthcare to influence health (Office of Disease Prevention and Health Promotion, 2014). Thus, social location, race (Dillaway, Byrnes, Miller & Rehan, 2008), management techniques, and support provided by family members and friends (Im, Lee, Chee, Dormire & Brown, 2010) all play a unique role in a woman's menopause experience. Furthermore, knowledge appears throughout the literature as a determinant in the overarching experience of menopause (Cooper & Kock, 2008; Holmes-Rovner et al., 1996; Im, Lee, Chee, Dormire & Brown, 2010; Im, Lee & Chee, 2010).

For African American women, experiences are less well-known, as literature has primarily included middle and upper-class Caucasian participants and has rarely explored menopausal symptom experience among diverse ethnic populations in the United States (Huffman, Myers, Tingle & Bond, 2005; Im, Lee, Chee, Dormire & Brown, 2010). However, literature has confirmed that many women, including African Americans, do not have adequate information about menstrual events (Im, Lee & Chen, 2010), leaving them confused about the symptoms they experience and unable to recognize signs of abnormal change.

Inability to recognize these signs puts women at heightened risk for diseases such as endometrial cancer, a cancer of the uterus lining. The most common symptom of endometrial cancer is abnormal uterine bleeding. For premenopausal women, this includes irregular bleeding, spotting and bleeding between menstrual periods. For postmenopausal women, any bleeding is viewed as abnormal (American College of Obstetricians and Gynecologists, 2016). For African Americans, endometrial cancer can be particularly dangerous as racial disparities are profound. African American women with endometrial cancer have a 55% higher 5-year mortality rate when compared to White women (Doll, Snyder & Ford, 2017). This racial disparity highlights the necessity of comprehensive menstrual event information that allows African American women to better understand abnormalities and seek treatment sooner.

Literature details how limited sources of menstrual event information targeted to this population exist (Cooper & Kock, 2008). While schools provide menstrual education, lessons rarely go beyond what happens after a woman's first period (2008). The healthcare system, as a source of menstrual learning, can be restricted due to distrust of medical providers among African American women stemming from the long-standing history of discrimination (Dillaway et al, 2008). Medical experimentation, inadequate healthcare coverage and the social determinants of

health have only further estranged African American women from healthcare systems (Prather et al., 2018).

Given the lack of information provided in schools and distrust-based restriction of knowledge from healthcare providers, family can serve as a fundamental tool for disseminating menopause knowledge to African American women. Cooper and Kock (2008) discussed the importance of mothers and female family members as sources for menstrual event information. However, this relationship is complex and underexplored. Little is known regarding how menstrual health knowledge, particularly surrounding menopause, is garnered and passed down within African American families. Existing studies suggest that at the core of this information is avoidance and negative discussion (2008). While many women report not discussing menopause with family members (Marsh, Brocks, Ghant, Recht & Simon, 2014), they express an interest in wanting to have those conversations, hear about their mothers' experiences and gain deeper knowledge on the subject (Cooper & Koch, 2008; Dillaway, 2007; Dillaway et al., 2008; Im et al., 2010).

As part of a broader qualitative study focused on determining how knowledge, attitudes, beliefs and behaviors of patients and providers influence the time from symptom recognition to histologic diagnosis of endometrial cancer, we conducted a secondary analysis of interviews with African American women who have been diagnosed with endometrial cancer. We plan to describe how knowledge, attitudes, and beliefs about menopause are shaped by family knowledge systems and identify opportunities to further shape menopause-related education throughout the reproductive life course for African-American women.

Methods

Study Setting and Recruitment

This study is a secondary analysis of data from a qualitative study seeking to characterize the experiences of symptom onset and diagnosis of African American women who have been diagnosed with endometrial cancer. Participants were recruited from Seattle-based gynecologic oncology clinics and via Cierra Sisters Inc, a support group for African American women with cancer. Furthermore, information about the study was disseminated on social media, the Endometrial Cancer Action Network for African Americans (ECANA) website, and cancer research recruitment websites.

To participate in the study, recruited individuals needed to identify as Black or African American and have a diagnosis of endometrial cancer. Individuals were screened using an interview guide (Appendix A) to confirm their endometrial cancer diagnosis.

Participants

The parent study recruited 13 women who identified as African American, with a recent (<5 years) endometrial cancer diagnosis. Participant age ranged from 46 to 74 years old. The mean age of participants was 63 years old. While some participants were unsure of the exact age of menopause, age when menopause began ranged from 41 to 60 years old.

Data Collection

In-depth, semi-structured interviews were conducted with African American women (N=13). The interview guide (Appendix B) was developed using the Health Belief Model applied to endometrial cancer symptoms and healthcare encounters and informed by the Public Health Critical Race praxis, with particular focus on the principles of race-consciousness, primacy of racialization, intersectionality and voice (Ford and Airhihenbuwa, 2010). Interviews were conducted by an experienced community advocate and founder of the cancer support group (B.H.) and a gynecologic oncologist trained in qualitative research (K.D.). Study participants were asked to describe their menopause experience and share what they expected menopause was going to be like, what happened when they disclosed their symptoms to healthcare professionals in addition to friends and family, and what medical advice they were given upon reporting their symptoms.

Data Analysis

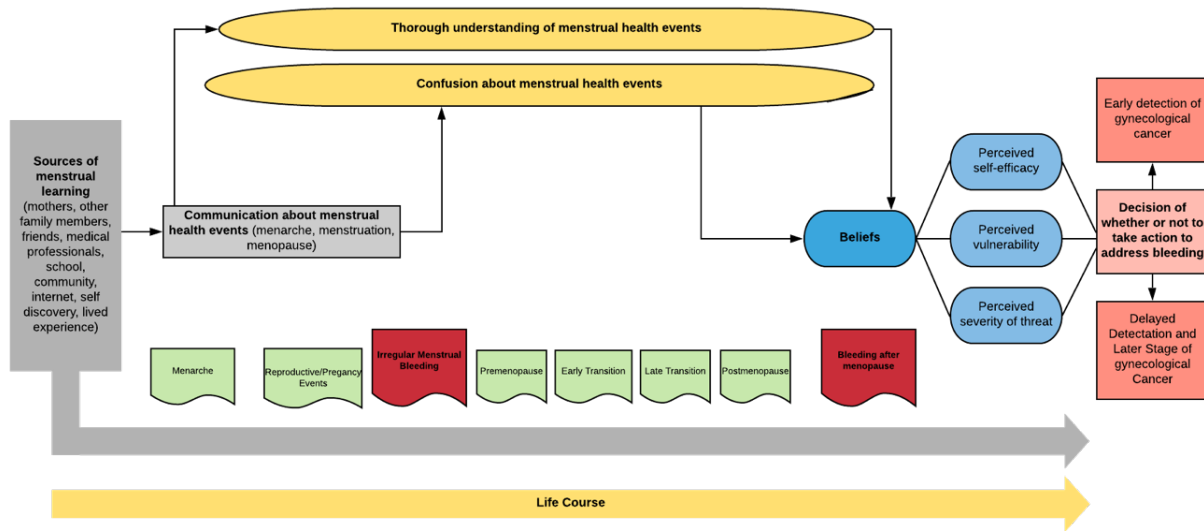
For this ancillary analysis, an initial codebook was developed using theories from our conceptual model and relevant findings from the literature. Inter-coder reliability was established by the master's level student (M.J.) and the principal investigator (PI) for the first three transcripts. Discrepancies were discussed and resolved. Once consistency was established, all interviews were coded by the student researcher using Dedoose software and reviewed by the PI.

Transcribed interviews were analyzed using directed content analysis, allowing thematic patterns to emerge from the data. The data were analyzed for themes for each interview, compiled into case summaries and compared across individuals for common themes and supporting data. This process was continued until thematic saturation was achieved.

Theoretical Framework

This study is informed by three frameworks: the life course approach, Fundamental Cause Theory and Protection Motivation Theory. The life course approach assesses how exposures produce health throughout an individual's life (Keyes and Galea, 2016). This theory highlights sensitive periods where exposures have greater effect during one stage of life, chains of risk where exposures are embedded in a causal sequence, and accumulation of exposures throughout the life course. Link and Phelan's Fundamental Cause Theory (1995) contextualizes risk factors to understand why people come to be exposed to risk. Here, resources become key mechanisms that allow individuals to avoid risk or minimize consequences of disease. Lastly, Protection Motivation Theory (PMT) examines how individuals are motivated to react in self-protective ways toward a perceived health threat (Rogers, 1983). Perceived severity, vulnerability, and self-efficacy influence whether or not a threat is recognized and the behaviors that follow. Combined, these theories guide our understanding of the opportunities for menopause learning that exist throughout a woman's life and how knowledge can shape perceptions of postmenopausal bleeding and act as a resource to minimize health risks such as endometrial cancer.

Figure 1. Conceptual Model



Results

Three overarching themes emerged from the data: family as an insufficient source of menopause knowledge, menopause knowledge gaps and resultant experiences and confusion regarding early signs of endometrial cancer. These themes, as well as related subthemes and associated quotes derived from the data, are summarized below and presented in Table 1.

Family as an insufficient source of menopause knowledge

The participants rarely gained sufficient knowledge from family members including mothers, sisters, aunts and grandmothers. This can be attributed to two sources: hysterectomy and stigma surrounding menopause.

Hysterectomy

Many of the family members in the participants' lives had undergone a hysterectomy, an operation to remove the uterus. Hysterectomy, which results in the cessation of any menstrual bleeding, can serve as a mediator of the limited menopause knowledge passed down within families.

I really didn't have any women around me that could really tell me a whole lot because my mom didn't go through menopause. She wound up having a hysterectomy, which is instant menopause.

Like I said my mother never talked about it. When I did finally ever speak to her on it, she said 'Well, I had a hysterectomy, so I just went through it overnight'. And so, there was nothing. And when she had it, actually I lived in Chicago at the time and she was living in Seattle, so I didn't have anybody to talk to and she didn't share any information, so. And I didn't know anyone else.

Stigma surrounding menopause

Stigma surrounding menopause in the black community served as an additional barrier to knowledge for the women in this study. Among participants and their families, menopause was often viewed as a private matter, not meant to be discussed openly.

I think that's the stigma with a lot of black women. You go through these things and no one talks about it. Or they just assume that you know. And some people won't ask questions because of embarrassment or out of 'oh but I should know this so let me just kind of figure it out or deal with it as it comes. So, it would be really wonderful to get rid of that stigma of things that are happening to our bodies and being just comfortable with having these conversations. As to, this is what to expect. And it may not be exactly like this for you but just so that you can see some of the signs ahead of time.

But even when I was a teenager growing up I think because my mom was from the south, and people from the south tend not to mention any medical issues, or problems, or things that you're gonna go through.

Well, the thing is, black women don't really talk so much about menopause. They talk more about hot flashes. They don't talk about ...you know, they'll say 'Oh, I'm going through these hot flashes I'm going through menopause'. They don't talk about the period thing, you know? That's not something they talk about. I mean, not within my group.

Hysterectomy, often working in tandem with stigma, played a significant role in the lack of menopause knowledge garnered from family members.

Menopause knowledge gaps and resultant experiences

Because families are an insufficient source of knowledge, the participants displayed expansive menopause knowledge gaps even as they transitioned into menopause. While the women often learned about menopause through the symptom lens of hot flashes, their depth of knowledge rarely extended beyond this connection. This was evidenced both by the direct expression of the lack of knowledge regarding menopausal symptoms and by a disconnect between expectations and actual menopause experience.

Direct expression of lack of knowledge

I think the most that I heard about it was the change, was the change that your body would be going through. First the hot flashes, most women, we all experience that. We all gonna experience the hot flashes. And that would be brought to your attention. And the changes in your menstrual cycle. That's basically all you hear about. And I know that there are more and there are more changes that we go through.

I didn't really know what that was. That was menopause, but I didn't know that. I thought I was just thought I was cracking up.

All I knew from hearing about, was the hot flashes, that was about it. That's kind of all I knew before.

Disconnect between menopause expectation and experience

Knowledge gaps were also seen in how most women had no expectations regarding the universal transition of menopause. When asked how their experiences compared to expectations, nine out of thirteen participants did not have any menopause expectations. While their menopause experiences varied, disconnect between experiences and expectations was a common finding throughout, as women often lacked clear expectations of what menopause would entail.

It was nothing like I expected...well I went through a horrifying time and I'm still going through it at certain times even now at 64, I still experience hot flashes. And of course, I'm not having a menstrual cycle but I'm still having some of the symptoms at this point. The only thing that I would just receive, I would just be going through hot flashes.

I think I expected it to maybe be a little worse than it was. I did experience vaginal dryness and that was kind of annoying, but you know, KY jelly.

I keep waiting and none of that happened. I wasn't even sure; have I went through it yet. If I went through menopause because I'm waiting for all these symptoms and I never went through any of that, never experienced it. To this day, haven't experienced it. So that was the main thing for me, just waiting to see if this was going to happen and it didn't.

Confusion regarding early signs of endometrial cancer

All of the women in this study subsequently went on to be diagnosed with endometrial cancer. The cardinal symptoms associated with endometrial cancer, specifically post-menopausal bleeding, did not cause immediate concern for many of the participants. Insufficient knowledge coupled with a lack of menopause expectations created a context where women had no prior knowledge to assess the symptom and confirm or refute whether it was abnormal. In this context, early signs of endometrial cancer were confused with menopause symptoms. This significantly dampened participant's perceived severity of the threat and vulnerability to negative health events including endometrial cancer.

I just only thought that maybe I wasn't done with menopause. You know, I didn't have enough history on menopause, so I thought maybe I had completed. Because I know menopause can take years to complete, to go through circle. So really that was the first thing that appeared in my mind that was 'Hmm I'm just not done with this yet.

I thought maybe I was still going through menopause. I couldn't think of anything else. Cancer was the last thing I would have thought.

Then I started spotting When I started spotting, I'm thinking 'Okay, Estrin is causing my periods to come.' I clearly did not want that to restart.

I was just surprised. Just surprised. Not alarmed, because it wasn't heavy at all. Very light. But it was there. And I'm like, 'Is that blood?' Like that. Because it was nothing compared to what I'd been used to since I was in my 20s. Nothing.

| Table 1. Qualitative Findings | |
|--|---|
| Theme + Subthemes | Representative Quotes |
| Family as an Insufficient Source of Menopause Knowledge | |
| | I didn't. Only from what I had seen my mother go through. And at that time, I was young enough I didn't pay much attention to it. |
| | My mother passed away when I was 22 years old, so we never had that conversation. |
| | I never had this conversation with my mother as to what truly menopause was. I mean, I went through it and it was just one of those things. |
| | You know sometimes in a family some things you just don't talk about. And, this was never discussed. |
| | My grandmother, I did not have that conversation with her either. |
| | So, I didn't think to ask my cousins who were older than me but only like eight to ten years older than me, so I never even thought about asking them. |
| | My mom was 21 years older than I am. So, I remember her going through it vaguely anyways. I was pretty young, but I remember some functions of it. |
| <i>Hysterectomy</i> | |
| | I really didn't have any women around me that could really tell me a whole lot because my mom didn't go through menopause. She wound up having a hysterectomy, which is instant menopause. |
| | Like I said, my mother never talked about it. When I did finally ever speak to her on it, she said ' Well, I had a hysterectomy, so I just went through it overnight. And so, there was nothing. And when she had it, actually I lived in Chicago at the time and she was living in Seattle, so I didn't have anybody to talk to and she didn't share any information, so. And I didn't know anyone else. |
| | Truthfully, most of them had had a hysterectomy. They wasn't going through the hot flashes and things like that. |
| <i>Stigma Surrounding Menopause</i> | |
| | I think that's the stigma with a lot of black women. You go through these things and no one talks about it. Or they just assume that you know. And some people won't ask questions because of embarrassment or out of 'oh but I should know this so let me just kind of figure it out or deal with it as it comes. So, it would be really wonderful to get rid of that stigma of things that are happening to our bodies and being just comfortable with having these conversations. As to, this is what to expect. And it may not be exactly like this for you but just so that you can see some of the signs ahead of time. |
| | Well, you know what? Things don't be among black women ... Things don't ... I'ma put it just separate. Things don't seem to interest black, African American women. Some things they don't ... things that ... I don't know if it's probably a lack of education or knowledge of things when it's concerning us as black, African American women. Some things don't hardly ever be brought up as a concern when it comes down to black, African American women. |
| | Well, the thing is, black women don't really talk so much about menopause. They talk more about hot flashes. They don't talk about ... you know, they'll say 'Oh, I'm going through these hot flashes I'm going through menopause'. They don't talk about the period thing, you know? That's not something they talk about. I mean, not within my group. |
| | But I think we talk about it less than other women. We're more closed mouth about it. |
| | I've never really talked to a lot of people about menopause. Most people I know don't want to discuss it. It's as simple of that. Since I have no family up here...all my family lives somewhere else. |
| | But even when I was a teenager growing up I think because my mom was from the south, and people from the south tend not to mention any medical issues, or problems, or things that you're gonna go through. |
| Menopause Knowledge Gaps and Resultant Experiences | |
| <i>Direct Expression of Lack of Knowledge</i> | |

| | |
|--|--|
| | I think the most that I heard about it was the change. Was the change that your body would be going through. First the hot flashes, most women, we all experience that. We all gonna experience the hot flashes. And that would be brought to your attention. And the changes in your menstrual cycle. That's basically all you hear about. And I know that there are more and there are more changes that we go through. |
| | All I knew from hearing about, was the hot flashes, that was about it. That's kind of all I knew before. |
| | I didn't really know what that was. That was menopause, but I didn't know that. I thought I was just cracking up. |
| | So, I really don't know when menopause started, it could have been menopause though, the way it was acting like, it could have been menopause. |
| | For me, I didn't even really know, I was going through menopause I had no symptoms. I had no hot flashes, no cold flashes, no sweats, no night sweats, no nothing. My cycle just stopped so I no long had periods, so nothing else. |
| | I keep waiting and none of that happened. I wasn't even sure, have I went through it yet. If I went through menopause because I'm waiting for all these symptoms and I never went through any of that, never experienced it. To this day, haven't experienced it. So that was the main thing for me, just waiting to see if this was going to happen and it didn't. |
| <i>Disconnect Between Menopause Expectations and Experience</i> | |
| | It was nothing like I expected. . .well I went through a horrifying time and I'm still going through it at certain times even now at 64 I still experience hot flashes. And of course, I'm not having a menstrual cycle but I'm still having some of the symptoms at this point. The only thing that I would just receive, I would just be going through hot flashes. |
| | I thought my experience was great, because I wasn't getting any of these symptoms, which for the most part the women that I did talk to it was bad, it was nothing good. It was going to be bad and something horrible to look to. When it didn't occur, I'm thinking maybe because I didn't have any kids. All these women had had children and I had never had any children, I said, maybe that had something to do with it, so therefore that's why none of this happened to me. |
| | I just felt it was the worst thing because I didn't understand what was happening. |
| | Compared to my friends? It was wonderful. I mean, it's not wonderful but I didn't have the same symptoms as those people did. |
| | I don't know that I had any real expectations what menopause would be like. |
| <i>Confusion Regarding Early Signs of Endometrial Cancer</i> | |
| | I thought maybe I was still going through menopause. I couldn't think of anything else. Cancer was the last thing I would have thought. |
| | I just only thought that maybe I wasn't done with menopause. You know, I didn't have enough history on menopause, so I thought maybe I had completed. Because I know menopause can take years to complete, to go through circle. So really that was the first thing that appeared in my mind that was 'Hmm, I'm just not done with this yet. |
| | Because I thought I was done with menopause. So, it was a surprise. I was like, "Surprise!" I don't like surprises. |
| | Then I started spotting When I started spotting, I'm thinking 'Okay, Estring is causing my periods to come.' I clearly did not want that to restart. |
| | I was just surprised. Just surprised. Not alarmed, because it wasn't heavy at all. Very light. But it was there. And I'm like, 'Is that blood?' Like that. Because it was nothing compared to what I'd been used to since I was in my 20s. Nothing. |
| | It would have been nice for someone to have said "You're in menopause and you're not having a regular cycle and then if you see any kind of spotting, irregularly, two or three times a year, make sure you come in or make sure you say something or..." 'Cause without pain, there's no way for me to... for me... And I did some research. I didn't do a whole lot, but I did do some research on menopause, so I felt like I knew enough, but obviously I didn't. Yeah, that would have been helpful |

Discussion & Recommendations

To our knowledge, this is the first study to qualitatively investigate knowledge and experiences of menopause among African-American women with endometrial cancer. When considering family systems of menopause knowledge among participants, our results support that although family was a primary source of knowledge, this knowledge was insufficient in quality. This resulted in a mismatch of menopause expectations and experience and subsequent vulnerability to misinterpretation of early endometrial cancer symptoms.

The first theme regarding family as an insufficient source of menopause extends Im, Lee and Chen's (2010) findings that women do not have adequate information about menstrual events and confirms Cooper and Kock's (2008) findings regarding limited sources of menstrual health information. Furthermore, many women did not discuss menopause with family members, underscoring Marsh, Brocks, Ghant, Rect & Simon's (2014) previous findings. The women repeatedly shared how they did not have menopause conversations with mothers, aunts, sisters and grandmothers. Hysterectomy, a sub-theme, highlighted how knowledge transference can be stymied due to the surgery's effects. This is particularly concerning as hysterectomy rates are higher for African American women when compared to white women (Bower, Schreiner, Sternfield & Lewis, 2009).

Stigma surrounding black women and their bodies added to the complexity of transferring knowledge within African American families. The lack of openness for black women to talk about menopause further support Cooper and Kock's findings (2008). The consensus for this group was that menopause was not a normal topic of conversation. Stigma coupled with hysterectomy served as an obstacle for participants attempting to gain accurate knowledge about menopause from family. While family can serve as a key social determinant in a woman's menopause journey, as discussed by Im, Lee, Chee, Dormire & Brown (2010), this was not the case for study participants.

Family members did play a role in shaping knowledge around menopause symptoms, particularly in regard to hot flashes. However, knowledge gaps persisted. The second theme, menopause knowledge gaps and resultant experiences occurred as a consequence of minimal knowledge transfer. Lack of understanding made menopause confusing to maneuver. The women in this study attempted to gain menopause knowledge via alternative sources of information including friends, healthcare providers and their own research. This echoes the literature connected to an interest in gaining deeper knowledge on the subject (Cooper & Koch, 2008; Dillaway, 2007; Dillaway et al., 2008; Im et al., 2010). Participants confirmed both needing and wanting education on menopause. However, as our research showed, these sources were not sufficient in filling menopause knowledge gaps.

In alignment with the literature (Cooper & Kock, 2008; Holmes-Rovner et al., 1996; Im, Lee, Chee, Dormire & Brown, 2010; Im, Lee & Chee, 2010), our findings emphasize the importance of knowledge in a woman's experience of menopause. The culmination of insufficient family knowledge and knowledge gaps about what menopause encompasses created a disconnect between menopause expectations and actual experiences. This led to missed opportunities for early identification of endometrial cancer. None of the women discussed their experiences matching their expectations. Thus, their experiences, whether good or bad, often took them by

surprise. This sheds light on two key opportunities for learning: the pre-menopause stage, to set expectations and the early transition stage, to see if experiences match expectations. This will better prepare women for potential post-menopausal experiences that may occur such as bleeding.

Confusion regarding early signs of endometrial cancer, the third and final theme, details how the majority of participants were unable to attribute bleeding post-menopause with endometrial cancer, instead believing that the bleeding was another cycle or continuation of menopause. Furthermore, many of the participants had not heard of endometrial cancer until receiving their diagnosis. Thus, their perceived vulnerability to the disease was low. Because both threat and vulnerability were not recognized, protective behaviors such as seeking medical attention, did not immediately follow symptom recognition. Atypical experiences, where it was recognized that bleeding was not connected to menopause, created an immediate cause of concern.

Our themes highlight the chains of risk that become embedded in a causal sequence so that when a woman experiences postmenopausal bleeding, the limited sources of knowledge, knowledge gaps, and disconnect between experiences and expectations, set her up for vulnerability to missing the signs and symptoms of reproductive disease later in life. This highlights the need for menopause learning opportunities to occur throughout the life course so that African American women can be better prepared for gynecologic health events that may occur post-menopause.

Within the family context, we recommend learning opportunities at the premenopausal, menopausal and postmenopausal stages, allowing time for comprehensive knowledge to be built and for expectations and experiences to be addressed. These opportunities may include town halls where families can openly discuss menopause and share their experiences. These events should occur in spaces where families of color gather, socialize and feel comfortable. To help set accurate expectations, we also recommend the provision of culturally appropriate roadmaps to guide families through menopause expectations. Materials such as these can be tailored to family dyads and can also supply the language needed to have conversations surrounding menopause. This is particularly important for individuals who have had a hysterectomy or who may not be comfortable speaking about menopause. Together, these recommendations can begin to normalize the subject of menopause and increase the availability of menopause resources for African American families.

Limitations

There are several study limitations. The uniqueness of the women's experiences with menopause and endometrial cancer create findings that are not suited to be generalizable. Furthermore, this study includes interviews with 13 women, a relatively small sample size. A larger study that incorporates family dyads in addition to women from various backgrounds who have experienced both menopause and gynecologic cancer is needed to further dissect menopausal knowledge and better understand opportunities to strengthen family knowledge systems.

Conclusion

While family, particularly mothers and female family members, has the potential to serve as a key source of knowledge for African American women, they often are not equipped to fill

menopause knowledge gaps. African American women need access to knowledge during three sensitive periods: before, during and after menopause in order to set expectations, navigate experiences and understand what to do if bleeding post-menopause occurs.

Our findings can inform the creation and implementation of resources that provide thorough and accurate information throughout the life course, allowing African American families to better understand normal and abnormal symptoms of menopause. Equipping families with this knowledge will allow African American women to recognize the severity of bleeding if it occurs and seek early, potentially life-saving treatment. Abnormal vaginal bleeding is a common sign of not only endometrial cancer but also cervical, ovarian and vaginal cancer. Thus, we must develop awareness of gynecologic cancers among families in tandem with increasing menopause knowledge. Ensuring accessible and culturally appropriate resources is a step toward addressing the full spectrum of needs that arose in our research.

Appendix A: Participant Screening Form

Endometrial Cancer Experiences among African-American Women Participant Screening

I am part of a research study exploring patient experiences with uterine (“endometrial”) cancer. We want to learn more about how women first notice any symptoms and what their experience is like after telling their doctor. We hope this work improves the quality of how we take care of women with uterine cancer, especially Black women.

To be participate in this study, you need to have a diagnosis of ENDOMETRIAL cancer. This is a cancer of the womb or uterus. It is different from a cancer of the cervix, or a cancer of the ovaries. First, I will need to ask you some screening questions to make sure you have the type of cancer we are studying. If you are eligible to be in the study, and you agree to be in the study, we will move on to a recorded interview.

Do you consent to answer these screening questions?

SCREENING QUESTIONS (check YES or NO for each)

- YES NO Were you ever told you have a diagnosis of cervical cancer?
- YES NO Were you told that your cancer came from or started in the cervix?
- YES NO Were you told that your cancer was a “leiomyosarcoma” or a cancer that starts in a fibroid? **IF YES – consult with Kemi**
- YES NO Were you told that your cancer started in the ovaries?
- YES NO Did you cancer start somewhere else and then spread to the uterus?

If NO to ALL of above, proceed to CONFIRMATION QUESTIONS.

✘ **If YES to ANY of the above – you likely did not have the kind of cancer we are studying.**

CONFIRMATION QUESTIONS:

- YES NO Were you ever told you have “uterine” or “endometrial” cancer?
IF NO – consult with Kemi
- YES NO Did you find out your diagnosis from a biopsy or a “D&C”?
If NO – ask the following:
- YES NO Did you find out your diagnosis only after you had a hysterectomy?

Appendix B: Interview Guide

Endometrial Cancer Experiences among African-American Women Interview Questions



I am part of a research study exploring patient experiences with uterine (“endometrial”) cancer. We want to learn more about how women first notice any symptoms and what their experience is like after telling their doctor. We hope this work improves the quality of how we take care of women with uterine cancer, especially Black women. Just as a reminder you will be recorded during this discussion.

TURN BOTH RECORDERS ON

Date: ____/____/____ **Time:** ____:____ AM PM

Do you consent to being recorded?

BEFORE the diagnosis

I am interested in hearing about your experience before the diagnosis and any symptoms you may had had. There are no right or wrong answers, we are interested in your experience.

Menopause:

Q1. Tell me about what menopause was like for you.

PROBES [If the participant doesn’t answer this herself]

- What changes did you notice that made you feel that menopause was happening?
- How did your periods change?
- How old were you when these changes started?

Q2. How did you know what menopause would be like?

PROBES

- What did your relatives (mother, sister, aunts, cousins) tell you menopause would be like?
- What did your friends tell you menopause would be like?
- Who else or how were told you what menopause would be like?
 - Probe: did you hear from any healthcare providers about it?
- How did your experience compare to what you expected menopause to be like?
- What did people say about menopause for Black women?

Vaginal Bleeding

Q3. Tell me about any vaginal bleeding or spotting you had before your diagnosis of uterine cancer.

PROBES

- When was the very first time you noticed it?
- What were your thoughts or feelings about it?
- Did you talk to anyone (friends or family) about it? What did they say?
- Did you try any remedies to deal with the bleeding/spotting on your own before telling a medical professional? If yes, what did you try?

The next few questions are about your encounters with healthcare providers and the health system. Please feel free to share whatever you felt about the experience – the good and the bad.

Q4. For the next few questions, I will ask you to tell me some details about the very first time you told a medical professional about your vaginal bleeding.

PROBES

- What kind of doctor/where was this visit? [**For interviewer: probe until answer is as specific as possible.**]
- Did you bring it up? Did your doctor or other medical professional ask you about it?
- Why did you decide to report your bleeding or other symptoms at this particular time?

Q5. When you first told the medical professional about your vaginal bleeding, were there any instances when your provider mentioned your race?

PROBES

- What did they say?

Q6. What did your doctor tell you to do after you reported your symptoms.

PROBES

- What options did the medical professional offer you?

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| <p>To the interviewer: patients may be simply told to "see a gynecologist", or given more specific information about what tests need to be done. We are trying to understand how much and what kind of information they were given after they reported their bleeding.</p> |
|---|

Q7. At this point, did you know uterine cancer may be the cause of vaginal bleeding?

- If NO: When did you realize that cancer may have been causing your bleeding? Did someone tell you this directly?

Q8. What were your thoughts on why you had the bleeding? Were you worried at all?

Q9. At any point, did you think or feel that being Black changed how you were seen or treated with these symptoms? Tell me about that.

DURING the work up

I am interested in hearing about your thoughts and experiences with the tests, procedures, or surgeries that were needed to determine you had uterine cancer.

I'm going to ask you about the tests you may have had that led to your diagnosis. First, I'm going to ask you some straight forward questions about your procedures, and then we'll get into more about your experience.

Q10. Do you remember having a biopsy in the office?

- If YES: Who did this procedure or who sent you to have it done?

Q11. Do you remember having a "D&C" procedure in the operating room or a special procedure room?

- If YES: Who did this procedure or who sent you to have it done?

Q12. Do you remember having a vaginal ultrasound?

- If YES: Who did this procedure or who sent you to have it done?

Q13. What was the order of these tests and procedures? Which came first?

Q14. Were there any problems or feelings that made it difficult to do any or all of the tests and procedures you needed? Examples

- feelings of discomfort with procedures on your uterus,
- worry your safety or complications,
- concerns about the doctor doing the procedures
- problems with transportation
- finding the time to go
- insurance coverage

AFTER the diagnosis

I am going to ask you some questions about how the results impacted you. We recognize that some results are sensitive, and we want to be respectful of your experiences. Again, there are no right or wrong answers.

Q15. Tell me about the time when you first received the news of your uterine cancer diagnosis.

PROBES

- What was the test or procedure that confirmed your diagnosis?
- How were the results shared with you?
- How long did it take to get the test results?
- By whom?
- How were those results explained?
- How did you get your questions answered?
- What did they say about next steps?

Q16. Had you ever heard that AA/Black women have more aggressive types of uterine cancer?

General reflection / Any additional points – IF time permits

For this last section, I'm going to ask you some general reflection questions and also some questions specifically about being an African-American/Black woman with this experience. Again, there are no right or wrong answers.

Q17. Looking back, is there anything that you wish you knew or had been told about bleeding after menopause?

Q18. What would you tell other women who may experience new vaginal bleeding after menopause?

Q19. Was there anything we haven't talked about that made it difficult for you to learn that you had uterine cancer?

Q20. Do you have anything else that you would like to share about this experience?

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