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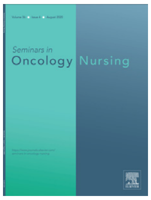

Treatment Decision-Making in West African Women With Breast Cancer: A Critical Ethnography

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ABSTRACT

Objectives: This study aimed to understand and characterize how culture affected behavior and decision-making about treatment and care in West African women with breast cancer living in the United Kingdom.
Methods: A critical ethnographic design was used with a sample consisting of 32 West African women, 27 supporters, and 18 health care professionals. Data were collected through 263 hours of participant observation and 98 informal and 10 formal interviews in a London cancer unit. Study materials and approach were informed by patient and public involvement group recommendations. Data were analyzed using an adapted Carspecken critical ethnographic approach.
Results: Three main themes were developed from the data: cultural knowledge, beliefs, and values; otherness; and cultural curiosity. West African women described a range of meanings and beliefs about their breast cancer diagnoses and treatments. They felt "Other" from, and were seen as "Other" by, their communities and health care teams. The clinical team exhibited varying levels of cultural curiosity, which evolved over time.
Conclusion: Cultural beliefs concerning cancer and its treatment were so strong that they led to some women refusing, delaying, or interrupting treatment. Nurses must seek to understand and value the perspectives and beliefs of people from unfamiliar cultures and consider how services might be made more flexible to meet their specific needs.
Implications for Nursing Practice: By being culturally curious and gaining understanding about how a woman's culture affects decisions about treatment and care, health care professionals began to understand that patients are more able to accept optimum treatment if adjustments are made to the service.

Breast cancer is the most diagnosed cancer globally with an estimated 2.3 million new cases each year, representing 11.7% of all new cancer cases diagnosed and 6.9% of all cancer deaths worldwide.[1] Improvements in breast cancer outcomes in the past two decades have been attributed to improved access to screening, early diagnosis, multidisciplinary team (MDT) working, evidence-based guidelines, and advancements in treatment and supportive care.[2-4] There are, however, significant inequalities in stage of disease at diagnosis, treatment received, morbidity and mortality, and experience of care for people diagnosed with breast cancer from different cultural groups worldwide.[1,5]

Late presentation, delays to starting treatment and delays during the treatment pathway have been reported in Black women more frequently than in women from other ethnic groups.[6-8] Some inequalities can be explained by lack of access to screening and treatment, poor breast cancer awareness education, lack of resources, and geographical location of services.[6,9,10]

In West Africa, multiple studies describe how women present with advanced stage cancers.[9,11] For many, there are logistical challenges in accessing affordable and accessible health care.[12] Many women opt for traditional treatments accessed via traditional healers or attend prayer camps before presenting for medical treatments.[13,14] Knowledge and cultural beliefs about breast cancer also play a part in decisions about accessing medical care.[15,16]

In the United States, where Black women have a 40% higher breast cancer mortality rate than White women, studies have suggested socioeconomic factors impacting on health insurance and finance

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Layperson summary

What we investigated and why

UK data shows black women with breast cancer are more likely to die than women from other ethnic groups. Research is needed to understand the reasons for this. The aim of this study was to understand what affects how West African women with breast cancer make decisions about their treatment and care and how health care professionals (HCPs) can help.

How we did our research

We observed consultations between 32 West African women, 27 people supporting them, and 18 HCPs. We did 98 informal interviews before and after consultations to gain a better understanding of what we were seeing and hearing. We conducted 10 formal interviews, which were recorded and subsequently transcribed. The observation notes, informal interview notes, and formal transcripts were analyzed. West African women and HCPs helped plan and advise on the study.

What we have found

Cultural beliefs led some women to refuse, delay, or interrupt their treatment. Some women hid their diagnosis as they may be treated differently. Views of family and community members affected treatment decisions. HCPs showed different levels of understanding of the cultural needs of the women and how this affected their care.

What it means

These findings offer important insight into the factors that influence decisions about treatment in West African women in the UK. They highlight the need for HCPs to be open and to listen to cultural needs of patients to understand what is important to people from different cultures.

play a part in treatment delays and delivery of suboptimal treatment.[6,17] Even when the location of services, health insurance, and other demographic factors are considered, delays in initiating and completing treatment still exist in Black African women, suggesting that other cultural factors may be important to consider.[18,19]

In the United Kingdom, Black African and Black Caribbean women with breast cancer have a higher proportion of poor prognostic tumor characteristics,[20] and young Black women have significantly poorer outcomes.[21] Barriers that prevent Black African women from attending for screening[22,23] and reasons why they may present with more advanced disease[20,24] and have poorer outcomes[21,25] have been studied in the UK, but there has been no study of factors that affect treatment decision-making. In the broader literature, there is growing evidence that health beliefs, cultural understanding, and experiences of health care services play an important part in women's approaches to making decisions about screening and care.[5,26-28]

The nature and process of health care professionals' (HCPs') communication of a breast cancer diagnosis and the wide range of treatment options present daunting communication challenges for patients, particularly those from diverse cultural backgrounds. Patients and their families interpret information and make treatment decisions informed by their previous knowledge and experiences, cultural beliefs, and understanding of illness and health care.

Poor communication with cancer patients can negatively affect treatment decision-making.[29] Some women feel disempowered and unable to ask questions, while others describe feeling pressured to make treatment decisions without adequate information.[30,31] Concerns that HCPs are exerting power by withholding information about treatment side effects lead to women considering stopping or not commencing recommended treatments.[30] Insensitive communication by HCPs and feelings of disempowerment can lead to women feeling mistrust or misunderstandings.[30,32]

It is clear there are cultural inequalities in care and outcomes. What is less clear is why people appear to receive less treatment and have poorer outcomes in different cultural groups. Therefore, there is a need to more fully understand factors that affect decision-making in different cultural groups. We report on a study exploring treatment decision-making in West African women diagnosed with breast cancer living in London. Forty-seven percent of the West African population in the UK lives in London, with the southeast London boroughs having the highest West African populations.[33] This study aims to understand and characterize how culture affects behavior and decision-making about treatment and care in West African women with breast cancer living in the UK. It further aims to discover how women's experiences of interactions with HCPs may influence this.

Methods

Design

The study set out through a critical ethnographic approach to explore the roles and impacts of culture, values, health beliefs, and communication on treatment decision-making in this context.

Critical ethnographies are concerned with the nature of power and examine who has what kind of power and why and the consequences. A critical ethnographic approach using participant observation, informal and formal interviews, and medical notes review was used to collect data in a London cancer unit.[34]

Critical ethnography not only aims to understand "what is" but also embraces "what could be."[35,36] Grbich[37] states that critical ethnography can bring about change by reporting findings to participants throughout the research process. It examines the rules that govern why people behave in particular ways and considers how rules could be changed or how people adapt to these rules.

Carspecken's[38] five-stage process for critical ethnography was modified for use in a health care research setting.[37,39] Stage 1 involves building the primary data record of what is happening in the setting by the researcher collecting observational data, noting behaviors and rituals. The second stage involves preliminary analysis of the data to begin interpreting meanings and challenging assumptions about what has been gathered. This is followed by stage 3, thematic analysis, where the data are examined to identify the location of power, cultural values, and further meanings for participants. In stage 4, dialogical data are gathered using interviews to support the ongoing participant observation; these data are examined further to look for system relations and how findings may link to wider social and economic issues. In stage 5, researchers review the findings in relation to wider cultural and social issues with a view to further explaining the findings from stages 1-4 and challenge and consider "what could be" in terms of change and improvements.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) were used to report these data[40] (available as Supplementary Material 1).

Patient and Public Involvement

Participant information sheets were reviewed by the patient and public involvement (PPI) group, which consisted of West African women who had completed treatment and West African HCPs. The PPI group suggested amendments to ensure they were culturally appropriate.[41,42]

Women and supporters gave verbal consent only for clinic observation and informal interviews. The PPI group advised against asking for written consent as this may contribute to feelings of mistrust of power and authority and impact on subsequent interactions with HCPs. Moreover, women may be reluctant to sign formal paperwork unless it was crucial to their treatment; some women and their supporters may be suspicious of all forms of research.[43]

Ethical Considerations

Ethical approval for the study (16/LO/0032) was obtained from the London-Southeast Research Ethics Committee, Health Research Authority.

Participants

All West African women attending the clinic were invited to take part in the study, whether they were newly diagnosed (early or advanced disease) or discussing a change in treatment due to advancing disease, unless they were judged to be in the last few weeks of life. Women were given participant information by clinicians and then asked if they would be happy to take part when they attended their next clinic appointment. With women's consent, participant information was offered to whoever was attending to support them. Supporters included family, friends, and people from the church.

All physicians and nurses in the breast cancer MDT were approached to take part in the study. Participant information to participate in the observation and informal interview element was provided in the clinic. Written consent was taken from MDT members on the day of consultations being observed. Toward the end of the observation data collection, team members were offered the opportunity to be interviewed.

Data Collection

Data were collected through 263 hours of participant observation, 10 formal interviews, and 98 informal interviews between March 2016 and March 2020 with two breaks, as the lead researcher experienced a bereavement (6 months) and ill health (1 year).

To compile the primary record (Carspecken stage 1[38]) AS, a breast cancer consultant nurse and PhD student conducted participant observation of consultations between West African women, their supporters, and HCPs in the breast surgery and oncology clinics of a London cancer unit. She also observed MDT meetings and reviewed medical notes. Following preliminary data analysis (Carspecken stages 2 and 3[38]), participant observation continued supported by interviews with the women, those identified as supporting them, and HCPs to further question meanings (stage 4 of the Carspecken process[38]).

Condensed field notes were written after each interaction and reviewed and expanded on after the clinic.[44] The researcher kept a reflective diary, noting feelings and assumptions and how her presence as an experienced cancer nurse may affect the dynamics of the consultation. The field notes and reflections were regularly reviewed and discussed with the research team to interrogate the researcher's role as a participant observer and minimize impact in ongoing observations. Informal interviews took place in waiting areas and consulting rooms before and after consultations. Formal semistructured (30-90 minutes) were conducted in a private room, digitally recorded, and professionally transcribed. Interview guides are available as Supplementary Materials 2 and 3. Participants were offered the opportunity to review the transcripts, but all declined. Field notes and other observations were added to the transcriptions. All participants were assigned a pseudonym to ensure anonymity.

Data Analysis

Analysis was an iterative process following the Carspecken stages[38] to allow ideas and concepts to be built on.[45] Impact of the researcher's experience and potential bias were considered throughout.[36]

The first stage of analysis (Carspecken stage 2[38]) involved preliminary coding and looking for meaning. A.S. and T.W. (professor of health care research and experienced ethnographer) coded the data individually, the results of which were discussed within the research team—A.S., T.W., and A.R. (professor of cancer nursing and end-of-life care)—questioning meanings, assumptions, and interpretations. Here, researchers particularly looked at meanings for the participants, where power was evident and how this influenced decision-making.

The next stage (Carspecken stage 3[38]) involved more questioning of meanings and increased dialogue between the researcher and participants to increase understanding. Research group discussions reviewed the influence of rules, boundaries, power, and culture on how West African women interpreted and experienced a breast cancer diagnosis, the impact on treatment and care decision-making, and the influence of their interactions with others.

While the earlier stages 1 to 4 emphasize understanding the culture or "what is," the analysis sections of stage 4 and stage 5 emphasize looking at "what may be." In stages 4 and 5, issues of power were revisited. As this study was adapted from Carspecken's education research,[38] it was decided that these stages would focus on the service and the meanings/understandings of participants to develop a more user-friendly service. Findings were fed back to HCPs, and difficulties with taboos, roles, and interpretations were shared. Staff became more culturally curious, developing cultural humility and service solutions.

Findings

Participants

Thirty-two West African women, 27 supporters and 18 HCPs took part in the study. The characteristics of participants are presented in Table 1. An additional 7 women were approached to take part, 3 declined study information, and 4 declined to take part after considering the information. Four additional West African women, who had been given information about the study, did not return to the hospital for further treatment discussions after their cancer diagnosis and were lost to follow-up.

The age range of the West African women was 30 to 85 years. Twenty-two women (69%) were Nigerian, 7 (22%) were Ghanaian,

TABLE 1
Characteristics of the West African Women and Their Supporters

Women's age (range 30-85 y)	30-49 y 47%	(n = 15)
	50-69 y 44%	(n = 14)
	70+ y 9%	(n = 3)
Country of birth	Nigeria 59%	(n = 19)
	Ghana 22%	(n = 7)
	Sierra Leone 6.5%	(n = 2)
	United Kingdom 12.5%	(n = 4)
Relationship status	Single 12.5%	(n = 4)
	Married/partner 69%	(n = 22)
	Widowed 12.5%	(n = 4)
	Divorced 6%	(n = 2)
Stage of disease	Early 66%	(n = 21)
	Local recurrence 6%	(n = 2)
	Advanced 28%	(n = 9)
Supporters	Husband/partner 41%	(n = 13)
	Adult child 19%	(n = 6)
	Sibling 6%	(n = 2)
	Church representative 6%	(n = 2)
	Attended alone 28%	(n = 9)

and 3 (9%) came from Sierra Leone. Twenty-eight women (88%) were first-generation immigrants to the UK. Three of the 4 women born in the UK spent significant periods of their childhood living with extended family in Nigeria.

Twenty-one (66%) women were being treated following a diagnosis of early breast cancer, 2 (6%) had local recurrence, and 9 (28%) had advanced disease. Of the 11 women who had developed a local recurrence or advanced breast cancer, 6 (55%) had not completed all or had significant delays in receiving recommended treatment modalities at the time of their original early breast cancer diagnosis.

Of 32 women, 23 (72%) attended clinic appointments with someone to support them. The relationships between the women and their supporters are presented in Table 1. Of the 9 women who attended alone, 3 had not told their husbands or families about their diagnosis.

Eighteen MDT members agreed to take part in the study. To maintain the anonymity of this small clinical team, staff members have been assigned pseudonyms. The clinical team was multicultural, including HCPs from the UK, Europe, Asia, and Africa. There were changes in staff during the data collection period.

Themes

Three main themes were developed: cultural knowledge, beliefs, and values; otherness; and cultural curiosity.

Data identified the different meanings and beliefs that West African women described about cancer and treatments and the rules and cultural boundaries that govern how the women make sense of their illness and decisions about their care.

Further analysis identified subthemes within each category (Fig 1).

Theme 1: Cultural Knowledge, Beliefs, and Values

This theme includes aspects of West African women's shared understanding, knowledge, and principles that guide how they make sense of their cancer diagnosis and recommended treatment options. It encompasses elements such as taboos and health beliefs, traditional treatments, religion and church influences, social norms, and gender-based role expectations.

Taboos and health beliefs

Women described the taboos and health beliefs about cancer in their community and how these affected them. Several women considered it to be a "White woman's" disease, not seeing themselves at risk of developing cancer. Bola described the secrecy and disbelief of a cancer diagnosis.

> "It's all shrouded in secrecy in our community, the dreaded C. It doesn't happen to us, so even when you say the word cancer—it's not your portion. Have you heard that expression before? So, it's almost like God forbid. When I've tried to talk about it, women say that's interesting but it's never going to be in my neighborhood."
>
> Bola (formal interview)

Participants spoke about cancer being a punishment for wrongdoing and that it could be contagious or affect those connected to the woman. Often women were outcast as Tiwa describes:

> "They said if somebody confirms that, I'm a witch, that is why I have this. They said because it's uncommon for such sickness..."
>
> Tiwa (formal interview)

Susan described how a cancer diagnosis was seen as a punishment from God.

> "I can tell you, in the Black race, when you get cancer, people think it's your sin, especially in the church."
>
> Susan (informal interview)

Bola described how her community deemed it "bad luck" to even talk about cancer. She said:

> "We must not give oxygen to these discussions... it's not your portion."
>
> Bola (formal interview)

Fear of cultural beliefs meant some women hid their diagnosis from family or community members, which affected their care. A nurse described how women often appeared unsupported

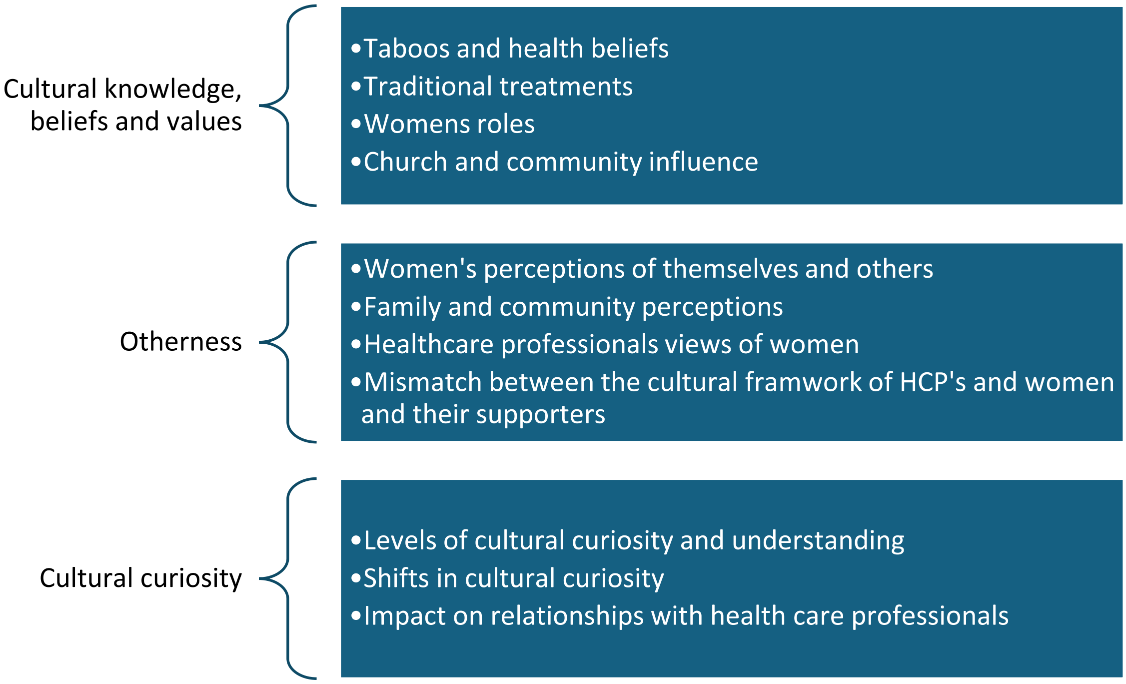

FIG 1. Themes and subthemes identified through the analysis process.

throughout their treatment and would avoid interventions like PICC lines as these were a visual sign of treatment.

> “We always encourage people to bring someone..., but they are often alone. One woman told me she hasn’t told her husband as he doesn’t need to know or be affected. Another told her husband she was having antibiotics. They are more likely to tell a friend who can help them with childcare etc., so their husband doesn’t know they’ve come for treatment. It’s difficult when access is a problem as they won’t have a PICC line in case people see it and ask why they have it. They pray while we are trying to cannulate them rather than agree to have one.”
>
> Nurse 4 (formal interview)

As Tinah explains in this quote, some women were suspicious of Western medicine, believing advances in science were dangerous.

> “The scriptures have predicted all the events that happen in the world and science is advancing too far and is dangerous. Scientific advances are weakening the world’s defenses to evil and making us susceptible to the devil...”
>
> Tinah Informal interview)

Others felt God was testing their faith with breast cancer, as a challenge to make positive changes in the community.

> “I kept asking God why me and then I felt some quiet and I said, ‘God you are my maker, and you need to give me the strength and wisdom to get through this. ... I felt his strength and knew that he wanted me to help others. I am very open at church and people ask to speak to me and say they have the illness as well. I guide and support them.”
>
> Susan (formal interview)

Women had differing health beliefs about the causes of the signs and symptoms they were experiencing. Women attributed their symptoms to reasons other than ill health. This was seen in women with early and with advanced breast cancer.

> “I had noticed the lump for a while, but I thought it might be a sign I could not have children, so I did not tell my husband—irrational I know.”
>
> Bola (formal interview)

Abimbola had been admitted to the hospital with pleural and pericardial effusions. This was her first presentation with advanced disease following her early breast cancer diagnosis 4 years earlier. She associated her symptoms with being cold.

> “I have been unwell for a while and thought it was because I am always cold as I work in Iceland (frozen food shop). I thought I’d been putting too much ice in my drinks. I stopped the ice but got worse and had to call the ambulance.”
>
> Abimbola (Consultation observation)

The clinical team spoke about consultations where women had not believed their cancer diagnosis and so did not return to receive treatment. Physicians spoke about how this made them feel.

> **“**It’s hard when they don’t believe the diagnosis but it’s natural to have some worries about treatments that might be toxic. I thought we were getting there with one lady after two or three visits, and one with the nurse and one with the GP, but then nobody was actually able to persuade her, and I heard later she was trying some anti-fungal treatment as someone was advising it was growing because it was a fungal infection. It was sort of distressing; we feel disempowered in some way...”
>
> Doctor 3 (formal interview)

Traditional treatments

Many women had either tried traditional treatments prior to seeking medical treatment for their breast cancer or were using traditional treatments alongside their Western medicine. Tiwa caused burns on her breast following advice from a traditional healer.

> “So, he [traditional healer] gave me a native pot to heat and use to heat the breast... it was so terrible, but I just say well, let me get results.”
>
> Tiwa (formal interview)

In an informal interview, Fatima became very animated, telling the researcher (A.S.) about traditional treatments, although she referred to them as “conventional treatments” that she had been using alongside her neoadjuvant chemotherapy. She spoke about soursop, which is a fruit; she ate the flesh and made tea with the leaves.

> “If you read the internet, it treats cancer. There is lots of research, but the pharmaceutical companies have hidden the research as they would lose money if the world knew fruit cured cancer.”
>
> Fatima (informal interview)

She also ate large amounts of garlic and onions, made juices and teas from guava and papaya, and drank sugar cane, honey, and baking soda together as she read that this cured a man’s cancer. She was rubbing frankincense into her breasts each day as she read online that this had cured a child’s brain tumor. She disclosed that she had no confidence that chemotherapy was effective but had agreed to go ahead so that she could get sick leave to pursue all her own “conventional” treatments.

> “If I’m doing ‘conventional treatments,’ I might not get sick leave to do that. If I do his treatment, at least I’ll get some sick leave as they believe I’m doing the right thing. But I’ll do my ‘conventional treatment’ as well.”
>
> Fatima (informal interview)

Her lack of interest in how the physician perceived her response to chemotherapy was observed during a consultation.

> “Fatima was not responding when the doctor said the cancer was shrinking due to the chemotherapy. She did not look at him or acknowledge the statement. When I asked her about it later, she told me ‘He may think it’s his treatment that’s working but I know it’s mine.’’
>
> Field notes from clinic observation)

Importance of women’s roles

Women spoke about the importance of women’s role and being able to fulfill caring responsibilities for their husband and family and looking good for their man.

> “In the Nigerian community, being a woman is about how you look. We are very strong women but how you present is important, soft skin, feminine things, nice nails and beautiful hair... how you look for yourself and your man. Chemotherapy can take that away and their essence of being a woman can feel diminished.”
>
> Bola (formal interview)

Fertility was particularly important in terms of proving men’s virility and women’s vitality. The potential impact of treatments on future fertility was something that concerned women and their supporters.

Fayola, a 30-year-old unmarried woman, had presented with a 15-cm breast cancer tumor and was to start neoadjuvant chemotherapy. She had delayed presenting and, to avoid further delays, egg harvesting was not being recommended. The plan was to offer Zoladex to protect her ovaries during treatment. Fayola and her female friend agreed that this was a good idea, but then her uncle started speaking to her in her native language.

> "Fayola's uncle had not spoken until this point, but he leant forward and spoke directly to Fayola whilst glaring at the doctor (Doctor 1). Fayola and her friend answered him in English, and it was obvious that he wanted assurance that she would be able to have a child in the future so he could tell her parents back home in Nigeria. He asked the doctor in English, 'why can't she have her eggs removed?' The doctor explained again that this would cause a delay to starting treatment and there was concern that the cancer was growing quickly."
>
> Field notes from clinic observation

For some, the wish to have a child remained a priority even when faced with advanced disease and poor prognosis. Tiwa had lung, liver, and brain metastases, and her wish to have a child was raised at every consultation.

> "I really want to have a child, a child like me. Every time I say it, they tell me you are going to die. You can't have a child and all that... I just want to trust in God, and I know there are miracles... if God wants me to have a child, I will have a child."
>
> Tiwa (informal interview)

Some West African men were not happy to use condoms when partners were unable to use other forms of contraception. Bola described conflicting views of herself and her husband when she became pregnant during her chemotherapy treatment.

> "I knew I couldn't have the child, but he was pleased, he felt God was showing us that I was still a woman and, as it was God's gift, the child may be well... I was clear in my head no."
>
> Bola (formal interview)

Church and community influence

Women described the different opinions and levels of support they received from their church. In some instances, the church had expressed negative views about women undergoing treatment. Susan felt pressured by people at her church not to have chemotherapy. She visibly struggled when it came to signing her consent form and later said that she had been reflecting on the views of her church and community.

> "I remember when I was at the appointment and I was meant to decide, knowing how people don't talk good about the chemo. They said it's a killer, demonic, and I remember telling Dr, you want to kill me?"
>
> Susan (informal interview)

When Chinwe was diagnosed with early breast cancer, she delayed starting neoadjuvant chemotherapy for 5 months at the advice of the church, which advocated prayer and faith. Her cancer increased in size, and she then agreed to chemotherapy, surgery, and radiotherapy. She was found to be heavily node positive by this time. She developed lung and liver metastases within 9 months of completing primary treatment and was again advised against treatment by the church.

> "My pastors tell me I shouldn't have treatment again, as they say they were right before because it did not work, and my cancer came back."
>
> Chinwe (Clinic observation)

Conversely, Elaine, a 34-year-old woman attending alone for the results of her biopsy was encouraged by the church to undergo treatment. She was distraught when told her diagnosis and threw herself on the floor sobbing. When she returned to the clinic with her partner, they were accompanied by an older woman from the church.

> "When Elaine entered the room, her partner went to sit next to her, but the older woman tapped his arm, and he moved to let her sit next to Elaine. The doctor explained that neoadjuvant chemotherapy was being recommended, and Elaine said she only wanted surgery. The older woman tapped Elaine on the arm and said, 'we all want you to be well and we need to trust in God who gives the doctors knowledge and skills... you know what you must do."
>
> Field notes from clinic observation)

Theme 2: Otherness

Otherness describes relationships that can be viewed as a way of defining one's "self" or own "identity" in relation to others.[46,47] It describes how individuals' or groups' cultural rules, boundaries, and behaviors differ from those of the dominant culture.[48] This can lead to shifts in power relationships, which in turn can lead to bias, racism, and exclusion.[26,49] This theme includes how the concept of otherness manifested in both the women and HCPs. It includes how women perceived themselves as "other" and were perceived as "other" by their family, communities, and HCPs.

Women's perceptions of themselves and others

Women described how they were regarded as "Other" by family and community members when they agreed to their recommended treatment plans.

> "I didn't feel that I had a decision to make—I needed treatment, but my aunt and cousins said you don't need to do the chemo, it won't help, women die from it. Some people say chemo means your womanhood has gone."
>
> Bola (informal interview)

Family and community perceptions

Some people in the community saw the women as "Other" for having a "White woman's illness" or accepting Western medicine. Susan described how a co-worker, who was a senior nurse, blocked her phone number as she did not want to 'catch' the bad luck from her as if she believed it was contagious.

> "I had people who didn't want to talk... one lady at work who apparently said in the office that she thought something bad would happen to her, so she actually blocked my number."
>
> Susan (formal interview)

It was clear that sometimes younger family members were frustrated when the women were not following medical advice. Isioma attended the oncology clinic with her adult daughter. She had declined chemotherapy when treated for early disease. She was lost to follow-up for 6 years before presenting with symptoms of advanced disease. She then travelled to Nigeria for several weeks while the team was trying to contact her to arrange treatment. When Isioma met doctor 1, he talked to her about treatment options, and she was again reluctant to start chemotherapy. Her daughter, clearly frustrated, said:

> "You must have proper treatment this time.' Isioma asked the doctor how long the treatment would last as she wanted to return to Nigeria for 3 months in 4 months' time. The doctor explained

> that the recommended treatment would last longer than 3 months. Isioma sighed and said, ‘I want to go.’ Her daughter said, ‘enough! This needs to stop, and you need proper treatment…’”
>
> Clinic observation

HCPs’ views of the women

HCPs viewed women and their supporters as different from other women in their care due to their behaviors and beliefs. They described finding these differences difficult to understand and deal with and felt that the beliefs and behaviors were different from other groups of women in their care.

> “They are very tricky; they present late and then refuse treatment from us… you cannot talk to them. They go to their traditional healers or just pray… It’s madness.”
>
> Surgeon 6 (informal interview)

During informal interviews, some HCPs described incidences where women’s behaviors had made them uncomfortable with loud displays of emotion, or praying during consultations. One oncologist described a consultation with Chuko.

> “I explained that her staging scans were clear, and she fell to her knees and started praying, I didn’t know what to do. I helped her up and then she got on the floor and prayed again while I was talking about the side effects of treatment. I didn’t know how to react or whether to stop or keep going.”
>
> Oncologist 3 (informal interview)

One of the nurses expressed how some women exhibited levels of distress that were uncommon. She told me about her experience when Elaine was diagnosed.

> “He (Doctor 5) told her that the biopsy showed cancer, and she became hysterical, so distraught. She threw herself on the floor and would not look at or speak to me. It was awful, I didn’t know what to do and he (doctor) left me with her as he said, ‘it was holding him up.’ She sat up after a while and was rocking but not speaking, I asked if I should call someone. She passed me her phone to call her partner. He was lovely and said he would come right away. She wouldn’t get up and kept saying ‘sorry God.’ I asked her what she meant, and she said God was angry with her for taking the pill. I didn’t know what to say.”
>
> Nurse 1 (informal interview)

The team expressed frustration that it was common for women to arrive late for appointments or attend on different days unexpectedly. One woman regularly attended several days late for chemotherapy, she occasionally disappeared for weeks. The team tried hard to be flexible to support the women who were finding it difficult to attend but this led to some operational issues and subsequently informal rules being agreed between women and the nurses. For example, Tiwa was not allowed to leave the department once she had arrived for treatment; her drugs were only prepared by the pharmacy once her arrival had been confirmed by the nurses.

> “When women are trying to hide their illness, they often need treatment on a certain day or at certain times because of what was going on, which can sometimes be a bit tricky to manage, getting the drugs from pharmacy and things like that. We must be strict as so many expensive drugs have been wasted when they don’t show.”
>
> Nurse 4 (formal interview)

Mismatch between the cultural framework/health beliefs of HCPs and the women and their supporters

Women viewed HCPs and health care systems as “Other” as they did not fit with their belief systems and cultural norms. Women described when HCPs lacked cultural understanding and insight and where information offered was presented with images of White women.

> “I really needed to talk to someone that understood black hair needs. The nurse was showing me wig pictures that were nothing like my hair… No one is going to truly understand unless they have a surname like mine or hair like mine, they are telling me things that happen to Caucasian women—this is what the West African population are struggling with and it’s the same for other cultures.”
>
> Bola (formal interview)

Theme 3: Cultural Curiosity

This theme encompasses how the women and HCPs showed different levels of cultural curiosity and understanding toward and about each other and how this affected their relationships and interactions. It includes shifts in power dynamics and understanding and the impact on clinician-patient relationships.

Levels of cultural curiosity and understanding

Women were curious about why this study was being undertaken. Most were positive about the need for the study and felt it was important that their cultural views and experiences were being considered.

> “It’s good you want to listen and learn… we need to be heard. They (clinical team) don’t know or understand us.”
>
> Chinasa (informal interview)

Others were suspicious of the researcher’s motivation and interest.

> “Why are you interested in West African women, are you really interested to help, or do you just want to get a PhD?”
>
> Bayo (informal interview)

HCPs demonstrated different levels of cultural curiosity and understanding. Some had more experience and insight into the views, needs, and experiences of this group of women.

Doctor 4 spoke to Doctor 1 about his frustration with Tiwa and her partner speaking of her wish for a child during her consultation. Doctor 4 had asked whether they were using contraception, and Tiwa said no. He said that he had been very firm about the need to use contraception whilst on treatment; otherwise, she would not be able to continue. Doctor 1 shared his concerns about the cultural impact of this discussion.

> “You need to be careful with this group of women, that partner may not know that she should not have children and now he may leave her.”
>
> Doctor 1 (Clinic observation)

Some HCPs acknowledged different priorities and needs between the women and the clinical team. At times, this led to negotiation and bartering between them to facilitate women attending for or continuing treatment. One nurse described how one woman’s priority was to ensure she got her tea and meal when she attended for treatment, and so the nurse went out of her way to arrange this as it meant the woman would attend regularly and on time.

> “The nurses and these patients have very different priorities. Our priority is to get them well, to get them in and give them their

> chemo. Their priority is to get a cup of tea and food first—it's frustrating before she says hello, she says, have you got my food? You can't be soft with her; you have to be firm otherwise you can't get through to her."
>
> Nurse 5 (formal interview)

Shifts in HCPs' cultural curiosity

Some HCPs described how they had started to think about and view the women differently during the study and were paying more attention to how the women behaved or interacted.

> "I've been thinking about these women because you are here doing the study; otherwise I probably wouldn't have thought about it as much. I remember one consultation you were in, and the lady muttered something under her breath, and you asked later if I had heard her. I didn't hear it, and I think . . . when consultations are hard, because they don't speak or ask questions and there are long silences, I'm too busy thinking about what to say next. There are probably other cues and things I miss."
>
> Doctor 6 (informal interview)

With some HCPs there was a shift from viewing the women as "difficult" to "different."

> "It can be really frustrating and difficult, but I was naïve about the population. I'm much more alert now to the specific care needs those women have and particularly how their social environments, the church influences their decision making. . . I now proactively ask. . . you know how the church influences their treatment, and whether they see that as a hindrance or a support, which I didn't really consider before. . . it's a different approach."
>
> Doctor 1 (formal interview)

Impact on relationships with HCPs

When HCPs showed interest, knowledge, or insight into the cultural challenges or views of the women, it embodied trust. This also led to a change in how women engaged with them. Some women were clear that they only wanted to see certain clinicians who they felt listened and understood them.

Esse transferred her care back to the hospital to see Doctor 1 when she was diagnosed with advanced breast cancer as she felt he allowed her to express her cultural views even if he did not agree with them.

> "So, you understand we have lots of different treatments, but this cancer cannot be cured.' Esse replied, 'you are talking medically.' The doctor continued 'are you one of these women who wants to try other things? I can tell you these things won't work on their own.' Esse replied, 'you don't know about these things. He replied, 'I think you are talking about alternative treatments like prayer, special diets and Vitamin C, what they all have in common is they are not proven to help. I can only recommend treatments that are proven to work.' Esse responded, 'you must take prayer out of that. I will have your treatment, but I only want to see you."
>
> Field notes from clinic observation

Others felt that some HCPs were dismissive of their cultural viewpoint.

> "I did mention my 'conventional' treatments, but he wasn't interested. I did ask him if there is anything else I could use and he said, 'I don't know anything about it.' I said, 'I know you know something, but you are not allowed to say—you are Mediterranean, and you know about olive oil and herbs. He didn't want to talk about it, he's not allowed. I won't see him again."
>
> Fatima (informal interview)

Discussion

This study has explored the cultural beliefs and behaviors that may affect how West African women make decisions about their breast cancer care and treatment. It is the first study to focus specifically on West African women with breast cancer in the UK.

Beliefs concerning cancer and its treatment were so embedded within the culture that it led to some women either refusing, delaying, or interrupting treatment. In some cases, the pastor/community directly forbade the women to have treatment. The treatment delays or deviations from treatment seen in this study resonate with those seen in health systems with inequitable access and limited resources (e.g., US and West Africa).[8,50-52] Previous research in the US and West Africa has indicated delays and deviations are not solely confined to limited access and suggests that cultural factors play a role.[14,53] It seems that even when access and resources are freely available (such as in the NHS), cultural factors determine treatment uptake and adherence.

Fear of cancer and taboos were so strong that some women were rejected by their loved ones and community. The belief that their diagnosis was a punishment or retribution for some wrongdoing led to not sharing their diagnosis with their family and going through treatment alone. There is evidence that women in West Africa also hide their diagnosis for fear of how they will be viewed.[54] Studies with African American women show how religious, spiritual, and cultural beliefs impact delay in diagnosis,[55] fear of stigma, and fatalism[56] and throughout the treatment trajectory.[57,58] Conversely, some women in this study believed they were "chosen" by God to be a "beacon" for change by sharing their experiences with the community. For the most part, these were women who were previously seen as having a high standing in the community, e.g., pastor's wife. In West Africa, women's treatment decisions may be influenced by other people and faith.[59]

Breast cancer was seen as a Western disease treated with Western medicine. Accompanying this belief, women spoke of mistrust and suspicion of established treatments. It was important for them to follow their "traditional treatments," believing these to be more effective. This sometimes led to individuals having chemotherapy to get time off work for traditional treatments. For the most part, women were using traditional treatments alongside their recommended breast cancer treatments. Positive effects of treatment were attributed to traditional treatments rather than established treatments. In West Africa, the use of traditional treatments are common but often easier to access and less expensive than medical care and also thought to be more effective in the context of cultural beliefs of causes of cancer.[59-61]

Differences of opinion about the benefits of conventional and traditional treatments were observed in consultations and interactions between women, their supporters, and HCPs. Some women described examples of perceived poor communication with HCPs that led to mistrust and doubt about treatments offered. Studies in the US have shown that women who perceive poor communication with HCPs around diagnosis and treatment options are more likely to refuse conventional treatment in favor of alternative therapies.[62] In West Africa, there is evidence women are not fully informed about treatment options and were sometimes misled or physicians omitted information about extent of surgery or side effects to encourage them to undergo treatment.[63,64]

HCPs in this study described feeling ill prepared to deal with displays of overwhelming emotion, prayer, and cultural expression shown by some women during consultations. It left HCPs feeling uncomfortable and unsure how to respond. Some women expressed that HCPs' negative responses to their expression of cultural or religious beliefs led to feelings of mistrust. Several studies in the US have shown HCPs lack knowledge about cultural health beliefs and understanding when caring for Black women, sometimes leading to distrust, lack of engagement with treatment, or stopping treatment completely.[29,65,66] In health care, the importance of providing culturally sensitive or culturally competent care, and providing a person-centered approach is stressed with the aim of reducing inequalities.[67] A criticism of a cultural competence approach is that it reinforces the “Other” by highlighting and considering differences in a cultural group without necessarily fully understanding the cultural complexity.[68]

Using critical ethnography provides the opportunity to explore the concept of power within the study setting, which can be used to inform service development.[37,69] At the beginning of this study, HCPs wanted to know how to change or manage West African women’s decision-making to get “them” to adhere to treatment. As the study progressed, staff developed cultural humility, demonstrating a willingness to learn and understand more about the women’s perspectives and the beliefs and rules that govern their behavior. During this process of understanding, some HCPs began to interact with women differently, listening and asking more questions and exploring how the service could better accommodate women’s needs. In the US, several studies have described HCPs’ poor understanding of cultural differences leading to poor communication and understanding of women’s beliefs and needs, and the impact these have on decision making and care.[30,65,70]

Cultural humility requires clinicians to enter into conversations with patients where they can learn and build partnerships, not only with the patients they care for but also with the communities they serve.[71,72] HCPs are required to self-reflect and critique their assumptions and beliefs and to engage on a lifelong process of change to enable mutual empowerment, partnerships, respect, and optimal care.[72-74] Findings align with other studies looking at how HCPs work with people from different communities, highlighting the challenges of balancing the traditional biomedical approach to care with a spiritual and traditional treatments approach.[75]

Strengths and Limitations

This is the first study exploring the impact of culture on breast cancer treatment decision making in West African women in the UK. A strength of this study is that data were collected from West African women, their supporters, and HCPs, allowing for multiple perspectives to be understood simultaneously. The strength of critical ethnography is that sharing findings with the participants can lead to cultural curiosity and reexamining practice. Services can then be developed and tailored to meet cultural needs more appropriately.

Findings from a critical ethnography pertain to a particular place, time, group of people, and research team. Although findings may be applicable to other areas and outcomes useful for planning change, they are not necessarily transferable. It is likely the three themes arising from these data could be applied to other cultural groups but may manifest in different ways. We acknowledge the perspectives and stories of women who did not have treatment are missing from this dataset.

A concern at the start was that the researcher was a White woman impacting on her own perceptions and on how she was perceived. The literature discusses the importance of the White researcher’s own understanding of self and their ability to question their own assumptions and biases before entering the field.[76] The importance of thinking about how these biases or assumptions may influence decisions about data collection and analysis was crucial before commencing the study.[77] This was a major discussion point with the PPI group who advised on study materials and recruitment strategies. Their advice was for the researcher to be curious and open, to build relationships and trust, and to sense check her understanding and approach. This kind of approach proved to be successful, and strong bonds were built with women, leading to them seeking the researcher out when in the clinic.

Implications for Practice

This study underlines the importance of understanding cultural beliefs and values held by the communities we serve. Understanding underlying reasons for non-adherence to treatment recommendations or late or non-attendance of appointments, such as practical barriers like childcare rather than unwillingness to conform, can lead to a more holistic and patient-centered approach to care. This may be especially pertinent when caring for people from diverse ethnic backgrounds where specific challenges and cultural barriers may play a role. The study showed by being flexible and offering alternative days or times for appointments, attendance and adherence improved, treatment delays and waste reduced, and patient and HCP relationships improved.

HCPs must seek to understand and value the perspectives and beliefs of people from unfamiliar cultures and consider how services might be made more flexible to meet their specific needs while being mutually effective.

Recommendations for Further Research

Further research is required to develop a deeper and more inclusive understanding of how culture and beliefs about health and illness influence how people from the different communities that we serve make decisions about their care and navigate cancer treatment. Further studies to identify cultural misunderstandings, mistrust of HCPs, and the influence of family and community are required to improve HCPs’ knowledge and understanding to guide service improvements to ensure culturally competent care.

Conclusion

The study aimed to understand and characterize how culture affected behavior and decision-making about treatment and care in West African women with breast cancer living in London. It demonstrates the importance of cultural curiosity among HCPs and understanding the perspectives of people from different cultures. To reduce inequalities, nurses and HCPs need to develop cultural humility by being open, listening, and understanding the cultural needs and preferences of patients. This will enable the development of culturally sensitive services.

Declaration of competing interest

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CRediT authorship contribution statement

Amanda Shewbridge: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Theresa Wiseman:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Alison Richardson:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization.

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Supplementary materials

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