Exploring Factors Contributing to Low Uptake of the NHS Breast Cancer Screening Programme among Black African Women in England

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ABSTRACT

Breast cancer is the most common cancer among women in the United Kingdom (UK) accounting for about 15% of cancer deaths. The National Breast Cancer Screening Programme in the UK was introduced in 1988 to assist with early detection and better management of breast cancer. Black and Minority Ethnic (BME) women however have a low uptake of the National Breast Screening programme when compared to their White counterparts. Within the BME group, Black African women have the lowest uptake of screening services and are more likely to have an advanced stage of the disease at diagnosis, leading to poorer survival rates than White women. This study aimed to explore the factors that lead to low uptake of the National Breast Cancer Screening Programme among Black African women living in Luton and present action points to local breast cancer services. Using a qualitative research design, six focus groups were conducted with a total of twenty-five Black African women residing in Luton between May and June in 2013. Data was analysed thematically using the framework approach. Four main themes emerged across the focus group discussions: knowledge and beliefs about breast cancer and risk factors, prevention of breast cancer and awareness of the NHS breast screening service, delays in attending the NHS breast screening service and suggestions for improving information on breast cancer and the NHS breast cancer screening service. The findings from this study suggest the need for more targeted information on breast cancer and screening services for Black African women. This could help improve the uptake of the NHS breast screening service, promote early help-seeking behaviour and improve breast cancer outcomes for this ethnic group.

Keywords: Breast cancer; Black African women; Breast screening; Luton

Introduction

Breast cancer is the most common cancer in the United Kingdom (UK), accounting for about 15% of all newly diagnosed cancers and affecting one in eight women during their lifetime [1]. The incidence of breast cancer varies according to age, family history and ethnicity [1]. Research conducted in the United States (US) and the UK reveals that although there is a lower incidence of breast cancer among Black African women when compared to their White counterparts, the former have poorer survival rates and are more prone to dying from
metastatic breast cancer [2-5]. This has been mostly attributed to a combination of genetic factors causing more aggressive tumours in Black women and advanced stages of the disease before presentation [6]. Late stage at diagnosis advances higher mortality from breast cancer [7]. Further evidence also suggest that differences in exposure to available breast screening services contribute to existing ethnic variations in breast cancer outcomes [8,9].

The National Health Service (NHS) introduced the National Breast Screening Programme (NHSBSP) in 1988 and invites women between the age range of 50-70 years old to free screening once in three years (and more frequently if there is a family risk of breast cancer) [10]. Whilst there have been debates around the benefits of breast screening versus its potential harm (over-diagnosis and overtreatment), it is well established that early screening improves chances of management and survival from breast cancer [11-13]. Evidence highlights that screening prevents about 1300 deaths from the disease annually (CRUK 2014). However, mortality from breast cancer continues to increase among Black African women, consequent upon their delayed diagnosis [14]. Black women are also known to develop breast cancer at a much younger age compared to their White counterparts [15]. Thus, early help seeking and stage at diagnosis have emerged as dominant predictors of breast cancer survival and can contribute significantly to reducing ethnic inequalities in breast cancer outcomes [7,13].

The existing evidence on ethnic inequalities in health argues that limited knowledge about cancer, cancer symptoms, cancer services and lower access to health-care services among BME groups contribute to their low uptake of cancer services [16-18]. Some research highlights that the Black African ethnic group remains marginalised in health promotion activities due to the ‘migration effect’, which suggest that recent migrants to the UK may have limited awareness of health programmes which may contribute to their low access and utilisation of specific services such as the breast screening programme [19].

Experiences of racism, stereotypes, linguistic and cultural barriers including the way in which screening guidelines are not culturally relevant have all been reported to result in disease going undetected for longer periods of time among BME populations [20-22]. Research has also reported that religion and culture influence patients’ health behaviour in terms of the perceived benefit of engaging in recommended disease prevention activities choice of treatment options and delays in help-seeking [23-26].

The aim of our study was to explore the factors that lead to low uptake of the NHSBSP among Black African women in England and present action points to the local breast cancer services. Our research focused on Black African women for three main reasons. Firstly, Black African women in England have the highest risk of death from breast cancer in the UK after adjusting for socio-economic deprivation, age, stage and treatment [8]. Secondly, there is limited UK based research reporting factors that lead to low uptake of the NHSBSP among Black African women compared to other ethnic groups. Thirdly, the Black African population in Luton (where our study’s participants were recruited) has been projected to increase by 32% from 9,600 in 2010 to 12,700 in 2030 due to significant immigration from West Africa (and the EU) [27,28]. This suggests that there is added pressure on local healthcare services to ensure that the needs of its diverse population are met in a culturally sensitive way.

Methods

Overview

There is a dearth of UK based research exploring the factors that lead to low uptake of the NHSBSP among Black African women. Therefore, a qualitative research design was used to explore this under-researched phenomenon among a sample of eligible Black African women recruited in Luton in South East England between May and June 2013 [29]. A qualitative research design enabled us to collect in-depth contextualised information in participants’ natural setting within a limited period [30]. The qualitative method has been successfully used in studies on cancer with BME groups [13,17].

Recruitment of focus group participants: The study used purposive sampling methods to recruit women who self-identified as being of Black African origin, between the age range of 35-70 years old, living in Luton and had a conversational level of English. The lower age limit was set at 35 years, as evidence highlights that there is an earlier risk of breast cancer in Black African women compared to women from other ethnic groups whilst the upper age limit of 70 years was set because this is the current maximum age limit for which women are routinely invited for the breast screening programme. Women were excluded if they had a diagnosis of breast cancer [14,31].

Participants were recruited through a local charity organisation providing walk-in social support and assistance to the Black African community in Luton and from a local church. After obtaining necessary permissions, the gatekeepers at the charity and local church enabled the researchers access to their members who were potentially eligible to participate in the research. The first author (OB) introduced the study to potential participants and provided them with an information pack containing a detailed information sheet and a consent form. Women were given the opportunity to ask questions and a minimum of 24 h to decide if they wanted to participate. Participants who registered their interest in taking part were asked to indicate their consent by signing a consent form during the OB’s follow up visit. They were then given information, time and venue for the focus group discussion to take place. Focus group discussions provided the opportunity to gather in-depth, contextualised information in this under explored area [32]. The aim was to continue recruitment until saturation was achieved in which further data did not generate any new themes [33].

Development of the discussion guide: The focus groups were conducted using a discussion guide which was developed after a review of the theoretical, empirical and policy literature on BME health, cancer, help-seeking behaviour, and with input from all authors. The discussion guide included questions
about the awareness of breast cancer (awareness of breast cancer services (information, attitudes, perceptions of cancer, risk factors, treatment options), and factors influencing the uptake of breast cancer services (awareness of breast cancer services, utilisation, role of culture and religion in decision-making), suggestions for improving help-seeking and uptake of the breast screening programme (participant suggestions). The discussion guide also included questions on demographic profile of participants such as age, country of origin, marital status, occupation, educational qualification and length of time since resident in the UK.

The focus groups: Focus group discussions were carried out between May and June in 2013. The focus groups were conducted in English Language and facilitated by the first author OB (who is a bilingual young woman in her early thirties and of Black African ethnic origin). Four focus groups (n=5; n=4; n=4; n=3) were held at the charity organisation during the women’s lunch club whilst two focus groups (n=6; n=3) took place at the church premises before the weekly bible study service. Each focus group discussion lasted for approximately 50-60 min. To ensure confidentiality, participants were requested to kindly keep all discussions within the focus group. They were also given a code to identify their narratives during the transcription of the discussion. All transcripts were kept securely on a password-protected computer with access restricted only to the first (OB) and second authors (NA).

Despite over recruiting potential participants to attend focus groups, many women did not attend due to family commitments and consequently two focus groups had 3 participants each.

Before the focus group began, the first author (OB) reconfirmed that participants were eligible, had read and understood the purpose of the study and what participation involved and given informed written consent using the consent form provided. Issues of confidentiality and audio-recording were also re-stated before the focus group commenced. As an incentive for participating, participants were provided with information materials on breast cancer (ordered from Cancer Research UK and Macmillan cancer support and written in English) and also sign-posted to other available breast screening resources.

Data analysis: The focus group discussions were audio-recorded and transcribed verbatim by the first author (OB) and checked for accuracy by the second author (NA). The data was analysed thematically using a framework approach [29]. The key stages of the framework approach of data familiarisation; identification of thematic framework; indexing; charting and mapping and interpretation, were followed to ensure rigour in the entire data analysis process [34]. The first author (OB) read and re-read the transcripts and generated the initial codes assisted with the QSR’s NVivo version 10 software package. Themes and sub-themes were identified as they emerged from the focus group discussions. To ensure reliability, the second author (NA) checked for consistency in the codes. Differences in opinion were discussed among both authors through face-to-face meetings and codes were refined after discussion. Furthermore, the demographic characteristics of participants were extracted from the focus group transcripts.

Results

Participants demographics

A total of twenty-five women (n=25) aged between 38 and 62 years took part across six focus groups. Participants originated from Kenya, Malawi, Nigeria, Zimbabwe and Zambia. Participants were married, divorced, widowed or single mothers. Most participants were of the Christian faith (n=24) whilst one (n=1) participant was a Muslim. A detailed description of participant’s demographic characteristics (Table 1).

Four main themes emerged across the focus group discussions 1) awareness and beliefs about breast cancer and risk factors, 2) prevention of breast cancer and awareness of the NHS breast screening programme, 3) low uptake of the NHS breast screening programming and 4) suggestions for improving information on breast cancer and the NHS breast cancer screening programme. These are discussed in more detail below using extracts from the focus group discussions.

| Table 1: Participants’ demographics (n=25). |
|--------------------------------------------|
| **Age (years)** |                  |                  |
| 38–44          | 11 (44)          |
| 45–55          | 12 (48)          |
| 56–65          | 2 (8)            |
| **Country of Origin** |                  |                  |
| Kenya          | 1 (4)            |
| Malawi         | 3 (12)           |
| Nigeria        | 10 (40)          |
| Zambia         | 3 (12)           |
| Zimbabwe       | 8 (32)           |
| **Marital Status** |                  |                  |
| Married        | 13 (52)          |
| Divorced       | 2 (8)            |
| Widowed        | 4 (16)           |
| Unmarried      | 6 (24)           |
| **Religion**   |                  |                  |
| Christian      | 24 (96)          |
| Muslim         | 1 (4)            |
| **Years of post–primary education** |                  |                  |
| <10 years      | 2 (8)            |
| >10 years      | 23 (92)          |
| **Occupation** |                  |                  |
| Skilled        | 16 (64)          |
| Unskilled      | 4 (16)           |
| Unemployed     | 5 (20)           |
| **Number of years resident in the UK** |                  |                  |
| >10 years      | 18 (72)          |
| >5 years <10 years | 18 (72)          |
| <5 years       | 1 (4)            |
Awareness and beliefs about breast cancer and risk factors

Awareness and beliefs about breast cancer and risk factors among our sample of Black African women came from the experiences of family or friends with cancer, information from family, friends, the Church pastor and the media. The majority of women explained that they had only heard about breast cancer after moving to the UK. All our participants associated a diagnosis of breast cancer with death:

“...It's really a death warrant because there is no cure for it, once you're told that is it” (P25, FG6).

Some women thought that cancer was a communicable disease or an infection and some felt it was a curse. All participants agreed that there was confusion about what cancer was and that there was not enough information about breast cancer:

“...I think it’s an infection...I don’t know but it is not something that you can contract...” (P11, FG3).

“We know that you can survive if it is caught early but one thing about cancer is that people don’t know much about cancer” (P4, FG1).

Participants explained that stigma associated with a cancer diagnosis is one reason why the Black African community do not discuss cancer openly. One participant explained that discussing a cancer diagnosis within the Black African community would suggest that the family carried the faulty cancer gene and this could reduce the marriage prospects of other members of the family:

“...let’s be honest, those of us that we are here you hear that the family that your daughter wants to marry into, they all have cancer; is that not a stigma? Is it not at the back of your mind that this family you want to marry into and all the women there they have cancer that what of the child you are going to have for them if she is a woman, she might have cancer as well...” (P16, FG4).

Participants mentioned a number of risk factors, which included genetic risk/‘complications’ and lifestyle factors such as diet (processed foods, red meat, a lack of natural herbs), lack of exercise, drinking alcohol and smoking, HIV, use of the contraceptive pill, overuse of prescription drugs, not breast feeding, keeping money close to the breast, standing too close to the microwave when it is on, breast enlargement procedures, engaging in particular sexual practices and using breast creams:

“...breastfeeding...it may reduce the risk because I mean the more you kind of breastfeed, I don’t know what it does to the mother but I know they said the mother does not stand the risk of contracting breast cancer and for a breast that has not really fed any baby, you know it kind of stands a chance of developing breast cancer...I don’t know...” (P20, FG5).

“I had a sister back in Africa who because her husband had another wife kept rubbing one something like that to make her very tight and that was how she developed the cancer...” (P8, FG2).

“...some [women] they allow men to...(suck the breast)...I think some they do it so much...” (P11, FG3).

“I’ve seen an African shop where they sell a cream that when people rub on their boobs, it makes it hard and firm, I think it can also cause cancer” (P7, FG2).

Despite having awareness of the risk factors associated with breast cancer, participants criticised science for not being able to identify the precise cause of breast cancer. The majority of participants explained that they associated a breast cancer diagnosis with long periods of painful treatment with poor outcomes and eventual death. Some women said that there was no treatment for breast cancer:

“...misery, pain you know people going through that chemotherapy, I hear it is quite painful...” (P13, FG3).

“yes people will feel bad because there is no treatment” (P9, FG2).

“...actually I think of death because there is no cure for cancer...” (P10, FG).

Prevention of breast cancer and awareness of the NHS breast screening programme

The majority of our participants said that they carried out breast self-examinations on a regular basis and explained that they did discuss any concerns with their GP. Some of our participants however did say that they were unsure if they were examining their breasts correctly, not sure how to examine their breasts or too frightened to examine their breasts:

“...I don’t know I’m scared...” (P18, FG2).

Whereas some participants who were eligible for breast screening were not aware of the service and had not received an invitation to the programme, many others had received an invitation to attend the NHS breast screening service and had a good awareness of the service. They explained that early screening, early detection and early treatment could lead to better outcomes:

“I think the earlier its detected, the better the chances of survival and I think it also help to reduce the cost for the NHS because it is cheaper to screen than to treat...” (P9, FG2).

Some of the participants who had received an invitation explained that they had not yet attended and those who had attended said that they delayed and had received several letter prompts from the hospital before accessing the service:

“...they asked me to come about three months ago but I just ignored it, the other invitation I got, I just tore it...myself, I just believe if there is something like that in me, I will find it out myself...” (P5, FG).

Some women expressed their sense of anxiety on receiving a letter inviting them to attend the breast screening service:

“...and when I read the letter...I just tear the letter and threw it away. I did not tell anybody because I was so panicked...” (P5, FG).
Some participants said that participating in the focus groups had prompted them to attend their next screening appointment:

"...yes...they wrote me a letter to come for breast screening but I haven’t been there...two letters... now that you have talked about it, I think I would go and try..." (P22, FG).

**Low uptake of the NHS breast screening programme**

Our participants discussed a number of reasons for their (and other Black African women) low uptake of the NHS breast screening programme. Not being registered with a GP, lack of time to attend and uncertainty about the screening procedure, the efficacy of screening, risk perceptions, anxiety about treatment options and an overreliance on religious/spiritual interventions were discussed and possible explanations for low attendance.

"I know for those who are not registered with the GP they might not get the information" (P13, FG).

"...cases of false positive or false negatives can also influence people’s decision to go for the screening especially if someone is close to somebody who had experienced it..." (P15, FG5).

Participants said that they did not feel the need to attend the screening service because they were not experiencing any symptoms requiring medical intervention. Discussions about perceptions of risk also highlighted that cancer was not seen as ‘a Black man’s disease’ and consequently screening was more relevant for White women. Awareness about treatment options focused on radiotherapy, chemotherapy and a mastectomy. Some of our participants had heard about radiotherapy and chemotherapy but explained that they did not know the difference between the treatments. All women had heard about a mastectomy and explained that fear of a mastectomy might delay attending breast screening services as the removal of a breast would have implications for their sexuality and marital relations:

"More often than not, they take off the breast...the husband might want the breast...he might not be thinking of the health implication, he might be thinking so am going to have a wife without breast, so that might influence people going for the screening because he might be saying so if there is something, they will cut your breast off and for a woman that is feeling insecure in her home..." (P17, FG).

Some women further explained that Black African women might not attend the breast screening services because they feared a diagnosis of cancer because it may mean that their husbands would leave them for another woman:

"...Sometimes they don’t want to lose their husbands and they may be thinking if I go maybe he might leave me for another woman...I know some people who have run away from their marriages because the wife is maybe HIV-positive or have breast cancer you know..." (P13, FG3).

For our participants, religious/spiritual beliefs delayed attendance at breast screening services in two ways. First some religious/spiritual ordains believe that to discuss cancer (or any other negative life condition) is to attract cancer (or that negative life condition), therefore discussion of the issue is not often promoted. Second, cancer (like other diseases) is seen as black magic/bewitchment and therefore this belief prompts ‘believers’ to opt for religious/spiritual help rather than medical intervention thus recording less attendance at breast screening services.

"...what I would say is that most African people don’t have access to facilities, most of the time when you have something like that they will just attach it to witchcraft, evil spirit..." (P16, FG).

"...that is African attitude and before you know it they will be moving from one spiritualist to another, spending money..." (P25, FG6).

"...it’s like oh my God who is that witch that has afflicted the person...so it’s...hindered some people to go for help, so instead of going to the hospital or something they start thinking of the mother in law or whoever...they don’t seek for medical help on time..." (P20, FG5).

**Suggestions for improving information on breast cancer and the NHS breast cancer screening programme**

Participants wanted more information about breast cancer and the NHS breast cancer screening service and suggested that this information should be provided through local media, local Black African media, at GP surgeries, and by the NHS at Black African community events as a way of encouraging Black African women to seek appropriate and timely interventions. Women also suggested that Black African patients who have experienced breast cancer could:

“talk about it and give encouragement to others to go for the screening” (P13, FG3).

"...you know, we can organize a kind of awareness programme even just for thirty minutes, nothing extensive, informing, so anywhere where you have small pockets of women, advise them, health issues because they will always listen...not just church...you have a small group...they will always listen..." (P16, FG6).

Specifically, in relation to the NHS breast screening programme, our participants suggested more information was needed on what happens during the screening process so that women would feel less anxious about attending appointments:

"...If we have better understanding of what the procedure is and what it entails, people might be more receptive..." (P14, FG4).

An important part of the discussion also centred on the need to include Black African church pastors and husbands in discussions on breast cancer, its risk, breast cancer services and treatment, so that they could transfer awareness to their congregations and wives.

**Discussion**

This study adds to the existing evidence base on factors that
contribute to low uptake of the NHS breast screening programme among Black African women and identified ways of improving the uptake of the service among this population in England. This is the first study in the UK that focuses on this subject area specifically among Black African women. Our findings suggest a number of salient reasons for delays in the uptake of the breast screening service, which are consistent with previous studies related to other BME groups in the UK [22,25,35-37]. Similar to our findings highlight limited awareness of the NHSBSP even though the majority of participants had arrived in the UK over ten years ago [38]. Our participants noted their fluency in English language (reading, writing, and understanding) but argued that there was a dearth of information available about breast cancer and the NHSBSP for them to confidently understand risk factors, services and treatment options. It is possible that study participants below the age of 50 years were not privy to breast screening information because they were not yet eligible for invitation to the NHSBSP, which is targeted at women aged 50 years and above. Nevertheless, given that, Black African women are prone to developing breast cancer at an earlier age compared to other ethnic women, increasing awareness regarding breast health and the importance of early cancer diagnosis among the general Black African community could help both younger and older women to be more breast aware and embrace screening opportunities whenever such arises.

Similar to previous studies, our study identified that risk perception impacts on access and utilisation of the NHSBSP. Although our participants acknowledged genetic/heritary and lifestyle as risk factors for breast cancer, they did not perceive themselves as being at risk of developing the disease and felt that being symptom-free meant that they did not need to attend breast screening [22,24,34]. There were a number of cultural and religious/spiritual explanations for risk associated with breast cancer and black magic/witchcraft was seen as an important risk factor. Our participants also did not see age as a risk factor for breast cancer, in resonance with evidence [35].

Overall, our participants perceived breast cancer as being a Western disease with higher prevalence in the UK than in their originating countries (International Agency for Research on Cancer), which also contributed to their perception of being at low risk of breast cancer. Obviously, participant’s perception of not being at risk of breast cancer contributes to their low uptake of the NHSBSP [39]. This finding supports the Health Belief Model (HBM) which incorporates risk perception as a core determinant of people’s health behaviour and their decision to utilise preventive health-care programmes [23]. Moreover, evidence shows that actions taken by ethnic minority populations to minimise their breast cancer risk is often influenced by their personal perception of risk which could emanate from cultural and possibly religious ideas regarding cancer [13]. Thus the decision to attend the NHSBSP becomes a complex process with differing patterns across different ethnic groups [23].

Religion and culture influenced Black African women’s uptake of the NHSBSP. Consistent with findings from other studies, our participants expressed fatalistic attitudes to cancer and attributed cancer diagnosis to inevitable death [22,40]. There was a reliance on God’s protection and consequently the first pathway to care was identified as religious/spiritual healing rather than cancer services. Supporting earlier recommendations from previous research, our participants suggested that religious leaders should be actively involved in disseminating breast screening information at the religious levels [41,42]. Participants explained that their cultural values meant that women were averse to exposing their breasts and consequently reluctant to attend breast screening. Our findings also highlight a high level of anxiety associated with the possibility of receiving a cancer diagnosis, which was leading to delay in attending the NHSBSP. Previous research also suggested anxiety as a barrier to the uptake of cancer services [22,36]. For some of our participants, a cancer diagnosis was seen as a threat to their femininity and had the potential of having a negative impact on marital sexual relations.

Interestingly, participants in this study did not report perceptions of racial discrimination or language barriers from health-care professionals or marginalisation in health promotion activities as predicated by Okereke [18]. When prompted, many participants noted that they do have access to their GPs whenever they require such services and did not report negative experiences of health-care. They unanimously attributed the low attendance of Black African women at the NHSBSP to limited awareness and information about breast cancer, breast cancer services and treatment options and consequently suggested the need for an increased awareness of the programme, targeted at Black African women.

Study limitations and next steps

The qualitative research design used for this study allowed for the collection of in-depth contextualised information and brings to fore the voices of ‘marginalised’ women by focussing on their narratives and identifying ways of improving their breast cancer awareness and help-seeking. However, this was a small-scale study carried out with twenty-five Black African women in Luton and generated culturally informed knowledge, which was context specific. The sample did not include all African national/ethnic or religious groups settled in Luton and thus we acknowledge that the findings may not be generalisable to all Black African settlers in the UK. Also, comments on influence of religion may only be applicable to the Christian faith as majority of the participants in this study were Christians with only one Muslim participant. Future research should explore the views of Muslim Black African women in the UK to compare and contrast findings and untangle cultural influences from national origin versus religious influences. Quite a few of our participants were below the current screening age of 50 years’ old which might have compounded their low breast cancer awareness. However, the women were able to provide useful culturally-specific information regarding their perceptions of breast cancer and breast screening uptake.

Conclusion

There is now an established evidence base highlighting that stage at diagnosis is the dominant predictor of breast cancer
survival and contributes significantly to the observed ethnic differences in breast cancer outcome. Black African women are identified as having the worst outcomes due to delayed presentation of breast cancer. Our findings identified salient factors leading to low uptake of the NHS Breast Screening programme by Black African women in England. Findings are similar to those found in previous studies that have focused on BME groups. Our participants suggest that disseminating cancer, cancer screening and cancer treatment messages through faith settings, religious leaders, Church/Mosque newsletters, target social centres and local Black African media channels could potentially facilitate an increased uptake of breast cancer services among this population. Information provided through breast health leaflets and media advertisements should also be tailored to appeal to the Black African audience. Offering appropriate and culturally sensitive pre-screening and post-screening counselling services could also help increase the women’s awareness about breast cancer, reduce their perceptions of the stigma associated with cancer and allay their fears of fatal breast cancer outcomes. Unfortunately, there is a dearth of evidence to inform productive interventions to improve breast-screening uptake by Black African women. This study makes a contribution towards understanding the complexity of issues that lead to the low uptake of breast screening services and highlights the need for culturally sensitive interventions tailored to help improve Black African women’s uptake of the NHS breast screening programme.

Ethical approval

The study was approved on 22nd April 2013 by the Ethics Committee of the Institute of Health Research, University of Bedfordshire (IHREC 189).

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The authors do not declare any conflict of interest regarding this research, authorship, and/or publication of this paper.

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