

ORIGINAL ARTICLE

Health care experiences of Black cancer survivors: A qualitative study exploring drivers of low and high Consumer Assessment of Healthcare Providers and Systems global ratings of care

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Abstract

Background: The purpose of this study was to understand the experiences of Black patients with cancer in health care by comparing drivers of high and low ratings.

Methods: Semistructured in-depth interviews were conducted with 18 Black patients with cancer recruited from cancer survivorship support groups and Facebook between May 2019 and March 2020. Interviews were coded across all transcripts by using a thematic analysis approach before comparing low- and high-rating groups.

Results: There were three major themes that influenced whether patients rated their care as low or high, which included the patient-provider relationship, health care staff interactions, and cancer care coordination. For example, the high-rating group described good communication with the health care team as physicians listening to their needs, being responsive to their concerns, and providing recommendations on how to address side effects. In contrast, the low-rating group described poor communication with their health care team as their needs being dismissed and being excluded from decision-making processes. Additionally, there were two distinct themes that influenced patients' low ratings: insurance and financial toxicity issues and experiences of health care discrimination.

Conclusions: In an effort to promote equitable cancer care experiences for Black patients, it is important that health systems work to prioritize patient interactions with health care providers and staff, comprehensive care management for patients with cancer, and reductions in the financial burden of caring for cancer.

KEYWORDS

cancer survivorship, health care experiences, qualitative

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INTRODUCTION

Patient experiences with health care are associated with clinical health outcomes and health care quality measures, including improved self-reported physical and mental health, decreased acute care use, and more highly rated physician quality.^{1,2} Specifically, responses to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey of patient experiences with care have been associated with the likelihood of receiving and complying with appropriate treatment for complex chronic conditions and receiving preventive care for these conditions.¹ As the clinical utility of CAHPS surveys has become more apparent, results of CAHPS surveys have become important metrics incorporated into standardized reporting of health care quality and outcomes, including public reporting on health plans and hospitals and inclusion as an element of Medicare reimbursement.^{3–6} However, as health systems attempt to improve patient experiences with care, an in-depth understanding of the factors contributing to poor experiences, particularly for racial and ethnic minorities, is necessary to reduce disparities in care experiences and health outcomes.

In the United States, over 445 people in every 100,000 will be diagnosed with cancer, and among Black people this figure jumps to approximately 459 people per every 100,000.⁷ With the growing number of patients with cancer in the United States, experiences with health care represent an important driver of health outcomes. Recent work has demonstrated that CAHPS patient experiences with care, such as excellent experiences with customer service, getting care quickly, and getting needed prescription drugs, are associated with earlier stages of breast and colorectal cancer at diagnosis and less aggressive prostate cancer at diagnosis.^{8–10} In addition, after a cancer diagnosis, CAHPS patient experiences with care, such as global ratings of personal physicians and specialist physicians, are associated with increased adherence to cancer surveillance guidelines.¹¹ Although findings among cancer survivors were not specific to patient race and ethnicity, results among newly diagnosed patients were consistently specific to only Black patients with cancer, which showed that experiences with care seem to have a unique influence on cancer detection outcomes among Black patients. Thus, it is crucial to understand the factors that influence excellent and non-excellent ratings of experiences with care among Black patients with cancer because improvements in these experiences are strongly associated with improved cancer outcomes for this vulnerable population.

We have previously found by using data from Surveillance, Epidemiology, and End Results–CAHPS surveys that non-Hispanic Black patients with cancer had significantly lower adjusted mean scores for getting needed prescription drugs, getting care quickly, and getting needed care and overall lower ratings of their health care compared to non-Hispanic White patients.^{8,9} Various studies have also shown that Black patients are often subject to discrimination in health care settings.^{12,13} For example, among Medicaid-insured patients, Black patients perceived the highest rates of discrimination in health care settings compared to other racial and ethnic groups. This

perceived discrimination was sequentially and consistently associated with lower ratings of experiences with care in CAHPS surveys.¹⁴ Black patients are at an increased risk of reporting poor experiences with their care, and poor patients' experiences with care appear to be highly influential components of early cancer detection and outcomes. Therefore, the present study used qualitative interviews to understand the underlying factors contributing to ratings of care among Black patients with cancer; specifically, we sought to understand the factors that influence high and low ratings of the experience of Black patients with cancer with their care.

MATERIALS AND METHODS

Study population and design

A qualitative study with semistructured interviews was conducted with 18 African American or Black patients with cancer. Ethical approval was granted by the University of Southern California's institutional review board before the study commenced.

Participant recruitment and data collection

Participants were recruited from cancer survivorship support groups and Facebook between May 2019 and March 2020 (detailed previously).¹⁵ Inclusion criteria were (1) a diagnosis of cancer, (2) completion of cancer treatment, and (3) self-identification as African American/Black.

Data collection procedures included the research team explaining the study information sheet, asking participants for verbal consent, and requesting permission to record the interview. The interview instrument asked participants four primary questions, which were to (1) rate their primary care provider, specialist, health plan, and prescription drug plan in the last 6 months and (2) elaborate on their ratings. The four questions were taken directly from the CAHPS Clinician & Group survey and used a scale of 0–10, with 0 being the worst care and 10 being the best possible care. Interviews were conducted in English and lasted approximately 45–60 min, and participants received a \$40 gift card for their cooperation. Interviews were recorded and professionally transcribed, and the content was uploaded into Dedoose software.

Data analysis

We used a three-step process to analyze these qualitative data.¹⁶ First, two researchers coded all of the interviews by using a thematic analysis approach of facilitators and barriers to patient experiences.¹⁷ Thematic analysis was selected as the analytic approach because it allowed a combination of both inductive and deductive methods to be used, whereby the main categories and themes were identified from the data (inductive) and refined in light of existing

research (deductive). The two research coders independently read, familiarized themselves with the data, and coded initial transcripts to identify early themes for discussion. We developed a list of codes inductively by using a constant comparison approach to identify concepts and themes that emerged within the data.¹⁸ Then, C.Y.O.-D., A.I.-P., and A.J.F. met to refocus the analysis at the broader level of the themes (e.g., from codes to themes). Lastly, we refined the codebook to include inductive and deductive concepts and capture emerging themes. During this iterative process, the research team noticed that there were some noticeable thematic differences in the survivors' experiences based on the participants' ratings. Therefore, the research team decided that separating the participants into two groups would help enrich our understanding of potential drivers of high- and low-rating experiences.

Once all the interviews were coded, we then grouped participants into two groups (low and high rating). We used the four global ratings of health care questions from the CAHPS survey, which asked about their ratings of primary care provider, specialist, health plan, and prescription drug plan in the last 6 months. Response options were from 0 to 10 (worst possible to best possible). To group participants into low- and high-rating groups, we averaged the scores of CAHPS overall rating questions and calculated the median split, which was 8. The median split was used because previous studies have found that patient ratings tend to trend toward the upper extremes. In our study, the low-rating group's scores ($n = 10$) ranged from 5.75 to 8 and the high-rating group's scores ($n = 8$) ranged from 8.25 to 9.75. Lastly, the coded interview transcripts were explored, compared, and contrasted between the two groups.¹⁶ Once all themes had been defined, the coded extracts for each theme were summarized for low and high raters to facilitate direct comparisons. At this final stage in the analysis, to improve the reliability of the findings, other team members not directly involved in the data collection or analysis met multiple times to discuss the findings.

RESULTS

Sample characteristics by low and high raters

Overall, the interviewees were predominantly female patients with breast cancer. Participants in the low-rating group were on average younger (56 years old), reported higher education levels (e.g., bachelor's and master's degrees), and had a higher income. Participants in the high-rating group were on average older (66 years old), and a larger proportion reported being widowed than participants in the low-rating group (Table 1).

Similarities of high- and low-rating groups

Both the high- and low-rating groups identified three common themes: patient-provider relationship, interactions with health care

TABLE 1 Participant characteristics ($N = 18$).

Characteristics	Low rating ($n = 10$)	High rating ($n = 8$)
Sex, No. (%)		
Male	1 (10.0)	2 (25.0)
Female	9 (90.0)	6 (75.0)
Age, mean (SD), years	56.2 (16.8)	66.0 (19.4)
Range	34–75	29–88
Marital status, No. (%)		
Single	3 (37.5)	2 (25.0)
Married	2 (25.0)	2 (25.0)
Divorced	3 (37.5)	1 (12.5)
Widowed	0 (0.0)	3 (37.5)
Highest education level, No. (%)		
High school	0 (0.0)	2 (25.0)
Some college	3 (37.5)	4 (50.0)
Bachelor's	3 (37.5)	1 (12.5)
Master's	2 (25.0)	1 (12.5)
Household income, No. (%)		
<\$20,000	1 (12.5)	3 (37.5)
\$20,000–\$39,999	1 (12.5)	0 (0.0)
\$40,000–\$59,999	1 (12.5)	1 (12.5)
\$60,000–\$79,999	1 (12.5)	2 (25.0)
\$80,000–\$99,999	2 (25.0)	0 (0.0)
≥\$100,000	2 (25.0)	2 (25.0)
Household composition, No. (%)		
1	2 (25.0)	3 (37.50)
2	5 (62.5)	2 (25.00)
3	0 (0.0)	3 (37.50)
4	1 (12.5)	0 (0.00)
Type of health insurance, No. (%)		
Public	3 (37.5)	3 (37.50)
Private	4 (50.0)	5 (62.50)
Other	1 (12.5)	0 (0.00)
Cancer type, No. (%)		
Breast	5 (62.5)	5 (62.50)
Prostate	1 (12.5)	2 (25.00)
Colorectal	2 (25.0)	1 (12.50)
Type of medical facility (initial treatment), No. (%)		
Private	5 (62.5)	4 (50.0)
Public	0 (0.0)	1 (12.5)
Teaching/academic	2 (25.0)	3 (37.5)
Other	1 (12.5)	0 (0.0)

(Continues)

TABLE 1 (Continued)

Characteristics	Low rating (n = 10)	High rating (n = 8)
Global ratings, mean (SD)		
Personal physician	6.6 (3.1)	8.3 (1.6)
Specialist	9.1 (1.1)	9.8 (0.5)
Health plan	6.5 (2.2)	9.0 (1.2)
Prescription drug plan	7.1 (1.9)	9.3 (1.8)

staff, and coordination of cancer care (see Table 2). However, there were contextual differences in how they described these themes.

Theme 1: Patient–provider relationship included communication and feeling respected

Participants in the high-rating group described good communication with the health care team as physicians taking the time to listen to their needs, being responsive to their concerns about health symptoms, and providing recommendations for treatment while addressing side effects. When physicians took the time to listen and explain information, participants felt comfortable communicating their health concerns with their medical care team, which is vital to monitoring and evaluating their overall health. One participant even shared that her physician explained everything to her, from what was going on to what could happen, and that his “willingness to help [her] and teach her, showed [her] how to survive.” The low-rating group, in contrast, described poor communication with their health care team as patients’ health care needs being dismissed or excluded in decision-making processes. These participants also described that their physicians did not share enough information regarding chemotherapy side effects, psychological effects, and survivorship, which put pressure on the patients to find health information and resources on their own. For example, one participant shared the following:

I wish we, as African Americans, could be told about all of the treatments available to us, so we are aware. I want to believe that my oncologist would have told me about the oral [chemotherapy], but I’m not sure if he would have had I not brought it up to him.

Participants in the high-rating group almost uniformly mentioned that being treated with respect by the health care team helped them develop relationships. Participants shared specific behaviors that conveyed respect, including being treated as an individual (versus just another patient or a statistic) and engaging patients as an active part of their health care team. Those who reported that being treated as an individual was a form of respect described their providers as polite, welcoming of their input, and not in a hurry to go to the next patient. One participant said, “I had the privacy, and I had the care at the same time,” and another said, “The doctor was very understanding.” Most members in this group perceived feeling like a team

when the physicians showed they cared, were considerate, and treated them equally when making medical decisions. With these demonstrations of respect, participants consistently expressed they “developed a good [patient–physician] relationship” and “received the best of care.”

On the contrary, the low-rating group described how their demographic background interacted with aspects of their care and, in some cases, led to lower ratings of care due to feeling a lack of respect from their health care team and poor connection with their medical providers. Some patients described instances where they felt a lack of respect as they were “pushed aside” or “forgotten about” when waiting to receive care. Other patients described that they felt their symptoms were dismissed in certain interactions with their providers or specialists and that their concerns were overlooked. This led to patients having delayed screening examinations or forgoing care altogether. Some patients described feeling like their interactions were rushed or transactional, which led to an overall feeling that there was no established relationship with their provider.

Theme 2: Interactions with health care staff

Both the high- and low-rating groups believed that the support received from medical staff before, during, and after a medical visit influenced their patient experience with their medical care. The high-rating group expressed that they were satisfied with the care they received because it was “welcoming,” “convenient,” and “personalized.” For example, participants described their customer service experience as “gentle, patient, humble and helpful” and shared that “the nurses advocated for [them].” These positive customer service experiences provided participants with trust in the medical care team throughout their cancer journey. In contrast, the low-rating group generally had a less favorable experience, often reporting a lack of organization, accessibility, and responsiveness within their medical care team.

Some respondents in the low-rating group also reported that their expectations were not met because their health care team “lacked empathy” and did not “pay attention” to them. For instance, one participant shared getting into an argument with the billing department because she was inquiring about making payments, and the billing department was “extremely rude” and refused to work with the patient to resolve their billing issues.

Theme 3: Coordination of cancer care

The high- and low-rating groups reported how receiving coordinated care from the various members of their health care team impacted their overall care. Both provided detailed accounts of the complex but necessary range of health care activities from members of a care team and various providers, which required a deliberate organization to facilitate the appropriate delivery of health care services. Participants with high ratings shared that effective care coordination

TABLE 2 Description of similar themes based on the high- and low-rating groups.

Theme	High overall rating	Low overall rating
Physician–patient relationship	<ul style="list-style-type: none"> Communication with health care team Physician takes time and listens to patient needs Responsive to patient concerns about health symptoms and provides recommendations Physicians make patients feel comfortable, reassure patients to ask questions, and answer all questions Explains and gives patients information to review and help with medical decision-making Patient is able to talk to their personal physician by phone even after treatment or via email <p>Feeling respected</p> <ul style="list-style-type: none"> Physicians who make a patient feel comfortable and welcomed and are personable Feeling like they are an active part of their health care team Development of a good patient–physician relationship Friendly and caring physician and staff 	<ul style="list-style-type: none"> Communication with health care team Health care team does not listen to or care for patient needs Lack of communication about psychological effects, chemotherapy effects, and life after cancer Patients are not told about all treatment options available and are not included in the decision-making process Patient does not feel comfortable talking to their personal physician <p>Feeling respected</p> <ul style="list-style-type: none"> Feeling like their provider interactions were rushed or transactional in nature Patients express there was no established relationship with their provider
Interactions with health care staff	<ul style="list-style-type: none"> Various ways to make a physician appointment, which helps with the timeliness of the physician visit Timely health screening procedures conducted Patient feels welcome and comfortable during their physician visit or hospital stay Nurses advocate on behalf of patient 	<ul style="list-style-type: none"> Physician visit felt like a business transaction and rushed Lack of organization, accessibility, and responsiveness from the physician's office Workers and staff lack courtesy or have bad attitudes Long wait times during physician appointment and to get prescriptions Difficulties making an appointment, getting a hold of, and communicating with physician
Coordination of cancer care	<ul style="list-style-type: none"> Ensuring that the patient's appointment meets their needs (e.g., during patient's work lunch break) Scheduling multiple procedures in a timely manner Timeliness and ensuring medical procedures are accessible to patients Communication between primary and specialist physicians 	<ul style="list-style-type: none"> Slow with referrals or lacking referrals to a specialist Physician does not do comprehensive testing that patient wants for cancer surveillance Primary physician is not available but the patient needs to go through the physician for a referral—delay of care Primary physician only communicates with specialist physicians but not patient after cancer diagnosis Difficulty in find a therapist who deals with medical post-traumatic stress disorder

consisted of a timely scheduling of procedures that met patients' needs and constant communication between all medical providers. One patient described how effective and timely communication between two physicians helps with care coordination because it is difficult for them to explain things to different providers.

[My] personal doctor is very big on making sure that any lab work that gets done with him, he'll send it completely to the oncologist to make sure that he knows what's going on, and then vice versa.... He'll have his office talk to this office, and they understand what's best, necessary for me to continue getting better in my health.

On the other hand, in the low-rating group, some expressed that it was "pretty inefficient" and challenging to share information between their different health systems and medical providers. Participants described that a lack of communication among the medical care team interfered with getting approvals for procedures and timely

referrals. At the same time, most participants described that to make an appointment to see their physician, they needed to communicate with the physician's staff. Some experienced difficulties that delayed them from seeing their physician. One participant recounted the following:

I would have to call back two, three times and... either...the referral girl was not at her desk, or they would call me back, and they never called me back, I always had to call back again. And then only, only to have them say, "Well, it hasn't been approved yet, I'll resubmit."

Distinct themes/factors of the low-rating group

The low-rating group consistently mentioned two distinct themes, which were (1) insurance issues and financial toxicity and (2) health care discrimination (see Table 3).

TABLE 3 Distinct research findings for the low-rating group.

Theme	Description and data sample
Health care discrimination	<ul style="list-style-type: none"> • African American/Black patients perceive care received as not the highest standard of treatment • Experience feeling pushed aside for another race and being made to wait longer than others because they are Black • Physician dismissive of patient symptoms and delays screening examinations • Metal detectors to get into facility make patient feel like a suspect
Insurance issues and financial toxicity	<ul style="list-style-type: none"> • Patients with cancer file bankruptcy “money factor” • Services/health plans are “expensive” with high deductibles and out-of-pocket costs • Health insurance barriers and costs of medication limit which prescription drugs patients get and where they fill their prescription • Lack of health insurance coverage and research on financial situations • Forgoing examinations because of lack of insurance coverage • “Pay [a] co-pay to see primary [physician] to get a referral and co-pay someone else” • Having to call a health plan for a procedure that was not approved • Difficulties with referrals and approvals to various aspects of care, including chiropractor, dental, and vision • Feeling stuck with their health plan because of not wanting to lose current providers • Health insurance approval for medical tests/examinations • Difficulties with talking to health insurance about coverage and flexibility from billing about payments

Theme 1: Insurance issues and financial toxicity

The low-rating group described “expensive” out-of-pocket costs and “having to fight [with] their health insurance” about the lack of coverage. These negative experiences often led to delays in screening services, difficulties taking prescription medications, and high copays that led to stopping health services prematurely or forgoing care, all of which ultimately contribute to financial toxicity.

Theme 2: Health care discrimination

Health care discrimination manifested via provider actions that made Black patients with cancer feel like they were being treated differently. Patients explained that their concerns and needs were dismissed by their providers or they were left unattended in the waiting room despite checking in before other patients. The overall cancer care environment could be described as unwelcoming by patients who had lower ratings, which contributed to feeling discriminated against. For example, one patient shared having to walk through metal detectors to enter his care facility, making him feel like a suspect. Furthermore, the lack of diversity and representation of providers and specialists within cancer care also contributed to low ratings. Some patients felt that “African Americans do not receive the highest standard of care,” and the lack of representation exacerbated this belief.

DISCUSSION

This qualitative study provides an in-depth understanding of the factors that affect the health care experiences of Black patients with cancer. Our analyses show common and unique factors driving low and high ratings among Black patients with cancer. Three major themes that influenced how patients rated their care were the

patient–provider relationship, health care staff interactions, and cancer care coordination. Patients who had a lower rating of care discussed insurance and financial toxicity issues and experiences of health care discrimination that made them feel they were not receiving the best standard of care.

Our findings of the three common themes for both groups are consistent with prior research that has found that interpersonal, organizational, and systemic factors contribute to the quality of care.^{15,19} However, our study extends prior research by describing differences between Black patients with cancer in the low- and high-rating groups of experiences with care. For instance, a previous qualitative study among Black patients with breast cancer found that even when women described their patient–provider communication as “good,” these conversations were often one sided, which meant that the physicians dominated the conversations and shared too much information, which resulted in a lack of information being retained by the patient.²⁰ In this study, we found that, compared to the low-rating group, the high-rating group noted the importance of two-way communication to develop a positive patient–provider relationship. Patients felt comfortable sharing concerns with their providers, which also establishes rapport. An essential step in building trust with the health care team is feeling respected; in our study, the high-rating participants shared that feeling respected by the health care team facilitated their involvement in making medical decisions. The low-rating participants described feeling dismissed and pushed aside. Prior qualitative work focused on understanding patient-centered care describes the importance of reciprocity in treating others with respect for Black patients with cancer.²¹ Thus, it is not surprising that those in the high-rating group emphasized the importance of feeling respected in our study.

The results of our study point to the need to improve patient experiences for diverse patient populations. A previous study among a random sample of primary care practices examined the use of a CAHPS survey to improve patient-centered medical home care and found that standardizing how care was delivered and sharing the best

practices to improve provider–patient interactions were most beneficial.²² However, this study did not report patients' demographic information, nor did it consider specific characteristics that may be important for Black patients. Our study suggests that interventions for Black patients with cancer should also include strategies to address financial toxicity and health care discrimination.

Our findings contribute to the literature about the distinct factors for Black patients with cancer with low ratings of their overall health care. Participants clearly expressed specific issues of financial toxicity as affecting all aspects of their cancer care, which ultimately affected their medication adherence, surveillance, and preventive care and interrupted their daily lives. Beyond insurance issues, patients described difficulties with billing options and pointed to a need to improve processes regarding the approval of procedures in a timely manner.²¹ Our results indicate that financial support and resources are essential for Black patients with cancer and should be offered to them because they are linked to the underuse of health care services and the subsequent risk of adverse health outcomes. The impact of social and economic need resources, commonly referred to as social determinants of health, has been widely found to affect cancer care delivery and the health of Black patients.²³ Furthermore, our study identifies how Black patients with cancer perceived health care discrimination via provider interactions and the overall health care setting. Our findings highlight modifiable factors that may be addressed to reduce discrimination in health care, which is a barrier for Black patients with cancer, such as listening to patients' concerns, creating a welcoming environment where patients feel comfortable sharing information, and increasing diversity representation in the health care workforce.

Furthermore, although our study did not make comparisons of Black patients with cancer compared to White patients, many of the emergent themes such as health care discrimination and financial toxicity may be specific to racial and ethnic minorities. For example, Anderson and colleagues conducted focus groups with women diagnosed with early-stage breast cancer to examine the similarities and differences in patient perspectives of communication needs between Black and White breast cancer survivors.²⁴ Black women were more likely to report experiencing poorer communication with providers than White women. Our study explores beyond the communication needs of Black patients with cancer to investigate other aspects of care that drive low and high ratings. Furthermore, within the Medicare population of beneficiaries, Collins et al. found that a joint test of the interaction between CAHPS measures and racial/ethnic/language subgroups was statistically significant ($p < .0001$), which suggested that the importance of the CAHPS measures such as physician communication and getting needed care varied across subgroups whereas physician communication and getting care quickly were the strongest predictors of global ratings of care for African Americans.²⁵ Still, further research is needed to determine how unique or similar these factors are in other racial and ethnic groups.

Overall, the use of a qualitative approach that consisted of a thematic and comparative analysis helped to improve our understanding of how patient experiences may be enhanced. By qualitatively comparing our low- and high-rating groups, we explored and highlighted the similarities and differences in factors that influence the experiences of Black patients with cancer. It is also important that we consider the limitations of our study. First, in the conceptualization of this study, we had not constructed our data collection procedures to compare these two groups. However, it is clear that there are similarities and differences in how participants describe their experiences based on how they rated their overall health care. Additionally, most participants had breast cancer, higher socioeconomic status, and private insurance, which may limit the generalizability of our findings. Future studies should explore how participants describe their health care experiences among cancer survivors who have lower socioeconomic status and who are not insured, given that their experiences may be different.

In conclusion, as health care practices aim to improve patient experiences with care, our study emphasizes the critical need to focus on the unique experiences of Black patients with cancer. Our study lays out various ways that health care teams may improve patient care experiences for Black patients with cancer and positively affect health care outcomes. The results of this study highlight how insurance issues, financial toxicity, and health care discrimination affect the low-rating group—which compounds existing risk and further marginalizes this population over those with high ratings.

AUTHOR CONTRIBUTIONS

Carol Y. Ochoa-Dominguez: Conceptualization, methodology, formal analysis, writing—original draft, and writing—review and editing. **Albert J. Farias:** Funding acquisition, conceptualization, data collection, and writing—review and editing. All authors contributed to the interpretation of data analysis, writing—review and editing, and approval of the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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