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Breast Reconstruction Awareness: Targeting Health Literacy through Community Engagement

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Abstract

Background: After mastectomy, women of color undergo breast reconstruction at disproportionately lower rates than their Caucasian counterparts. In this study we address health literacy, a modifiable contributor to this disparity, through community engagement. **Methods:** In collaboration with a large church in West Philadelphia PA, the Abramson Cancer Center, the division of plastic surgery at the University of Pennsylvania, and with funding from the Plastic Surgery Foundation, the authors developed a health awareness symposium centered on breast reconstruction. This program, targeting women of color, included lectures, patient testimonials and a Q&A session. Participants completed pre and post-symposium surveys focusing on the availability, timing and options for breast reconstruction. **Results:** A total of 63 community members attended the symposium. Participants were mostly female (88.9%) and of African American descent (87.3%). Half were current breast cancer patients while 24% identified as family members/friends of a breast cancer patient. Prior to the session, 12.7% of participants were unaware of breast reconstruction as a treatment option after mastectomy, while 42.8% were unaware of insurance coverage for breast reconstruction and contralateral balancing procedures. There were statistically significant increases in the number of participants responding correctly to questions regarding insurance coverage, timing of reconstruction, and reconstruction options after the program as compared to before. **Conclusions:** The etiology of the existing disparity in breast reconstruction is complex and multifactorial. Partnerships between community groups and healthcare professionals from plastic surgery and breast surgery to create targeted interventions can improve community awareness in an effort to alleviate the current disparity.

Keywords

Breast Reconstruction, Disparity, Health Literacy, Community Engagement, Patient Education

1. Introduction

With the introduction of The Women's Health and Cancer Rights Act (Department of Health and Human Services, 2018), mandating complete insurance coverage of reconstructive procedures related to breast cancer surgery, post mastectomy breast reconstruction has become well regarded as a standard of care. Unfortunately, despite well-documented psychosocial benefits (Fanakidou et al., 2018; Eltahir et al., 2013), women of color continue to undergo breast reconstruction at disproportionately lower rates than their Caucasian counterparts (Butler et al., 2016; Nelson et al., 2012). This disparity persists even when both insurance status and geographical access to a plastic surgeon are taken into account (Butler et al., 2017). The underlying etiology of the observed trend represents a complex interplay between patient preference/choice, cultural image of self, beliefs about medicine, health literacy and awareness, and physician implicit/explicit bias. In this study, we address community health literacy, one of the modifiable contributors to this disparity.

Identifying and implementing strategies to mitigate the various disparities observed in surgery have rightfully become a major research focus within the field; to the extent that in 2015 the American College of Surgeons and the National Institutes of Health-National Institute of Minority Health and Disparities convened a research summit to develop a national surgical disparities research agenda. Fostering engagement and community outreach in order to optimize patient education and health literacy was identified as one of the five priorities for surgical disparities research (Haider et al., 2016). Interventions concentrating on community engagement have been successfully implemented across multiple surgical disciplines (Hoffman et al., 2016; Santos et al., 2017; Hempstead et al., 2018; Hurd et al., 2003). Through a community-based symposium directed at women of color in Philadelphia, we sought to improve knowledge of breast reconstruction options after oncologic breast surgery.

2. Methods

In collaboration with a large well-known church in West Philadelphia, PA, the Abramson Cancer Center, and the division of Plastic Surgery at the University of Pennsylvania, we developed a health awareness symposium about breast reconstruction after mastectomy. The 4-hour program, held in April of 2017, consisted of short lectures on breast health, breast cancer screening, treatment modalities, breast reconstruction options, patient testimonials, and concluded with a panel-based Q & A session. The lecture sessions were followed by an exhibitor fair, during which samples of implants, wigs, bras, and prosthesis were available for patients to experience. Participants were also introduced to the survivorship resources provided by the Abramson Cancer Center. These include an annual survivorship event hosted by the cancer center and long-term clinic and telephone follow up carried out by a breast nurse navigator, several breast health nurse practitioners, and survivorship/high-risk clinic providers. The number of participants who presented to the educational session determined the sample size of the study. All participants were invited to complete pre and post surveys without exclusion criteria. The surveys, designed by the senior author, consisted of questions about the availability, insurance coverage, timing and options for breast reconstruction to assess knowledge attainment designed. Survey questions were formatted as general statements with three response options: true, false and I don't know. One question regarding the impact of breast reconstruction on body image was presented as statement with response options on a 5-point Likert scale (strongly agree, somewhat agree, neutral, somewhat disagree, strongly disagree). The pre-symposium survey included an additional seven questions specifically for symposium participants who were breast cancer patients/survivors.

The Hospital of the University of Philadelphia serves an ethnically diverse region. Women of color in the local area made up the target demographic for this intervention. The event was advertised via distribution of over one thousand physical flyers, advertisements placed in two local West Philadelphia newspapers for a month prior to the date of the symposium, and email notifications sent within the University of Pennsylvania Health System. Flyers were distributed by the Abramson Cancer Center outreach services and the Traci's BIO-breast cancer support group, a local non-profit organization founded by a breast cancer survivor, that works to support, educate and pamper African American women diagnosed with cancer. A Plastic Surgery Foundation grant awarded to the senior author funded the program in its entirety.

Statistical Analysis

Descriptive statistics on program participant demographics are presented as means and standard deviations for continuous variables and as numbers and percentages for categorical variables. Percentage of correct responses for each individual survey question on the pre and post symposium surveys were compared using Mcnemar's test for paired data after responses were dichotomized as correct or incorrect. For ease of analysis, missing and "I don't know" responses were categorized as incorrect. All tests were two-tailed and statistical significance was defined as $p < 0.05$. Statistical analysis was performed using Stata/IC 13.0 software (StataCorp, College Station, Texas).

3. Results

A total of 63 community members attended the 4-hour health awareness symposium. The majority of the attendees were female (n = 56, 88.9%) and of African American descent (n = 55, 87.3%). Participants were on average 58 years old (SD 12.8). Approximately half (n = 31, 49.2%) of the attendees were current breast cancer patients or survivors while 23.8% (n = 15) identified as a family member or friend of a breast cancer patient. 19.1% of participants reported having a high school diploma or equivalent while 23.8% and 22.2% had college or graduate degrees respectively. The majority of the symposium attendees were from the local Philadelphia area, with 33.3% from West Philadelphia, 15.9% from North Philadelphia and 11.1% from Northwest Philadelphia. Table 1 presents demographic information of symposium participants. Of the 31 breast cancer patients/survivors, 35.4% (n = 11) reported undergoing breast reconstruction. All of these women received their oncologic treatment at hospitals that also provided breast reconstruction. 81.8% (n = 9) had discussions about reconstruction with their doctors prior to initiating oncologic treatment. Almost half of those patients (n = 5) discussed breast reconstruction with friends and family members prior to making a decision. Of the 20 women who did not undergo reconstruction, 45% (n = 9) were offered breast reconstruction by their physician and declined. A quarter of these women reported being afraid of reconstruction while 15% (n = 3) were unaware that breast reconstruction was available to them. 10% of the women in this group reported regretting their decision to forgo reconstruction. Table 2 presents responses to the breast cancer patient portion of the pre-symposium survey.

Prior to the educational session, 73% of participants were aware of breast reconstruction as a treatment option after mastectomy surgery. In response to survey questions about general breast reconstruction, 7.9% of respondents believed that breast reconstruction could not be performed safely in women over the age of 60, while 31.8% were unsure. When asked if breast reconstruction must be done immediately after mastectomy, 12.7% of participants responded incorrectly while 27% were uncertain of the correct response. 20.6% of participants were unsure if the need for chemotherapy or radiation therapy precluded a patient from undergoing breast reconstruction. Less than half (49%) of participants responded accurately when asked if breast reconstruction was covered by insurance, while 52.9% of participants were not aware of insurance coverage of balancing contralateral procedures. 31.8% were unsure of the impact of breast reconstruction on cancer recurrence and detection.

In response to survey questions about implant reconstruction, 5% of participants incorrectly believed that implants were the only reconstructive option after mastectomy while 31.8% were uncertain. Only 14.3% of respondents acknowledged that silicone implants were as safe as saline implants, while 50.8% were unsure. Only 36.5% of participants appropriately identified a statement indicating ruptured implants could cause cancer as false while 42.9% of respondents were unsure of the implication of implant rupture in the development of cancer. Table 3 presents pre-symposium survey responses. When comparing pre and post symposium surveys, the percentage of correct responses for all survey questions increased. Table 4 presents the comparison of pre and post symposium surveys responses. The percentage of correct responses about insurance coverage of breast reconstruction increased significantly from 46% to 73% (p = 0.001) while the percentage of correct responses about insurance coverage of balancing

Table 1. Demographics of survey respondents.

	N	%
Respondents, N (%)	63	100.0
Age in years, mean (STD)	58.1	(12.8)
Female, N (%)	56	88.9
Race, N (%)		
African-American/Black	55	87.3
Caucasian/White	3	4.8
Asian	1	1.6
Missing	4	6.4
Ethnicity		
Hispanic or Latino	1	1.6
Not Hispanic or Latino	31	49.2
Missing	31	49.2
Education		
Some high school	3	4.8
High school or GED	12	19.1
Some College	12	19.1
College degree	15	23.8
Graduate degree	14	22.2
Vocational or trade school	3	4.8
Missing	4	6.4
Patient location		
West Philadelphia	21	33.3
South Philadelphia	2	3.2
Southwest Philadelphia	5	7.9
North Philadelphia	10	15.9
Northwest Philadelphia	7	11.1
Northeast Philadelphia	1	1.6
Center City	0	0.0
Other	12	19.1
Missing	5	7.9
Breast reconstruction awareness		
I am aware that breast reconstruction is an option after breast cancer surgery	46	73.0
I am NOT aware that breast reconstruction is an option after breast cancer surgery	8	12.7
Missing	9	14.3
Interest/Relationship		
I am a breast cancer Patient/Survivor	31	49.2
I am the Spouse/Partner of a breast cancer Patient/Survivor	0	0.0
I am a Caregiver for someone with breast cancer	1	1.6
I am a Family Member/Friend of someone with breast cancer	15	23.8
I am a Health Professional	2	3.2
I am a Community Resident/Stakeholder	4	6.4

Table 2. Breast cancer patient survey responses.

		Yes	No
Reconstruction n = 11	My doctor talked to me about breast reconstruction before I started treatment.	81.8	18.2
	I talk to friends or family about breast reconstruction before deciding if it was right for me.	45.5	54.5
	Breast reconstruction was offered at my hospital.	100.0	0.0
No Reconstruction n = 20	I was offered breast reconstruction by my doctor but declined it.	45.0	55.0
	I was afraid of breast reconstruction.	25.0	75.0
	I was not aware breast reconstruction was available.	15.0	85.0
	I regret not having breast reconstruction.	10.0	90.0

N = 31. All values represented as percentages.

Table 3. Pre-symposium responses (%).

	True	False	I Don't Know
1) I can only get breast implants as a form of breast reconstruction. No other options exist.	4.8	46.0	49.2
2) If I have or need chemotherapy or radiation therapy, I can't have breast reconstruction.	1.6	60.3	38.1
3) Breast reconstruction can't be performed safely in women over the age of 60.	7.9	46.0	46.1
4) Breast reconstruction is not covered by insurance.	9.5	46.0	44.5
5) My insurance company will pay for me to have a breast reduction, breast lift, or breast augmentation on the unaffected breast to match the reconstructed breast.	28.6	9.5	61.9
6) Having breast reconstruction makes my cancer more likely to return and harder to detect if it does return.	4.8	49.2	46.0
7) Breast reconstruction must be done immediately after my mastectomy (a surgery to remove the breast).	12.7	44.4	42.9
8) If my breast implant ruptures, I will get cancer from the ruptured implant.	3.2	36.5	60.3
9) Silicone breast implants are just as safe as saline breast implants.	14.3	17.5	31.8
10) If your mother or other women in your family don't have breast cancer, you are not going to get breast cancer.	1.6	69.8	28.6
11) Mammograms cause cancer.	1.6	73.0	25.4
12) Cancer only spreads when the air hits it.	6.4	71.4	22.2
13) A majority of women who get breast cancer will die of breast cancer.	4.8	71.4	23.8
14) The only treatment for breast cancer is mastectomy (a surgery to remove the breast).	4.8	73.0	22.2

Values represented as percentages.

Table 4. Comparison of percentage correct responses for pre and post symposium survey questions.

	Pre	Post	*p*-value
I can only get breast implants as a form of breast reconstruction. No other options exist.	46.0	69.8	0.002
If I have or need chemotherapy or radiation therapy, I can't have breast reconstruction.	60.3	73.0	0.077
Breast reconstruction can't be performed safely in women over the age of 60.	46.0	57.1	0.230
Breast reconstruction is not covered by insurance.	46.0	73.0	0.001
My insurance company will pay for me to have a breast reduction, breast lift, or breast augmentation on the unaffected breast to match the reconstructed breast.	28.6	65.1	<0.001
Having breast reconstruction makes my cancer more likely to return and harder to detect if it does return.	49.2	69.8	0.007
Breast reconstruction must be done immediately after my mastectomy (a surgery to remove the breast).	44.4	69.8	0.002
If my breast implant ruptures, I will get cancer from the ruptured implant.	36.5	71.4	<0.001
Silicone breast implants are just as safe as saline breast implants.	14.3	66.7	<0.001
If your mother or other women in your family don't have breast cancer, you are not going to get breast cancer.	69.9	76.2	0.455
Mammograms cause cancer.	73.0	79.4	0.481
Cancer only spreads when the air hits it.	71.4	79.4	0.302
A majority of women who get breast cancer will die of breast cancer.	71.4	82.5	0.144
The only treatment for breast cancer is mastectomy (a surgery to remove the breast).	73.0	76.2	0.754
Breast reconstruction can improve a woman's body image.	55.6	76.2	0.004

Values represented as percentages. Responses to questions 1 - 14 were true, false, or I don't know. Responses to question 15 were strongly agree, somewhat agree, neutral, somewhat disagree or strongly disagree. Missing responses were categorized as incorrect.

contralateral procedures, increased from 28.6% to 65.1% ($p < 0.001$). Pre-symposium, only 14.3% of participants believed that silicone implants were just as safe as saline implants. This number increased to 66.7% after the educational sessions ($p < 0.001$). Compared to 36.5% of respondents in the pre-symposium survey, 57.1% of respondents in the post-symposium survey strongly agreed that breast reconstruction could improve a woman's body image ($p = 0.0004$) (see **Figure 1** and **Figure 2**).

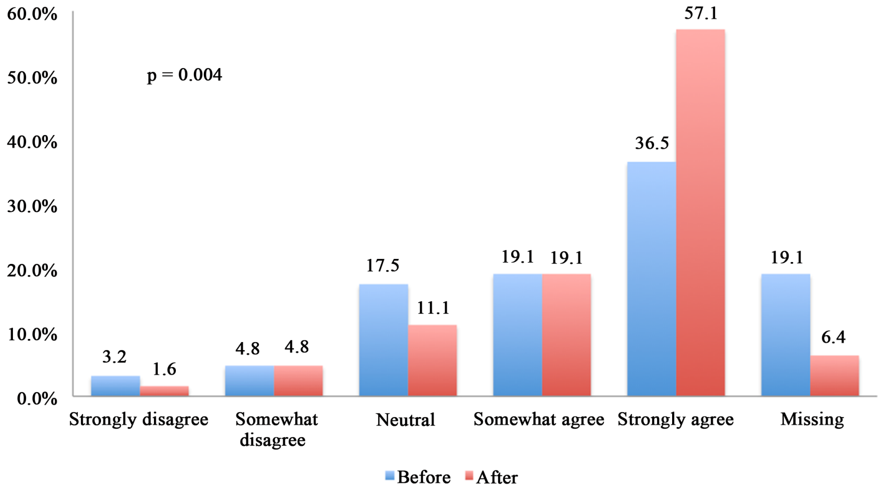

Figure 1. Pre vs. post symposium responses to "breast reconstruction could improve women's body image".

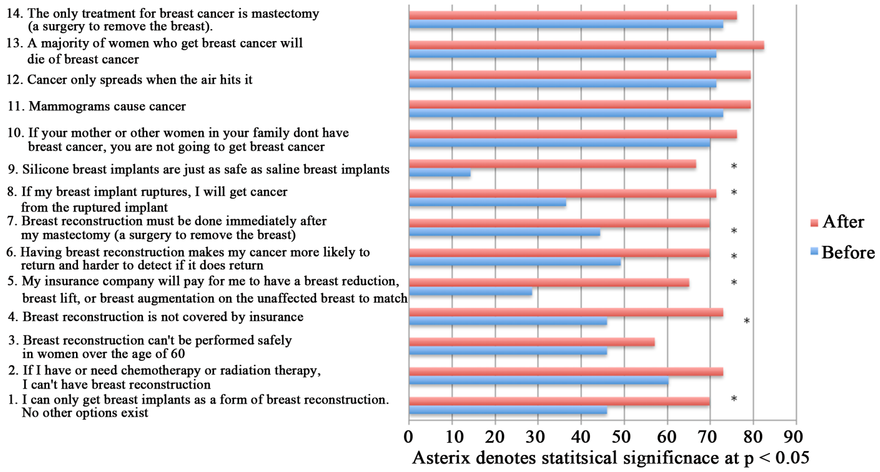

Figure 2. Correct responses on pre vs. post symposium survey (%).

4. Discussion

With increased media attention driven by celebrities like Angelina Jolie (Lebo et al., 2015), and the advent of breast reconstruction awareness campaigns such as BRA Day, launched by Dr. Mitchell Brown of Toronto, Canada in 2011 and adopted in the US the following year, (Breast Reconstruction Awareness, 2018; Breast Reconstruction Awareness Campaign, 2018) public knowledge of breast reconstruction has become more common. Despite this, disparities exist in the rates of breast reconstruction among women of color and their Caucasian counterparts. In 2004, Tseng et al. noted significantly lower rates of breast reconstruction in African American women (Tseng et al., 2004). Furthermore, their study revealed that African American women were less likely to be offered referrals for reconstruction, less likely to accept referrals if offered, less likely to be offered reconstruction, and less likely to chose reconstruction if offered. Similarly, in an analysis of 48,000 patients from 2005 to 2011, Butler et al. reported significantly lower rates of immediate breast reconstruction in women of color despite no association of added surgical morbidity (Butler et al., 2016). Only a third of the 31 breast cancer patients participating in our symposium underwent reconstruction. Of the 74.6% who did not, less than half were offered breast reconstruction. Of that same group, 15% were not aware of reconstruction as an available option and 10% regretted not pursuing reconstructive surgery. Although complex and multifactorial, we believe that poor health literacy in the context of breast reconstruction is one of the major contributors to the existing disparity. In a population based study of disparities in post mastectomy reconstruction, Alderman et al. notes that between a third and a half of minority women in their study (n = 805) desired more information about breast reconstruction, as compared to 17.0% of Caucasian women (Alderman et al., 2009). In an effort to address this desire, we developed a community based health awareness symposium centered on breast reconstruction directed at women of color in Philadelphia, Pennsylvania.

In this study, we present the results of an analysis of survey responses before and after lectures on breast cancer screening, treatment, surgical management and reconstruction options and patient testimonials. The overall uncertainty noted on all pre-symposium survey responses was fairly striking, with large percentages of participants responding, "I don't know" to the presented questions. This is even more alarming given that 46% of the symposium participates reported having a college degree or higher. This highlights the fact that even within well-educated groups, knowledge of breast reconstruction may remain poor. Overall, the percentage of correct responses for all survey questions increased on the post-symposium survey. With the exception of questions with greater than 60% correct responses in the pre symposium survey, there were statistically significant increases in the percentage of correct responses when comparing pre and post-symposium surveys. This suggests that as intended, the symposium served to increase knowledge in areas where significant deficiencies initially existed. Survey questions that touched on breast cancer diagnosis, treatment and spread (Questions 10 to 14) had the highest number of correct responses in the pre-symposium (69.8% to 73%). This is unsurprising as breast cancer awareness rightfully continues to remain at the forefront of discussions amongst healthcare providers and the general public.

A more in-depth evaluation of the questions with the lowest initial scores helps identify specific topics that can become the focus of future interventions. Two of the three questions with the lowest percentage of correct responses (Questions 8 and 9) in the pre-symposium survey, focused on the safety of implant-based reconstruction and its implication on cancer spread. Prior to the symposium, less than a fifth of participants believed that silicone implants were as safe as saline implants, while only 36.5% of participants understood that implant rupture could not cause cancer. Comprehension of both questions increased significantly after the symposium to 66.7% and 71.4%, respectively. Insurance coverage of breast reconstruction appears to represent another area of knowledge deficit to be addressed, with 54% of participants unaware of insurance coverage of breast reconstruction and 71.4% unaware of insurance coverage of contralateral balancing procedures prior to symposium. As expected, these numbers improved significantly after the educational sessions. With the introduction of The Women's Health and Cancer Rights Act 20 years ago, one would expect knowledge of its benefits to be more ubiquitous. Nevertheless, the thought of paying out of pocket for a procedure that a patient might incorrectly assume would be considered cosmetic could manifest as a major deterrent to actively seeking additional information about reconstruction. Providing assurance of insurance coverage of reconstruction as early as possible in the course of a patient interaction should become an imperative of the diagnosing physician, surgical oncologists, and consulting plastic surgeon.

While the decision to pursue breast reconstruction after mastectomy remains a personal choice, the counsel of physicians, previous patients, family and friends can play a significant role. A documented discussion of reconstructive surgery with a physician has been reported to be the greatest predictor of a patient undergoing breast reconstruction (Greenberg et al., 2008). We found that 81.8% of the women in our study who underwent breast reconstruction had discussions about reconstruction with their doctors prior to initiating oncologic treatment. Almost half of those undergoing reconstruction also had conversations with family and friends before making their decision. Similarly, in a survey based study of patient motivations for choosing post-mastectomy breast reconstruction, Duggal et al. noted that 51.6% of patients reported that they were urged by their referring physician to consider reconstruction. 58% of their study participants also discussed the surgery with other breast cancer patients prior to their decision (Duggal et al., 2013). A few studies have explored the larger effect of these individual discussions on existing disparities in reconstruction. Mahmoudi et al. sought to determine whether the 2011 New York legislation mandating physicians to communicate about breast reconstruction with their patients undergoing mastectomy would be associated with reduced racial/ethnic disparities in immediate post mastectomy breast reconstruction (Mahmoudi et al., 2017). They found that introduction of the legislature was associated with a reduction in disparities in immediate breast reconstruction rates by 9% between Hispanic and white patients and by 13% between other minority groups and white patients. Although the reduction in disparity did not reach statistical significance in African American women, the study suggests that communication on the part of the physician can have large-scale impact on existing disparities. Our symposium not only increased breast reconstruction awareness and overall health literacy but also provided a new avenue to facilitate these patient-surgeon conversations. Furthermore, it created the opportunity for participants to interact with other patients who have undergone reconstruction.

Health education programs such as the one presented in this study represent a continuously evolving process. The information disseminated to the community must change to reflect new scientific discoveries and growing medical knowledge. One of the survey questions touched on the equivalent safety of silicone and saline implants. This could be considered an over-simplification of a recently more nuanced topic. In the light of more convincing literature and FDA warning about the association of textured silicone implants with anaplastic large call lymphoma (ALCL), future symposium lectures and survey question will reflect this distinction (Doren et al., 2017; Breast Implant-Associated Anaplastic Large Cell Lymphoma, 2018).

5. Limitations

Admittedly, the conclusions and generalizability of this study are limited by the small sample size. The target audience of the symposium was women of color in West Philadelphia that were interested in learning more about breast cancer and breast reconstruction. This would include both women that personally were diagnosed with breast cancer at one point in their life and those that were not. If we were solely targeting breast cancer survivors, seeking more specific information from them regarding their type of cancer, stage at diagnosis, laterality, etc. would have been prudent and likely impact their questionnaire responses. However, our intent was to be more general to the community and limit intrusiveness. Additionally the survey was not validated prior to use. With these limitations in mind, we believe that our methods and findings can serve as a guide for the development of similar community based educational programs. This study also highlights areas of deficiencies that can be targeted in individual patient interactions and larger scale community based events. Due to the overwhelmingly positive feedback from participants, we plan to continue the symposium as an annual educational event with the hopes that it will have a larger impact on the existing disparity in breast reconstruction.

6. Conclusion

The etiology of the observed disparity in breast reconstruction rates between women of color and Caucasian women is complex and multifactorial. Noting that health literacy and awareness are critical to a patient's decision-making process about their diagnosis and treatment, this study demonstrates that targeted community based educational programs can improve awareness about breast reconstruction.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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