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Prostate-Specimen Antigen (PSA) Screening and Shared Decision Making Among Deaf and Hearing Male Patients

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Abstract

Some deaf men who use American Sign Language (ASL) experience barriers in patient-physician communication which may leave them at disparity for shared decision making compared to hearing men. Transparent communication accessibility is needed between deaf male ASL users and their physicians to maximize the benefit to risk ratio of using the prostate-specific antigen (PSA) as a screening tool for early detection. The objective is to compare shared decision-making outcomes between deaf and hearing males who are (1) age-eligible for PSA screening and (2) younger than 45 years old with a family history of cancer. An accessible health survey including questions about PSA test, PCC, modes of communication, and cancer history was administered in ASL to a nationwide sample of deaf adults from February 2017 to April 2018. Two subsamples were created: (1) 45- to 69-year-old men who were age-eligible for PSA testing and (2) 18- to 44-year-old men with a family history of cancer. Age-eligible and younger deaf men with a family history of cancer are at disparity for shared decision making compared to their hearing peers. Regardless of age and PSA testing status, deaf men felt significantly less engaged in shared decision making with their health care providers compared to hearing men. Participation in shared decision making requires not only accessible communication but also cultural competency in working with deaf patients. This is critical in the shared decision-making era in maximizing the benefit of prostate cancer screening in deaf male patient population.

Keywords Deaf · Men · PSA · Prostate · Sign Language · Shared Decision Making

Introduction

In the USA, prostate cancer (PCa) is the second most frequent cause of cancer death. In 2018, an estimated 20 million men will begin to consider whether to be screened for PCa [1]. While some randomized trials demonstrated a survival benefit from screening using the prostate-specific antigen (PSA) for PCa [2, 3], other studies have not [2].

As a result of these inconclusive findings, thoughtful debate continues regarding the positive and negative consequences of routine screening for prostate cancer. This debate is further complicated by the lack of tools to distinguish indolent prostate cancer from aggressive cancer. Other elements fueling the debate are the potential for adverse consequences following surgery to remove cancer in the prostate gland and the associated morbidity and mortality risks with and without early intervention. There are also increased health care costs associated with the over-detection of indolent disease [4, 5], the potential exposure to unnecessary diagnostic and treatment procedures, and the emotional toll these uncertainties place on patients and their families.

Even among those who conclude that regular PCa screening is appropriate, there are variations in recommendations. For example, the Göteborg arm of the European Randomized Study of Screening for Prostate Cancer (ERSPC) reported that, compared to annual screening intervals, biennial screening can lead to a lower overdiagnosis rate (2.4 vs. 3.3%), a 59% reduction in total tests, and a 50% reduction in false-positive results [6].

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Based on current evidence, the US Preventive Services Task Force (USPSTF) recommends against annual screening in favor of patients and physicians engaging in shared decision-making (SDM) regarding the risks and benefits of screening in men 55 to 69 years of age [5, 7], whereas the National Comprehensive Cancer Network (NCCN) guidelines recommend informed testing beginning at 45 years of age [8].

Lacking a clear consensus regarding screening for men in the age- and risk-appropriate cohort, the SDM process becomes critical in allowing patients to make informed decisions to maximize the benefit of screening, especially in higher-risk populations. A systematic review of SDM studies found that engaging patients as active participants in health-related discussions was particularly successful for patients who came from medically underserved groups and presented with lower health knowledge [9].

Accessibility to health information and comprehending the available health information are critical in the process of making informed decisions. The SDM processes become difficult when there are communication barriers between the patient and doctor. For deaf people who use primarily American Sign Language (ASL), a tendency towards suboptimal health literacy is exacerbated by non-concordant language with the physician, creating negative implications for adherence to preventive care and treatment recommendations [10, 11]. Furthermore, poor health-related outcomes in deaf adults who use ASL have been directly linked to communication barriers in addition to low health literacy [12, 13]. The communication barriers and low health literacy are particularly concerning because educational materials and physicians were identified as the first and second most preferred sources of health information in a sample of 109 deaf men in Southern California [14]. A Rochester-based sample of 89 (46% male) deaf patients reported that they were more likely to pursue preventive services if their health care providers utilized ASL [11]. However, an ASL-based prostate cancer education study found that only 56% of 121 deaf male participants communicated in ASL directly or through interpreters with their physicians despite self-reported preference for communication in ASL by 70% of the deaf male participants [14]. In this education intervention study, there was a slight, but nonsignificant, increase in the PSA and DRE (digital rectal exam) screenings post-intervention among older men (50+ years). Yet, this study reported that only 14% (17) of the deaf male sample felt well informed about screening tests by their doctors.

Engaging deaf adults in discussions using their preferred language is a necessity for deaf patients to make informed decisions about their prostate health. Accessible language in health education programs can also increase a deaf person's cancer health literacy level. In an ASL-accessible, captioned testicular education intervention study with primarily deaf young men in Southern California ($n = 85$), there was a significant increase in general cancer and testicular knowledge post-intervention [15]. This knowledge gain was maintained at 2-month interval, and

the deaf participants demonstrated a preference for active learning [16]. In another study, participants who were reportedly active in the SDM process were less likely to have a PSA screening compared to those who reported lack of involvement in SDM [17].

Deaf men who use ASL may experience barriers in patient-physician communication and/or receiving access to health information which leaves them at a disadvantage for participation in SDM. Transparent communication accessibility is needed between deaf male ASL users and their physicians to maximize the benefit to risk ratio of using the PSA as a screening tool for early detection in this patient population. This study focuses on self-reported shared decision making among deaf and hearing male patients who received PSA-based screening. The aims are to compare shared decision-making outcomes between deaf and hearing males who are (1) age-eligible for PSA screening according to the USPSTF and NCCN guidelines and (2) younger than 45 years old who report a family history of cancer, after controlling for race, education, and health-related characteristics.

Methods

The Health Information National Trends survey (hints.cancer.gov), which included items about PSA screening and shared decision making, was translated and linguistically validated in ASL (HINTS-ASL [18]). Following approval from the institution's human subject review board, the HINTS-ASL survey was administered between February 2017 and May 2018 to a national sample of early deafened adults who used ASL. Informed consent was obtained from all individual participants included in the study. Secondary data for English-speaking hearing men were drawn from the NCI-HINTS 5, cycle 1, survey. Study-relevant items include the following:

- Regular provider: *Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often?*
- Modes of patient-physician communication: *How do you communicate with your doctor, nurse, or health professional that you see the most?*
- Decision making: *How often did the health care provider involve you in decisions about your health care as much as you wanted?*
- PSA screening: *Have you ever had a PSA test?*
- Language preference: *What language do you prefer to use?*
- Personal history of cancer: *Have you been diagnosed as having cancer?*
- Family history of cancer: *Have any of your family members ever had cancer?*

Statistical Analyses

Using the National Comprehensive Cancer Network (NCCN) PSA screening guidelines, two subsamples of the hearing and deaf participants were created according to the following criteria: (1) 45 to 69 years old who were age-eligible for PSA testing and (2) 18 to 44 years old with family history of cancer. Chi-squared tests were used to describe the relationships among the variables. A bivariate correlation analysis was conducted to identify variables that were associated with PSA testing at p value of 0.05 or lower. These variables were then entered as covariates in logistic regression models.

Among the participants in the 45- to 69-year-old group, binomial logistic regression analysis was used to compare PSA testing between deaf and hearing participants, after controlling for sociodemographics and personal/family histories

of cancer. A separate analysis was conducted on the deaf and hearing male groups younger than 45 who had reported a family history of cancer. The statistical program SPSS version 25.0 was used for all analyses.

Sample Description

A total of 318 deaf and 900 hearing men met the criteria for inclusion in this analysis. Tables 1 and 2 display the sociodemographic characteristics of the two samples categorized on the basis of age and hearing status. Table 1 describes and compares the characteristics of 162 deaf and 708 hearing men who are PSA age-eligible at 45 years of age and older. Table 2 includes 156 deaf and 192 hearing men who were at least 18 years old, but less than 45 years old and presented with a family history of cancer.

Table 1 Sociodemographic characteristics for PSA testing in deaf and hearing age-eligible (45 years old and up) men

	Received PSA test		χ^2, p value	Did not receive PSA test		χ^2, p value
	Deaf ($n = 106$)	Hearing ($n = 464$)		Deaf ($n = 56$)	Hearing ($n = 244$)	
Race			$11.60, p < 0.05$			NS
White	91 (85.8%)	303 (69.7%)		38 (67.9%)	138 (60.5%)	
African-American	7 (6.6%)	51 (11.7%)		9 (16.1%)	24 (10.5%)	
Hispanic	6 (5.7%)	55 (12.6%)		5 (8.9%)	37 (16.2%)	
Other	2 (1.8%)	26 (6.0%)		4 (7.1%)	29 (12.7%)	
Highest school level			NS			NS
HS graduate	48 (45.3%)	246 (53.1%)		28 (51.9%)	154 (63.4%)	
College graduate	58 (54.7%)	217 (46.9%)		26 (48.1%)	89 (36.6%)	
Personal cancer history			$11.71, p < 0.001$			$6.096, p < 0.05$
Yes	33 (31.1%)	77 (16.6%)		11 (20%)	21 (8.6%)	
No	73 (68.9%)	387 (83.4%)		44 (80%)	223 (91.4%)	
Family cancer history			$31.77, p < 0.001$			$26.43, p < 0.001$
Yes	67 (64.4%)	333 (72.4%)		37 (67.3%)	141 (58.3%)	
No	37 (35.6%)	127 (27.6%)		18 (32.7%)	101 (41.7%)	
Regular provider			$10.81, p < 0.001$			NS
Yes	72 (67.9%)	379 (82.2%)		31 (55.4%)	140 (57.9%)	
No	34 (32.1%)	82 (17.8%)		25 (44.6%)	102 (42.1%)	
Health insurance			$8.75, p < 0.05$			NS
Yes	102 (96.2%)	453 (98.3%)		54 (96.4%)	218 (90.8%)	
No/not sure	4 (3.8%)	8 (1.7%)		2 (3.6%)	22 (9.2%)	
Language preference			–			–
ASL	50 (48.1%)	–		29 (51.8%)	–	
English	54 (51.9%)	–		27 (48.2%)	–	
Mode of communication with doctor			–			–
ASL (direct/interpreter)	72 (68.6%)	–		33 (63.5%)	–	
English (written/oral)	33 (31.4%)	–		19 (36.5%)	–	
Decision making			$42.77, p < 0.001$			$11.91, p < 0.01$
Always	32 (30.8%)	225 (55.8%)		17 (31.5%)	94 (51.6%)	
Usually	36 (34.6%)	137 (34%)		17 (31.5%)	58 (31.9%)	
Sometimes to never	36 (34.6%)	41 (10.2%)		20 (37.0%)	30 (16.5%)	

Results

Regardless of PSA testing status among deaf and hearing men who were age-eligible, deaf men generally felt less engaged in shared decision making with their health care providers compared to hearing men (had PSA test $\chi^2 = 42.88, p < 0.001$; no PSA test $\chi^2 = 16.33, p < 0.001$). Among age-eligible men who did not receive PSA testing, a significantly higher percentage (20%) of deaf male with a personal history of cancer in general never took a PSA test compared to 9% of hearing males also with a personal history of cancer ($\chi^2 = 6.10, p < 0.05$). As shown in Table 1, with age-eligible men, education did not associate with PSA testing for both deaf and hearing men. However, for deaf age-eligible men, those who self-identified as white and presented with a personal history of cancer were more likely to have received PSA testing. In contrast, age-eligible hearing men who received PSA testing

were more likely to have a family history of cancer, a regular provider, and report themselves to be engaged in health-related decision making.

As shown in Table 2, for younger men in the 18- to 44-year-old age group and with a family history of cancer, deaf and hearing men were comparable for PSA testing status. However, similar to the findings for deaf men in the age-eligible PSA group, younger deaf men reported feeling less engaged in shared decision making compared to younger hearing men. This finding was consistent across PSA testing status (had PSA test $\chi^2 = 9.28, p < 0.05$; no PSA test $\chi^2 = 8.49, p < 0.05$).

Bivariate correlation analysis was conducted to identify sociodemographic and patient variables that have significant relationships with PSA testing and shared decision making at *p* value of 0.05 or less. These variables (age, regular provider, race/ethnicity, health status, income, education, language

Table 2 Sociodemographic characteristics for PSA testing in deaf and hearing younger (ages 18–44) men with a family history of cancer

	Received PSA test		χ^2, p value	Did not receive PSA test		χ^2, p value
	Deaf (<i>n</i> = 24)	Hearing (<i>n</i> = 30)		Deaf (<i>n</i> = 132)	Hearing (<i>n</i> = 162)	
Race			NS			NS
White	14 (58.3%)	20 (69.0%)		83 (62.9%)	103 (65.2%)	
African-American	2 (8.3%)	6 (20.7%)		13 (9.8%)	10 (6.3%)	
Asian	2 (8.3%)	0 (0%)		5 (3.8%)	7 (4.4%)	
Hispanic	5 (20.8%)	2 (6.9%)		19 (14.4%)	34 (21.5%)	
Other	1 (4.2%)	1 (3.4%)		12 (9.1%)	4 (2.5%)	
Highest school level			NS			NS
HS graduate	10 (41.7%)	12 (40.0%)		53 (41.7%)	65 (40.1%)	
College graduate	14 (58.3%)	18 (60.0%)		74 (58.3%)	97 (59.9%)	
Personal cancer history			NS			NS
Yes	0 (0%)	1 (3.3%)		1 (0.8%)	2 (1.2%)	
No	24 (100%)	29 (96.7%)		131 (99.2%)	160 (98.8%)	
Regular providers			NS			NS
Yes	13 (45.8%)	19 (66.5%)		66 (50%)	83 (51.6%)	
No	11 (54.2%)	10 (34.5%)		66 (50%)	78 (48.4%)	
Health insurance			NS			NS
Yes	22 (91.7%)	29 (100%)		122 (92.5%)	150 (93.8%)	
No/not sure	2 (8.3%)	0 (0%)		10 (7.5%)	10 (6.3%)	
Language preference			–			–
ASL	10 (41.7%)	–		56 (42.4%)	–	
English	14 (58.3%)	–		76 (57.6%)	–	
Mode of communication with doctor			–			–
ASL (direct/interpreter)	16 (66.7%)	–		64 (51.2%)	–	
English (written/oral)	8 (33.3%)	–		61 (48.8%)	–	
Decision making			8.84, <i>p</i> < 0.02			7.01, <i>p</i> < 0.03
Always	7 (29.2%)	16 (64%)		45 (34.1%)	61 (50%)	
Usually	7 (29.2%)	7 (28%)		51 (38.6%)	39 (32%)	
Sometimes to never	10 (41.7%)	2 (8%)		36 (27.3%)	22 (18.0%)	

preference, mode of communication with doctors) were then entered in binominal logistic regression analyses to investigate the contribution of SDM to PSA testing. As shown in Table 3, age was the only positive predictor for PSA testing in age-eligible men regardless of hearing status. In Table 4, for younger men with a family history of cancer, age was a significant predictor for PSA testing only in the deaf ASL user group. Yet, the confidence interval range overlaps with the hearing controls (1.01–1.16 and 0.99–1.15, respectively), indicating that there is no true difference for age across hearing status. In addition, feeling always or often involved in shared decision making was positively associated with PSA testing in young hearing male adults with a family history of cancer, but negatively associated for young deaf male adults with a family history of cancer.

Although not significant, there were other covariates associated with PSA testing. In the age-eligible sample, having a

higher income, being of white race, or being a college graduate are positively associated with PSA testing, whereas these did not have positive associations with PSA testing in younger men with a family history of cancer. Regardless of age or hearing status, having a regular provider increased the likelihood of getting a PSA test. Finally, in both age groups, deaf men who used sign language (directly or through an interpreter) with their health care provider had nearly two-fold increased odds of getting PSA tests compared to those who preferred to use English (written or orally).

Discussion

In this analysis of deaf and hearing male patients, the frequency of shared decision making and use of PSA tests results revealed that some deaf male ASL users may have

Table 3 Summary of binary logistic regression analysis for predictors of PSA testing (Did not get a PSA test was the reference group) in age-eligible men (45+)

Variable	Deaf ASL users				Hearing English speakers				
	<i>B</i> (SE)	aOR	95% CI		<i>B</i> (SE)	aOR	95% CI		
			Lower bound	Upper bound			Lower bound	Upper bound	
Age ^b	0.10 (0.03)	1.11***	1.06	1.16	0.13 (0.02)	1.14***	1.10	1.18	
Regular provider ^c	0.70 (0.45)	2.01	0.84	4.86	0.73 (0.26)	2.07**	1.25	3.45	
White ^c	0.88 (0.48)	2.40	0.94	6.15	0.01 (0.23)	1.01	0.65	1.58	
General health ^c	Very good/excellent	1.31 (0.95)	3.69	0.58	23.57	−0.10 (0.31)	0.91	0.49	1.68
	Good	2.04 (1.02)	7.69*	1.03	57.22	−0.04 (0.31)	0.96	0.53	1.74
Income ^c	Upper	0.43 (0.58)	1.54	0.49	4.83	0.81 (0.33)	2.25*	1.19	4.25
	Middle	0.65 (0.50)	1.92	0.72	5.08	0.23 (0.27)	1.26	0.74	2.14
College graduate ^c	0.37 (0.48)	1.44	0.56	3.72	0.14 (0.22)	1.15	0.74	1.78	
Prefer to use ASL ^c	0.12 (0.44)	1.13	0.48	2.66	–	–	–	–	
Use sign language with doctor ^c	0.69 (0.46)	1.99	0.80	4.94	–	–	–	–	
Felt included in SDM ^c	Always	0.34 (0.54)	1.40	0.49	4.05	0.19 (0.33)	1.20	0.63	2.30
	Often	0.36 (0.51)	1.43	0.53	3.86	0.24 (0.34)	1.27	0.65	2.49f

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

^b Age is a continuous variable

^c Reference groups were no regular provider, non-white, fair/poor health, lower-income class, HS graduate, prefer English in conjunction with ASL, use English to communicate with doctor, and sometimes/never felt included in SDM

Table 4 Summary of binary logistic regression analysis for predictors of PSA testing (Did not get a PSA test was the reference group) in men with a family history of cancer (18 to 44 years old)

Variable	Deaf ASL users				Hearing English speakers				
	B (SE)	aOR	95% CI		B (SE)	aOR	95% CI		
			Lower bound	Upper bound			Lower bound	Upper bound	
Age ^b	0.08 (0.04)	1.08*	1.01	1.16	0.06 (0.04)	1.07	0.99	1.15	
Regular provider ^c	0.29 (0.48)	1.33	0.52	3.45	0.65 (0.534)	1.91	0.67	5.44	
White ^c	-0.06 (0.49)	0.95	0.36	2.45	-0.20 (0.51)	0.82	0.30	2.23	
Health status ^c									
	Very good/excellent	0.31 (0.92)	1.36	0.22	8.31	0.10 (0.84)	1.11	0.22	5.74
	Good	0.29 (0.93)	1.34	0.22	8.33	-1.02 (0.92)	0.36	0.06	2.18
Income ^c									
	Upper	-0.03 (0.83)	0.97	0.19	4.90	-0.37 (0.75)	0.69	0.16	3.03
	Middle	-0.05 (0.54)	0.95	0.33	2.73	-0.48 (0.74)	0.62	0.15	2.63
College graduate ^c		-0.46 (0.54)	0.63	0.22	1.81	-0.07 (0.51)	0.93	0.34	2.56
Prefer to use ASL ^c		-0.35 (0.50)	0.70	0.26	1.88	-	-	-	-
Use sign language with doctor ^c		0.65 (0.51)	1.92	0.71	5.16	-	-	-	-
Felt included in SDM ^c									
	Always	-0.43 (0.62)	0.65	0.19	2.19	1.79 (1.10)	5.96	0.69	51.52
	Often	-0.53 (0.59)	0.59	0.19	1.88	1.14 (1.15)	3.12	0.33	29.51

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

^b Age is a continuous variable

^c Reference groups were no regular provider, non-white, fair/poor health, lower income class, HS graduate, prefer English in conjunction with ASL, use English to communicate with doctor, and sometimes/never felt included in SDM

experienced barriers to effective SDM that left them at a disparity in comparison to their hearing counterparts. Regardless of age, the perception of their level of engagement in the SDM was a significant factor in whether they received or did not receive a PSA test in deaf and hearing male subjects. After controlling for correlates, the binominal regression analysis did not find the level of engagement to be statistically significant for PSA screening, which should be interpreted with caution. In one case, being engaged in SDM may appropriately lead to a low-risk patient appropriately declining or, at the very least, opting for an extended screening interval. On the other hand, a high-risk patient may after discussion of the risks and benefits opt for screening or consider more frequent screening intervals. A caveat is that deaf males were relatively less likely than hearing males to perceive themselves as always being included in the SDM process, irrespective of age or if they received a PSA test. However, further analysis

suggests that the deaf male cohort may be experiencing sub-optimal accessibility due to communication barriers and not having a relationship with a regular provider.

Again, regardless of whether deaf men received or did not receive PSA testing, relatively lower percentages of deaf men felt engaged in shared decision making compared to hearing men. Although not significant after controlling for other variables, our findings suggest that using sign language, either directly or through an interpreter, with a physician did significantly increase the likelihood of getting a PSA test. Moreover, patient preference for ASL as their language of choice was negatively associated with getting a PSA test for younger deaf men. This parallels findings from another study that analyzed data from the same HINTS-ASL survey. In that analysis, which used 188 deaf adults aged 55 to 80 years old with a smoking history, a similar significant association was reported between having accessible communication with the

doctor in ASL and asking about a lung cancer screening test (Kushalnagar, Engelman, & Sadler 2018). Thus, it is critical that physicians have communication accessibility in the patient's preferred language in order to achieve the level of engagement required for effective SDM. There was a significant relationship between getting a PSA test and having a regular provider for hearing male patients, but this relationship was not significant for the deaf cohort. Linguistic and cultural competency barriers may be preventing physicians from engaging in physician-patient relationships and the opportunity to engage in SDM that can lead to the optimal application of oncologic screening recommendations with their deaf patients [19]. The impact of this cannot be understated because communication in medical care is associated with better patient adherence to treatment recommendations [20–22]. Furthermore, a review of studies on navigating language barriers found that the use of a patient navigator helped improve cancer screening adherence rates among patients who had limited English proficiency [19].

Effective utilization of SDM should, in theory, lead to better screening rates in patient populations at higher risk for having PCa. Despite being more likely to develop aggressive PCa, African-American men are still less likely to be screened than their white male counterparts. Woods-Burnham et al. reported on the importance of the patient-physician conversation in predicting for knowledge about PCa and identified a relationship between higher than normal PSA values in men who discussed PCa screening with a physician compared to those who had not discussed PCa screening [23].

While being of the white race was significantly associated with receiving a PSA test in age-eligible deaf male patients, this was not statistically significant after controlling for another variable in the regression analysis. Further research is needed to identify whether deaf black male patients are greater risk of not engaging in SDM for PCa screening compared to their white deaf male counterparts. In recent years, studies have reported on a familial basis for PCa [24–26], and moreover, certain germ-line mutations, such as *BRCA 1/2* [27], may be associated with increased risk of progression after local therapy and decreased overall survival. Moreover, certain syndromes may confer a higher risk for malignancy especially in patients with a known prior history of personal malignancy. Thus said, it is notable that these two factors were not significant on covariate analysis for the age-eligible cohort of men. It may be that the incidence rates of patients also with a family and/or personal history of cancer were too low to reach significance.

The limitations of this study included those inherent in survey-based approaches such as the reliability of self-reported responses and potential sampling bias that creates a sample that is not reflective of the actual population. However, this approach allowed the researchers to generate a robust data set of both deaf and hearing male cohorts.

Conclusion

Compared to a sample of hearing men, deaf men who are age-eligible for prostate cancer screening and younger deaf men with a family history of prostate cancer are more likely to report suboptimal communication between themselves and their physicians, a fact that reduces the opportunity to engage in shared decision making. This may be secondary to language and cultural barriers, as well to their higher likelihood of not having a regular physician. Participation in shared decision making is facilitated by accessible communication and cultural competency in working with deaf patients, but also by an ongoing relationship with a physician.

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Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of Interest The authors declare that they have no conflict of interest.

Financial Disclosure No competing financial interests exist.

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