Barriers to Cancer Clinical Trial Participation among Native Elders

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Objectives: American Indians/Alaska Natives are underrepresented in clinical trials. Therefore, they must participate in large-scale cancer clinical trials to ensure the generalizability of trial results and improve their access to high-quality treatment. Our goal was to identify factors that influenced participation in cancer clinical trials among American Indians/Alaska Natives.

Methods: An anonymous survey that assessed willingness to participate in a hypothetical cancer clinical trial and how 37 factors influenced their willingness to participate was administered to 112 older American Indian/Alaska Native adults at an annual social event honoring elders. Responses ranged from one (definitely would not participate) to five (definitely would participate). Data were analyzed with ordinal logistic regression.

Results: Factors that most strongly increased willingness to participate were having a lead researcher of Native descent, having a study physician with experience treating American Indians/Alaska Natives, personal experience with the cancer being studied, family support for participation, and belief/hope that the study would result in new treatments. Factors that decreased willingness to participate most strongly were living far from the study site and a high risk that confidentiality could be breached.

Conclusions: Our results identify conventional and culturally unique barriers to research participation among older American Indians/Alaska Natives. These data emphasize the need to establish partnerships with Native communities and include American Indian/Alaska Native and culturally competent professionals in research efforts. Of equal importance are disseminating information about clinical trials and recognizing the role of family in decisionmaking in this group. (*Ethn Dis*. 2008;18:210–217)

Key Words: Clinical Trials, Patient Participation, Decision-Making, North American Indians

Introduction

Cancer is the second leading cause of death in the United States. Persons from under-served populations are more likely than the overall US population to be diagnosed with, and die from, preventable and curable cancers, present with late-stage cancers that are detectable through screening, and receive suboptimal treatment and palliative care.[1–5] The Institute of Medicine[3,4] and the Agency for Healthcare Research and Quality[6] have underscored the need to understand barriers and promoters of research participation as a means to reduce such health disparities. Large disparities in mortality rates for all cancers combined among American Indians/Alaska Natives compared to their all races counterparts suggest they could benefit from participating in clinical trials to ensure accrual of the benefits from, and access to, more advanced cancer treatment.[7]

Many studies have substantiated that minorities and the socially disadvantaged are underrepresented in cancer clinical trials.[8,9] Randomized controlled clinical trials have historically been conducted in the majority culture, rarely including American Indians/Alaska Natives.[10] For example, a recent National Cancer Institute-funded systematic review on barriers and promoters of accrual to therapeutic trials in underrepresented populations found that only 10% of studies reported subgroup data; only 15 of >35,000 participants could be identified as American Indian/Alaska Native.[6] In an earlier publication, potential American Indian study participants knew little about cancer clinical trials and had no opportunity to participate.[11] Although they believed participating could be beneficial, they expressed concerns about "mistrust of White people" and being treated like "guinea pigs." This situation is contrary to the 1993 mandate that requires federally sponsored clinical trials to include minorities in all human subjects research.[12]

Enrolling racial, ethnic, and cultural minorities in clinical trials is crucial because without adequate representation, the generalizability of study results to all segments of the population is questionable. Participation in trials also provides access to state-of-the-art cancer care, which itself may be a major determinant of racial disparities in cancer mortality.[2] The purpose of this investigation was, therefore, to identify factors that influence willingness to participate in cancer clinical trials among older American Indians/Alaska Natives.

Methods

Study Sample and Design

Potential participants for this study were American Indian/Alaska Native adults attending a dinner and social event in Seattle, Washington. An anonymous, written survey was offered to attendees as they arrived and were seated at tables before the meal was served. Potential respondents were informed the survey was about factors that influence participation in clinical research studies and asked to complete it independently. Participants were entered into a raffle to win gifts upon completion of the survey. The study was

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approved by the University of Washington's institutional review board.

Measures

The survey included a brief vignette describing a hypothetical cancer study, followed by the following question on willingness to participate in the trial: "Given only what you know from the story above, how likely would you be to participate in the study?" We then assessed how 37 additional factors, such as institutional sponsorship, community involvement, human subjects' issues, and convenience, might influence respondents' willingness to participate in the hypothetical cancer clinical trial. For both the vignette and each factor, respondents rated their willingness to participate on a Likert scale with these possible answers: 1=I definitely would not participate, 2=I probably would not participate, 3=I'm not sure, 4=I probably would participate, and 5=I definitely would participate. The vignette and factors were based on materials used in a previous study;[13,14] the original vignette and factors were reviewed by American Indian/Alaska Native faculty and focus groups for cultural relevance and comprehensibility.

The outcome for this analysis was willingness to participate in the cancer trial, scored from one to five, as described above. For each survey respondent we created an indicator variable with 38 categories. The first category corresponded to the original vignette, and categories 2–38 represented the potentially influential factors. Covariate measures were age (40–54 years, 55–64 years, ≥65 years), education (did not graduate from high school, high school graduate, some college, college graduate or beyond), current residence (urban, non-reservation rural, reservation), marital status (married, never married, divorced/widowed/separated), and yes/no indicators of female sex, 50% of life lived on or near a reservation, previous participation in research, and having a home telephone. The latter question was included because up to a third of American Indian/Alaska Native homes do not have telephones.[15]

Table 1. Demographic characteristics of 112 Native American/Alaska Native elders surveyed about clinical trial participation

Variable	Number missing	% (of valid observations)
Age	4	(108 valid)
40–54 years		16%
55–64 years		33%
65–84 years		51%
Sex	1	(111 valid)
Female		71%
Male		29%
Education	6	(106 valid)
Did not graduate from high school		27%
High school graduate		21%
Some college		35%
College graduate or beyond		17%
% of life lived on or near a reservation	12	(100 valid)
≤49%		63%
50%–100%		37%
Current residence	4	(108 valid)
Urban		56%
Rural, non-reservation		16%
Reservation		29%
Marital status	3	(109 valid)
Married		29%
Divorced/widowed/separated		54%
Never married		17%
Previous participation in research	4	(108 valid)
Yes		19%
No		81%
Telephone in home	10	(102 valid)
Yes		85%
No		15%

Statistical Analysis

Respondents who did not rate willingness to participate in the vignette were excluded from the analysis. Because of sample size limitations, we did not require complete data for all covariates. We calculated descriptive statistics by using percentages for each categorical variable and included the total number of valid observations for each measure. We also calculated the percentage of respondents that endorsed each of the five participation categories for each scenario in the survey. We used ordinal logistic regression to evaluate the association of each factor with willingness to participate. The dataset was structured so that each respondent had 38 outcomes, 1 for the vignette and 37 for the additional factors. We used the robust variance estimator to account for within-person correlation of the 38 outcomes. This model structure allowed respondents to have missing data for some factors, with the missing values assumed to be missing completely at random.[16] Results for each factor are given as odds ratios (ORs) with 95% confidence intervals (CIs). ORs >1.0 indicate a greater willingness to participate in the trial when the factor was considered compared to the vignette alone. We ran models adjusting for covariates, but because of sample size limitations and the large number of factors, we included these variables in the final model only if they confounded

Table 2. Frequency distribution of willingness to participate in a hypothetical cancer trial among American Indian/Alaska Native elders

Factor	Willingness to participate				
	Definitely would not %	Probably would not %	Not sure %	Probably would %	Definitely would %
Vignette alone	8	18	24	30	20
Factors that did not influence participation:					
You knew that members of your community were involved in developing and conducting the study	6	13	22	39	20
Your local healthcare provider referred you to the study	6	10	21	48	15
The study was conducted by an organization like the American Cancer Society or the Lance Armstrong Foundation	5	13	21	50	11
You were reimbursed for the costs of traveling to the study visits	7	14	24	39	16
Your treatment would be more closely monitored with the experimental cancer drug than with the approved drug	8	13	25	35	18
Free child care was provided during the study visits	10	17	16	45	12
The study was conducted by your state university	7	15	27	39	12
You felt sure that the experimental cancer drug was at least as likely as the approved drug to help you	9	14	28	34	15
Factors that decreased participation:					
The study was conducted at a healthcare facility located 20 miles away from your home community	9	18	29	36	7
A doctor you did not know referred you to the study	13	20	31	27	9
Your doctors felt the approved cancer drug would not help you very much	14	23	22	32	8
You think you would be assigned by chance to the experimental cancer drug	16	19	28	30	7
Nausea or pain were common side effects of the drugs used in the study	16	20	34	22	8
The study was conducted by the federal government	15	19	38	23	5
You thought that confidentiality might be broken, and your personal experiences, thoughts, feelings, opinions or health problems became known to other people	28	20	23	23	6
The study was conducted at a healthcare facility located 50 miles away from your home community	19	32	24	23	2
Factors that increased participation:					
You, a family member, or friend had the type of cancer being studied	3	9	13	38	37
Your doctor in the study had experience treating Americans Indians and Alaska Natives	4	6	16	39	35
What was being studied was lung cancer and you, a family member, or friend had this type of cancer	1	13	14	39	34
You thought that the study would lead to new treatments for the cancer	3	9	13	45	31
The researcher was American Indian or Alaska Native	6	6	19	34	35
What was being studied was cancer of the colon or rectum and you, a family member, or friend had this type of cancer	2	12	15	40	32
You were paid for your participation	5	5	21	37	32
Your doctor in the study was an expert in the type of cancer you have	6	5	15	45	29
What was being studied was breast cancer and you, a family member, or friend had this type of cancer	5	11	15	38	32
The study was conducted in a health care facility with a cancer unit designed especially for Native people	6	8	16	39	31
You thought that the study would help other people with cancer in your community	3	10	15	47	25
What was being studied was cervical cancer and you, a family member, or friend had this type of cancer	4	11	17	39	29
You felt sure that all the study procedures were clearly explained	7	5	18	42	27
It was easy for you to get information about the study	4	11	16	43	26

Table 2. Continued

Factor	Willingness to participate				
	Definitely would not %	Probably would not %	Not sure %	Probably would %	Definitely would %
You knew that you would receive feedback about the study results	4	10	21	38	28
Free transportation was provided to the study visits	6	6	19	45	23
You felt sure that all the risks, benefits, and side effects were carefully explained	6	7	19	43	24
You felt your chance for cure was higher with the experimental cancer drug	7	7	23	44	19
The study was conducted at a health care facility in your home community	6	11	16	50	16
You were given written information about the study to take home	4	10	25	41	20
Your family was in favor of your participation in the study	6	7	23	49	16

the primary association. We considered an α level of .05 as the threshold for statistical significance. All analyses were conducted with Stata version 9.0 (StataCorp LP, College Station, Texas).

RESULTS

We handed out 148 surveys, of which 136 (92%) were returned to us. Of these 136 completed surveys, 1 was excluded because of a missing response for the original vignette, and 23 were excluded because the respondent did not self-identify as being of American Indian or Alaska Native heritage. This left 112 observations available for analysis. Age ranged from 40 to 84 years, and half the respondents were $\geq$65 years (Table 1). Most respondents were female, had graduated from high school, and a minority reported living at least half of their lives on or near a reservation. Nineteen percent reported previous participation in clinical research. In response to the original vignette question, 20% responded ''I definitely would participate,'' 30% responded ''I probably would participate,'' 24% responded ''I'm not sure,'' 18% responded ''I probably would not participate,'' and 8% responded ''I definitely would not participate'' (Table 2).

Figures 1–3 show results from the ordinal logistic regression analysis. None of the covariates confounded the primary association, and the results reflect the unadjusted analysis. Confidence intervals that span the vertical line at 1.0 are not statistically significant. Figure 1 presents ORs for factors that did not significantly influence participation, including community involvement in the trial (OR 1.4, 95% CI .9–1.9), and the level of monitoring during treatment (OR 1.1, 95% CI .8–1.6). As shown in Figure 2, the factors that most significantly lowered the odds of participation were longer travel distance to the study site (OR .3, 95% CI .3–.5) and the threat that confidentiality would be breached (OR .3, 95% CI .2–.5). Figure 3 illustrates the odds significantly associated with increasing participation in the clinical trial. Among those with the highest odds were personal experience with cancer (OR 2.9, CI 2.0–4.5), having a study physician with experience treating American Indians/Alaska Natives (OR 2.9, 95% CI 2.0–4.1), belief/hope that the study would lead to better treatments (OR 2.6, 95% CI 1.9–3.7), and American Indian or Alaska Native researcher (OR 2.5, 95% CI 1.7–3.7). Family support for participation also significantly increased odds of participation (OR 1.5, 95% CI 1.1–2.0).

DISCUSSION

Recruitment of American Indians/Alaska Natives for clinical trials is affected by a complex mixture of cultural, heathcare system, and societal barriers including patient-provider communication patterns, illness beliefs, and family organization and influence in decisionmaking.[10] We found the strongest predictors for increased trial participation were involving a study physician experienced in working with American Indians/Alaska Natives, having personal experience with the type of cancer being studied, and believing the new treatment would be beneficial. Factors most strongly predicting decreased participation were the distance to the study site and concern about confidentiality being compromised. Comparing our results to other studies on barriers to participation in cancer clinical trials is difficult as virtually none reported data for American Indians/Alaska Natives. Even so, themes emerging from the literature on the barriers most frequently experienced by minorities include the time required to participate, mistrust of the medical establishment, unknown effects of medications or placebos, lack of information about clinical research, and the need for culturally relevant education on clinical trials.[17–20]

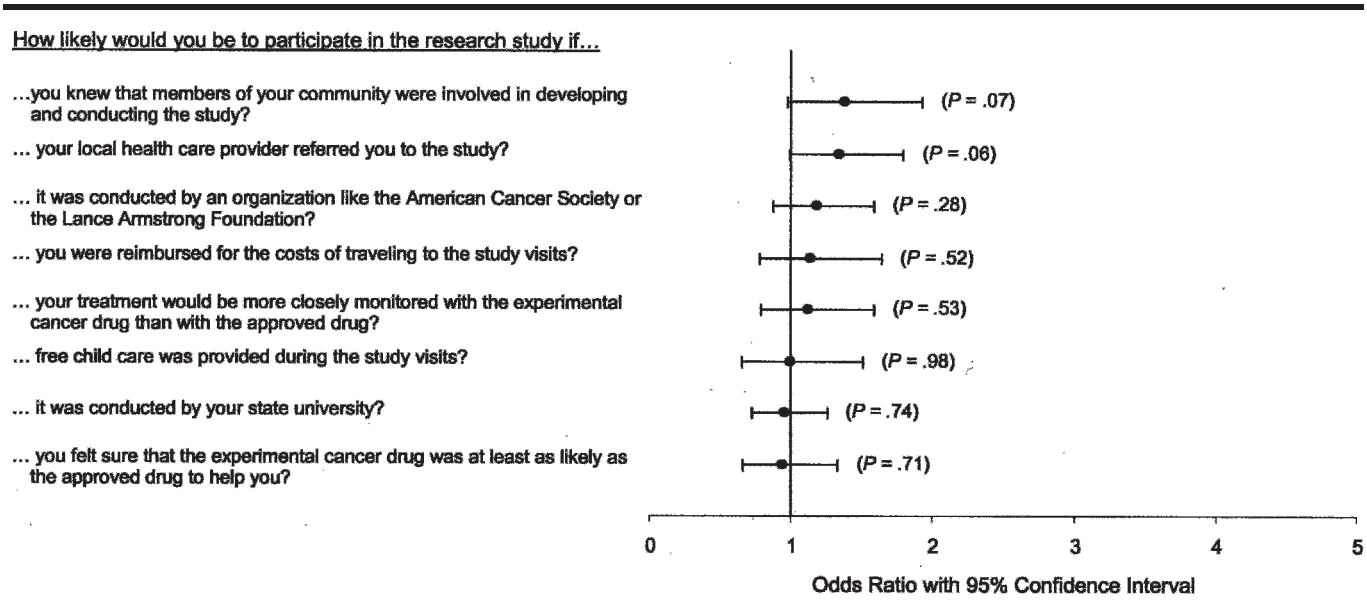

Fig 1. Factors that did not influence participation in cancer clinical trials. ♦=odds ratio with 95% confidence interval

The importance of building community trust was demonstrated in our study by the positive influence of having Native researchers, study physicians with experience treating American Indians/Alaska Natives, and being referred to a clinical trial by local providers. Many studies have cited mistrust of the healthcare system and research establishment as barriers to participation in cancer clinical trials,[10,19–24] but we found only two that specifically discussed American Indians/Alaska Natives as a subgroup of participants.[11,20] In one study of 19 African American and 7 American Indian focus group members, mistrust of the medical establishment and a lack of understanding and knowledge about clinical research were noted as barriers to participation in cancer clinical trials.[20] In another report, potential American Indian study participants knew little about cancer clinical trials and were suspicious of the majority culture and experimental treatments.[11] The negative influence of a federal government-conducted study was demonstrated in our results. Multiple sociocultural barriers underlie the scant representation of American Indians and Alaska Natives in clinical trials;[10] however, mistrust, specifically of the federal government, may be

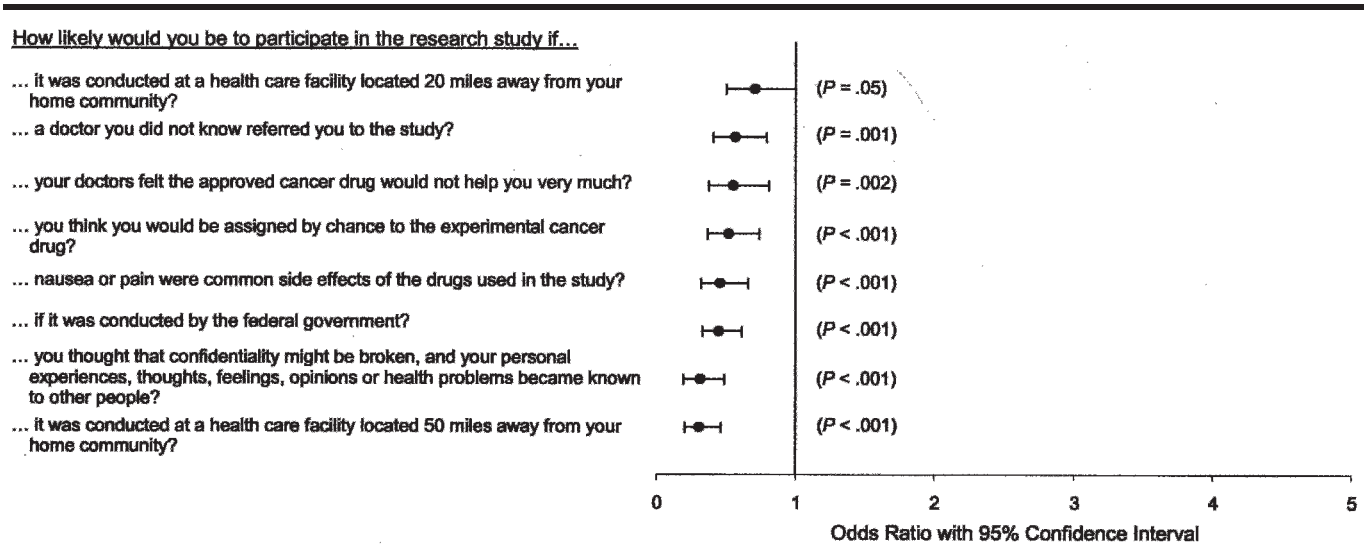

Fig 2. Factors that decreased participation in cancer clinical trials. ♦=Odds Ratio with 95% confidence interval

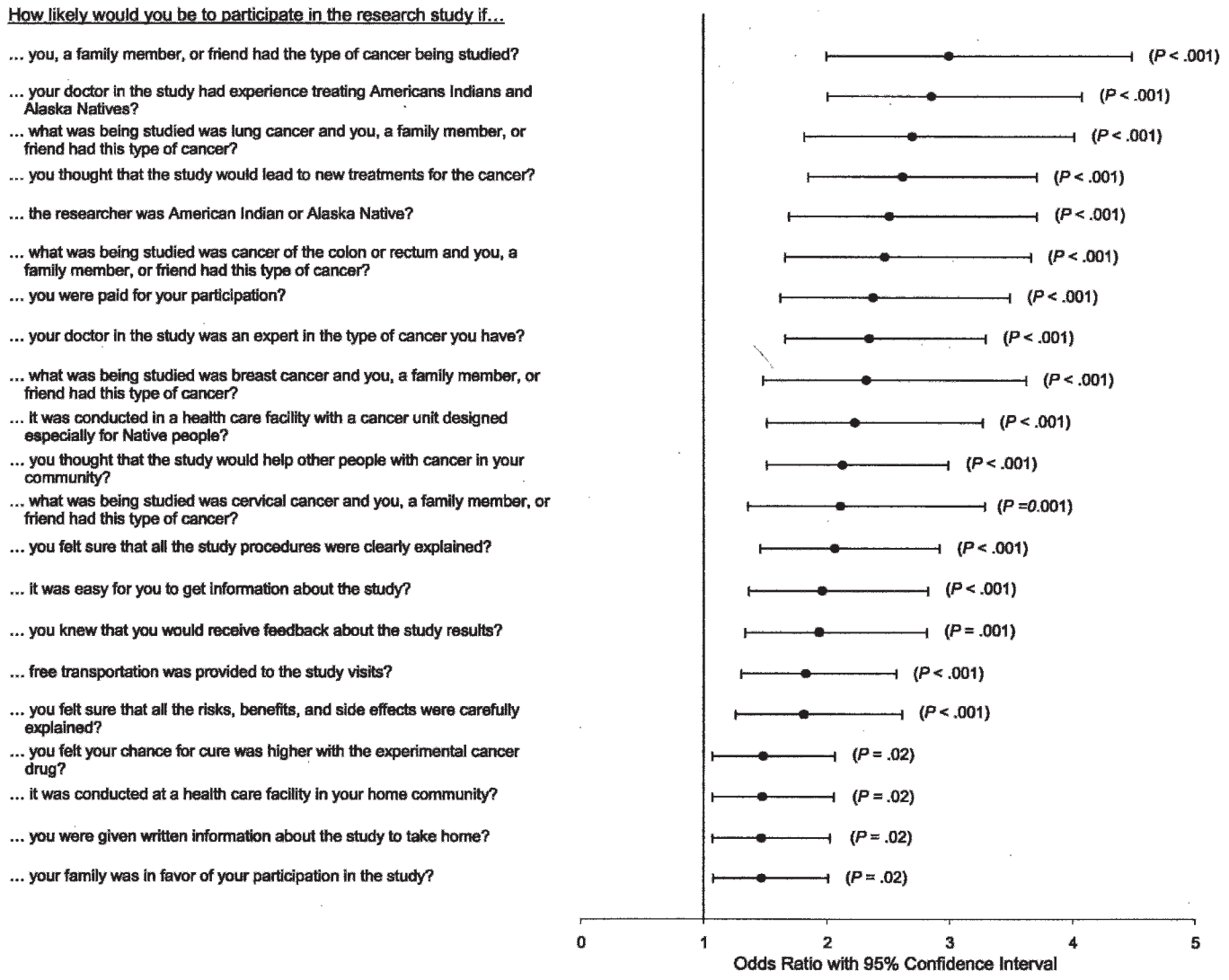

Fig 3. Factors that increased participation in cancer clinical trials. ♦=Odds Ratio with 95% confidence interval

promulgated by the significant health disparities that persist, >50 years after the Indian Health Service was established. American Indian and Alaska Native health status improved after the establishment of this service; however, the government has failed to adequately fund this system[25]—inaction conceptually analogous to the unfulfilled, signed treaties that date back to the 1800s.

Similarly, suspicion of medical research and lack of information about cancer clinical trials were the most frequent reasons given by community-based physicians and oncologists for the underrepresentation of minorities in cancer clinical trials.[17,19] The comprehensive Agency for Healthcare Research and Quality evidence-based review also found mistrust of researchers and research institutions were obstacles to cancer therapeutic and prevention trial participation among many minority groups; in contrast, culturally relevant education promoted participation.[6] The literature search for this review yielded virtually no information on American Indian/Alaska Native populations, precluding salient conclusions or recommendations.

In addition, we substantiated that feedback regarding study results was key. Others have pointed out the vital importance of sharing study results with Native communities and the negative effect of lack of community interaction concerning study planning and conduct, especially in regard to value and potential benefits of the study for the community.[10] Our study also examined the salience of personal experiences with cancer. In contrast to other studies,[20,26] we observed these survey questions were among the strongest predictors, at least doubling the likelihood of trial participation. In an earlier study of Canadian cancer patients seen at a regional center, family and friends did not influence the

decision to enter into a randomized clinical trial.[26] Likewise, a qualitative study on minorities in cancer clinical trials did not find personal experience predicted trial participation.[20] Conversely, experience with a problem, either personally or through a close relative or friend, was more likely to be cited as a reason for participating in a pertinent treatment clinical trial among cancer-free African American women interested in joining a clinical trial, as opposed to those not interested in joining a trial.[26,27] The strength of our findings may speak to the critical role of family in recruiting American Indians/Alaska Natives, and their ultimate decision to be involved in clinical trials.[10]

Surprisingly, items relating to randomization inconsistently influenced decisions to participate. For example, the likelihood of participation was lowered when individuals were informed they would be assigned by chance to the experimental cancer drug. In contrast, information that the experimental cancer drug was as least as likely to help as the approved drug had no effect on participation. Many studies have documented patient concerns about randomization and entering a randomized clinical trial.[28–30] Although previous work has not examined randomization in the context of clinical trials among under-served or minority populations, our findings may be explained by respondents' incomplete understanding of the ramifications of being randomized in a clinical trial.

We documented the importance of access, since a long distance to the research study site was a strongly negative influence on the likelihood of participation. This theme is consistent with previous investigations conducted in minority populations.[6,20] According to the 2000 census, an estimated 34% of American Indians/Alaska Natives resided on Indian reservations, trust lands, or other tribal areas,[31] and transportation difficulties are commonly experienced by American Indians/Alaska Natives in both rural and urban settings.[32]

Several limitations to our study should be noted. First, our analyses are based on 112 respondents who are not representative of all American Indians/Alaska Natives. Thus, our findings cannot be generalized to other settings, rural populations, or individual tribes and cannot address intertribal variation in cancer prevalence. Even so, our sample consisted largely of older adults, who are at highest risk for the more prevalent cancers. Second, although vignette-based research is an established form of qualitative research,[33,34] it has not been widely used in quantitative research. Our use of vignettes may not have adequately captured all relevant constructs, especially because our survey was brief enough to be completed during a social event. A related issue is that some participants may have been unfamiliar with research studies, and therefore might not have fully understood the questions. Third, we conducted hypothesis tests on a large number of alternative scenarios, increasing the likelihood of a type I error in our conclusions. Most of the scenarios that were significantly associated with participation, however, were highly significant, with P values $<.001$, and we are confident that the risk of type I error for these factors is low. Finally, the hypothetical vignette and subsequent questions may not accurately reflect decisions that individuals make when presented with opportunities to participate in actual studies. In this regard, the actual response rate for this study, which was $>90\%$, was far higher than that for the study vignette on which we queried people regarding research participation, suggesting American Indians/Alaska Natives are quite willing to engage in minimally demanding forms of research, if not clinical trials. Despite these limitations, our report is the first to describe and quantify barriers and promoters of involvement with clinical cancer trials among the most underrepresented minority in research.

In conclusion, these data emphasize the importance of establishing partnerships and building trust with American Indian/Alaska Native communities, increasing efforts to disseminate information about cancer clinical trials, maintaining confidentiality, including family in decisionmaking, and addressing geographic concerns. Future research should explore in more detail American Indian/Alaska Native peoples' understanding of cancer clinical trials, test interventions to enhance understanding, and assess methods of disseminating cancer clinical trials information. Lastly, the strong preference our participants voiced for American Indian/Alaska Native researchers and culturally competent physicians illustrates the need to increase diversity and cultural awareness among professionals in cancer care and research.

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