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Understanding Willingness to Participate in Cancer Clinical Trials Among Patients and Caregivers Attending a Minority-Serving Academic Cancer Center

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Abstract

Advances in cancer treatment are impeded by low accrual rates of patients to cancer clinical trials (CCTs). The national rates of recruitment of underserved groups, including racial/ethnic minorities, are limiting the generalizability of research findings and are likely to enhance inequities in cancer outcomes. The goal of this study was to examine willingness to participate (WTP) in CCTs and factors associated with this willingness among patients and caregivers attending a minority-serving university cancer center in the Southwest. A cross-sectional survey design was utilized ($n = 236$, 135 patients and 101 caregivers). Fear was the strongest predictor of WTP in CCTs. The only ethnic differences observed related to Spanish-speaking patients exhibiting increased WTP in CCTs, and Spanish-speaking caregivers' decreased WTP, compared to others. These results underscore the importance of future interventions to reduce CCT-related fear among patients and caregivers, with particular need for family-focused tailored interventions designed to meet the needs of Spanish-speaking patients and caregivers.

Keywords

Cancer communication; Caregivers; Clinical trials; Health disparities; Hispanics/Latinx; Rural patients

Background

Scientific advances across the cancer continuum are contingent upon effective recruitment of participants to cancer clinical trials (CCTs) [1, 2], but national accrual rates to CCTs remain low [3–6]. Further, certain groups experience increased barriers to participation in CCTs; these underrepresented groups consist of racial/ethnic minorities, people over the age of 65, residents of rural areas, and individuals with low socioeconomic status [1]. This inequity introduces bias and limits generalizability of research [1]. Studies documented

that African American and Hispanic patients who were offered participation in a CCT in a manner that they understood were as likely to consent as non-Hispanic Whites [1, 7]. However, assessment of the National Cancer Institute's efforts to reduce inequity in CCT recruitment concluded that the proportion of minority participants in CCTs declined in the past 14 years [8]. Greater understanding of barriers and facilitators to CCT participation among underrepresented groups is essential for the design of interventions and services that meet their informational and socioemotional needs.

Willingness to participate (WTP) in CCTs is an essential component in successful accrual to CCT. African Americans' WTP has been extensively examined [1, 6, 9–15], but only few studies explored predictors of such willingness in other underrepresented groups [16]. Similarly, although family members and caregivers are important in supporting patients in the decision to join a CCT and later in the care associated with this decision [17], their perceptions of participation in CCT are largely unexplored. Understanding factors associated with WTP in CCTs among patients and caregivers from different underrepresented groups is essential for guiding providers' communication on the topic and for informing effective, patient-centered, culturally competent policies and interventions [18, 19]. Therefore, the goal of this study was to examine WTP in CCTs and factors associated with this willingness among diverse patients and caregivers who attend a minority-serving university cancer center in the Southwest.

Predictors of WTP in CCTs

Research suggests that trust is an important factor in the decision to participate in CCTs [20], but at least one previous study indicated that medical trust was not a predictor of WTP in CCTs [21]. Notably, this study's respondents were largely non-Hispanic Whites, and the authors did not report trust-related comparisons between the different racial/ethnic groups. Other studies reported that African Americans overall indicated lower levels of medical and research trust and hence lower levels of WTP in CCTs [1, 8, 22]. These studies are important in guiding educational interventions and prevention-related recruitment efforts in these communities. However, it is unknown to what degree these attitudes are relevant to decision-making about CCT participation post diagnosis, decisions that typically take place in the context of physician-patient communication. Observational studies of CCT-related communication reported that most patients consented to participate when they were offered a CCT by their physician, regardless of race or ethnicity [7, 23]. It is therefore unclear to what degree studies conducted in community settings about CCT-related attitudes are predictive of WTP among those diagnosed with cancer. Moreover, although increasing trust among minority patients is a common recommendation [24], scholars cautioned against labeling minority patients as distrustful of healthcare providers [25].

Fear might also play a role in patients' WTP in CCTs [2, 26]. Such fears are related to the uncertainty inherent in CCT participation, for example, side effects of the experimental treatment, experiencing harm, and receiving placebo [1]. CCT-related fears were recently explored using qualitative research methods [27], but the relationship between CCT-related fears and WTP in CCTs among patients and their caregivers was not previously studied.

Western medicine focuses on the individual patient [28]. However, studies point at the complex role of family members and caregivers in medical decision-making, including in CCTs [29]. Whereas a review of the literature listed lack of family support as a deterrent of CCT enrollment [1], researchers did not examine caregivers' endorsement of future CCT participation of their loved ones. In view of patients' and caregivers' different roles, experiences, and engagement in care, it is likely that endorsement of CCT participation between the two groups would also differ.

Despite the importance of CCT participation for advancement of cancer care and the challenges related to CCT accrual and retention, only a few studies documented the experiences of participants in such trials [30, 31]. Consequently, it is unknown whether cancer patients who participated in CCTs and their family members are more (or less) likely to endorse future CCT participation compared to those who were not previously enrolled in such trials.

Communities Underrepresented in CCT

In view of the extant literature on African Americans' barriers to CCT accrual [15, 32–35], including patient-level factors associated with WTP [9, 12, 36], it is important to examine such factors in other communities. However, only a few, small-sampled qualitative studies investigated CCT-related participation and perceptions of Hispanic patients [37], Native Americans [38], Asians [39], rural patients [40], and the elderly [41–44]. Further, research to date has not explored WTP in CCTs in rural patients, despite their underrepresentation in CCTs [45]. Due to this limited evidence, whereas factors associated with failure to meet recruitment goals of African Americans in National Institute of Health (NIH) studies are largely understood, those associated with CCT enrollment of other underrepresented groups are unknown [46].

Two racial/ethnic groups that have been underrepresented in previous studies regarding patient-level barriers and facilitators to CCT participation include Hispanics and Native Americans. Constituting the fastest growing minority group in the nation, Hispanics suffer from inequities in access to care and cancer outcomes [47]. In particular, immigrants with limited English proficiency suffer disproportionately from increased structural barriers to care [48] including to research [49]. Perhaps due to this inequity, most studies that examined Hispanics' perceptions of CCTs focused only on Spanish speakers [50, 51] and overlooked the experiences of English-speaking Hispanics, who constitute more than half of Hispanic adults in the USA [52]. Quantitative data collected with a sample of non-patient, Spanish-speaking community members revealed low awareness and high WTP in CCTs [51]. In view of the significantly different propensity to indicate WTP in CCTs among non-patient compared to cancer patient populations [22], it is important to examine Hispanic patients and caregivers' WTP in CCTs. Further, it is important to include English-speaking and non-migrant Hispanics along with immigrants due to their different experiences and backgrounds.

Native Americans (American Indian/Alaskan Native) comprise another racial/ethnic group that experience inequities in access to healthcare and cancer outcomes [53, 54]. Previous research examined Native Americans' WTP in different type of studies [55]. In addition,

qualitative and anecdotal data were collected with Native Americans from the Northern Plains [56] and Buffalo, New York [25]. These studies pointed at some levels of research mistrust, along with beliefs that research can also be beneficial. However, previous studies did not explore WTP in CCTs among Native Americans diagnosed with cancer and their caregivers. Better understanding of such willingness is important in view of health inequities experienced by Native American communities that might negatively affect WTP in CCTs, including cancer burden, limited access to healthcare [53, 54], and lower levels of medical trust [57].

Research Questions

In this study, we explored patient-level barriers regarding CCT participation among a sample of patients and caregivers attending a minority-serving University Cancer Center in the Southwest. In view of our goal to better understand WTP in CCTs among diverse patients and their family members, we posed two research questions. First, to better understand WTP in this population and potential differences related to their demographics and past participation in CCTs, we presented the following research question.

RQ1: What is the relationship between demographics (race/ethnicity, English/Spanish language, educational attainment, patient and caregivers, rural/nonrural residence, and age) and past participation in CCTs and WTP in CCTs among participants?

Second, in view of past research that identified fear and trust as possible predictors of WTP in CCTs, the second research question states:

RQ2: What is the relationship among trust, fear, and WTP in CCTs in a diverse sample of patients and caregivers?

Methods

Research Design and Procedures

The research reported here is part of a larger, cross-sectional mixed-methods research project that explored recruitment of minority patients to CCTs. It received the Cancer Center and a University Health Science Center Institutional Review Board approval. Participants were eligible to participate if they were 18 years of age or older, had a diagnosis of cancer, or were accompanying a person diagnosed with cancer to their medical appointments. Direct recruitment approach [63, 64] and the screening strategy [65] were used to recruit hard-to-reach patient populations [63, 64] in the context of ethnic-related health inequities [67–69]. Following consent of the physician, a member of the research team approached patients and caregivers who attended an oncological clinic at a minority-serving University Cancer Center.

The research team included members who were bilingual in English and Spanish. To increase linguistic accessibility including access to individuals with different literacy competencies, a team member read the first seven questions of each survey to participants. Following these questions, the research team member offered to continue to read the survey or to have participants fill in the survey on their own. The survey was first tested with

a small group ($n = 10$) of minority participants who were not included in this sample. This pilot stage resulted in adjustment to the readability of the survey, including provision of explanation about CCTs that was read to participants. This addition was necessary as many participants have not heard about CCTs prior to the interview and were visibly uncomfortable to acknowledge their uncertainty. We chose a definition of CCTs that was identified on the National Cancer Institute and was at acceptable literacy level. All participants received \$10 gift card for their participation in the survey.

A third of participants ($n = 80$) preferred to have the survey administered by a team member, and two thirds filled it in themselves ($n = 153$). Team members remained with all participants until the completion of the surveys and were available to answer questions.

Measures

The dependent variable, WTP in CCTs, was measured by one item that was previously tested and validated [58]: “I would be willing to participate in a clinical trial in the future.” Respondents answered on a 5-point Likert scale ranging from strongly disagree to strongly agree. Answers were recoded into a binary that equaled one if respondents strongly agreed or agreed with the statement.

Trust was measured using a validated scale of trust in medical research by Hall and coauthors [59], who used a national sample to test the four-item scale, reporting a Cronbach’s alpha of 0.72. We utilized a 5-point Likert scale ranging from strongly disagree to strongly agree. Items were averaged to obtain the final score.

Since no previous CCT-related fear scale was available, we created items based on the literature on CCT-related fears. This four items scale addressed general fear of participating in a CCTs, fear of side effects, fear of being harmed, and fear of being randomized to placebo. Cronbach’s alpha was 0.70.

We measured previous CCT participation by including an indicator variable for respondents who had or were relatives of those who had participated in a CCT. Additional demographics pertained to whether the respondent was a patient or a caregiver; age, using those under 65 years of age as reference; race/ethnicity, with non-Hispanic Whites as reference; whether individual resided in a rural area; having high school education or less; and being female.

Analysis

Data are reported as means and standard deviations (SD) for continuous variables and percentages for all other descriptive data. Multiple logistic regression analysis was performed to produce odds ratios (OR) with robust standard errors for variables associated with being willing to participate in clinical trials. All analyses were performed using STATA version 14 (StataCorp LP, College Station, TX). For clarity of presentation, the section below shows individual regressions in results for the entire sample, as well as for patients and for caregivers. The table presents the full results, whereas the narrative highlights key findings.

Results

Participants Characteristics

Of the 273 individuals we approached, 249 agreed to answer the survey. The final sample for this analysis included 236 participants for whom all information was complete (95% of the sample). Of these, 135 were patients and 101 were caregivers. The response rate was 91.2%, with those declining citing lack of time, emotional state, or lack of interest. See Table 1 for descriptive statistics for each of the variables included in the analysis. About a third of participants (33.9%) had participated in a CCT. Native Americans comprised 10.6% of the sample, 8.5% were Asians, 21.2% were Spanish-speaking Hispanics, 33.9% were Hispanic who answered the survey in English, and 25.7% were non-Hispanic whites. Almost a quarter (24.6%) were rural residents. Compared to caregivers, patients were older, with 30.4% of patients 65 years or older, compared to 15.8% among caregivers ($p = 0.011$). Patients also had lower educational level compared to caregivers, with 23.1% of patients reporting some college compared to 36% of caregivers ($p = 0.031$). See Table 1 for more details on sample's demographics.

Relationship Between Demographics and WTP in CCTs

The first research question explored the relationship between demographics that have previously been shown to be linked to underrepresentation in CCTs, including race/ethnicity, English/Spanish language, educational attainment, rural/nonrural residence, older age, and WTP in CCTs. It also examined WTP among patients and family members. Results in Table 1 show that nearly 59% of the participants indicated WTP in CCTs. Among patients, this percentage was 65.4%, compared to 50% among caregivers, a statistically significant difference. Table 2 shows descriptive statistics for those willing, as well as those not willing to participate. Overall, the two groups had similar trust scores (mean = 3.7) but differed in their fear scores, with those willing to participate showing a lower mean compared to those not willing to participate in a CCT (2.6 versus 3.2, respectively).

Of those willing to participate in CCTs, 42.8% reported past participation in CCT, compared to 21.4% among those not willing. This difference was statistically significant for the entire sample as well as the patient group, but not for caregivers. Regarding education, 25.5% had high school education among those who expressed WTP compared to 32% among those not willing, but the difference was only statistically significant for the caregivers, with 29% of caregivers indicating WTP reporting high school degrees or less compared to 50% among those caregivers not willing.

Patients who answered the survey in Spanish were more likely to indicate WTP in CCTs than others. Analysis of the patient group shows that, among those who expressed WTP in CCTs, 26% were Spanish speakers, compared to 10% among those not WTP. Being a patient was also correlated with endorsing CCT participation in the future. Of those indicating WTP, 63.7% were patients compared to 47.9% among those not willing.

Predictors of WTP in CCTs in the Future

The second research question focused on the relationship between WTP in CCTs in the future and participants' (a) trust and (b) CCT-related fear. Each column in Table 3 shows the odds ratios of the logistic regression for the entire sample, patients only, and caregiver only.

Regarding the trust score, results were not statistically significant in any of the regressions. In contrast, the fear score shows that each additional point on the fear scale decreased the probability of WTP by nearly 70% for the entire sample (OR = 0.278, CI = 0.174–0.446). Having participated in CCT was correlated with higher WTP for the entire sample (OR = 2.003, CI = 0.981–4.092), but only significant at $p < 0.10$. This finding was not significant for the caregiver and patient groups even at the higher p value. Being a Spanish speaker was associated with a higher likelihood of WTP if respondents were patients (OR = 5.2, CI = 1.128–24.48). However, Spanish-speaking caregivers were less likely to endorse CCT participation compared to other caregivers although the result was not significant (OR = 0.212, CI = 0.041–1.275). Finally, patients were twice as likely to indicate WTP compared to caregivers, a statistically significant result (OR = 2.06, CI = 1.069–3.9). No other covariates were statistically significant.

Discussion

WTP in CCTs is an essential component in the process of CCT accrual, and this study aimed at understanding correlates of WTP in a diverse sample of patients and family members. The results indicate that WTP in CCTs in underrepresented groups is not lower compared to other groups as some studies reported [2]. Specifically, participants who were 65 years or older, those residing in rural communities, and racial/ethnic minorities were not more likely to demonstrate resistance to future CCT participation. In fact, patients who answered the survey in Spanish indicated the highest WTP in CCTs in the future. These findings contribute to the increasing body of evidence that inequities in CCT accrual among racial/ethnic minorities are not related to lower WTP in CCTs [60].

Our focus on a sample of diverse cancer patients and family members in a minority-serving academic center is unique. In contrast to past studies about CCT-related attitudes that were conducted in community settings with the general public [61], we recruited a sample of patients and caregivers for whom participation in CCTs constituted at least a possibility. Whereas surveys and interviews of participants recruited in the community highlighted trust as a barrier to CCT accrual [61], our results show that in fact fear was more salient in predicting WTP. CCT-related fears were identified as barriers to CCT accrual in past research [62], and our study is the first to examine these fears among patients and caregivers as a correlate of CCT-related attitudes.

Moreover, our study is the first to examine the relationship between previous participation in CCTs and CCT-related attitudes and specifically WTP in the future. Not surprisingly, previous participation in CCTs was positively correlated with WTP in CCTs in the future. Patients (and their caregivers) who opted to participate in a CCT in the past might have been predisposed to the benefits of such participation and/or might have been more open to this option prior to CCT enrollment. Notably, CCT-related fears predicted WTP, even for those

who were previously enrolled in one. It is possible that individuals who enrolled in CCTs and their loved ones do not always have their information and uncertainty-reduction needs met or that the inherent experience of such participation often involves some level of fear that education and communication cannot fully resolve.

Similarly, past research did not explore similarities and differences in patients and family members' CCT-related attitudes. Consequently, our study is the first to underscore that patients are more likely than caregivers to endorse future participation in CCTs. It is likely that caregivers are concerned about their loved one's well-being, whereas patients feel more confident to take the perceived risk of such participation. Family members are less likely to have their information needs met by clinicians compared to patients [63] and therefore might be more fearful of CCT participation. This trend was particularly strong among Spanish speakers. This difference might be related to the increased barriers that these caregivers experience in communicating with healthcare providers [64]. Although WTP in CCTs among Spanish-speaking patients is a positive sign, it is important to guarantee that these patients are fully informed in the face of the increased barriers to recruitment and education of these patients including the paucity of Spanish-speaking healthcare providers and limited translation services [61].

Practice Implications

These results have important implications for future educational interventions and for clinicians' communication with cancer patients and their caregivers. Such interventions should focus on alleviating CCT-related fears of patients and their families, including those who previously enrolled in such trials. In view of the chasm between patients and caregivers in their likelihood to endorse future CCT participation, interventions should be designed to target family members, meet their CCT-related informational, and support needs in order to alleviate CCT-related fears. Caregivers are important in supporting patients in their decisions to participate in CCTs, and the skepticism among caregivers regarding CCT participation is likely to increase patients' stress and could lead to lower CCT accrual and retention due to a desire to address caregivers' concerns.

Furthermore, clinicians should include caregivers in CCT-related conversations and secure that their information needs and concerns are being met. Awareness of family members' overall lower willingness to endorse participation of their loved one in CCT and their higher levels of CCT-related fears should inform such conversations. In particular, Spanish-speaking caregivers should be provided with CCT-related educational interventions and support and be included in medical conversations to minimize potential familial conflicts and distress. Providing tailored interventions about CCT that reduce fears and uncertainty regarding the process and safe-guards built into regulations of CCT are likely to reduce fears and increase not only WTP in CCTs but also the well-being of patients and their caregivers.

These findings contribute to the body of literature that examined patients' perceptions of CCT participation and reported no significant differences between minority and nonminority patients concerning WTP in CCTs. As Spanish-speaking patients were significantly higher in their WTP and in view of the additional barriers to informed consent that this group experiences, it is also important to design interventions that would educate Spanish-

speaking patients about their rights in CCT participation and secure informed consent. It is important to design interventions specifically targeting Spanish-speaking caregivers that would alleviate possible CCT-related fears and provide information to allow them to support patients in their CCT-related decision-making. Clearly, there is a need for ongoing, nuanced conversations between healthcare providers, patients, and their family members about CCT participation. Such conversations should be focused on meeting patients' and caregivers' information and support needs, in order to reduce uncertainty and alleviate fears.

Limitations and Future Research

This study is not free of limitations. Our focus on patients and participants attending a minority-serving academic center expands the scope of current research on accrual to CCTs, but it does not allow for generalization. In addition, using a cross-sectional survey design does not allow for inferences of causality and might provide limited insights into individuals' perspectives. Future studies should be conducted in different geographic locations. Randomized control trials should be utilized to shed light on causality, whereas qualitative research methods could provide insights to participants' experiences.

Qualitative studies should also focus specifically on the experiences of Native American patients and family members, in view of their low numbers as well as their specific cultural and health experiences. Despite using direct recruitment efforts, including recruiting a team member who identified as Native American, the sample did not include sufficient numbers of Native Americans to draw statistically significant conclusions on this populations. Past scholars discussed the difficulty of reaching Native Americans [65]. We call for a longer, community-based participatory research that would focus on the specific needs of Native Americans concerning CCT participation.

Extant studies and reviews of the literature documented the numerous factors that create inequities in CCT recruitment. Many of these factors are at the institutional and policy levels. This study focused largely on the individual level and extended this exploration to the families by surveying caregivers. Future studies should expand this scope by inviting additional family members to share their experiences and insights for a more holistic understanding of CCT-related familial process. Furthermore, this study did not aim to examine institutional and policy-related factors and the interactions between different levels on CCT accrual. Future studies should not only examine these interactions but also focus on designing and implementing multilevel interventions. Such interventions are essential in order to reverse national trends and inequities.

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Table 1

Descriptive statistics for the entire sample, patients, and caregiver only. Percentages based on column total

	Patient n (mean/%)	Caregiver n (mean/%)	Total n (mean/%)
Total observations	135	101	236
Would participate in CCT in the future or endorse participation of the patient (dependent variable) *	88 (65.4%)	50 (50%)	138 (58.9%)
Trust score	135 (3.6)	101 (3.7)	236 (3.7)
Fear scale	135 (2.8)	101 (2.9)	236 (2.8)
Has participated in CCT	47 (34.8%)	33 (32.7%)	80 (33.9%)
Age			
Under 45 years of age	19 (14.1%)	33 (32.7%)	52 (22%)
45 to 64 years of age	75 (55.6%)	52 (51.5%)	127 (53.8%)
65 or older *	41 (30.4%)	16 (15.8%)	57 (24.1%)
Education			
Less than high school *	34 (25.7%)	14 (14%)	48 (20.5%)
High school	40 (29.8%)	26 (26%)	66 (28.2%)
Some college	31 (23.1%)	36 (36%)	67 (28.6%)
College or more	29 (21.7%)	24 (24%)	53 (22.6%)
Race/ethnicity			
Non-Hispanic White	39 (28.9%)	18 (18.9%)	59 (25.7%)
Native American	12 (8.8%)	12 (12.6%)	25 (10.6%)
Asian	10 (7.4%)	9 (9.5%)	20 (8.5%)
Spanish-speaking Hispanic	26 (19.3%)	23 (24.2%)	50 (21.2%)
Non-Spanish-speaking Hispanic	39 (34.1%)	32 (33.7%)	80 (33.9%)
Female *	64 (47.4%)	25 (25.8%)	89 (37.7%)
Rural resident	30 (22.2%)	26 (26.8%)	58 (24.6%)

* Statistically significant difference between patient and caregiver

Table 2

Descriptive statistics for the entire sample, those willing, and not willing to participate in CCT. Percentages based on column total

	Willing to participate <i>n</i> (mean/%)	Not willing to participate <i>n</i> (mean/%)	Total <i>n</i> (mean/%)
Total observations	138	98	236
Patient (vs. caregiver) †	88 (63.7)	47 (47.9%)	135 (57.2%)
Trust ‡	138 (3.8)	98 (3.6)	236 (3.7)
CCT-related fear †‡○	138 (2.6)	98 (3.2)	236 (2.8)
Has participated in CCT †‡	59 (42.8%)	21 (21.4%)	80 (33.9%)
Age			
Under 45 years of age	25 (18.1%)	27 (27.5%)	52 (22%)
45 to 64 years of age	78 (56.5%)	49 (50.5%)	127 (53.8%)
65 or older	35 (25.4%)	22 (22.5%)	57 (24.1%)
Education			
Less than high school	27 (19.7%)	21 (21.6%)	48 (20.5%)
High school ○	35 (25.5%)	31 (32%)	66 (28.2%)
Some college	45 (32.8%)	22 (22.7%)	67 (28.6%)
College or more	30 (21.9%)	23 (23.7%)	53 (22.6%)
Race/ethnicity			
Non-Hispanic White	45 (32.6%)	14 (14.3%)	59 (25%)
Native American	11 (8%)	14 (14.3%)	25 (10.6%)
Asian	11 (8%)	9 (9.2%)	20 (8.5%)
Spanish-speaking Hispanic †○	27 (19.6%)	23 (23.5%)	50 (21.2%)
Non-Spanish-speaking Hispanic	43 (31.2%)	37 (37.8%)	80 (33.9%)
Female	53 (38.4%)	36 (36.7%)	89 (37.7%)
Rural resident	31 (22.5%)	27 (27.5%)	58 (24.5%)

† Statistically significant difference between those willing to participate in CC and not willing

‡ Statistically significant difference between those willing to participate in CC and not willing, patient only

○ Statistically significant difference between those willing to participate in CC and not willing, caregiver only

Table 3

Logistic regression odds ratios on the willingness to participate in clinical trial

	All	Patient	Caregiver
Total observations	236	135	101
Trust score	1.296 (0.773–2.171)	1.442 (0.744–2.793)	1.075 (0.455–2.539)
Fear scale	0.278*** (0.174–0.446)	0.309*** (0.158–0.603)	0.225*** (0.108–0.471)
Has participated in CC	2.003* (0.981–4.092)	2.356 (0.833–6.660)	2.364 (0.587–9.518)
Age 65 and older	1.076 (0.522–2.218)	0.991 (0.428–2.295)	1.846 (0.504–6.760)
High school or lower education	0.716 (0.351–1.459)	0.812 (0.319–2.065)	0.598 (0.159–2.255)
Native American	0.660 (0.226–1.923)	0.988 (0.265–3.688)	0.558 (0.0757–4.120)
Asian	0.743 (0.238–2.321)	0.498 (0.0997–2.487)	0.764 (0.171–3.413)
Spanish-speaking Hispanic	1.199 (0.501–2.869)	5.253** (1.128–24.48)	0.212* (0.0410–1.097)
Female	0.936 (0.480–1.827)	0.805 (0.351–1.844)	1.556 (0.366–6.613)
Rural resident	0.692 (0.335–1.432)	1.023 (0.345–3.038)	0.267* (0.0560–1.275)
Patient (caregiver ref)	2.059** (1.069–3.966)		
Constant	16.05** (1.471–175.1)	12.13 (0.491–299.6)	90.02** (1.889–4291)

Robust 95% confidence intervals in parentheses.

** $p < 0.01$ ** $p < 0.05$ * $p < 0.1$