Cancer beliefs and patient activation in a diverse, multi-lingual primary care sample

Jennifer L. Hay, PhD[1], **Emily C. Zabor, MS**[2], **Julie Kumar, MPH**[1], **Debra Brennessel, MD**[3], **Margaret M. Kemeny, MD**[4], and **Erica I. Lubetkin, MD, MPH**[5]

[1]Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York

[2]Department of Epidemiology and Biostatistics, Memorial Sloan Kettering Cancer Center, New York, New York

[3]Department of Medicine, Division of Ambulatory Care, Queens Hospital Center, Jamaica, New York

[4]Queens Cancer Center, Queens Hospital Center, Jamaica, New York

[5]Department of Community Health and Social Medicine, The Sophie Davis School of Biomedical Education at The City College of New York, New York, New York

Abstract

Objectives—Greater patient activation, defined as having the knowledge, skills, and confidence to manage one's health, is associated with cancer control behaviors. Cancer risk beliefs may be associated with patient activation, and delineating this relationship could inform cancer control interventions across diverse patient subgroups. This study examines associations between cancer risk beliefs, language preference, and patient activation within a multi-lingual urban primary care setting.

Design—Patients aged 18 and older within a New York City public hospital serving a large proportion of non-native born Americans were surveyed regarding their cancer risk beliefs and patient activation in Haitian Creole, Spanish, or English based on language preference during a health care visit.

Results—The sample (N=460) included 150 Haitian Creole speakers, 159 Spanish speakers, and 151 English speakers, and was primarily non-white (92%). Most participants (84%) had not been born in the United States. Cancer risk beliefs differed across language preference. Beliefs that cancer could be avoided by minimizing thoughts about cancer risk were significantly higher in Haitian Creole speakers compared to others; reported negative emotion when thinking about cancer risk was higher in Spanish and English versus Haitian Creole speakers. These cancer risk beliefs were positively related to patient activation, even when controlling for language preference.

Conclusion—Cancer risk beliefs differ across language preference, and are related to patient activation, making them potential important in cancer control. Consideration of language

Corresponding author: Jennifer L. Hay, PhD, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th floor, New York, NY 10022, Tel: 646-888-0039; fax: 212-888-2584, hayj@mskcc.org.

represents important demographic stratification for understanding the frequency and relevance of different beliefs about cancer and patient activation.

Keywords

Cancer risk beliefs; patient activation; cancer; oncology

Introduction

The term "patient activation" refers to the knowledge, skills, and confidence needed by persons to manage their health and health care [1]. Greater patient activation is related to greater adherence with behaviors that prevent cancer, such as sun protection and tobacco abstinence, as well as cancer screening adherence [2–4], and to greater screening and follow-up care in cancer patients [5]. There are ethnic, racial, acculturation, and other socioeconomic disparities such as language fluency in patient activation [1, 6–8]. This is true in the cancer context, as well; among cancer survivors, poorer patient activation, defined as self-efficacy in making personal medical decisions, has been identified in Asian cancer survivors compared to White survivors [9]. Improving patient activation has been postulated as a means to reduce health disparities, improve quality health care, and reduce costs associated with cancer treatment and prevention [1, 10, 11].

Patient activation combines constructs including information seeking, self-efficacy, behavioral adoption, and stress management [12, 13]. At lower levels of patient activation, patients express lower levels of endorsement concerning whether an active role in their health is important, and low confidence that they can proactively reach out to physicians with their health concerns. At higher levels of patient activation, patients report adopting and maintaining lifestyle changes. The highest level of patient activation is characterized by confidence in one's ability to maintain lifestyle changes even under stressful conditions [14, 15].

It is well-accepted that beliefs about cancer risk are key motivators of health behavior adoption [16]. This assertion is consistent with most health behavior theories [17] and empirical research [18, 19]. Since health behavior adoption is an important element of patient activation, it is possible that in the cancer context patient activation levels may differ by specific cancer risk beliefs. For example, Haitians may be very heterogeneous in their familiarity with the concept of prevention, having reported that it is "better not to know" about an illness such as cancer. This belief may lead to non-adherence with screening [20–22].

Cancer risk beliefs may be related to patient activation in important ways that differ across ethnicity, race, and acculturation. Examination of cancer risk beliefs across English and non-English speaking populations will contribute to efforts to address cognitive barriers to patient activation in the cancer context, contributing to intervention strategies to activate patients of diverse backgrounds to take action regarding their health.

The current study examines cancer risk beliefs and patient activation across Haitian Creole, Spanish, and English speaking patients seen at an inner-city hospital ambulatory care

practice. Queens County in New York City is home to one of the five largest Haitian populations in all United States counties [23]. Of the Haitian population in Queens, 82% claim that they do not speak English at home and, of those not speaking English at home, 14% note not speaking English well or at all [23]. Hispanics comprise 28% of our Queens, New York population, and 30% of Spanish speakers in Queens reported that they do not speak English well [24, 25]. The routine use of English only surveys limits examination of demographic variation solely to that variation represented among English speakers. Thus, one of the primary goals of the current research program is to extend our examination of cancer risk beliefs to non-English speakers in New York City. While language preference is confounded with other important characteristics, such as culture and ethnic background, non-English fluency is an important marker for cancer health disparities [26] that warrants focus in the context of patient activation issues.

The study has two objectives. First, we examine the extent to which cancer risk beliefs differ across three urban primary care subpopulations (Haitian Creole, Spanish, and English speakers). This objective will also allow us to examine whether there are specific cancer risk beliefs that are particularly prominent in one or more subpopulations. Second, we examine associations between cancer risk beliefs, survey language, and patient activation in this population. Based on prior work indicating that cancer risk beliefs can present a barrier to cancer screening [27, 28], we hypothesize that cancer risk beliefs will be *lower* in those with higher patient activation. Given the importance of patient activation in cancer control, understanding the relation of specific cancer risk beliefs to patient activation levels will enhance opportunities for tailored cancer control intervention development across diverse, multi-lingual populations.

Methods

Sample

The study was reviewed and approved as exempt research by the Institutional Review Boards at The City College of New York (CCNY), Memorial Sloan Kettering Cancer Center (MSKCC), and Queens Hospital Center. This cross-sectional study surveyed people who were aged 18 and older and attended Queens Hospital Center Ambulatory Center between June 2011 and August 2012. Queens Hospital Center is a member of the New York City Health and Hospitals Corporation, the public safety net healthcare system of New York City, and serves communities in central and southeastern Queens with large proportions of non-native born Americans.

Procedure

Research study assistants (RSA) were bilingual and fluent in both their native languages (Haitian Creole or Spanish) as well as English. Patients were approached in the waiting room prior to a health care visit. They were told that participation was voluntary and the interview would be anonymous and confidential. Participants were given the choice of having the study administered in English, Spanish, or Haitian Creole, based on the language with which they had the highest level of fluency. Participants received a transportation card ($15.00) for completing the study.

Measures

Cancer risk beliefs—Cancer risk beliefs were assessed via five scales [29]. The first factor, <u>Cognitive Causation</u>, includes 10 items that tap into the belief that thoughts about cancer risk may encourage the development of disease, and that minimizing such thoughts could actually reduce cancer risk. Higher cognitive causation is related to reduced colorectal cancer screening adherence [27]. The second factor, <u>Negative Affect in Risk</u>, includes 6 items and taps feelings generated during the risk perception process; this factor is also associated with reduced colorectal cancer screening intentions [28]. The third factor, <u>Unpredictability of Cancer</u>, keys into beliefs about irreducible uncertainties regarding whether any one person might get cancer. The fourth factor, <u>Preventability</u>, assesses beliefs around the extent to which cancer development is controllable. The fifth factor, <u>Defensive Pessimism</u>, taps beliefs around the potential negative outcomes associated with being too optimistic about avoiding cancer. Each of these scales used 4-level response options indicating level of agreement, from "strongly disagree" to "strongly agree." These scales have been translated and adapted into Haitian-Creole and Spanish with high comprehensibility [30]. Scales were scored to range from 0 to 100 in order to achieve comparable relative levels across scales with different numbers of items and for ease of interpretability [31].

Patient activation—Patient activation was measured using the PAM, which has strong psychometric properties and has been shown to be valid and reliable [14, 15]. This measure is a 13-item scale indicating the degree to which individuals take an active role in managing their health and health care [15]. The five possible responses on the PAM range from disagree strongly to agree strongly and include not applicable (NA). The PAM score is based on a scale of 0–100 and falls into one of four levels of activation: (1) not yet taking an active role, (2) gaining confidence and knowledge to take action, (3) taking action, and (4) maintaining behavior. Spanish and Haitian Creole versions of the PAM were available from Insignia Health [12].

Demographics—The final section contained a number of sociodemographic characteristics, including age, sex, education, race and ethnicity, years living in the United States, country of birth, employment, and marital status.

Statistical approach

Differences in patient characteristics across language preference were compared using the Chi-square test for categorical variables and the Kruskal-Wallis test for continuous variables. Internal consistency of the cancer risk belief scales was assessed using Cronbach's alpha, where an alpha value 0.7 is considered reliable. Differences in cancer risk beliefs across language preference were assessed using the Fisher's exact test for individual items and the Kruskal-Wallis test for sub-scale scores. Associations with PAM score were assessed using univariable and multivariable linear regression. Variables associated with PAM with $p<0.05$ on univariable analysis were incorporated into multivariable analysis.

Statistical significance was defined as $p<0.05$. All analyses were conducted using SAS software, Version 9.4 of the SAS System for Windows [32].

Results

Sample Characteristics

Of all approached patients, 80% agreed to participate. The overall sample (N=460) was balanced across language preference by design, with 150 Haitian Creole speakers, 159 Spanish speakers, and 151 English speakers. Overall, this primary care sample was non-white (91.5%), had not been born in the United States (non US nativity, 84.3%), and was very diverse in terms of income and educational attainment. English speakers had significantly higher patient activation scores, followed by Spanish and Haitian Creole speakers (Table 1).

Cancer risk beliefs across languages

As shown in Table 1, levels of cancer risk beliefs differed across language preference. As noted in the Supplementary File, cognitive causation and negative affect in risk scales showed high internal consistency across the entire sample, as well as within each language group (all alpha reliabilities .80). The correlation between negative affect in risk and cognitive causation was low, r=0.057. Cognitive causation levels were significantly higher in Haitian Creole speakers compared to the other two groups. For example, 42% of Haitian Creole speakers agreed that, "If I think too hard about the possibility of getting cancer, I could get it," compared to 28% and 23% of Spanish and English speakers, respectively. In contrast, negative affect in risk levels were highest in Spanish and English speakers. For example, 79% and 70% of Spanish and English speakers, respectively, agreed that, "I can't think about getting cancer without feeling afraid," compared to 54% of Haitian Creole speakers. Also shown in the Supplementary File, items not in the cognitive causation or negative affect in risk scales did not reliably load onto specific factors (all alpha reliabilities < 0.7), but individual items still showed systematic differences across language preference.

Cancer risk perceptions and patient activation

Both cognitive causation and negative affect in risk were significantly and positively related to patient activation (alpha reliability for patient activation = 0.84). As such, those with greater beliefs in the role of wishful thinking and avoiding too much thought about risk in helping them avoid cancer (characterized by higher cognitive causation scores), and those with greater emotion when thinking about their cancer risk (characterized by higher negative affect in risk scores) both demonstrated higher levels of patient activation (b=0.07, SE(b)=0.04, p=0.046 and b=0.12, SE(b)=0.03, p<.001, respectively, see Figure 1). High levels of patient activation represent the belief in personal ability to sustain health behaviors even in times of stress. These findings remained significant in multivariable analysis adjusting for language preference (Haitian Creole, Spanish, or English) and years living in the US (Table 2). Interaction effects between cognitive causation and language preference on patient activation, and between negative affect in risk and language preference on patient activation were not significant (p=0.590 and p=0.600, respectively).

Discussion

In this paper we examine cancer risk beliefs and patient activation among primary care patients with diverse language preferences. Patient activation is gaining acceptance as an important goal in maximizing health and healthcare for the general population as well as those diagnosed with illnesses such as cancer [1, 33]. Patient activation may be particularly important in cancer control across diverse populations [5], yet little is known about the cancer-relevant beliefs that may underlie patient activation levels. We found that patient activation and cancer risk beliefs differed by language preference, but that cancer risk beliefs and patient activation remained positively associated when controlling for language preference. These findings have implications for patient activation interventions in cancer prevention and control.

Our findings regarding cancer risk beliefs and language preference indicated that the Haitian Creole speakers endorsed higher superstitious thinking about cancer risk, as evidenced by their higher cognitive causation scores, and that the Spanish speakers endorsed more negative affect as they think about their cancer risk, as evidenced by their higher negative affect in risk scores. There were also patterns across language preference within the other cancer risk belief items. Most cancer prevention and control research uses a narrow range of risk perception items, generally magnitude judgments [17]. The findings from the current study indicate that different subpopulations may have different beliefs about risk. Future research on cancer risk beliefs must continue to engage diverse populations, including non-English speakers, to fully capture cultural, racial, and socioeconomic variation in how people think about and manage their health [21, 34–37]. The use of multiple cancer risk belief assessments – that assess both judgments about magnitude as well as intuitive beliefs about risk – are necessary to examine potentially culturally different aspects of risk beliefs.

Cancer risk beliefs, including both cognitive causation and negative affect in risk, were significantly related to patient activation scores even when controlling for language. Counter to our hypotheses, these relations were in the positive direction, with those at highest patient activation, characterized by high levels of confidence in their ability to manage health and maintain health behaviors even under stressful conditions, endorsing high levels of cognitive causation and negative affect in risk. Superstitious thinking has been examined in the social psychological literature [38–41], but only recently in health [29, 42]. Orom and colleagues [42] found that inquiries regarding cancer risk perceptions generated reports of wishful thinking and a desire to avoid thinking negatively among African American community members. Superstitious thinking about risk – characterized by beliefs such as hopefulness in protecting against the development of cancer – as assessed via cognitive causation, is significantly associated with internal and external health locus of control [43]. It is possible that high perceived control is associated with endorsement of patient activation at the highest levels, such that high levels of perceived control are also operative among those who believe that cancer risk can be influenced by thoughts. Indeed, prior work confirms that a common superstitious behavior, knocking on wood, is higher among those with a greater desire for control [44]. As such, the highest levels of patient activation may be characterized by strong – perhaps unrealistically strong – confidence that health behaviors can be well maintained even under stress. In other words, there may be an element of wishful thinking or

overestimation of personal control that is operative at the very highest levels of patient activation. Interestingly, AuYoung and colleagues [45] recently found that obese individuals with higher patient activation were able to adopt fruit and vegetable consumption but not necessarily regular physical activity. Further research could examine whether there are subsets of highly activated patients who are more or less realistic concerning their ability to maintain health behaviors under challenging, stressful conditions. For our Haitian Creole speakers, in particular, who had the highest levels of superstitious thinking about risk, examining these beliefs may help us to better understand the cognitive underpinnings of patient activation, as well as Haitian Creole speakers' differential receptivity to health interventions that seek to raise cancer risk awareness and cancer control behaviors.

In terms of negative affect in risk, those with the highest levels of patient activation may also have more salient emotions and affect when they think about cancer risk, which may motivate them to remain actively focused on their health behaviors even under stress. Affect can highlight salient concerns [46] and tends to promote cancer screening behaviors rather than impede them [47, 48]. Other cancer risk belief items were also systematically related to patient activation, and require further study given their prevalent endorsement; they may have important implications for behaviors to prevent and control cancer.

Superstitious beliefs that certain thoughts or behaviors ward off negative events [35, 39, 41, 49–53] are likely embedded in cultural beliefs systems. They may be more common in Latino or Asian populations [39, 54]. Such cultural belief systems may also encompass supernatural causes of illness, influencing cancer decision-making among individuals already diagnosed with a malignancy [55]. African-Americans, Latinos, and Asians are more likely to endorse supernatural causes of illness than whites [56]. Haitians, in particular, may believe in the role of spirits or the supernatural in the development of disease [57]. Nonetheless, superstitious beliefs are quite ubiquitous in the general population [53]. For instance, the widespread acceptance of superstitions concerning risk is evidenced by the lack of 13th floors in many hospitals and hotels, the continued presence of horoscopes in magazines and newspapers, the ubiquity of "knock on wood" and "crossing fingers" to avoid tempting fate [41, 49], as well as rituals meant to gain the best outcome among sports figures and fans, and gamblers [52, 58, 59]. Patient activation interventions that engage diverse patient groups – across language and other cultural factors – may need to directly address and minimize superstitious beliefs that could encourage unrealistic perceptions of control about health behavior maintenance under challenging conditions. Relevant interventions may have physician communication as a primary intervention channel [60] or may target patients directly through broader public health messaging such as mass media channels. For example, such interventions may focus on finding alternative and potentially less superstitious ways to maintain actual control over health, by engagement with risk reduction behaviors and screening.

Study limitations include the fact that patient activation is a self-report measure. Prior empirical work has established that patient activation is related to higher knowledge, skills, and confidence to manage health and healthcare. Ongoing research is examining the relations of risk beliefs to behavior adoption and maintenance. Second, patient activation is not specific to cancer-related prevention or control behavior per se, even though it has been

found to be related to cancer screening activities [4]. Third, our study is limited by the cross-sectional dataset that precludes us making causal inferences. Finally, despite the fact that culture, ethnic background, and language preference are related but not identical constructs, we were unable to fully examine how culture may influence cancer risk beliefs and patient activation due to our limited assessment battery; future work is needed to accomplish this important goal.

In conclusion, we identify different patterns of cancer risk beliefs across language preferences in inner-city non-Native born Americans seeking primary care services. These cancer risk beliefs are significantly related to patient activation in diverse populations, regardless of language group, warranting continued research of this important outcome in cancer prevention and control, making cancer risk beliefs potentially informative in understanding activation and behavior in diverse populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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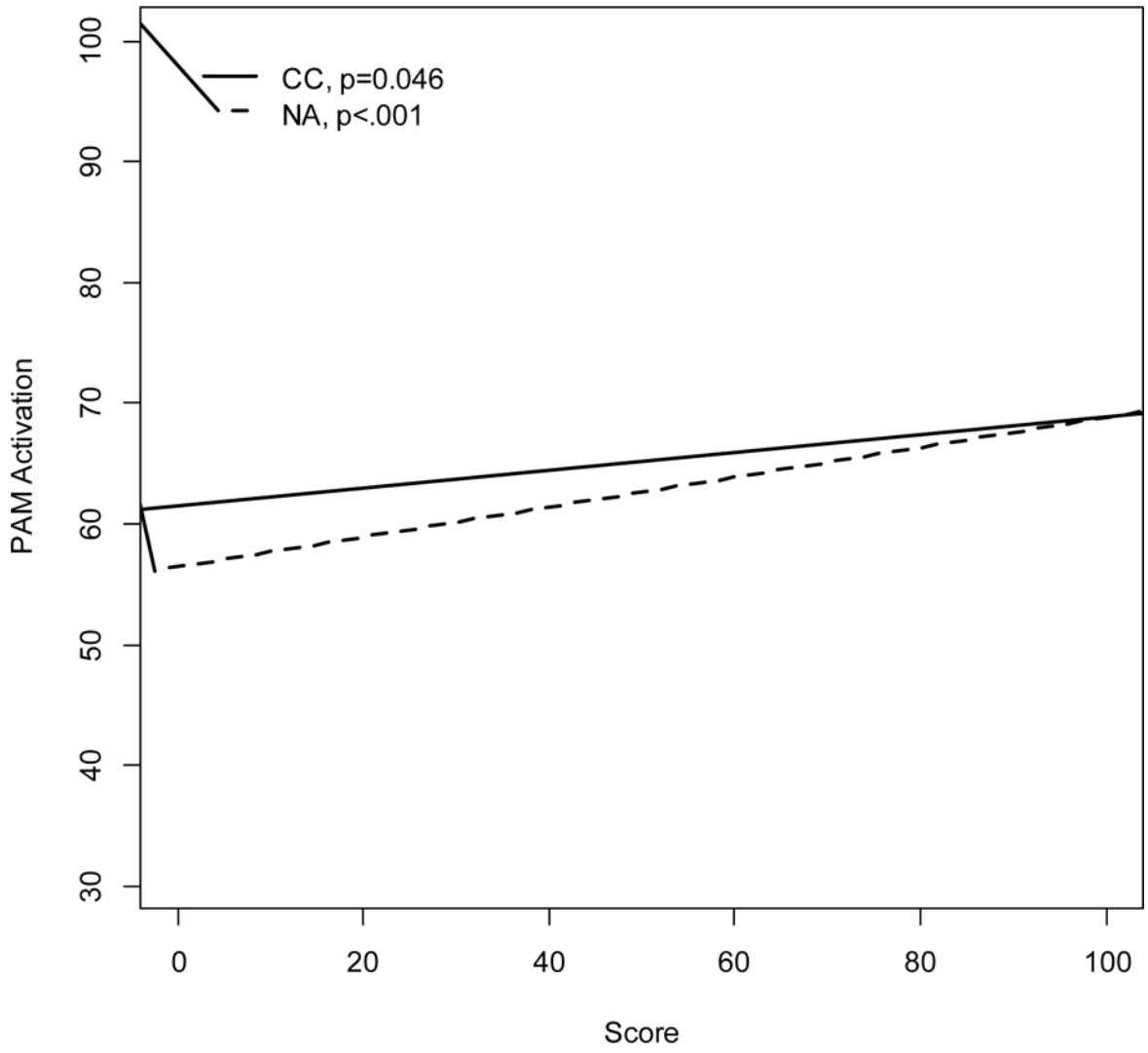
Figure 1.
Univariable associations between CC and NA scores with continuous PAM activation

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Table 1

Selected characteristics of 460 survey participants.

	Overall (n=460)	Haitian creole (n=150; 33%)	Survey language		p-value[1]
			Spanish (n=159; 34%)	English (n=151; 33%)	
Age (years), Mean (SD)	48 (15)	49 (15)	50 (13)	44 (15)	<.001
Sex, N (%)					0.093
Male	185 (40.2)	62 (41.3)	54 (34.0)	69 (45.7)	
Female	272 (59.1)	88 (58.7)	104 (65.4)	80 (53.0)	
Missing	3 (0.7)	0 (0.0)	1 (0.6)	2 (1.3)	
Family history of cancer, N (%)					0.022
Yes	162 (35.2)	38 (25.3)	63 (39.6)	61 (40.4)	
No	271 (58.9)	98 (65.3)	90 (56.6)	83 (55.0)	
Missing	27 (5.9)	14 (9.3)	6 (3.8)	7 (4.6)	
Hispanic ethnicity					<.001
No	281 (61.1)	146 (97.3)	0 (0.0)	135 (89.4)	
Yes	173 (37.6)	4 (2.7)	157 (98.7)	12 (7.9)	
Missing	6 (1.3)	0 (0.0)	2 (1.3)	4 (2.6)	
Race, N (%)					<.001
White	39 (8.5)	0 (0.0)	32 (20.1)	7 (4.6)	
Black	64 (13.9)	23 (15.3)	1 (0.6)	40 (26.5)	
American Indian or Alaskan Native	6 (1.3)	0 (0.0)	2 (1.3)	4 (2.6)	
Asian/Pacific Islander	15 (3.3)	0 (0.0)	0 (0.0)	15 (9.9)	
Other	139 (30.2)	0 (0.0)	113 (71.1)	26 (17.2)	
Caribbean Black	192 (41.7)	127 (84.7)	9 (5.7)	56 (37.1)	
Missing	5 (1.1)	0 (0.0)	2 (1.3)	3 (2.0)	
Born in US, N (%)					<.001
Yes	66 (14.3)	6 (4.0)	7 (4.4)	53 (35.1)	
No	388 (84.3)	143 (95.3)	150 (94.3)	95 (62.9)	
Missing	6 (1.3)	1 (0.7)	2 (1.3)	3 (2.0)	

	Overall (n=460)	Haitian creole (n=150; 33%)	Survey language Spanish (n=159; 34%)	English (n=151; 33%)	p-value[1]
Years living in US, N (%)					<.001
< 1 year	18 (3.9)	9 (6.0)	2 (1.3)	7 (4.6)	
1–10	110 (23.9)	46 (30.7)	30 (18.9)	34 (22.5)	
11–20	112 (24.3)	47 (31.3)	41 (25.8)	24 (15.9)	
>20	149 (32.4)	42 (28.0)	77 (48.4)	30 (19.9)	
NA	66 (14.3)	6 (4.0)	7 (4.4)	53 (35.1)	
Missing	5 (1.1)	0 (0.0)	2 (1.3)	3 (2.0)	
Living with anyone, N (%)					0.012
Yes	379 (82.4)	122 (81.3)	142 (89.3)	115 (76.2)	
No	72 (15.7)	28 (18.7)	14 (8.8)	30 (19.9)	
Missing	9 (2.0)	0 (0.0)	3 (1.9)	6 (4.0)	
Marital status, N (%)					<.001
Married/living with partner	246 (53.5)	58 (38.7)	120 (75.5)	68 (45.0)	
Single	126 (27.4)	50 (33.3)	22 (13.8)	54 (35.8)	
Divorced/Separated	61 (13.3)	31 (20.7)	11 (6.9)	19 (12.6)	
Widowed	21 (4.6)	11 (7.3)	4 (2.5)	6 (4.0)	
Missing	6 (1.3)	0 (0.0)	2 (1.3)	4 (2.6)	
Education, N (%)					<.001
Less than 7th grade	42 (9.1)	11 (7.3)	26 (16.4)	5 (3.3)	
Junior HS or partial HS	70 (15.2)	25 (16.7)	25 (15.7)	20 (13.2)	
High school/GED	139 (30.2)	40 (26.7)	60 (37.7)	39 (25.8)	
Partial college or vocational	122 (26.5)	40 (26.7)	34 (21.4)	48 (31.8)	
Standard college +	80 (17.4)	34 (22.7)	12 (7.5)	34 (22.5)	
Missing	7 (1.5)	0 (0.0)	2 (1.3)	5 (3.3)	
Employment status, N (%)					<.001
Employed	245 (53.3)	80 (53.3)	86 (54.1)	79 (52.3)	
Disabled	31 (6.7)	8 (5.3)	11 (6.9)	12 (7.9)	
Homemaker	44 (9.6)	3 (2.0)	34 (21.4)	7 (4.6)	

	Overall (n=460)	Haitian creole (n=150; 33%)	Spanish (n=159; 34%)	English (n=151; 33%)	p-value[1]
Retired	48 (10.4)	22 (14.7)	18 (11.3)	8 (5.3)	
Unemployed	48 (10.4)	18 (12.0)	5 (3.1)	25 (16.6)	
Student	35 (7.6)	19 (12.7)	2 (1.3)	14 (9.3)	
Missing/other	9 (2.0)	0 (0.0)	3 (1.9)	6 (4.0)	
Income, N (%)					0.003
<$10,000	78 (17.0)	14 (9.3)	31 (19.5)	33 (21.9)	
$10,000–$29,999	134 (29.1)	44 (29.3)	53 (33.3)	37 (24.5)	
$29,999–$49,999	110 (23.9)	38 (25.3)	43 (27.0)	29 (19.2)	
$50,000	31 (6.7)	8 (5.3)	5 (3.1)	18 (11.9)	
Missing	107 (23.3)	46 (30.7)	27 (17.0)	34 (22.5)	
CC score, mean (SD)	39.3 (21.5)	44.1 (20.4)	41.9 (20.9)	31.8 (21.4)	<.001
NA score, mean (SD)	64.6 (24.1)	59.9 (22.5)	66.7 (23.0)	67.1 (26.1)	0.006
PAM score, mean (SD)	64.4 (16.7)	60.8 (16.8)	63.5 (15.2)	69.2 (17.2)	<.001

Survey language

[1] p-value from Chi-square test when categorical and Kruskal-Wallis test when continuous.

Table 2

Univariable and multivariable associations with continuous PAM activation.

	Est (SE)	p-value[1]	Est (SE)	p-value[2]
Cognitive causation	0.07 (0.04)	0.046	0.12 (0.04)	<.001
Negative affect in risk	0.12 (0.03)	<.001	0.11 (0.03)	<.001
Survey language		<.001		<.001
English	Ref		Ref	
Haitian Creole	−8.33 (2.07)		−8.9 (2.04)	
Spanish	−6.68 (2.13)		−8.0 (2.03)	
Years living in US		0.005		0.006
Born in US	Ref		Ref	
<1	−12.84 (4.52)		−10 (4.42)	
1–10	−8.22 (2.62)		−4.8 (2.66)	
11–20	−5.51 (2.60)		−.55 (2.71)	
>20	−3.59 (2.49)		1.46 (2.63)	

[1] p-value from univariable linear regression;

[2] p-value from multivariable linear regression adjusted for all variables included in table