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Authors

De La Torre, CL
Dumbauld, JN
Haughton, J
et al.

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Development of a group based community health worker intervention to increase colorectal cancer screening among Latinos

CL De La Torre[1], **JN Dumbauld**[1], **J Haughton**[1], **S Gupta**[2], **J Nodora**[3], **R Espinoza Giacinto**[1], **C Ramers**[4], **B Bharti**[5], **K Wells**[6], **J Lopez**[4], **M Díaz**[4], **J Moody**[7], **EM Arredondo**[1]

[1]School of Public Health, San Diego State University, Institute for Behavioral and Community Health (IBACH), 9245 Sky Park Ct, Suite 221, San Diego, CA 92123, USA

[2]San Diego Veterans Affairs Healthcare System, Division of Gastroenterology, Department of Internal Medicine, UC San Diego Moores Cancer Center, La Jolla, CA 92093, USA

[3]Department of Family and Preventive Medicine, UC San Diego Moores Cancer Center, La Jolla, CA 92093, USA

[4]Family Health Centers of San Diego, San Diego, CA 92105, USA

[5]Cancer Prevention Program, UC San Diego Moores Cancer Center, La Jolla, CA 92093, USA

[6]Department of Psychology, San Diego State University, 6363 Alvarado Court, suite 103, San Diego, CA 92120, USA

[7]UC San Diego, School of Medicine, Department of Pediatrics, Center for Community Health, San Diego, CA 92105, USA

Abstract

Introduction: Latinos are at higher risk of colorectal cancer (CRC) mortality than Non-Hispanic Whites due, in part, to disparities in cancer screening. There is a need to evaluate community based CRC interventions as they may reach underinsured communities and those at highest risk for CRC. This paper describes the development of a group based CRC intervention (*Juntos contra el Cancer*).

Method: Purposive sampling was used to recruit Latino men and women ages 50–75 years not-up-to-date with CRC screening. The development of the intervention was guided by the Socio-Ecologic Framework, a community needs assessment, literature reviews, five focus groups (n=39) from the target community and feedback from a Community Advisory Board (CAB).

Results: Findings from focus groups suggested that a group-based, promotor or Community Health Worker (CHW) led, cancer prevention education with linkages to care would address barriers to CRC screening.

CORRESPONDING AUTHOR: Elva A. Arredondo, Graduate School of Public Health, San Diego State University, Institute for Behavioral and Community Health (IBACH), 9245 Sky Park Ct, Suite 221, San Diego, CA 92123, Fax: (619) 594-2998, Tel: (619) 594-4281, earredon@sdsu.edu.

Conclusion: Development of community-based CRC screening interventions should be informed by early and sustained community engagement. Interventions led by CHWs with linkages to care are feasible and can reach populations not connected to health care settings.

Introduction

Colorectal cancer (CRC) is one of the most preventable and treatable cancers when detected early (Edwards et al., 2010; American Cancer Society, 2018). Since the 1980s, CRC incidence and mortality have decreased significantly in the general population due to increased access to screening and effective treatment (Potter, 2013; American Cancer Society, 2018). Despite this, CRC remains the second leading cause of cancer mortality in the United States (Edwards et al., 2010; America Cancer Society, 2018). Among US Latinos, CRC is the third leading cause of cancer diagnosis and cancer deaths (American Cancer Society, 2018). Studies show disparities in CRC screening among low-income populations and many racial/ethnic groups including Latinos (Liss & Baker, 2014; American Cancer Society, 2018). In 2015, the CRC screening rate was 47.4% among Latinos compared to 64.2% for non-Hispanic Whites (White et al., 2017). Considerable evidence shows that CRC screening reduces CRC incidence and mortality, (Edwards et al., 2010; American Cancer Society, 2018) suggesting that improving access to CRC screening in Latinos would help reduce the burden of CRC among this population (Gonzales, Qeadan, Mishra, Rajput, & Hoffman, 2017).

Interventions to increase CRC screening rates have primarily been tested and implemented in primary care settings, which tend to be one-on-one (Davis et al., 2018; Mojica, Parra-Medina, & Vernon, 2018). In the US, most CRC screening orders are either opportunistic, when the patient attends a health care visit, or programmatic, when patients of a healthcare are offered screenings through an organized approached (Caldwell et al., 2011; Interventional Agency for Research on Cancer, 2005; Miles, Cockburn, Smith, & Wardle, 2004) A group-based education intervention in a community setting could be an alternative to one-on-one clinic-based interventions, and help reach populations who do not have access to health. According to the Community Preventive Services Tasks Force (CPSTF), though there is sufficient evidence supporting the efficacy of group based intervention in breast cancer screening, there continues to be limited evidence based interventions specific to CRC screening interventions (Guide to Community Preventive Services, 2018; Sabatino et al., 2012). Thus, research is needed to evaluate the effectiveness of group-based education in increasing CRC screening rates (Sabatino et al., 2012) among underserved population outside primary care settings.

Federally Qualified Health Centers (FQHCs) serve the uninsured, underinsured, and racial/ethnic minorities that have traditionally lower rates of cancer screening, and are now federally mandated to publicly report screening rates annually. With the provisions within the Affordable Care Act, such as the new access to health insurance and Medicaid expansion for populations that commonly use FQHCs, these clinics are in a unique position to implement CRC prevention programs that target underserved populations. In 2015, FQHCs served 24.3 million patients of which 35.2% were Latino (HRSA Health Center Program). FQHCs are motivated to increase cancer-screening rates and intervention strategies that

would help increase the CRC screening rates (Allen et al., 2014; Gwede et al., 2013). Thus, FQHCs are ideal agencies and settings to build community-academic partnerships and implement interventions to promote CRC screening among underserved communities.

Community Health Workers as Agents of Change

Community health workers (CHWs) are trusted members of the target community who act as liaisons between health care providers and the community, and are known by different names including *promotores de salud* (in Spanish), lay health advisors, community health aides, peer educators, and peer outreach educators (Ayala, Vaz, Earp, Elder, & Cherrington, 2010). The CHW model can improve Latinos' access to health care (Ayala et al., 2010) and promote cancer screening among Latino populations (Ayala et al., 2010; Larkey, 2006; Mojica, Almatkyzy, & Morales-Campos, 2019; Mojica, Morales-Campos, Carmona, Ouyang, & Liang, 2015; Moralez, Rao, Livaudais, & Thompson, 2012). As lack of health care access is the largest barrier to screening completion (American Cancer Society, 2015; Byrd, Calderón-Mora, Salaiz, & Shokar, 2018; Fedewa, Sauer, Siegel, & Jemal, 2015; Fernández et al., 2015; Ogedegbe et al., 2005), effective CRC screening programs should also focus on facilitating access by linking community members to clinical services (linkages to care).

To our knowledge, no studies have examined a CHW-led group-based education plus linkages to care in both community and clinic settings to promote CRC screening among Latino men and women. To decrease CRC mortality rates among Latinos, there is a need to investigate culturally appropriate approaches with that have the potential to reach underserved communities with limited access to affordable health care. This manuscript describes the development of the *Juntos Contra el Cáncer*/United Against Cancer (JUNTOS) intervention to increase CRC screening rates among underserved Latinos in San Diego, CA. Program development followed an Socio-Ecologic Framework (Glanz, Rimer, & Viswanath, 2008) to identify personal, interpersonal, and organizational level factors that impact access to CRC screening services and inform the development of the group-based workshops, and was guided by a needs assessment, literature review, focus groups, and feedback from a Community Advisory Board (CAB). The San Diego State University (SDSU) Institutional Review Board approved all research protocols and data gathering methods. We will report JUNTOS outcomes in a forthcoming publication.

Methods

In collaboration with an FQHC, we aimed to increase participation in CRC screening among a primarily Hispanic/Latino community through a CHW-led education intervention that included linkages to care.

Community Needs Assessment

Over five months, investigators from SDSU and the University of California San Diego Moores Cancer Center met in-person with clinical leaders from five FQHCs from San Diego and Imperial Counties to discuss the health and resource needs in the clinic and community. During these meetings, we asked clinical leaders what their cancer prevention priorities

were. We identified that a priority was to facilitate CRC screening in the largely underserved population in predominantly Latino communities of San Diego. We identified an FQHC partner (Family Health Centers of San Diego) that serves a large percentage of Latinos (60%) in San Diego (HRSA Health Center Program).

Literature Review

We conducted a literature review to identify community and clinic-based interventions and evidence-based strategies to increase CRC screening rates in Latino communities. The review supported the involvement of CHWs to help develop and implement cancer screening programs (Larkey, 2006; Moralez et al., 2012). We identified acceptable and feasible intervention strategies such as clarifying misconceptions about cancer and screening methods, having bilingual female and male staff, leveraging social support networks, providing linguistically-tailored screening instructions, and including interactive activity games to reinforce learning such as “bingo” (Baker et al., 2014; Coronado, Golovaty, Longton, Levy, & Jimenez, 2011; Elder et al., 2017; Enard et al., 2015; Goldman, Diaz, & Kim, 2009; Larkey, 2006; Larkey et al., 2012; Mojica et al., 2015; Moralez et al., 2012)

Focus Groups

Between May and July 2016, we conducted five focus groups with Latino men (n=8) and women (n=31) from the target community (Table I) to determine factors impacting screening services and inform the development of the group-based educational intervention. Using purposeful sampling, the research team recruited individuals via community outreach activities including resource fairs, tabling, and flyers. Participants were screened in-person or by telephone by trained Spanish-English bilingual research staff to assess eligibility. Eligible community members were included if they met the following criteria: 1) were between the ages of 50 and 75, and 2) self-identified as Latino. Eligible participants were scheduled for one of five focus group stratified by gender and CRC screening adherence status. We conducted three focus groups with CRC screening adherent participants and two with non-adherent participants. CRC adherence was defined as having undergone a colonoscopy within the past ten years or a Fecal Immunochemical Test (FIT)/Fecal Occult Blood Test (FOBT) kit within the prior year. The focus groups were held in community locations in our catchment area (community center, public library, and at a local business). A Spanish-English bilingual research staff member administered a written informed consent form and moderated the discussion using a standardized focus group guide based on the Socio-ecologic Framework (Glanz et al., 2008) Two co-authors (EA and JN) along with research assistants facilitated the focus groups. At the beginning of the focus groups, participants also completed a questionnaire on demographic characteristics and CRC cancer screening status based on the 2016 US Preventive Task Force recommendations (US Preventive Services Task Force, 2016). Participants received a $15 gift card from Wal-Mart for their participation. All focus groups lasted two hours, were conducted in Spanish, audio recorded, transcribed verbatim, and then translated into English. Two research staff selected themes independently and then compared and compiled the results in a matrix under selected focus group questions according to standard protocol. The results were further stratified by individual, interpersonal, and organizational level factors as the related to barriers or facilitators for CRC screening.

Barriers and Facilitators to CRC Screening.—In the focus groups, participants were asked about barriers and facilitators to adherence to CRC screening guidelines (Table II). At the individual level and consistent with previous research (Byrd, Calderón-Mora, Salaiz, & Shokar, 2019; Goldman et al., 2015; McLachlan, Clements, & Austoker, 2012). Our focus groups suggested that lack of insurance, cost, time, work, and transportation impeded adherence to cancer screenings. Primary barriers were cost and uncertainty regarding what to do with an abnormal result, particularly for those with no health insurance ("not having health insurance is always a huge problem"). Moreover, among the uninsured, many had negative experiences relating to large debt incurred for health services ("Thank God they made arrangements for me to pay installments, but that is why, even when I am sick, if I am not too ill, I do not go to the doctor"). Both adherent and non-adherent groups reported limited knowledge of the digestive system, CRC, and CRC screening methods. At the interpersonal level, family support ("My kids motivate me [to seek care") was a facilitator to healthcare whereas relying on family members to take them to health care appointments was reported as a barrier to care. Both non-adherent and adherent participants reported that the language barriers, lack of *personalismo* (i.e., formal friendliness) from the doctor, feeling rushed during interaction with their providers, not being in an environment where they could ask questions to providers, and receiving poor care from medical staff as barriers to CRC screening ("the doctor doesn't talk to you. So, usually you become a statistic, not a patient with a doctor, you are not a human being with a doctor, you are just a number"). Not speaking English was reported more commonly as a barrier among women than men. At the organizational level, the high volume of patients and waiting periods in comparison to the actual consultation visit was a barrier to visit the doctor regularly. Also, scheduling appointments weeks or even months in advance affects participants' motivation to attend appointments. The facilitators to completing screening included doctor's recommendation ("I did the exam [colonoscopy]; my doctor told me to"), having health insurance that would cover screening costs, clear instructions on how to complete the test, transportation provided by health insurance and good rapport and treatment from providers.

Focus Group Recommendations for a CRC Intervention.—In the focus groups, we asked participants for recommended strategies and methods to integrate into a CRC intervention aimed at increasing CRC screening among members in their community. Participants recommended providing CRC education and having community members participate in the educational sessions. They explained that having their peers lead such programs increases trust among community members their willingness to learn about the recommended screening tests. The men in the focus groups suggested providing CRC screening education in written formats such as pamphlets to men as they would rather read about it in their own time. Both adherent and non-adherent participants noted that they need clear instructions of how a FIT/FOBT and a colonoscopy are conducted to ensure the completion of CRC screening. As the lack of transportation was a barrier to completing CRC screening among non-adherent participants, participants recommended that health programs provide transportation services or public transportation vouchers. Overall, focus group findings reaffirmed the need for a program to provide not only education but also building trust by having peers from the community implement such programs, providing transportation, and recognition of existing barriers to care.

Community Advisory Board

We solicited recommendations and feedback on the development and implementation of the intervention and materials from a Community Advisory Board (CAB) composed of a network of cancer survivors and representatives from community-based and health care organizations from the American Cancer Society (ACS), Office of Binational Border Health of the California Department of Public Health, Family Health Center of San Diego, Sherman Heights Community Center, Barrio Logan College Institute, Every Woman Counts, and the California Colorectal Cancer Coalition. The research team met quarterly with the CAB. The CAB created an ad hoc group to review in detail and provide feedback on all the curriculum, materials, and assessments. The CAB also provided advice on strategies for recruiting men and underserved populations. Suggestions for recruiting men included visiting worksites, senior centers and apartments, and involving men's partners. The CAB reinforced the importance of intervention content that is easy to understand and free of jargon, making room for discussion and questions, identifying celebrities who are CRC screening advocates, providing information about resources for risk factors for CRC (e.g., tobacco cessation, diet, PA) and including light refreshment at the workshops. The CAB also recommended that the messages emphasize that there are no symptoms for early-stage CRC. Other recommendations included presenting CRC mortality rates in the Latino community to grab community members' interest in the topic, and partnering with other organizations when doing outreach. Also our initial baseline assessment included approximately 70 items, which the ad hoc group recommended we cut down because of literacy challenges.

Community Health Workers

Since the intervention targeted Latino men and women, we hired one male and one female CHW. Through the partnered clinic, the CHWs were recruited from the community based on their experience promoting health and leading group sessions, bilingual fluency (English/Spanish), and commitment to teaching others to engage in the targeted preventive behaviors. As employees of the partnered clinic (30 hours/week), the CHWs had the capacity to provide linkages to care. The Community Health Educator and the clinic's Patient Engagement Specialist provided the CHWs with over 80 hours of training. The training curriculum, including homework, focused on increasing their knowledge of cancer screening services in the communities, reviewing current cancer screening guidelines, and developing skills as health educators and research implementers (Table III)(Elder et al., 2017) The CHWs received feedback on recruitment, workshop presentation, public speaking, and the use of interactive activities to discuss CRC and CRC screening methods and create cohesion among the workshop participants.

As implementers of community-based research projects, it is important for CHWs to be trained on ethics and confidentiallity, basic research concepts, and the importance of following research-based procedures (e.g., data collection) to obtain meaningful results (Nebeker & López-Arenas, 2016) In addition to the BRIC training, the CHWs completed the Collaborative Institutional Training Initiative Human Subjects Research Training as part of the SDSU onboarding process.

Intervention Design

Program Development and Rationale—The formative work led to the development of a community and clinic-based intervention combined innovative and traditional methods for promoting CRC screening among Latinos. Based on the key priorities of our partnered clinic and prior research with Latino communities (Elder et al., 2017) and focus groups with the target population, we designed a program tailored to Latino men and women aged 50–75 years, consisting of a CHW-led cancer prevention intervention that includes a 2.5-hour group workshop on CRC prevention. Based on the geaographical area and similiarities of our intented audience, we indentified components of the cancer prevention cirruculum from the Faith in Action trial (e.g., discussion of lifestyle behaviors that increase risk of cancer) to inform the curriculum (Arredondo et al., 2015; Elder et al., 2017). The JUNTOS educational workshop includes 75 minutes of CRC and CRC screening education, discussions, and interactive learning activities. Post-workshop telephone follow-up calls address individuals' barriers to CRC screening and scheduled visits with a primary care provider at the partnered FQHC. Because some workshop participants may seek cancer screening from a provider outside the partnered clinic, The JUNTOS study's primary outcome is self-reported CRC screening assessed at six months following participants' enrollment in the intervention. The screening assessment is supplemented by direct review of the EHR for those who are patients of the partnered clinic.

Individual Level—At the individual level, the intervention aims to educate participants about CRC, its risk factors, screening methods, and to empower participants to ask providers about their CRC screening tests. We structured to adminiser the consent form, participant enrollment, the pre-test, CRC workshop, and the post-test assessing knowledge of CRC and its prevention/detection methods in one workshop, as time away from home or work and limited transportation were noted as barriers to attendance in previous interventions led by our team (Elder et al., 2017) and confirmed by the focus groups. To further address these barriers, workshops are offered at various times, including evenings and weekend, and offered at or near one of the clinic sites of the partnered clinic to accommodate participants' schedules. To engage participants, the educational component includes a discussion of participants' current knowledge of cancer and CRC, their perceived risks, and where cancer screening falls on their list of health priorities. From the literature review (Baker et al., 2014; Coronado et al., 2011; Elder et al., 2017; Enard et al., 2015; Goldman et al., 2009; Larkey, 2006; Larkey et al., 2012; Mojica et al., 2015; Moralez et al., 2012) and focus groups, we identified information about CRC and CRC screening that are misguided or incorrect and created an interactive slide presentation to debunk CRC myths and misconceptions. This was followed by an educational component that covered CRC, CRC risk factors, and screening methods. A public service announcement video clip on CRC screening is included near the end of the presentation to address common excuses and misconceptions that lead people to delay or avoid getting screening for CRC cancer (Centers for Disease Control and Prevention, 2013).

Educational handouts are also included in the intervention, as recommended by the Community Guide by the CPSTF (Guide to Community Preventive Services, 2018). Staff and CHWs gave participants two American Cancer Society handouts about CRC prevention

and two additional handouts created by CHWs and tailored to the community: 1) an up-to-date list of resources and services in the community such as shelter, immigration and legal services, and food banks and 2) a handout on health insurance that covered Medicaid, Medicare, and the Affordable Care Act. We developed all educational materials to be culturally and linguistically relevant and appropriate for Latinos and individuals with low literacy skills in the target area in English and Spanish. At the end of the workshop, CHWs reviewed all handouts with participants.

Interpersonal Level—At the interpersonal level, the intervention included instrumental and social support in the form of group-education and follow-up telephone calls to address barriers the participant may encounter in seeking CRC screening. The CHWs led the CRC workshop that includes group activities, didactic presentations, interactive discussion, and games to reinforce material and keep participants engaged. The workshop encourages participants to ask questions and share experiences openly with the group. Before beginning the CRC educational session, there is an ice breaker to build social support and cohesion among participants, as they are not likely to know each other before the workshop. The educational component includes a discussion of participants' current knowledge of cancer and CRC, their perceived risks, and where cancer screening falls on their list of health priorities. As a follow up to the PSA, CHWs lead the group in a discussion about the messages in the video. To reinforce the educational content of the workshop on CRC risk factors and screening, a customized Mexican Bingo game called "*La Loteria*" in Spanish is integrated with prizes given to winners.

CHWs conduct follow-up telephone calls with all participants within two weeks of workshop completion. These personal calls allow discussion of the workshop material and address any questions or concerns that might be too personal to share during the workshop. CHWs conclude each follow-up call by helping participants set cancer screening goals. CHWs note important information from these calls and conversations to keep track of each participants' progress in scheduling and attaining CRC screening.

Organizational Level—Our intervention aims to improve access to health care, as health care access is an important barrier to cancer screening adherence.(American Cancer Society, 2015; Byrd et al., 2018; Fedewa et al., 2015; Ogedegbe et al., 2005) At the organizational level, we hired two members from the community through the partnered clinic to increase trust between the clinic and the community and link program participants with clinics. We incorporate linkages to care at the end of the workshop and during the follow-up calls. CHWs training on linkages to care emphasize reducing participants' barriers to CRC screening, recommending community services as needed, and helping or motivating participants to schedule appointment with a health care provider as needed. For participants who are patients of the partnered clinic or those without a medical home, CHWs offer to schedule appointments with a health care provider from the partnered clinic to discuss CRC screening options. For participants who have a different medical home, CHWs encourage participants to schedule an appointment with their provider to discuss CRC screening. The partnered clinic provided CHWs with office space and supplies, and management support. CHWs share information about cancer screening resources and services available in the

community with participants. To address cost barriers associated with access to care, investigators work with our partnered clinic and other institutes to provide no-cost or low-cost CRC screenings to uninsured and underinsured individuals.

Conclusion

Low CRC screening contributes to the high CRC mortality and incidence in Latinos, and there is a lack of research on CRC prevention interventions in underserved communities and uninsured populations. Culturally appropriate and cost-effective interventions are needed to dissemination information on CRC screening and facilitate access to health care in their communities. This paper describes the development of the JUNTOS intervention, which aims to increase CRC screening rates among Latino men and women in San Diego using a CHW-led group-based intervention with linkages to care. From the beginning, community stakeholders were involved in the development of the intervention, including CAB review and feedback on intervention materials and identification of community resources and implementation strategies.

JUNTOS is a bilingual, culturally-tailored, interactive, group-based intervention targeting individuals not up-to-date with CRC screening. The 2.5-hour CHWs –led workshop provides CRC cancer screening information to Latino men and women, and links them to an FQHC. Delivering cancer prevention and control interventions through FQHCs has great potential to increase the number of individuals exposed to evidence-based cancer prevention and control strategies. Community-based programs outside primary care settings can reach uninsured and underinsured community members who are at most need of health care services. CHWs play a key role in improving health outcomes as they are more likely to access monolingual Spanish speaking Latinos who are not connected to health care settings. At the same time, CHWs programs supported through clinics have the potential to be sustained given their ability to strengthen linkages with community organizations. To our knowledge, this is the first study to connect uninsured/underinsured and insured Latino males and females to a cancer screening program involving CHWs with linkages to care component.

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Table 1.

Descriptive characteristics of JUNTOS focus group participants (n=39).

Characteristic	*n (%)*
Age, y, mean (range)[a]	59.4 (50–74)
Gender	
Female	31 (79.5)
Male	8 (20.5)
Education Level[b]	
Less than or some high school	25 (71.4)
High school diploma or higher	10 (28.6)
Country of Birth	
Mexico	34 (87.2)
USA	4 (10.3)
El Salvador	1 (2.6)
Years Living in US	
<1 to 10 years	2 (5.1)
11 to 20 years	6 (15.4)
>20 years	31 (79.5)
Colorectal Cancer Screening[c,d]	
Up to date	19 (52.8)
Not up to date	17 (47.2)

[a] Missing *n*=7

[b] Missing *n*=4

[c] Based on 2016 US Preventive Task Force recommendations for screening intervals

[d] Missing *n*=3

Table 2.

JUNTOS Focus Groups' Reported Barriers and Facilitators

Barriers to CRC screening	Facilitators to CRC screening
• Cost of screening	• Knowledge
• Lack of insurance	• Health insurance
• Uncertainty of abnormal results	• Clear screening instructions
• Fear of debt incurred for services	• Interpreters
• Lack of knowledge	• Transportation covered by health insurance
• Time away from work	• Provider recommendation
• No/limited transportation	
• Language barriers	
• Lack of provider *personalismo*	
• Feeling rushed during interactions with providers	
• Not feeling being in a setting where they could ask questions to providers	
• Mistrust of health care system/providers	

Table 3.

JUNTOS CHW Training Curriculum Session and Objectives

1. Study Introduction	**1**	Understand the primary goals of the study and the outreach program
	2	Understand the CHW role and responsibilities
	3	Understand the importance of completing and storing all paperwork in a timely and professional manner
	4	Understand the study protocol regarding confidentiality
2.The Importance of Prevention	**1**	List various cancer statistics for Latinos
	2	Understand the concept and importance of social cohesion as a determinant of health
3. Patients' Rights and Responsibilities	**1**	Locate reliable sources of health information
	2	Understand the Patient Bill of Rights and Office of Minority Health CLAS standards
	3	Explain how to establish good communication skills with your doctor/provider
4.Presentation Skills	**1**	Identify different strategies for effective public speaking
	2	Practice speaking in front of an audience
5a.Colorectal Cancer Overview	**1**	Identify and name major digestive system organs
	2	Understand why screening is so important in preventing colorectal cancer
	3	List at least three colorectal cancer risk factors
	4	List strategies for detecting colorectal cancer
	5	Increase understanding of common barriers to screening
5b.Supplemental Materials on Colorectal Cancer	**1**	Identify motivational interviewing strategies to approach people regarding colorectal cancer screening
	2	List evidence-based messaging about colorectal cancer screening for Hispanic/Latinos
6.Colorectal Cancer Intervention Workshop	**3**	Increase familiarity with leading a group discussion regarding colorectal cancer
	4	Increase understanding of common myths and facts regarding CRC
	5	Gain a greater understanding of CRC health statistics
	6	Increase understanding of digestive system organs as they relate to colorectal cancer
	7	List at least three colorectal cancer risk factors
	8	List strategies for detecting colorectal cancer
	9	Identify the key steps to attain screening
	10	Practice CRC Session 1 in order to gain familiarity, confidence and feedback on presentation techniques