

# Study of an Educational Telenovela to Teach Genomics among Latino Farmworkers and Non-farmworkers: Lessons Learned

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## **ABSTRACT**

**Background:** Genomic knowledge is becoming increasingly relevant to health care. Development of linguistically and culturally appropriate educational resources for Latino adults with limited education and English skills is needed.

**Objectives:** The effectiveness of a telenovela was analyzed and lessons learned provided.

**Methods:** The team developed a telenovela to convey key genomics concepts and delivered it to 100 Latino farmworkers and non-farmworkers in North Carolina. Participants completed a pretest measuring genomic knowledge and self-efficacy, viewed the telenovela, then completed a posttest. Twenty-four participants repeated the posttest six months later. Changes in genomic knowledge and self-efficacy were calculated.

**Results:** Overall, genomic knowledge and self-efficacy increased significantly after viewing the telenovela. Responses to two items indicated that the emphasis on epigenetics overshadowed other genomic mechanisms. Six-month follow-up results were not significantly different from pretest.

**Conclusion:** Increased attention to graphic design principles, presentation across multiple sessions, and supplemental activities may increase telenovelas' impact.

**KEYWORDS:** Latino; Hispanic; health communication; telenovela, communication; genomics; genetic knowledge

## Introduction

Genomic literacy is becoming increasingly important during patient-provider encounters, as genomic advances are being integrated into medical care.<sup>1-6</sup> The advent of “precision medicine,” which offers the ability to assess disease risk and tailor therapeutic options based on an individual’s underlying genomic profile, and the increased availability of consumer-based genomic testing services (e.g., Ancestry.com), highlight the importance of educating the general public about genomics. Grasp of general concepts that undergird genomic research may enable patients to better understand their health risks, treatment options, and why their treatment options may be different from those with similar health conditions. Development and evaluation of health communication strategies that may increase genomic knowledge is warranted.

Most lay people, Latino and non-Latino, do not have the knowledge to adequately understand potential benefits and limitations of genomic information, including epigenetic information.<sup>7-9</sup> The Latino community is diverse, and includes both immigrants and those born in the United States (US). Educational opportunities and attainment vary widely. Forty-eight percent of foreign-born Latinos currently living in the US ages 25 and older have not graduated from high school, compared to 19% of US-born Latinos.<sup>10</sup> This population may find some types of health communication materials intimidating and inappropriate. Genomic content needs to be presented to Latino adults with limited education in a culturally and linguistically appropriate manner. Telenovelas, videos with dramatic storylines, have been used effectively to convey health information to Latino adults.<sup>11-15</sup> Telenovelas are visually compelling, do not require reading skills, use plot lines to engage Latino adults, and, when presented in Spanish, are particularly appropriate for Latino adults with limited education and English-language skills. Not only can video-based educational interventions improve knowledge, they can also improve health

behaviors.<sup>16</sup> This pilot study evaluated the effectiveness of an educational intervention on (1) genomic knowledge and (2) self-efficacy, defined as the perception that participants could positively affect their health,<sup>17</sup> and identified lessons learned from the intervention evaluation.

## **Methods**

The educational intervention was part of a larger community-based participatory research (CBPR) project that examined cognitive and neurological outcomes of pesticide exposure among urban and rural Latino communities.<sup>18</sup> One component of the larger project examined whether pesticide exposure is associated with epigenetic changes among farmworkers. As with other components of the larger study, we wanted to be able to share research findings with study participants, and were aware that epigenetics is difficult to explain to most people, particularly those with limited formal education. This educational intervention was therefore developed in parallel with the research about pesticide exposure and epigenetics to enable the research team to share the study findings with participants.

The research team includes members from Wake Forest School of Medicine (WFMS), the NC Farmworkers Project, and El Buen Pastor Latino Community Services. WFSM faculty and staff have worked collaboratively with NC Farmworkers Project and El Buen Pastor Latino Community Service, two organizations associated with this project, for over twenty years to achieve shared goals. This partnership has provided benefits to the community organizations, including advancing skills of their staff, providing resources for their organizations, and providing opportunities for members of their communities to learn about environmental health. The NC Farmworkers Project works to improve the living and working conditions of farmworkers, and build a better future for farmworkers and their families. It has therefore

partnered with the WFSM team members since 1996 to advance knowledge about work, residential, and regulatory environments that contribute to farmworker pesticide exposure, to document the actual pesticide exposure and dose experienced by farmworkers and the members of their families, and to document the effects of this pesticide exposure on health (cognitive, depression). Research results have been routinely returned to study participants. The director of the NC Farmworkers Project was a valuable member of the research team, and participated in the bi-monthly team meetings across the years, including for this project.

El Buen Pastor Latino Community Services has partnered with members of the research team on previous projects that addressed the health and well-being of the Latinx community. Research team members have collaborated with El Buen Pastor since the organization was established in 2000. The community organization focused its effort on promoting the educational achievement, health, and well-being of the Latinx immigrant community, and therefore held priorities that overlapped with the goals of this project. El Buen Pastor team members were actively involved in project team meetings and advanced their own research skills which could then be used for their organizational needs.

After data collection was complete, NC Farmworkers Project staff showed the video on a tablet at some of their mobile clinics and discussed it informally with farmworkers. This strategy was designed to advance health literacy of the farmworker community that contributed to its development, thereby benefitting the farmworkers and advancing the goals of the NC Farmworkers Project. The collaborative efforts between the WFSM researchers and the NC Farmworkers Project remain ongoing.

### *Intervention Development*

The educational intervention component consisted of presenting a linguistically and culturally appropriate Spanish-language telenovela that explained epigenetic concepts, followed by a short discussion led by native Spanish speakers. The telenovela was a cartoon with limited animation developed by an interdisciplinary research team, including a geneticist, anthropologists, sociologists, and graphic artists. Team members included native Spanish speakers. The telenovela was created after analyzing transcripts of 16 interviews conducted with Latinos born in Mexico and Central America about their beliefs about genomics and trait transmission.<sup>19</sup> Findings from the qualitative analysis enabled the research team to use appropriate terminology and minimize potentially confusing explanations. References to blood in the context of trait transmission were frequent, and appeared to be used metaphorically by some and literally by others. For instance, some participants who participated in the qualitative component indicated children look like the parent who has stronger blood. The telenovela therefore used text that recognized commonly reported sayings about blood, then placed them in the context of factually correct statements about genetics. For instance, the telenovela includes the following statement: “Even though some people believe that one family’s blood is stronger than the other, we actually inherit equally half of our genes from our mom and half from our dad.” Content about behaviors that could improve health, such as not smoking, was integrated into the telenovela.

Video development included several steps. The team geneticist identified concepts central to genomics, including epigenetics (Table 1). The research team developed a plot line about a couple expecting their first child. The expectant father had a twin brother who had been diagnosed with cancer. The expectant parents met with their doctor to learn whether the brother’s health problems meant that the father and in utero child would become ill. The doctor explained basic genomic content, including epigenetics. This plot was intended to engage the target

audience and provide a vehicle through which central genomic concepts would be explained. The telenovela also provided concrete strategies to improve health, such as eating a healthy diet and reducing exposure to cigarette smoke, while integrating genomic content. A professional artist developed a set of storyboards.

Trained, bilingual, native Spanish-speaking moderators led focus groups with a total of 29 Latino participants from Latino farmworker and non-farmworker communities. The moderator showed the storyboard images on a tablet device to the group while reading the script aloud; participants then completed tests about genomics, including epigenetics. The focus group interview guide addressed participant general perceptions and comprehension about genomic content, interest in the story, and adequacy of and engagement with the visual images. The moderator elicited feedback about each image, while a second bilingual team member took notes. The research team revised the images and script based on focus group findings. For example, some participants remained unfamiliar with the word “*epigenetica*” after hearing the text and seeing the images. The Spanish word for epigenetics was therefore made more visible in the telenovela by increasing the printed word’s use in the telenovela against a bright red background. The artistic team added animation and Spanish language voice-overs. The 6.5 minute telenovela was uploaded to YouTube. (<https://www.youtube.com/watch?v=96Rz8hmLHLw>)

### *Recruitment & Data Collection*

We recruited 103 adults to participate in the evaluation component who met the following inclusion criteria: (1) age 18 or older, (2) fluent in Spanish or English, and (3) self-identified as Latino or Hispanic. Exclusion criteria included (1) having participated in the formative evaluation phase (i.e., having completed in-depth, semi-structured interviews about trait



transmission,<sup>19</sup> or in the focus groups), or (2) unable to provide informed consent. By design, approximately equal numbers of men and women and farmworkers and non-farmworkers were recruited. The research team recruited individuals from predominantly immigrant and migrant communities whose adult members have limited formal education. Women who were agricultural laborers or shared a household with an agriculture laborer were considered farmworkers. Only males who were themselves agricultural laborers were considered farmworkers. With the assistance of a community partner, the NC Farmworkers Project, the research team recruited men who lived in farmworker camps (group living quarters) in eastern NC and women who attended a farmworker festival in eastern NC. A second community partner, El Buen Pastor Latino Community Services, facilitated recruitment of men and women living in Winston-Salem, NC, who were not working in agriculture. These adults were considered “non-farmworkers”. The research team also recruited participants from other community organizations and locations to fit into the two groups. Due to the recruitment strategies, refusal rates are unavailable. Data for three participants were excluded, two due to incorrectly entered identification numbers, and one due to a hearing impairment that became apparent after posttest completion.

Participants completed the Spanish-language pretest and then viewed the Spanish-language telenovela on a tablet. Team members were aware that some participants could not read. Therefore, participants were taught how to click on the text to have the tablet “read” the selected question aloud, and the community health educator ensured that all participants were able to understand the questions and record their responses accurately. A trained and trusted community health educator fluent in Spanish led a discussion, using a flip chart with key images from the telenovela to facilitate conversation. A list of frequently asked questions and responses,

developed by the investigative team, was available to the health educator. After the discussion facilitated by the flip chart was completed, participants completed an immediate posttest.

A six-month follow-up was completed by 24 of the original participants, with equal numbers of men and women, and farmworkers and non-farmworkers. To recruit these individuals, the list of 100 participant identification numbers was divided into four gender/location categories; a computer program randomly ordered identification numbers within each list. Participants were approached in the order they appeared on the randomized list. Some male farmworkers had not yet returned to NC for the 2015 agricultural season, and were therefore unavailable. No more than two farmworker men from one farmworker camp completed the follow-up interview. Participants received a \$10 incentive for their involvement in the pre- and posttest component; participants in the 6-month follow-up component received an additional \$10 incentive.

The pretest, posttest, and 6-month follow-up were completed primarily on tablets. The initial data were collected in 2014; six-month follow up data were collected in 2015. Data were entered into REDCap, a secure application that builds, creates, and manages surveys and databases.<sup>20</sup> The **WFSM** Institutional Review Board approved all study procedures. Research team members explained the study to potential participants, including its purpose, duration, and incentives. Potential participants were screened to ensure they met the inclusion criteria. Participants provided written informed consent.

### *Measures*

The evaluation instrument used at pretest, posttest, and follow-up interviews included 10 knowledge items. These items were developed to correspond to the 5 sub-points previously

identified by the team and listed in Table 1. One question was taken from an existing measure,<sup>21</sup> others were developed by the research team for this project. One knowledge item was replaced after focus groups were conducted; other minor changes were made. For each knowledge question, participants could select “True,” “False,” or “Don’t Know.” For each of the 10 knowledge items, incorrect responses were coded as “-1,” correct responses as “1” and don’t know responses as “0.” A “Genomic Knowledge Scale” summary measure was created by summing each of the re-coded knowledge items, for a range of possible values of -10 to 10, with higher values indicating greater genomic knowledge.

Self-efficacy data were collected at the pre- and posttests, and follow-up. Three items measured participants’ health self-efficacy, the perception that they could positively affect their health: 1) I am confident that I can have a positive effect on my health; 2) I feel well informed about behaviors I can take to be healthy; and 3) I am confident in my ability to make healthy choices. For each self-efficacy statement, a participant used a visual analog device in which he or she could move a slider bar to a region marked “disagree,” “neutral,” or “agree.” Segments corresponding to “disagree,” “neutral,” and “agree” were coded as -1, 0, and 1, respectively. A “Self-efficacy Scale” summary measure was created by summing each of these re-coded items, for a range of -3 to 3. Cronbach’s alphas for the pre- and posttest self-efficacy scores were 0.48 and 0.83, respectively.

The pretest questionnaire recorded gender (male, female), age in years, and highest level of education completed. Age and education were dichotomized to < 35 and  $\geq 35$  years, and less than a high school diploma/GED or at least a high school diploma/GED, respectively, for analyses that examined the relationship between change scores and individual characteristics.

### *Data analysis*

Descriptive statistics were calculated for participant characteristics. Means and standard deviations were calculated for each of the 10 individual knowledge items and the knowledge and self-efficacy summary measures for both the pre- and posttest and 6-month follow-up. The difference between the posttest and pretest was calculated and the Wilcoxon signed rank sum test was used to examine the differences in scores at the two time points. For the knowledge and self-efficacy summary measures, the relationship between each of the change scores and farmworker status, gender, age and education were examined using a generalized linear model, adjusting for the pretest score of each variable. Finally, the difference between the 6-month follow-up visit and the pretest scores were calculated, and the Wilcoxon signed rank sum test was again used to look for differences between the time points. All analyses were completed using SAS 9.4 (SAS Institute, Cary, NC); p-values of less than 0.05 were considered statistically significant.

### **Results**

Almost half (N=49) of the 100 participants were male (Table 2). Thirty-four participants were ages 18-29 years old, 33 were ages 30-39, and 33 were at least 40 years of age. Thirty-two participants had completed at least a high school education or a GED; 31 had some secondary education; and 37 had no secondary education, of whom 7 had less than an elementary education. Almost half (N=49) were farmworkers, of whom 29 were male.

Overall genomic knowledge increased significantly ( $p < 0.0001$ ) between the pre- and posttest. Participants' genomic knowledge improved significantly for seven of the 10 items as well as the genomic knowledge scale after viewing the telenovela (Table 3). Participants also reported greater self-efficacy ( $p = 0.0004$ ). However, genomic knowledge decreased significantly for two

items: “Only people who have epigenetic changes can become sick,” and “The only way that diet and smoking affect people’s health is through epigenetic changes.” None of the individual characteristics (farmworker status, education, age, or gender) was associated with an increase in total genomic knowledge. However, the increase in self-efficacy was significantly greater among farmworkers and younger participants than non-farmworkers and older workers ( $p < 0.05$ ).

Among the subset of 24 participants who completed a 6-month follow-up test, no significant changes were observed from pretest to six-month follow-up for any specific item. Furthermore, increases in total genomic knowledge and self-efficacy between the pretest and 6-month follow-up test were not statistically significant (data not shown).

## **Discussion**

The use of a telenovela in this study increased short-term self-efficacy and knowledge about genomics and epigenetics on several points among participants. However, these data also indicate that (1) the telenovela simultaneously conveyed misinformation on two points about epigenetics (“Only people who have epigenetic changes can become sick”; and “The only way that diet and smoking affect people’s health is through epigenetic changes”); and (2) after 6 months, the level of genomic knowledge and self-efficacy returned to pre-intervention levels. However, lessons were learned about the process and suggestions for the development of future telenovelas are identified.

### *Lessons Learned:*

1. A one-time, limited telenovela intervention may be sufficient to teach some sophisticated science concepts to low educational attainment individuals.

2. Knowledge about some science concepts does not persist without reinforcement.
3. The decision to increase the visual emphasis on the term epigenetics by placing the word against a red background (and increasing the frequency of the use of that printed word in the telenovela), may have overemphasized the contribution of epigenetics.
4. Community members need to provide feedback after any changes are made to determine appropriateness.

*Recommendations for creating meaningful health and science learning opportunities:*

- A. The narrative format can facilitate engagement with scientific content when presented in a culturally and linguistically appropriate format.

Narratives can provide a beneficial strategy to convey complex science information when using integral components of visual design principles.<sup>22,23</sup> An orderly progression of events directly related to the scientific narrative can create a foundation for the learning process.<sup>22</sup> A broader narrative, an entertaining story that exists apart from the science content per se, can draw viewers who have a very limited science background into the story, thereby making the viewing experience less intimidating while increasing engagement.<sup>24</sup> Use of characters with whom viewers identify can increase acceptance of the content of interventions designed to both entertain and educate,<sup>25</sup> including in the context of health education. Narrative educational videos can increase their impact when viewers are most transported, i.e., identify highly with the characters and experience strong emotions.<sup>26</sup> Increased imagery, details, and associations with the scientific content itself could improve learning.<sup>27</sup>

B. To maximize the transmission and retention of genomic content, video producers should integrate graphic design principals to convey the content clearly.<sup>22,28</sup>

Increased attention to graphic design principles may also improve telenovelas.<sup>22,28</sup> In our study, the visual prominence that was given to epigenetics appears to have overshadowed the non-epigenetic content, leading participants to perceive that epigenetics was the overarching explanatory mechanism. Therefore, increased attention to design principles, including compositional prominence and functional minimalism, which recognize that every aspect of the image conveys meaning, even if unintentional, is warranted.<sup>22</sup> The impact of using red, for instance, in the background of the video when the word for epigenetics was displayed can result in distraction, reduced attention to other content, , or misinterpretation.

C. To enhance the retention of genomic content, providing several exposures to the genomic content in combination with activities that require viewers to recall the content multiple times to enhance knowledge retention.<sup>29</sup>

Complex topics may be conveyed more effectively through a series of educational interventions that integrate multiple activities, requiring participants to engage in verbal and non-verbal activities that require information recall.<sup>29</sup> Multiple experiences retrieving information is required for individuals to retain information in their long-term memory.<sup>29-31</sup> Educational interventions designed to increase genomic knowledge among Latino adults with limited education should therefore integrate opportunities, including hands-on activities, for participants to recall information from prior educational

encounters and to reinforce this information. Quandt and colleagues, for example, used a series of six educational encounters presented by lay health advisors to educate women in farmworker families about residential integrated pest management across several weeks to months, and included dramatic video presentations, flip chart guided presentations, hands-on exercises, and discussion.<sup>32</sup> Participants increased their knowledge and behaviors relevant to the topic.

D. To ensure that the telenovela is achieving its objective, multiple iterations should be shown to community members to ensure that “corrections” don’t introduce new miscommunication of information.

We are currently applying these principles in an expanded community education program, *Nuestra Familia Sana*. Participants in this community science, technology, engineering, and math (STEM) education program have five encounters with a community educator in which different aspects of genetics and genomics information is presented with videos and hands-on activities.

The challenges to long-term knowledge retention are not unique to health literacy in the context of telenovelas. College students provide correct responses to approximately half the questions they had answered correctly six months prior.<sup>33</sup> Even among medical students who are highly motivated to learn and retain course content, one-third of their knowledge gain is lost after one year.<sup>34</sup> Given the loss of knowledge among students motivated to study and learn content, it is unsurprising that a one-time exposure to complex content was not retained long-term.

## **Conclusion**



This study recruited participants from migrant farmworker and new immigrant communities in NC. The participants may therefore not be representative of adult Latinos living in migrant and immigrant communities more generally. However, the overall short-term increase in knowledge suggests that telenovelas may offer an effective strategy to convey genomic concepts to vulnerable Latinos in these communities. Furthermore, the effectiveness of telenovelas as teaching resources may be maximized by following the recommendations above.

Advances in genomic knowledge have already entered clinical practice and are expected to increase.<sup>2,35</sup> The rapid advancement in genomics knowledge may pose challenges to health care providers and educators as they work with patients to understand how to maintain and improve their health. Telenovelas that are culturally and linguistically appropriate, across a series of learning opportunities that include activities that require recall, including hands-on activities, may enable Latinos with limited formal education to understand complex genomic content.

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Table 1. Key concepts to be conveyed through telenovela

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Genes are tiny and are everywhere in your body.

Genes contain instructions for all the functions that take place in our bodies.

We receive half of our genes from each parent.

Identical twins are born with the same genes.

Genes remain the same throughout lifetime.

The genes or instructions don't change, but the way the genes work can be changed by our lifestyles and environment (such as diet and chemical exposures). These changes are considered to be "epigenetic" changes.

One way that epigenetics can occur is by having "marks" attached or removed from one's genes.

Not all lifestyles behaviors and environmental exposures cause epigenetic changes.

Lifestyle behaviors and environmental exposures can still affect us, even if they don't cause epigenetic changes.

Even though identical twins are born with the same genes, the way some of their genes work may be different because they had different lifestyles and environment.

Having a healthy lifestyle can have a positive effect on the way one's genes work, and give one a better chance to being healthy.

Table 2. Participant Characteristics

	N
Gender	
Male	49
Female	51
Age (years)	
18-29	34
30-39	33
40-49	26
50+	7
Education	
< Elementary	7
Completed elementary	30
Some secondary	31
High school diploma or GED	30
Some university or university degree	2
Region	
Rural	49
Urban	51



Table 3. Evaluation of the effectiveness of telenovela educational intervention on genomic knowledge<sup>a</sup> and self-efficacy<sup>b</sup>

Item <sup>c</sup>	Pretest	Posttest	P-value <sup>d</sup>
	(n = 100)	(n = 100)	
	Mean (SD)	Mean (SD)	
Genes contain instructions for functions that take place in our bodies. (T)	0.50 (0.72)	0.73 (0.66)	0.02
Everyone, except for identical twins, has slightly different genes or instructions. (T)	0.36 (0.84)	0.45 (0.88)	0.45
The way that genes work remains constant during an individual's lifetime. (F)	-0.32 (0.83)	-0.08 (0.99)	0.04
Only people who have epigenetic changes can become sick. <sup>e</sup> (F)	0.31 (0.72)	-0.31 (0.92)	<.001
Epigenetic changes cause genes to change the way they work. (T)	0.15 (0.72)	0.75 (0.61)	<.001
Exposure to some chemicals, including those in cigarettes, can cause epigenetic changes. (T)	0.63 (0.61)	0.98 (0.14)	<.001
Identical twins look alike because they were born with identical genes.(T)	0.61 (0.72)	0.94 (0.31)	<.001
If an identical twin becomes ill, the other identical twin will always develop the same illness. (F)	0.53 (0.76)	0.78 (0.58)	0.01
Half your genes come from your mother and half from your father. <sup>17</sup> (T)	0.52 (0.75)	0.95 (0.30)	<.001
The only way that diet and smoking affect people's health is through epigenetic changes. <sup>e</sup> (F)	-0.03 (0.86)	-0.80 (0.57)	<.001
Genomic Knowledge Scale	3.26 (2.18)	4.39 (2.29)	<.001
Self-efficacy Scale	1.47 (1.56)	2.15 (1.68)	<.001

<sup>a</sup>Value for genomic responses: Correct = 1; Do not know = 0; Incorrect = -1.

<sup>b</sup>Value for each item in self-efficacy scale: 1 = Agree; 0 = Neutral; -1 = Disagree

<sup>c</sup>Correct response, True or False, indicated after each knowledge item.

<sup>d</sup>P-value was calculated using the Wilcoxon signed rank sum test.

<sup>e</sup>Direction of change indicates poorer posttest knowledge.