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The Transformative Power of Narrative as a Behavioral Change Communication Tool to Reduce Health Disparities in Cervical Cancer among Latinas: Global Implications

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Authors Description

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Key words: health communication, health disparities, cervical cancer, cancer screening, cultural competence, role modeling, and narrative

URL : *Tamale Lesson* – short 3.37 clip version: http://www.youtube.com/watch?v=-s4fm1DaAG0

Conflict of Interest Statement

There is no known conflict of interest among any of the authors on this paper.

Ethical Approval Statement

Institutional Review Board approval has been obtained for the conduct of this study at the University of Southern California. Informed consent has been obtained from study participants. All authors are current regarding their Human Subjects certifications.

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Josefina Lopez wrote the initial script for *Tamale Lesson* inserting cervical cancer-related information from focus groups led by Dr. Murphy. *Tamale Lesson* and *It's Time* were directed by Professor Jeremy Kagan from the Change-Making Media Lab, produced by Professors Doe Mayer, Jeremy Kagan and Dave O'Brien, from the USC School of Cinematic Arts; with executive producers, Dr. Sheila Murphy at the Annenberg School for Communication and Journalism at USC and Dr. Lourdes Baezconde-Garbanati at the Institute for Health Promotion and Disease Prevention Research, Department of Preventive Medicine, Keck School of Medicine of USC. The project was funded by the National Cancer Institute (NCI), through a Transformative Research Award (TR01) (1CA144052) (Murphy/Baezconde-Garbanati). This project was possible also in part by funding from the SC Clinical and Translation Science Institute at USC (CTSI) award number UL1TR000130 (Baezconde-Garbanati/Murphy), and the Norris Comprehensive Cancer Center (NCCC) (NCI - P30CA014089). We wish to acknowledge our co-PIs, Dr. Sandra Ball-Rokeach, Dr. Robert Haile, and co-investigators, Dr. Jennifer Unger, Dr. Tom Valente, Dr. Chi Ping Chou, Dr. Vickie Cortessis and Dr. Laila Muderspach. In

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ABSTRACT

Cervical cancer is the third most common type of cancer in women globally. Latinas carry a disproportionate burden of this disease. In the United States, when compared with non-Hispanic Whites (NHW), Latinas endure much higher incidence rates (13.86 vs. 7.70 per 100,000)[2] with mortality rates 1.5 times greater than for non-Hispanic white women[3]. In order to address this disparity, a multidisciplinary team engaged in a transformative study to test if narrative, developed in culturally specific ways as a behavioral change communication tool, works better than non-narrative in increasing knowledge and changing attitudes and behaviors and, if so, why. This case study presents findings from *Tamale Lesson,* an award winning video that promotes cervical cancer screening via Pap test and prevention (via use of the Human Papillomavirus vaccine (HPV)). *Tamale Lesson* was compared with a non-narrative film, *It's Time,* to determine if the narrative produced a stronger impact between pre-test to two weeks later and six months after viewing the film. The films are each 11 minutes in length and

contain the same facts. *Tamale Lesson* depicts a Mexican American family's preparation for the youngest daughter's 15th birthday as the narrative vehicle. Findings reveal a high level of acceptance of *Tamale Lesson,* and significant reductions in cervical cancer disparities among Mexican American women. This case study highlights the benefits of creating a culturally competent narrative intervention, and underscores the powerful potential of narrative/storytelling in eliminating disparities worldwide.

CASE STUDY: *TAMALE LESSON*

OVERVIEW

Worldwide cervical cancer represents a significant public health problem. In 2008 alone, more than 530,000 women were diagnosed with cervical cancer, leading to over 270,000 deaths. It is the third most common type of cancer in women worldwide, and the developing world carries a disproportionate burden, accounting for an estimated 85% of cases (1). Latinas carry a large burden of this disease both globally and domestically. In Latin America and the Caribbean (LAC), cervical cancer kills more women than any other type of cancer (2). In the United States, when compared with non-Hispanic White (NHW) women, Latinas endure much higher incidence rates (13.86 vs. 7.70 per 100,000) (3) and mortality rates 1.5 times greater than non-Hispanic White women (4). The American Cancer Society reports Latina women experience cervical cancer incidence rates higher than any other ethnic group (5). Despite the fact that cervical cancer is a preventable disease, it contributes to more lost life years than maternal conditions, AIDS, and Tuberculosis (TB) combined (6).

Cervical Cancer Screening: Cervical cancer is considered highly treatable if precancerous lesions are identified through screening and removed early (5). Currently, the most widely available screening test is the Papanicolaou or Pap test. The Pap test involves taking a sample of the cervix to look for abnormal cells. This technology has resulted in significant reduction in the incidence and mortality

rates of cervical cancer in the past 70 years in the United States and many parts of the world (2). However, not all countries have benefited equally from this test, and even within nations with strong screening programs such as the United States, not all populations and regions enjoy the same success. Latinas in the United States and indigenous women throughout Latin America and the Caribbean continue to experience alarmingly high rates of cervical cancer (1,6). In explaining this inequity, experts point to a lack of early and regular screening via Pap test; as well as slow uptake or incomplete dosing of the HPV vaccine (7).

Human Papillomavirus Infection and Vaccine: The Human Papillomavirus, or HPV, is the leading cause of invasive cervical cancer (8,9). Although there are over 40 types of HPV, certain "high risk" types have a higher chance of malignant transformation, including two strains- HPV 16 and HPV 18- which are responsible for an estimated 70% of cervical cancers (10). Two different HPV vaccines have been introduced in over 39 countries around the world — one prevents infection with HPV types 16 and 18, and the second prevents infection with HPV types 16 & 18 as well as HPV 6 & 11, which cause genital warts (11). In a multinational study in Latin America, both vaccines were shown to be safe and effective in preventing high-grade cervical intraepithelial neoplasia (CIN) and adenocarcinoma *in situ* associated with HPV 16 and 18 in individuals not currently infected with these strains (12-15). Although the vaccine is still not available in many parts of the world, it has become a priority and is seen by many as the most important strategy for cervical cancer control in the future (16,17). It has been estimated that a 70% vaccine coverage rate would prevent over 1.1 million cases of invasive cervical cancer in Central American and Caribbean region over a 10-year period (18). The vaccine has been promoted in the U.S. since 2006, with varying degrees of uptake and completion among Latinas.

PROGRAM GOALS

Today public health is dealing with ever increasing health disparities. Among the most vulnerable groups are Latinas in the United States, Latin America and the Caribbean. Interventions that can produce lasting changes in behaviors and reduce health inequities in these vulnerable populations tend to be hard to come by, lack evidence of their efficacy over time, and have very small sample sizes making it impossible to make significant predictions regarding their long term ability to change behavior. The goal of this case study was to explore the transformative power of narrative as a behavioral change communication tool among Latinas. Although the particular narrative, *Tamale Lesson*, deals with cervical cancer, it is important to note that narratives could be used to address virtually any health topic. This NIH funded Transformative R01 research brought together an interdisciplinary team of medical and communication scholars, scriptwriters, cinematographers, physicians, psychologists, and public health professionals in an effort to re-examine and reinvent how health-related information is conveyed.

As part of the larger study, we tested the efficacy of using a narrative format against a non-narrative format to assess changes in knowledge, attitudes and behaviors regarding cervical cancer screening and prevention via the HPV vaccine. The results from the comparison of the narrative versus the non-narrative films is overviewed in the sections below (also see 19). The purpose of this paper, however, is to take a more in-depth look at the process of creating a culturally competent narrative intervention that can be an effective tool in the elimination of health disparities. Thus, the current paper will focus solely on the evaluation results of *Tamale Lesson* for Latinas -- the primary target audience of this narrative intervention.

THEORETICAL FRAMEWORK: USE OF NARRATIVES FOR HEALTH PROMOTION

Storytelling has been used for thousands of years to convey information. However, when communicating critical health information, Western medicine has in the past heavily favored conveying health information in a non-narrative, fact-based manner, typically presenting it in a list of risk factors, recommended prevention steps, symptoms, and treatment options. Over the past decade, however, the interest and research on the potential use of narrative as a tool for health promotion – especially in cancer prevention and treatment - has been gaining ground. Narrative-based interventions, it has been argued, can be an invaluable tool in cancer communication by reducing resistance to information, facilitating processing of new and/or difficult information, producing cognitive and emotional effects that create stronger attitudes and intentions, and providing social connections and role models for behavior (20, 21). Consequently, their use in the elimination of disparities is fairly new but seen as promising.

Narratives can be defined as ‘‘a representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed” (21, p. 222). Theoretically, among the reasons why narratives are found to be so effective is that the audience are transported or absorbed into the narrative, can identify with the characters, experience the events and emotions evoked by the story, and see desired behaviors modeled which in turn impact intention and actual behaviors (22-28). Further, this line of research suggests that narrative communication may be particularly important for changing behavior among vulnerable populations, those with low income, low education, and low literacy levels, who also tend to be the ones suffering the most health disparities worldwide.

PROGRAM CHARACTERISTICS & KEY MESSAGES

The purpose of this study was to challenge the underlying assumption in Western health communication that the traditional recitation of the facts is the optimal way to convey health-related information. The project developed and empirically compared the delivery of health information via a narrative and non-narrative format to test whether the former might produce a greater and longer lasting impact on cervical cancer knowledge, attitudes and prevention behavior. The team produced two original 11-minute short films, one fiction/narrative (*Tamale Lesson* - the focus of this paper) and one non-fiction/non-narrative (*It's Time*), both containing the same facts regarding causes of cervical cancer, detection (via Pap tests) and prevention (via HPV vaccine). The relative efficacy of these two films was tested by surveying 1000 randomly selected women (300 African American, 300 European American, 300 Mexican American and 100 Korean American) via phone before viewing the film, then randomly assigning these same women to receive either the narrative or non-narrative film. This was followed by a survey two weeks later, and then a follow-up survey six months later. The results revealed that the narrative was indeed more effective in increasing cervical cancer-related knowledge and attitudes, and behavioral intentions (19) and in changing participants' perceived social norms about cervical cancer screening and vaccination rates (30).

Looking at theoretical factors, in response to the narrative featuring Latinas, Mexican American women in the study were most transported, identified most with the characters, and experienced the strongest emotions of any group. Regressions revealed that transportation, identification with specific characters, and emotion contributed to shifts in knowledge, attitudes, and intent to be screened for cervical cancer (19). Additionally, the research indicates that because of its capacity to affect identification among viewers, narrative communication was particularly appropriate for impacting social

norms and, consequently, behavioral intention. The narrative film was, in fact, more effective at producing positive changes in perceived norms (i.e. viewers of the narrative film more likely to perceive the rate of cervical cancer screening to be higher among their peers than women who viewed the non-narrative) and intention (30). Given findings from our previous research, this case study shares lessons learned on the creation of an effective narrative designed with cultural elements that appeal to Latina audiences of Mexican origin.

INTENDED AUDIENCE & STAKEHOLDERS

Our primary intended audience for the intervention was 25-45 year old Latina women of Mexican origin living in Los Angeles County. Our secondary audience included women of other ethnicities living in Los Angeles County – specifically European American or non-Hispanic White women, African American women and Korean American women - who served as comparison groups for our primary audience. Outreach efforts were also made to have viewings of the film for grassroots health care providers, who serve our population of interest and are invested in reducing health disparities as related to the cancer burden among vulnerable populations.

Experts and stakeholders across various disciplines produced both the narrative and non-narrative films as a team. Medical doctors, cancer and health specialists from the Department of Preventive Medicine, Institute for Health Promotion and Disease Prevention and from the Norris Comprehensive Cancer Center at the USC Keck School of Medicine, University of Southern California provided health information and cancer expertise for the content of the films, in addition to providing cultural and language expertise and a focus on health disparities. Professional filmmakers and their associates from The Change Making Media Lab, the USC School of Cinematic Arts, wrote, directed and produced both films. Researchers from the Annenberg School for Communication and Journalism developed the methods and study design, facilitated the baseline and evaluation research, which

included a series of focus groups at various stages of film production; and the evaluation of the intervention. In addition, Promotoras y Promoters Foundation, a network of promotoras de salud (community health workers) also provided input in the creation of the films along with Kaiser Permanente and community physicians. Further funding was sought from the Southern California Clinical and Translational Science Institute (CTSI) that enabled us to dub the films into Spanish in order to reach even lower income, less acculturated Spanish speaking women. Promotoras de Salud from Vision y Compromiso, a network of over 4,000 promotoras in California collaborated in translation and cultural adaptation of the script into Spanish, as well as in dissemination of the films throughout their network.

PROGRAMMATIC ACTIVITIES: DESCRIPTION AND DEVELOPMENT OF THE NARRATIVE FILM

The film *Tamale Lesson* conveys facts regarding the cause of cervical cancer, as well as how to prevent it (via the HPV vaccine) and detect it (via Pap tests) using Latino cultural tradition and the value of "familism" with a Mexican-American family's preparation for their youngest daughter's *quinceañera* or 15th birthday as the narrative vehicle. The film opens with the oldest daughter (Lupita) and middle daughter (Connie) in the family kitchen in the midst of preparing tamales for the upcoming celebration. After overhearing Lupita talking on the phone with her boyfriend about her recent Human Papillomavirus (HPV) diagnosis, her sister, Connie, questions Lupita about HPV and its cause and detection, as she is unfamiliar with the disease. During the conversation, their mother, Blanca, and her older best friend/ "comadre", Petra, join the sisters. Lupita shares key facts about cervical cancer prevalence, leading cause (HPV), detection via Pap tests, and prevention via the HPV vaccine. Lupita points out that her youngest sister, Rosita, could be vaccinated against HPV and encourages both her sister Connie and her mother's friend Petra, who have never had a Pap test, on the need to get one.

Blanca and Lupita do an impromptu demonstration of a Pap test using a chicken and the ingredients on the kitchen table to allay the fears that Connie and Petra had regarding Pap tests. The film ends with both Connie and Petra modeling the behavior of going to the free clinic to get Pap tests.

Tamale Lesson Development

To inform the development of the film, twelve focus groups were conducted (29). The goals of these focus groups were to identify barriers to cervical cancer screening and assess overall knowledge and attitudes regarding HPV and, at later stages of production, to assess participants' reactions to the script and finally to the two films. The lead investigators analyzed the data and identified key themes and information to inform the development of the films. Specifically, the focus groups were used to (a) identify key barriers that the films should address; (b) determine the best way to deliver the health information in a culturally competent manner; and (c) identify key factors, such as language use, to ensure the films would be culturally relevant. For example, many women in the focus groups reported that they were unaware Pap tests were offered for free at many local clinics, so the films addressed that specifically. And, throughout the focus groups, women used the phrase "down there" when referring to the reproductive organs and vagina, so we incorporated that phrase into the dialogue. We also found that women would often speak in 'Spanglish' or use a Spanish word when it was more culturally appropriate than an English word, so the characters in the film similarly spoke in English with Spanish words used for emphasis. These analyses then formed the backbone of the information provided to the scriptwriter and filmmakers. This was an essential step in creating a narrative that reflected the everyday lives, cultural nuances, and language preferences of the primary audience in the English version of the film.

The well-known playwright Josefina Lopez, whose previous credits include the acclaimed play and film *Real Women Have Curves*, wrote the initial script for *Tamale Lesson*. In addition, cervical cancer facts were provided by medical experts and approved by the National Cancer Institute for

inclusion. Once the script of *Tamale Lesson* was written, additional focus groups were conducted with Mexican American and non-Hispanic white women separately, who watched a staged reading of the script. The information from these focus groups was used to make additional changes to the script. The script was finalized and a "roughcut" of *Tamale Lesson* was produced and reviewed by the scientific team. The final version was tested once again in focus groups with the primary and secondary audiences. Focus groups were done at various stages of the process to refine the script. Once the film was finalized and developed, a print version of the narrative was created (to enable testing the impact of the media channel) as well as dubbed into Spanish to test the efficacy of narratives among low acculturated and low literacy populations (see future plans).

As is evident from the above description of the process, producing the final version of *Tamale Lesson* involved a number of iterations and consultations with not only the primary and secondary audiences but with other stakeholders such as the researchers and the funding agency as well.

METHODS

As reported previously (19), a random sample of women between the ages of 25-45 living in the Los Angeles area was recruited for the project. All participants first completed a pre-test via phone, and then were randomly assigned to receive a DVD of either the narrative or non-narrative film in the mail. They were contacted to complete the post-test two weeks later, and they responded to a follow-up survey six months after that. Other work (30, 19, 31) reports on the comparison between the efficacy of the narrative and non-narrative film. As previously mentioned, in this case study, we will focus mainly on the experience of the Mexican American women in our sample (N = 117) who viewed the narrative film, *Tamale Lesson,* and the film's impact on these Latinas by examining their post-test response to the film and behavior change at the six-month follow-up; as well as comparing them to the 129 non-Hispanic White participants who also viewed *Tamale Lesson*.

RESULTS

Overall, participants responded very positively to viewing *Tamale Lesson.* However, there were statistically significant differences in the responses to the film between our primary audiences, Mexican American women, and the broader audience represented by the non-Hispanic white women. Enjoyment of the film was assessed with three items measuring how much participants liked *Tamale Lesson*, how interesting they found the film, and how much they enjoyed it on three separate Likert-type scales with 1 indicating "not at all" and 10 indicating "extremely" ($\alpha = 0.93$). For both Mexican American ($M = 8.7$, $SD = 1.4$) and non-Hispanic white women ($M = 7.4$, $SD = 1.9$), enjoyment of the film was quite high, well above the scale midpoint. However, Mexican American women enjoyed the film significantly more than non-Hispanic white women ($t(244) = 6.04$, $p < .001$). Very few women found the Spanish words in the film distracting with Mexican American women being marginally less likely to be distracted by the Spanish words than non-Hispanic white women (2% vs. 6%, $t(244) = 1.79$, $p = .075$).

The design of this field study allowed women to watch the film in their own homes at their leisure. Thus, we were interested to see the extent to which women chose to view the films more than once or to share the films with their friends and family. All participants watched the film at least once. This was verified prior to the posttest survey by asking questions such as "What was the color of Rosita's dress?" and "Who gets a Pap test at the end of the film?" Women who were unable to answer this simple manipulation check were asked to watch the film prior to completing the posttest. Mexican American women were particularly likely to voluntarily view the film a second time. Of the 117 Mexican American participants, 45 (38%) watched *Tamale Lesson* two or more times with some women reporting watching it as many as four times in the two weeks after they received the DVD. In contrast, only 14% of non-Hispanic white women watched *Tamale Lesson* twice and none reported watching it more frequently. This difference in mean number of times watching the film by ethnicity is statistically

significant, $t(244) = 4.99$, $p < .001$. Moreover, Mexican American women were also more likely to show *Tamale Lesson* to others, $\chi^2(1) = 20.4$, $p < .001$. Of the Mexican American women, 29 (24.8%) shared the film whereas only 4.7% ($N = 6$) of non-Hispanic white women did. Mexican American women were especially likely to view the film with their daughter ($N = 10$, 8.5%) or husband, boyfriend, or partner ($N = 9$, 7.7%).

A comparison of women's pretest or baseline level of cervical cancer-related knowledge, attitudes and behavioral intentions to that at the two-week post-test survey revealed that the culturally specific narrative (*Tamale Lesson*) was effective (19). Moreover, at the baseline pre-test, non-Hispanic White women in our sample were far more likely to have had a Pap test in the previous six months than Mexican American women (50% vs. 32%, respectively, $\chi^2(1) = 7.93$, $p < .01$), evidencing a large health disparity. However, by the six-month follow-up, the narrative virtually erased the ethnic disparity regarding cervical cancer screening rates. Mexican American women were more likely to have had a Pap test between the pre-test and the six month follow-up than non-Hispanic white women (38% vs. 22% respectively; $\chi^2(1) = 6.7$, $p < .01$). Overall, Mexican American women who watched *Tamale Lesson* went from having the lowest rate of screening to having the highest percentage of women who had a Pap test within the previous year or had scheduled one (32% to 82%). This suggests that narrative formats may provide an invaluable and underutilized tool in reducing health disparities, especially if done with rigorous background research and culturally targeted to the primary audience (here Mexican Americans).

CONCLUSIONS

This case study strongly suggests that narrative may be a valuable communication tool in the elimination of health disparities given that audiences find the narrative personally relevant. To achieve this goal, communication experts and public health professionals need to work in multidisciplinary

teams, relying on extensive formative research on the issue and target audience, enlisting professionals who understand this craft and have the skills and abilities to engage audiences in ways that will result in behavior change and pre-test the materials with the target audience. Culturally appropriate narratives that utilize audience values and feature positive role models that underserved populations can identify with can produce powerful effects and these activities help ensure that the narratives are engaging and targeted, thus increasing the likelihood of success.

Narrative also appears to be a promising vehicle for interventions in global health with the aim of reducing health disparities worldwide. However, as reiterated above, it is particularly critical to pretest whether the audience can relate and that it has the intended effect. Translating concepts across cultures is often difficult, and diverse audiences may more closely relate to different aspects of a narrative. Although our research on narrative focused on cervical cancer, the results have implications for virtually all health communication. These findings call for incorporating storytelling into health education by focusing on culturally appropriate messages that resonate with the target audience and a script that is in tune with the audience's values.

Upcoming milestones and future directions

We have just wrapped up the data collection of the "print" arm of the study at the beginning of 2014 and are in the process of analyzing the comparative efficacy of the same narrative, *Tamale Lesson*, in print versus video. With funding from the SC Clinical and Translational Science Institute (CTSI (UL1TR000130) we plan to compare Spanish language versions of the narrative and non-narrative films among low literacy Spanish speaking women -- a population who is especially vulnerable to cervical cancer, with documented disparities. We also plan to test if narrative can improve understanding of health-related information, and if it may have an impact on health literacy in diverse populations. In addition, a colleague is running a series of focus groups to test the use of the film with an international

audience in Panama. Data from Panama is currently being compiled and preliminary data already seem promising. We have screened *Tamale Lesson* in Bogota, Colombia, at a meeting with eight Latin American and Caribbean countries, where it was very well received, showing promise for expansion into Latin America. In the future, we plan to develop additional narratives on other topics following a similar process to confirm how well narrative messages translate across topics.

These findings have clear implications for the elimination of cancer disparities in global settings. The persistence of health inequalities represents one of the greatest challenges in global health. Narratives have the potential for providing a culturally acceptable innovation that may improve health and reduce inequalities in a variety of settings.

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