



Nina Mikhailenko. *Boy & Goats*. Oil on canvas, 20" × 24".

The contents of educational pamphlets on cervical cancer do not meet the needs of local Mexican immigrant women.

Cervical Cancer Educational Pamphlets: Do They Miss the Mark for Mexican Immigrant Women's Needs?

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The rate of invasive cervical cancer in US Hispanic women is nearly doubled that of non-Hispanics. Using in-depth interviews and content/grade level analysis of educational materials, this study explores the relevance of cervical cancer education materials to the needs of Mexican immigrant women. It also addresses health literacy issues that create barriers to learning. Findings show aspects of language, content, reading level, structure, and visual images in 22 cervical cancer pamphlets from 11 health care sites in a Midwest city were not relevant to the learning needs or health literacy levels of local Mexican immigrant women. Further research is recommended to establish an evidence base regarding optimal presentation of key elements of the cervical cancer educational message for Mexican immigrant women.

Introduction

The patient education pamphlet could well be thought of as the icon of US health education. Within increasingly hectic schedules, health care providers struggle to provide

one-on-one patient education, and handing out a pamphlet is one way of substituting for what time does not allow. Pamphlets can be found in most clinical settings, and they are a good representation of educational content found in various formats, including video/CD, Internet, television, and kiosk.

Recent studies in health literacy raise concern, however, about the ability of many Americans to read and comprehend health-related materials. The 1992 National Adult Literacy Survey found that approximately one fourth of the US population is functionally illiterate, with another 25% possessing only marginal literacy skills.¹ Low literacy is associated with low income and poor health status. It disproportionately affects ethnic minorities, including immigrants who often arrive in the United States with low

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Abbreviations used in this paper: HPV = human papillomavirus.

levels of education, less income, low English proficiency, and conflicting models of cultural knowledge about disease and prevention as compared with US models.^{1,3} Health literacy influences preventive behavior and has been shown to be a better predictor of cervical cancer screening than ethnicity or education.^{1,3,4}

Cervical cancer education for immigrant groups is important because the disease affects the world's poorest, most vulnerable women, with at least 80% of deaths from this cancer occurring in underdeveloped countries.⁵ As women from underdeveloped regions immigrate to the United States, cervical cancer becomes an increasing concern and area of health disparity.⁶ A recent report by the Centers for Disease Control and Prevention⁷ indicates that, between 1973 and 1999, the incidence of invasive cervical cancer among Hispanic women was 16.9 per 100,000, compared with 8.9 per 100,000 in non-Hispanic women. Cancer mortality is markedly higher among Hispanic women, yet Papanicolaou (Pap) testing for early detection remains relatively low.⁷⁻¹² Factors involved in underuse of Pap tests include limited awareness and knowledge, cultural beliefs and patterns, low educational and literacy levels, and poor language skills.^{2,4,8,10,12-19} Increasingly, patient educational materials are translated into different languages, are culturally tailored for specific ethnic groups, and pay more attention to the needs of low literacy readers.²⁰⁻²² How widely these materials are used, however, is unknown. This study examined clinical settings in a major Midwest city to see what cervical cancer education pamphlets were available and how relevant and readable they were for Mexican immigrant women.

Purpose and Objectives

The purpose of the study was to evaluate cervical cancer knowledge and screening behavior among first-generation Mexican women living in the Kansas City metropolitan area and to study the adequacy of local health education response. Kansas City (Missouri and Kansas) has a long-standing and continually growing Latino population. This population is concentrated in three counties, with estimates of size between 95,303 and 138,910, up from the census figure of 78,374 in 2000. The majority are of Mexican descent who report coming to Kansas City for job opportunities and to join already established family members.²³

The research project included three arms of study. The first explored Mexican immigrant women's knowledge of cervical cancer and their screening behavior, situated within their pre- and post-immigration life context. The second explored health care providers' perceptions of Mexican women's cervical cancer understanding and prevention behaviors, as well as the ways in which the providers assessed and interacted with them in clinical encounters. The third arm involved collecting printed

patient education materials related to Pap smears and cervical cancer from local clinical sites and analyzing the materials in relation to women's needs identified in the interviews. Specific research questions were addressed: (1) What is the nature of cervical cancer knowledge and prevention behaviors among first-generation Mexican immigrant women? (2) How relevant is the content of locally used patient education materials in relation to identified learning needs of the immigrant women? (3) What health literacy issues in the written materials create barriers to learning for this population?

Methods

Methods used in this study included semi-structured in-depth interviews and content and grade level analysis of printed patient education materials. The overall research approach was ethnographic, as interviews did not stand alone as a qualitative method but were situated contextually into a background of several years' participant observation of various aspects of the Latino community in Kansas City, previous study in Peru,²⁴⁻²⁷ participant observation of local Breast and Cervical Cancer Control Program activities, and the work of a local group, the Coalition of Hispanic Women Against Cancer. Approval to conduct the study was obtained from the University's Institutional Review Board.

In-Depth Interviews

Women were recruited for in-depth interviews by individuals familiar to them, such as the pastor of a local church or a staff member at a local social agency that focuses on needs of the city's Latino population. A \$50 grocery store gift certificate was offered as an incentive. A purposive sample of 20 women was recruited; 18 of these met inclusion criteria (over 18 years of age, born in Mexico, now living in the United States) and completed the interview (Appendix A).

The women in the sample ranged in age from 20 to 66 years, and time living in the United States ranged from 7 months to 37 years. The majority had lived in the United States less than 5 years. The women came from throughout Mexico, but two thirds had immigrated from northern states close to the border. The women now lived in households ranging from 2 to 10 people, household income ranged from \$500 to \$2,000 per month, and only two of the women had health insurance. Educational levels ranged from no schooling to college degrees; two thirds had a high school education or less. The women were predominantly Spanish-speaking.

Interviews were conducted in the participants' homes or at the social service agency. Each interview lasted 1 to 1½ hours and was conducted in Spanish with assistance of an interpreter. The interviews were audiotaped, translated, and transcribed into English by the interpreter

who assisted with the interview. Transcribed interviews were read repeatedly by the investigator and a second reader to look for themes related to women's familiarity with cervical cancer and Pap smears, whether their knowledge matched or differed from biomedical knowledge, terms used to talk about their knowledge, their participation in Pap screening, and related positive and negative motivators. Both readers identified similar themes.

Interviews were also conducted with 17 health care professionals regarding their perceptions related to Hispanic women's lower rates of cervical cancer screening

and how they interact with these women in clinical encounters (Appendix B). Those interviewed included 6 nurse practitioners, 4 physicians, 1 clinic nurse, 1 parish nurse, and 5 medical interpreters. Interviews took less than 30 minutes and took place at the work site.

Collection and Analysis of Printed Educational Materials

Available patient education pamphlets related to cervical cancer control were collected from 11 clinical sites in the city, with emphasis on sites most likely to serve immigrant

Table 1. — Pamphlets Collected From Eleven Kansas City Sites and Analyzed by Group

Group 1: Concerning Cervical Cancer and Pap Tests		Group 3: Concerning Human Papillomavirus	
#1	<i>What You Need to Know About Cancer of the Cervix</i> National Institutes of Health, National Cancer Institute, NCI Pub. No. 95-2047, July 1994 Reading level: grade 11	#13	<i>Human Papillomavirus Infection</i> American College of Obstetricians and Gynecologists (ACOG), 1999 Reading level: grade 9
#2	<i>The Pap Test</i> American College of Obstetricians and Gynecologists (ACOG), April 1989 Reading level: grade 11	#14	<i>HPV (Human Papillomavirus): Understanding This Common Virus</i> Krames Communications, 1997 Reading level: grade 9
#3	<i>The Pap Test</i> American College of Obstetricians and Gynecologists (ACOG), July 1994 Reading level: grade 9	Group 4: Promoting a Specific Product	
#4	<i>The Pap Test</i> American College of Obstetricians and Gynecologists (ACOG), August 2003 Reading level: grade 9	#15	<i>Now You Can Feel Even Better About Your Pap Test: Introducing the ThinPrep Pap Test</i> www.thinprep.com, 1999 Reading level: grade 10
#5	<i>Pap Smears</i> American Academy of Family Physicians, January 1999 Reading level: grade 9	#16	<i>What Women Should Know About Cervical Cancer and HPV</i> www.puttingwomenshealthfirst.org Digene Corp. DNA with Pap promotion, 2003 Reading level: grade 12
#6	<i>Cervical Cancer: What Every Woman Should Know</i> Channing. Bete Co, 1994 Reading level: grade 9	Group 5: Addressing Multiple Health Messages	
#7	<i>Cervical Cancer: What Every Woman Should Know</i> Channing. Bete Co, 1997 Reading level: grade 9	#17	<i>Disorders of the Cervix</i> American College of Obstetricians and Gynecologists (ACOG), 1992 Reading level: grade 9
#8	<i>Have a Pap Test /Hagase la Prueba Pap</i> National Institutes of Health, National Cancer Institute, NIH Pub No 01-3211, July 2001 Reading level: grade 7	#18	<i>Disorders of the Cervix</i> American College of Obstetricians and Gynecologists (ACOG), 1996 Reading level: grade 9
#9	<i>La Prueba Pap: Un Metodo Papa Diagnosticar Cancer del Cuello del Utero</i> US Dept of Health and Human Services, Public Health Service, National Institutes of Health NIH Publication No. 90-2694. Revised February 1989	#19	<i>Cancer Facts for Women</i> American Cancer Society, 1998 Reading level: grade 11
Group 2: Focusing on Abnormal Pap Test Results		#20	<i>Mujeres Saludables: Auto Ayuda para la Prevencion del Cancer</i> Cancer Research Foundation of America. Undated
#10	<i>Abnormal Pap Test Results: Understanding Your Diagnosis and Treatment</i> Krames Communications, 1991 Reading level: grade 11	#21	<i>Early Detection Guidelines for Women</i> Breast and Cervical Cancer Control Project (BCCCP). Undated Reading level: grade 8
#11	<i>Resultado Anormal Del Papanicolaou: Como Entender su Diagnostico y las Opciones de Tratamiento</i> StayWell featuring Krames, 1999	#22	<i>Women & Self-Care: Wellness Maps</i> StayWell Co, 1998 Reading level: grade 10
#12	<i>Do I Have Cancer of the Cervix?</i> US Dept. of Health and Human Services. Updated October 1997 Reading level: grade 10		

Hispanic women. Twenty-two different pamphlets were located, including some of the same pamphlets across various years of publication. The materials fell into 5 categories: (1) those that addressed primarily cervical cancer control and Pap smear testing, (2) those that more specifically addressed abnormal Pap results and follow-up, (3) those that addressed human papillomavirus (HPV), (4) those that promoted a specific product within educational material, and (5) those that addressed multiple topics, such as prevention of various types of cancer or disorders of the cervix. The materials were analyzed for year of publication and scientific accuracy, reading level, availability in Spanish, and content relevant to learning needs identified in the interviews. Pamphlets are listed in Table 1.

Results

Key findings are addressed in two sections. The first addresses themes related to the immigrant women's knowledge, screening behavior, and learning needs, and the relevance of related content in the educational materials. The second section addresses health literacy related

issues in the pamphlets that create barriers to learning, and scientific accuracy of the materials. Findings are summarized in Table 2.

Learning Needs of the Women and Relevancy of Educational Materials

Inconsistent Naming of the Cancer: An important theme that emerged from interviews was confusion regarding the name of the cancer. In the United States, cancer that originates in the cervix (the "neck" or opening of the uterus) is referred to as cervical cancer. It is distinguished from uterine cancer, which originates in the body of the uterus. The Pap test screens only for changes leading to cervical cancer. The terms most commonly used by the Mexican women, however, were *cancer de la matriz* or *del utero* (cancer of the uterus). These terms did not differentiate between the cervix and the body of the uterus as the site of origin of the cancer. Less often, the terms *cancer del cuello de la matriz* or *del utero* (cancer of the neck of the uterus), or *del vientre* (of the abdomen, or womb) were used, but the women rarely used or recognized the term "cervix." The following interview segments highlight this confusion.

Table 2. — Key Gaps Between Pamphlet Content and Mexican Immigrant Women's Learning Needs

Problematic Content/Structure of Pamphlets	Mexican Immigrant Women's Learning Needs
The cancer is referred to as "cervical cancer" or "cancer of the cervix" in English pamphlets but "cancer of the uterus" or "neck or the uterus" in Spanish pamphlets.	They may lack recognition and understanding of the terms "cervix" and "cervical" and lack differentiation between cervical and uterine cancer.
Other anatomical and medical terms, such as "cell," "vagina," "virus," and "speculum," are often used without definition.	Anatomical and medical terms are often not understood by low literacy/low educational level readers. The women often lack the basics with which to understand anatomical explanations, basic pathophysiology of cancer, and the relationship of HPV to cervical cancer.
Pap smear may be defined as a "test for cervical cancer" (ie, in terms of diagnosis vs prevention).	Mexican immigrant women fear finding cancer and will not get undergo screening in order to keep from knowing if they have cancer. If "cervix" is not understood, some women think of a Pap as a test for all cancers.
May explain a pelvic examination and how a Pap is done, but few clarify that a Pap is one test that may be done during a pelvic examination.	Many women think that if they have had a pelvic examination, they have had a Pap test.
Cultural issues around discomfort regarding genitalia and women's understanding of their bodies are not addressed.	Many women, especially older-generation women, consider discussion of female parts inappropriate and do not pass on health information to their daughters.
Visual images of female anatomy present side views of internal organs in a section of the body, magnified sections of smaller pictures, and other complicated visuals and graphics.	Such visuals are difficult to understand for low literacy readers and those unfamiliar with anatomy.
Meaning of results of Pap tests are either not addressed or explained with confusing classification terms.	Women do not understand the meaning of normal or various abnormal results or the recommended response to each result.
Financial concerns relating to cost of screening and cost of possible needed treatment are not addressed.	Lack of preventive behavior often relates to limited resources and reluctance to look for problems for which there is no money to solve.
Reading level of most pamphlets is grade 9 and above; few available in Spanish.	Grade 5 to 6 is recommended for patient education materials, lower for low literacy readers.
Pamphlet structure is foldout, without pagination.	Difficult to know chronological order of pages.
Outdated materials are available to patients.	HPV causation, new classification system for results, and new recommendations for screening are not included in older materials.

Interviewer: *There is a type of cancer they call cervical cancer — it's also known by other names. Do you know of this kind of cancer?*

Participant #14: No.

Interviewer: *Can you tell me what you've heard about uterine cancer or cervical cancer?*

Participant: *What is cervical cancer? Well, no, I've only known of uterine cancer and that they take them out [the uterus].*

Interviewer: *But you don't know of cancer of the cervix?*

Participant: No.

Interviewer: *There is a type of cancer they call cervical cancer — it's also known by other names. Do you know of this kind of cancer?*

Participant #17: *No, I don't know too well.*

Interviewer: *Has a doctor or nurse talked to you about cervical cancer?*

Participant #17: No.

Interviewer: *Did you mother talk to you about cancer?*

Participant #17: No.

Interviewer: *How about other women — maybe an aunt, a cousin, or a sister?*

Participant #17: *Maybe on television.*

Interviewer: *What have you read or seen on television?*

Participant #17: *More on uterine cancer — it's one they talk about most. And if you have it you have to go get checked.*

Interviewer: *Are there exams specifically for that?*

Participant #17: *I couldn't tell you.*

Interviewer: *Do you know someone who has had cervical cancer here or in Mexico?*

Participant #17: No.

Interviewer: *When you were in Mexico, did you know of any way that women could prevent cervical cancer?*

Participant #17: No.

Interviewer: *You do know about the Pap?*

Participant #17: Yes.

Interviewer: *What do they do in that exam?*

Participant #17: *They take a sample of I don't know what.*

The term “cervix” was defined in 12 of 18 English language pamphlets (#1–7, 10, 13, 16–18) and 3 of 4 Spanish language pamphlets (#8, 9, 11). None of the English pamphlets addressed other possible names for cervix or cervical cancer, such as those commonly used in Spanish, and only 1 English pamphlet (#1) and 1 Spanish pamphlet (#8) differentiated between cervical and uterine cancer. Of the four Spanish pamphlets (#8, 9, 11, and 20), only #11 used both English and common Mexican terminology for “cervix” in a way that the reader could understand the terms in relationship to each other. It refers to “*celulas del cervix (cuello de la matriz) que es la parte mas baja del utero*” (cells of the cervix, or neck of the uterus, which is the lowest part of the uterus).

Lack of Understanding of the Basics: Lack of familiarity with the term “cervix” was part of a bigger problem related to low educational and health literacy levels and a resultant lack of basic understanding of the body, its parts and their functions, pathophysiology of cancer, and related medical terminology and procedures.

Nurse Practitioner: *They [immigrant women] may have had surgery, but they do not really understand what was done. So you have to do a lot of exploring — whether the uterus is*

there, whether it was a hysterectomy. They really don't have this understanding.

Medical Interpreter: *They just nod and say okay, and they seem to understand, and then we find out that they had a hysterectomy, but they think they are pregnant.*

Participant #2: *I don't really know how [cancer] affects the woman. I've never talked about cancer with anyone. Only when I go to see the doctor I see posters about cancer awareness, but that's it. I would like to talk about it, though. I go regularly to get my Pap. I don't know why! I know it's for cancer but I don't know how you can contract it.*

An understanding of basic anatomy is often assumed in patient education material. The word “cell” was often used in pamphlets to explain cancer and what is done in a Pap test. A definition of “cell” was present in only four pamphlets (#1, 2, 3, 4), and a basic cancer explanation in only three (#1, 17, 18). Risk factors for cervical cancer were discussed in fourteen pamphlets and the relationship of HPV to cervical cancer mentioned in twelve, but without a basic understanding of physiology and pathogens (per biomedical culture), this information is unlikely to be understood.

Cultural Discomfort with Discussion of Female Genitalia: Complicating the lack of basic knowledge is an “uneasy relationship with female genitalia” among many Mexican women²⁸ and lack of mother-to-daughter teaching of female anatomy, reproduction, and normal body functions.

Participant #14: *My mother wasn't like mothers today where one talks to their daughters. My mother never told me anything. I remember that when she was pregnant — she never told me she was pregnant. She seemed to hide. She never told me anything. Nothing. In the old days the mothers were different.*

Interviewer: *Did your mother teach you about Pap smears?*

Participant #3: *There are many mothers that do tell their daughters — I knew that my friends' mothers talked to them about the Pap smear. But my mother never told me anything. It's more common for women to talk to their daughters today, but not before. My mother never talked to me about my period. When I got my period, I was very scared because I didn't know what it was and I was like 14 years old — it was taboo.*

Health professionals related that many Mexican immigrant women, particularly the older women, endured their pelvic examinations but didn't ask questions and didn't seem to want information. A discussion of this cultural pattern of silence around female genitalia and understanding one's body is never included in educational materials examined. Naming or drawing of female anatomy was present in 14 of the pamphlets, 2 in Spanish (#1–7, 9–11, 13, 14, 17, 18), although drawings were problematic, as discussed in next section.

The Pelvic Examination vs the Pap Test: Although the women had heard of Pap tests, and many got them, their real knowledge of what they were getting and when they were getting it was fuzzy. Understanding of the Pap test as one possible component of a pelvic examination was often lacking.

Nurse Practitioner: *What I find is that they don't know what the exam entails. So if they've had their feet in stirrups in the past, they think they've had a Pap. They don't understand what that is all about. They can't really tell you if [a Pap] has been done or not.*

Nurse Practitioner: *I do have women who don't know if they've had a Pap before. They know they've had a pelvic exam, but they don't know if they've had a Pap smear.*

An explanation of a pelvic examination and differentiation between a pelvic examination and a Pap test was explained minimally in 4 English pamphlets (#1, 6, 17, 18) and 2 Spanish pamphlets (#9, 20). How a Pap is done was explained minimally and often in anatomical terms in 13 pamphlets (2 in Spanish) (#1-9, 13, 15-17). Differentiation between a pelvic examination and other procedures that might be done within a pelvic examination was explained in only 1 pamphlet (#1).

Confusion and Fear Related to the Purpose of Pap Tests: Educational materials and health professionals interviewed described the purpose of Pap tests in one of two ways: as a test for cervical cancer or, more accurately, as a test for abnormal or precancerous cells or an infection that can be found before the abnormality changes to cancer. The Pap smear was defined in all but one of the pamphlets (#2). Five (#5, 6, 8, 19, 22) defined the Pap as a test for cervical cancer, while the others said its purpose was to look for changes in cells that could lead to cancer. Two (#3, 8) included both, but “a test for cervical cancer” came first, creating the initial impression.

The description “a test for cervical cancer” is problematic for two reasons. Initially, when a woman does not know what “cervical” means, she likely will ignore the unknown word, and hear only “a test for cancer.” Some Mexican immigrant women had come to the conclusion that a Pap was a test for cancer in general, rather than a specific type.

Interviewer: *Can you tell me why they do a Pap?*

Participant #14: *Well, I want them to check me because I'm scared of having cancer.*

Interviewer: *What type of cancer are they looking for?*

Participant #14: *Well, I think, cancer anywhere — wherever it's “born.” It could be in the uterus, or like one of my husband's relatives that died of pancreatic cancer.*

Interviewer: *Well, that type of cancer is very different. The Pap doesn't find that type of cancer.*

Participant #14: *Well, I think cancer just starts growing everywhere.*

Participant #13: *Last time I went to the doctor for the cancer test...*

Interviewer: *The Papanicolaou?*

Participant #13: *Because I was having stomach problems in that sometimes I wasn't able to go to the bathroom and my stomach would hurt more often. I had a lot of gas.*

A medical interpreter interviewed later in the study also commented:

Interviewer: *What do they (Mexican women patients) say the Pap is for?*

Interpreter: *The cancer test. They always say, “the cancer test.”*

A second problem resulting from describing a Pap as “a test for cervical cancer” is that it taps into the greatest fear expressed by the women interviewed: the fear of finding cancer. There is high emotional cost associated with finding a disease that you believe you can do nothing about.

Participant #6: *One always talks about cancer, especially if you are among women. We believe that if you have cancer, nothing could be done for you, you can't be saved. The majority of the women, it's just talk. They don't take action because they are afraid. When one is talking, you ask if they have seen the doctor to get a Pap done and they respond that they haven't had it done because they are scared. “I don't want to know that I have cancer and that I'm going to die. I'm not going to go.” They would rather live the remaining months happy instead of being miserable.*

This common fear was not addressed in any of the materials examined. Based on women's fear of finding cancer, defining the test in terms of prevention — cellular changes that happen before cancer starts — would be less frightening and more accurate, and it would encourage more women to accept the Pap smear than a definition that emphasizes cancer detection vs prevention.

Cultural/Economy-Related Lack of Preventive Behavior: The emotional cost of screening is coupled with the financial cost. Not having enough money was a reason participants stated for not getting Pap tests, but this barrier was not addressed in educational materials, nor was the realistic concern of how treatment could be afforded if needed. Only one locally designed pamphlet (#21) included specific information about the Breast and Cervical Cancer Control Program's free screenings. Several referred readers to National Cancer Institute, Cancer Information Services, American Cancer Society, or local health departments for more information. Associated with limited economic resources is a cultural pattern of not going to the doctor unless a health problem is severe and certainly not going to look for problems, as in screening. Neither this pattern of delayed health care seeking nor reasons to reconsider it within a new society with new resources were addressed in educational materials examined.

Interviewer: *When do you decide that it's time to see a doctor?*

Participant #6: *When it's unbearable. Yes, because you know it's very expensive to see a doctor. And so many people buy herbs. They also sell ointments such as ointments for pain.*

Interviewer: *Do you ever go to the doctor?*

Participant #11: *Me, no.*

Interviewer: *Do you stay pretty healthy?*

Participant #11: *No ... like this month I have had a pain in my back, but we just don't go. We don't see a use of it.*

Participant #15: *Like I mentioned before, people aren't used to seeing a doctor for every little thing. We would first use*

home remedies and when you were really sick, that was the time to see a doctor. Another reason is not having enough money. It is only when you are truly sick — that is when you go see a doctor.

Physician: *I found that most other countries do not do preventative medicine. To do a preventive Pap smear is almost unique to the United States. Even in some of the urban areas, that's just not what health care is ... in those countries. Generally, Pap smears are not a standard of care. I think it's just not part of their culture to even think about having a pelvic exam ever. Even the birthing process is usually done at home with the women helping, so a pelvic exam is just beyond their experience. There's been no passing down through generations, "Well, honey, when you get older you'll have to do this." There's been none of that. So, it's a totally foreign thing. And the whole idea to them of medicine is not a Pap smear or cholesterol screening — if you're not in pain, if you're not having a problem, you don't go to the doctor.*

Lack of Understanding of the Results of Pap Screening: Not surprisingly, the meaning of the result of the Pap test was also a mystery to some of the women:

Participant #7: *But the thing is that they don't explain the results — they don't say what is normal and what is bad. If they don't find anything they don't call. [Or they say everything came out fine] but you don't know what came out fine — they just tell you that everything's fine. If they find something wrong they call. We would rather have a detailed explanation as to why this result is normal, for example, such and such was normal and in order for this to be normal it needs to have the following things. Or what makes this result abnormal is that such and such was missing, or something like that.*

Eleven of the pamphlets, 2 in Spanish (#1-5, 7, 9, 17, 18, 20) discuss the meaning of Pap results but with a variety of approaches. Some use terminology from the older cervical intraepithelial neoplasia (CIN) classification system, some use terminology from the Bethesda system, some use confusing charts that involve both systems, and some avoid classification terminology and use simpler lay language.

Educational Materials: Problems Related to Health Literacy Issues and Scientific Accuracy

Beyond the use of undefined anatomical and medical terms, 4 other aspects of health literacy emerged as problematic for population studied. These included the language (Spanish or English), the reading level, the structure of some of the pamphlets, and the complexity of the visual images used. Eighteen of the pamphlets found were written in English; only 4 were in Spanish. The women interviewed in this study spoke predominantly or exclusively Spanish.

The reading level of the English language pamphlets, calculated using the Simple Measure of Gobbledygook (SMOG) readability formula,²⁹ ranged from grade 7 to grade 13, with only 2 below grade 9. The average grade level completed by the women interviewed was 9.4 (rang-

ing from 0 years to 16 years), and comprehension is approximately 2 to 3 years lower than that of highest grade completed. Health care providers interviewed in the study estimated the educational level of their Mexican immigrant patients at grade 3 to 6, with few completing high school. (Readability of Spanish language pamphlets was deferred, as readability tools are not well researched or readily available for Spanish language.)

The physical nature of some pamphlets was also problematic. While many pamphlets were structured in a book-like manner, with a clear page-by-page chronology, others were folded multiple times like a roadmap, confusing even the author as to the order the "pages" were intended to be read. Also, like road maps, the pamphlets were rarely refolded the same way twice.

Health literacy includes skills of chart reading or comprehending pictures or diagrams. Of note is that many of the anatomical diagrams in the materials were cross-sectional views of the female abdomen (without the rest of the body shown), with uterus, surrounding organs, and often a speculum shown inserted in the cross-sectioned vagina. Another variety included sections of small pictures circled, then enlarged nearby, with the two pictures connected by dotted lines. It may be difficult for a woman with a low educational level or little knowledge of anatomy to decipher the meaning of these diagrams and understand them in relationship to her own body.

Outdated materials created issues related to scientific accuracy rather than health literacy. Of the 22 pamphlets gathered, only 3 were published since the year 2000. Six were published from 1989 through 1995, 10 from 1996 through 1999, and 2 were undated. This is significant because (1) it has only been since the mid 1990s that HPV has been known with certainty to be the major causal factor of cervical cancer,³⁰ (2) the classification system for abnormal Pap results changed through the mid 1990s to various revisions of the Bethesda System but overlapped with still-popular terminology from the previously used cervical intraepithelial neoplasia (CIN) system,³¹ and (3) recommendations regarding when to get Pap smears changed in 2002.³² Thus, significant content in much of the literature available to local patients is outdated.

Conclusions

This study was an initial deconstruction and analysis of elements of the cervical cancer educational message for their relevance and readability in relation to a specific population. Findings from this study show that (1) there is a disconnect between Mexican immigrant women's identified learning needs and the educational content in many cervical cancer patient educational materials, and (2) aspects of language, readability level, structural format, and visual images within the materials examined would likely pose learning problems for local Mexican immigrant

women, blocking their comprehension of the message at a fundamental level. Moreover, outdated materials are providing patients with inaccurate information.

Limitations of the study include that educational materials gathered are not exhaustive, but a convenience sample of available pamphlets in a few local health care sites. Another limitation is the lack of readability scoring of the Spanish language pamphlets. This calculation was deferred while readability tools were researched; to this author's knowledge, only the Fry readability graph has been applied to Spanish language.³³ Also, there is limited transferability based on a small sample of Mexican immigrant women from one locale, however, in-depth interviews from a small sample such as this one can provide a deep level of understanding and detail that is difficult to obtain in survey research. It provides the groundwork for future research.

All of the pamphlets examined had strengths and limitations. Recommendations regarding their use would depend on teaching priorities for a particular situation and on the level of knowledge and literacy of the individual patient. Simple changes in presentation of educational content could be made based on these findings alone, but further research is recommended to establish an evidence base regarding the optimal presentation of key elements of the cervical cancer educational message for Mexican immigrant women. A future multisite study to compare various presentations of key elements of cervical cancer education, using learner verification and revision strategies,³⁴ is planned by the author.

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Appendix A: Immigrant Women's Interview Guide

Household & History

What is your name?
How long have you lived in the United States?
How old were you when you came to the United States?
How long have you lived in Kansas City?
Where else, if time is different?
In what area of Kansas City do you live?
Who lives with you here in Kansas City?
Do you have other family, friends in the city?
Do you have other family still in Mexico?
Where are you from in Mexico?
What was it like growing up in Mexico?
What made you decide to come to the United States?
What made you decide to come to Kansas City?
Many things are different between the two countries. What do you like about living here?
What has been most difficult for you?
Are you married? (probably answered earlier)
How old are you now?
Do you have children? How many? Girls/boys? Ages?
How old were you when your first child was born?
How many pregnancies have you had? Have you lost any children?
What happened (eg, miscarriage, death from what cause)?

Work, Income, Health Insurance

Do you work outside the home?
What work does your husband have?
How much income do the two of you have?
Do others in the household work?
Do you have any health insurance? Medicaid?
Do you have a car? How do you get where you need to go?
Do you have a bank account?
Do you send money home to Mexico?

Household Illness Behaviors

Has anyone in your household been ill in the last year?
What illnesses have they had?
What do you do for illness at home?
Who takes care of the sick person?
Do you have a doctor that you go to? (If you wanted to go to a doctor, where would you go?)
When do you go to the doctor?
Do you know any _____ (traditional healers, curaderos, herbalistas) here in KC? When might you go to them for help? If you need medicines, where do you buy them? (plant medicines?)

Cancer Questions

In my work, I have a special interest in cancer.
Have you ever known anyone who had cancer?
What type of cancer was it?
Can you describe what you know about their experience? (May include symptoms, diagnosis, help seeking, treatment available, treatment tried, course of illness, outcome, financial implications for household, dying process, grief, feelings toward health care system.)
Why do you think people get cancer?
Describe cancer — what does it do in the body?
Is it possible to cure cancer? How?
There is a kind of woman's cancer that I call cervical cancer. It may also have other names — it is a cancer in the neck of the uterus. Do you know of this cancer?
Describe what you know or have heard about this cancer.
What did you learn about cancer from your mother? From your other important women in your life? Television/Magazines? Doctor? Other?
Do you know anyone who has had cervical cancer? Here? Mexico?
Describe their experience.

Cervical Cancer Screening Questions

When you lived in Mexico, was there anything that you knew about that a woman could do to help prevent cervical cancer (Pap, behaviors, food, medications)?
Do you know what a Papanicolaou test is? Describe.
How did you learn about them?

Where could you get a Papanicolaou test?
Did many women get them? When and why?
Were there reasons (in Mexico) that women did not want to get this examination and test?
Have you heard of any times that a woman was treated badly by her doctor?
Were there ever times that things were done by the doctor without the woman's permission or knowledge?
Did women talk to each other about such things?
What about here in the United States? Are women afraid of getting Pap tests, or do they want to have the test?
Have you ever had a Papanicolaou, or Pap test? Why did you get it? Why not? Where? How many? How often? Last one? Results?
How often should women get these tests, do you think?
Where would you go now if you wanted to get a Pap?
Do you talk to your children about cancer?
What do you tell your daughters about cervical cancer?
(Provide relevant teaching regarding cervical cancer/Paps and direct to next scheduled BCCCP screenings.)

Appendix B: Health Professional Interview Guide

Name/profession
Type of practice/location
Approximately what percent of your patient population is Hispanic?
Approximately what percent of those have minimal or no English language skills?
You are probably aware of a recent CDC study citing that (1) incidence of invasive cervical cancer among Hispanic women over age 30 is twice that of non-Hispanics and that (2) utilization of Pap screening is lower among Hispanic women. Do you have a sense of this problem reflected in your own practice?
From your experience and knowledge, what do you think are the major barriers to cervical cancer screening among Hispanic women, particularly those who are first generation immigrants to the United States?
Have your perceptions developed from (a) literature and/or media? (b) observation and clinical judgment? (c) direct statement from Hispanic women in clinical encounters? (d) direct statement from Hispanic women in nonclinical encounters?
When you have a clinical encounter with an immigrant patient, do you approach the assessment any differently than with other patients? Describe.
Are there specific questions that you ask that are different?
In what situations might you initiate a discussion of cervical cancer and/or promote cervical cancer screening?
Would you do that predominantly through dialogue or written patient education material?
What would you say in that dialogue?
Do you have a copy of the material that you use that I might have?
"Cultural competency" is a current buzzword in health care. How would you rate your level of cultural competency?
What things in your educational, clinical, or life experiences do you feel have most contributed to your understanding of other ethnic cultures and improved your cross-cultural communication skills?
What do you think would further improve your comfort level and skill in cross-cultural clinical encounters?
When you have initiated dialogues about cervical cancer and screening with Mexican immigrant women, how would you characterize their response (eg, open responses, comfortable, silent, uncomfortable, agree to recommendations, discuss fears)?
Thank you for your time. This is a small exploratory study, looking at both immigrant women's knowledge, perceptions, and fears — and health care providers' perceptions and approaches to cervical cancer control. Would you like a copy of the report when it is written?