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When a Common Language is Not Enough: Transcreating *Cancer 101* for Communities in Puerto Rico

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Abstract

In Puerto Rico (PR), cancer is the leading cause of death. Previous research has identified the need for cancer education in PR. Using culturally adapted cancer curricula to train local health educators may effectively increase cancer education and reduce health disparities. This article

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describes the three-phase process used to transcreate the *Cancer 101* curriculum to train Master of Public Health (MPH) students to educate PR communities. First, an expert panel collaboratively reviewed the curriculum for content, legibility, utility, and colloquialisms. Recommendations included incorporating local references and resources, replacing words and examples with culturally relevant topics, and updating objectives and evaluation items. Subsequent focus groups with 10 MPH students assessed the adaptation's strengths, weaknesses, and utility for future trainees. Participants were satisfied with the curriculum's overall adaptation, ease of use, and listed resources; further improvements were suggested for all modules. Final expert panel revisions highlighted minor feedback, with the final curriculum containing nine transcreated modules. The transcreation process identified the need for changes to content and cultural translation. Changes were culturally and literacy-level appropriate, represented PR's social context, and were tailored for future trainees to successfully deliver cancer education. Findings highlight the importance of adapting Spanish educational materials across Hispanic sub-groups.

INTRODUCTION

Hispanics are the second-fastest growing minority in the US, accounting for 16% of the general population in 2010 [1]. Current projections suggest 31% of the general population will be of Hispanic origin by the year 2060 [2]. Hispanics also have high incidences of chronic diseases, with cancer at the top of the list [3]. Trends are similar in Puerto Rico (PR), a US territory, where cancer is the leading cause of death [4].

Previous literature highlights the importance of culturally adapting health educational materials for US Hispanic populations [5–7]. However, cancer educational materials available in Spanish are limited. Furthermore, studies have demonstrated the importance of not merely translating, but ‘transcreating’ educational materials [7–9]. Transcreated materials have been adapted to include culturally relevant themes, images and context, ensuring text is reconstructed to meet the target audience's informational needs [7,8]. Studies show transcreated educational materials are not only more culturally relevant [7,9], but have also improved knowledge when compared to materials that were merely translated [8]. However, these studies have focused on transcreating materials from English to Spanish for ethnically diverse Hispanic populations. While Hispanics in the US share a common language, there are colloquialisms and idioms present among various sub-ethnic groups. Additionally, there are differences influenced by socioeconomic, environmental, and other sociocultural factors, such as religious beliefs or local customs [10,11]. Therefore, it is important to consider tailoring educational materials to specific Hispanic sub-groups based on state or geographic regions that may not have diverse Hispanic populations [7]. Yet, we identified only one cancer curriculum transcreated for a specific US Hispanic sub-group, where cervical cancer screening messages were targeted to female Mexican immigrants [12].

In addition to adapting educational materials, many Hispanic health education initiatives utilize community health workers (*promotoras*) to educate community members. Previous literature highlights the importance of tailoring training tools and resources to ensure the educator is confident in his or her delivery and ability to respond to questions [13,14]. “Train-the-trainer” curricula used to educate *promotoras* takes into account logistics,

formats, materials, cultural competence strategies, and interactive skill-building activities. However, a limitation in using *promotoras* or other lay community health workers is a lack of funding mechanisms to support their work in the community [15]. As such, it is important to identify other ways to sustainably train health educators and ensure transcultural curricula meet their needs.

[Blinded] [16]. Results from previous research identified the need for cancer prevention education in [Blinded] PR [9, 16–18]. Training health educators by using cancer curricula tailored to the PR community may be an effective way to increase cancer education, reduce cancer health disparities and expand the availability of locally trained health educators. “Cancer 101: A Cancer Education and Training Program” (*Cancer 101*) is an educational resource tool designed to provide basic information about cancer that has reported increased cancer knowledge, attitudes, and cancer control activities [19,20]. This article describes the process of transcultural the Spanish version of *Cancer 101*, to train Master of Public Health (MPH) students enrolled in the [Blinded] Public Health (PH) Program, creating a sustainable infrastructure of trained *Cancer 101* health educators.

METHODS

Cancer 101 was originally developed in 2002 for American Indians and Alaskan Natives through collaborative efforts between Fred Hutchinson Cancer Research Center’s CDC-funded Northwest Tribal Comprehensive Cancer Project, the Mayo Clinic’s NCI-funded Spirit of the EAGLES program, and the NCI Cancer Information Service [19]. In 2011, it was revised and expanded to include 10 modules addressing basic information regarding cancer, cancer control and prevention, diagnosis and treatment, biospecimens and biobanking, cancer and genetics, cancer and chronic disease, and patient and caregiver support [21]. This revised version was later translated into Spanish by a consensus panel (Katherine Briant, MPH, email communication, July 2013). Each module consists of a curriculum, pre/post assessments, PowerPoint presentations, and additional learning resources. The curriculum was designed for educators to use in the community settings to improve cancer education and uses a “train-the-trainer” format to deliver content in multiple communities. While *Cancer 101* is available in Spanish, it was pilot tested with a predominately Mexican American community (Katherine Briant, MPH, oral communication, July 2013). It is important to transcreate the content to the population in PR, which has a strong sense of identity influenced by both acculturation and cultural nationalism [22].

The research team identified a local expert panel to highlight areas in the curriculum requiring further adaptation. Afterwards, focus groups were conducted with future trainees to assess the adaptations strengths and weaknesses and provide additional user feedback. The transcultural curriculum was revised one last time by the original expert panel. Using a three-phase process to transcreate the curriculum ensured it represented PR’s social context; was culturally and literacy-level appropriate; and is an effective tool for future trainees to disseminate cancer information (Figure 1). This study was deemed exempt by the Institutional Review Boards of [Blinded].

Phase 1: Expert Panel Consensus

An expert panel of six members was identified to review each module, for content and cultural translation components. Panelists with expertise in cancer and public health were selected by the research team from local institutions such as the PR Health Department, the Hospital Interamericano de Medicina Avanzada (HIMA) Cancer Treatment Center, and [Blinded].

Panelists were sent an electronic version of the original Spanish curriculum and asked to review each of the 10 modules using a rubric to evaluate content, legibility and utility on 4-point Likert scale, with higher scores indicating higher levels for each component. Panelists also provided a list of specific words, phrases or concepts that may need to be adapted for PR audiences; additional glossary terms; and summary feedback on the strengths and weaknesses of each module. Panelist evaluations were analyzed and aggregate scores used to rank modules from lowest (needing more adaptation) to highest (needing no adaptation). Panelists then met in-person with the study team to discuss each module and reach consensus about specific module adaptations, word changes, and additional glossary terms. Panelists provided resources or references to compliment the suggested changes. The meeting was audio recorded, and notes taken by two research team members and compared upon completion of the meeting. The recordings and notes were used to develop detailed meeting minutes and a final adaptation action plan, which guided all incorporated module changes. All changes were implemented by two bilingual research staff members, and reviewed by a third team member, using the action plan and detailed minutes as a reference.

Phase 2: Focus Groups with Future Trainees

After incorporating the suggested changes, each module was tested in a group setting with MPH students enrolled in the [Blinded] PH Program. Students represented future trainees who would potentially use the curriculum. Ten students were recruited to participate in a two-day focus group to discuss curriculum adaptation via purposive sampling methods, representing the expected student distribution by class level (6 first year MPH students and 4 second year MPH students). Participants were: (1) [Blinded] students enrolled in any Master's level PH program; (2) 21 years of age or older (3) self-identified as PR; and (4) spoke Spanish. Students were recruited through class announcements informing them about the study. Eligible participants agreed to attend a two-day focus group (6 hours each day) to assess adapted *Cancer 101* modules; review the curriculum prior to the sessions; and prepare a 15 minute educational session on an assigned module, using the provided materials. Selected participants were compensated for their time.

Focus groups were held on two consecutive days, and five modules were discussed at each session. Each student presented an assigned module. Presentations were followed by a 45 minute group discussion using a focus group guide informed by the Social Cognitive Theory (SCT), which addresses the dynamic nature between communication and behavior change [23]. Using the SCT constructs of self-efficacy, observational learning, and facilitation to develop the guide improves the likelihood the curriculum truly has the potential to educate and inform. The guide included questions and probes assessing each module's satisfaction; comprehensibility; utility; strong and weak points; and any confusing, sensitive or

controversial elements. Participants also identified any additional tools needed for the effective delivery of *Cancer 101* in PR. The guide was read aloud and a group discussion took place. All sessions were audio recorded and a verbatim transcript created for analysis.

A content analysis was conducted to assess each module's strengths and weaknesses. Two research staff members individually coded each module transcript and discussed codes to achieve consensus. Final memos summarizing findings were prepared for each module and shared with the research team. Suggested edits were incorporated by two research staff members, and reviewed by a third team member, using the memos as reference.

Phase 3: Final Expert Panel Revisions

The research team submitted the transcreated curriculum to the expert panel for a final assessment. Panelists met with the research team to discuss revisions and provided feedback, which was incorporated into the final version of the curriculum.

RESULTS

Phase 1: Expert Panel Recommendations

The expert panel stated that, while the curriculum's content was informative, all modules needed adaptation for use in PR (Table 1). Overarching changes included reducing text on all PowerPoint slides, including local references and resources, updating and simplifying module objectives, updating module evaluation items and replacing specified words and phrases. They also suggested adding a "Myths and Truths" section to each module and changing some module titles.

Panelists agreed Modules 1 (Cancer in the Hispanic Population); 4 (The Role of Genes in Cancer); and 5 (Early Detection in Cancer) needed the most revisions to content and cultural relevance. For example, while language as a cancer screening barrier was discussed in Module 5, panelists suggested replacing this topic with the importance of understanding health literacy levels. Panelists also suggested only discussing cancer statistics as they relate to PR. Lastly, panelists believed Module 4 needed the most revisions, indicating it was too complex for anyone without a basic science background. They suggested the module should highlight the reality of genetic testing in PR (e.g. costs, barriers, access) and discuss how community members can seek help from their healthcare providers as well as family members.

Modules 7 (Beginning Steps in Cancer Treatment); 8 (Biological Samples & Biobanks); and 9 (Cancer and Chronic Diseases) also needed content-specific and literacy-level revisions. For example, panelists suggested removing the discussion of "curanderos" and other alternative medicine practices common to other Hispanic sub-groups (mainly Mexicans) from Module 7. They also advised changing Module 8's title to "How can I help find a cure for cancer?" to appeal PR's altruistic nature, and highlight human subjects research safeguards and the informed consent process.

The remaining modules required minor revisions, such as adding culturally relevant images and using words known to the PR community when discussing screening or treatment

options. For example, many community members know common procedures by the English abbreviations (e.g. MRI and CT scan). A summary of all suggested edits are listed in Table 1.

Phase 2: Focus Group Recommendations

Basic demographic information was collected from focus group participants (n=10). More than half of participants were female (n=6) and between 21–24 years old (n=6).

Participants were satisfied with the overall adapted curriculum, in the areas of comprehensibility of covered cancer education topics; ease of use; and appropriateness of resources included to effectively deliver cancer education in PR. However, they believed additional content was required in some modules and stated accompanying presentations needed to be better tailored to the PR community by adding local words and images. They also suggested changing the order of some modules to facilitate curriculum delivery as a whole. Based on feedback, modules were thematically grouped as either ‘well-received modules’, ‘modules needing improvement’ or ‘most problematic modules’ (Table 2). Within each, satisfaction, comprehensibility, functionality and utility were addressed.

Well-received modules—Modules 1 (New title: Cancer in Puerto Rico), 3 (New title: Possible Cancer Risk Factors), 5 (New title: Cancer Early Detection), 7 (Beginning Steps in Cancer Treatment) and 10 (New title: Support for Cancer Survivors & Caregivers) had the highest satisfaction and were deemed the most useful in providing culturally relevant information for the educator, as well as appropriate presentation content. Students believed the adapted content was adequate for the PR community; they also stated they would feel comfortable delivering the information. Students were most satisfied with Module 3, indicating it was well-structured and provided all information and materials necessary to educate the public about cancer prevention.

All students agreed these modules were easy to use and highly functional, indicating all resources and references were appropriate and accessible. They also stated the objectives were realistic and attainable, and all instructions were clear. Minor revisions included adding additional resources to assist with the learning objectives, such as a video depicting tumor growth or cancer screening guidelines chart.

Modules needing improvement—Students indicated Modules 2 (What is Cancer?), 6 (Cancer Diagnosis & Staging) and 9 (Cancer and Chronic Diseases) were also highly informative, provided culturally relevant information and had clear instructions. They indicated all resources and references were appropriate and accessible. However, they believed each module needed to be revised for comprehensibility. For example, students reported Module 2’s chronological order was not optimal. These revisions, coupled with additional training, would be necessary for them to feel comfortable delivering the information to community members.

Students also indicated the accompanying presentations needed many improvements to effectively educate the community. They also stated some modules’ objectives needed simplification for community members to better learn the information disseminated. Module

9 stood out as needing the most edits, with all students agreeing it had too many objectives to effectively cover in one educational session.

Most problematic modules—Lastly, students stated Modules 4 (The Role of Genes in Cancer) and 8 (New title: How can I help find a cure for cancer?) were the most difficult to comprehend and were not appropriate for all PR audiences. They agreed each module could be given as an independent educational intervention with healthcare professionals or other individuals interested in learning about the impact of genetics and biobanking in cancer research.

Students were least satisfied with Module 4, mainly with content related to the realities of genetic testing and genetic counseling in Puerto Rico. Students were concerned that the module highlighted local disparities instead of addressing them (such as the lack of availability of genetic counselors in PR and the costs associated to testing), which may create controversy or unnecessary angst in those who learn about the topic. They also stated discussing genetic therapies would be both confusing and controversial and should be removed altogether. Instead, the module should focus on the basics of genetics, genetic mutations, genetic testing and expand more on the importance of knowing your family cancer history as it relates to hereditary cancers. Students also believed these topics could be discussed in Module 3 (Possible Cancer Risk Factors) in more detail, thus eliminating the need to present Module 4 as part of a general *Cancer 101* community educational intervention.

Students similarly expressed low levels of satisfaction with Module 8. They indicated the content discussed was technical and would be better suited for an audience of healthcare professionals. While they believed the text was comprehensive, they did not believe the accompanying PowerPoint was appropriate for general community members (both in length and content). Specifically, they believed the presentation attempted to accomplish “too much” by discussing biological samples, biobanking, ethics, informed consent, and personalized medicine in-depth. Instead, they suggested streamlining the message by explaining how and why biobanking is beneficial and its ramifications to the Puerto Rican community. Finally, they indicated this module should be placed last in the curriculum, as it focuses on future cancer research and how biobanks can contribute to finding a cure. However, they believed it was not appropriate to discuss this with general community members as part of the standard *Cancer 101* curriculum, unless a study currently requesting biospecimen donations was available.

Phase 3: Final Revisions

After revising the transcreated curriculum, panelists provided minor feedback and suggestions to complete the adaptation. These included: combining Modules 1 (Cancer in Puerto Rico) and 2 (What is Cancer?), which explain what cancer is and discuss cancer in PR; adding genetics and family history core concepts from Module 4 (The Role of Genes in Cancer) into Module 3’s presentation (Possible Cancer Risk Factors); using local tools when developing a cancer screening chart in Module 5 (Cancer Early Detection); adding biobanking core concepts from Module 8 (How can I help find a cure for cancer?) into

Module 7's presentation (Beginning Steps in Cancer Treatment); changing the order of some modules; and using Modules 4 and 8 as supplemental modules, only in specific communities when requested or as a resource for other research initiatives. Lastly, the module order was finalized (Table 2).

DISCUSSION

The authors set out to identify whether the available Spanish version of the *Cancer 101* curriculum could be used in its current state to provide cancer education in PR communities, where cancer is the leading cause of death [4]. By using a three-phase approach, the team was able to identify specific changes to content and cultural translation components, as well as modifications to ensure graduate public health students can deliver information to community members effectively. This ensured the adaptation was culturally and literacy-level appropriate, represented PR's social context, and provided all resources necessary to successfully disseminate cancer information.

Using an expert panel to assess the original curriculum and achieve consensus on final changes identified specific areas that needed further review. The team anticipated changing words and images, as well as making modifications to cancer statistics for the general US Hispanic population and examples tailored to Mexicans in the US (such as the term "curanderos"). However, the panelists also recommended tailoring cancer genetics and biobanking information to the resources available in PR, which are not readily accessible to the community. While [Blinded] has established [Blinded] [24], tissue donation is currently limited to cancer patients. Additionally, genetic testing and counseling services are limited on the island and can be cost-prohibitive [17,25]. These suggestions highlight the importance of further tailoring health education tools to specific Hispanic sub-groups, even when a common language is present. This is consistent with findings from other adapted curricula, such as the AMIGAS cervical cancer intervention designed to increase screening rates among Mexican and Mexican-American women [12].

Curricula adaptations must also take into account the needs of those delivering the content. According to Koskan *et. al*, training programs should ensure materials are pilot tested with trainees to ensure they are well understood and trainees feel comfortable disseminating the information [13]. Students' assessment of the adapted curriculum identified further improvements for each module, highlighting the importance of testing materials with trainees prior to establishing a training program. Students identified specific topic areas that must be complemented with additional skills at the training to ensure self-efficacy in educational delivery. They also highlighted several modules needing further improvements not identified by the panelists (Table 2). For example, while panelists stated Module 6 (Cancer Diagnosis & Staging) needed minor modifications, students requested more information be included to increase their capacity for educating community members about disease staging and diagnosis. Additionally, students suggested changing the order of the modules to improve topic flow. Having insight from both students and the panelists allowed for a more comprehensive transcreation that accounts for appropriate cultural competencies and training methods.

Among the limitations of this study is the lack of generalizability of the transcultural curriculum to other Hispanic sub-groups. However, our findings emphasize the importance of further adapting Spanish educational materials across Hispanic sub-groups. Although the original curriculum was already in Spanish, some elements did not resonate well when tested with this specific Hispanic population. This is consistent with other studies that have highlighted the importance of tailoring educational materials to specific Hispanic sub-groups based on state or geographic regions that may not have diverse Hispanic populations [7]. Future studies should consider assessing the cost-effectiveness of transcultural materials for specific Hispanic sub-groups.

Next steps include developing a *Cancer 101* training program tailored to graduate students enrolled at the [Blinded] PH Program. These students will be trained to effectively deliver cancer education in the community through an elective course designed to complement the *Cancer 101* curriculum. These efforts will also provide a sustainable infrastructure to train health educators to deliver cancer prevention information to the community without relying external funding, a limitation faced by other programs that use community health workers as their main educational resource [14].

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Fig 1.
Three-Phase Process using an Expert Panel and Future Trainees to Transcreate the *Cancer 101* Curriculum for Communities in Puerto Rico

Table 1Summary of Specific *Cancer 101* Curriculum Module Edits Suggested by an Expert Panel

Module	Summary of Adaptations
1) Cancer in the Hispanic Population	<ul style="list-style-type: none"> • Include PR statistics • Remove information regarding US Hispanic population • Change title to “Cancer in Puerto Rico”
2) What is Cancer?	<ul style="list-style-type: none"> • Include visual aids
3) Possible Risk Factors in Cancer	<ul style="list-style-type: none"> • Replace examples irrelevant to PR population with culturally appropriate topics • Change title to “Possible Cancer Risk Factors”
4) The Role of Genes in Cancer	<ul style="list-style-type: none"> • Minimize science-heavy detail • Lower the literacy level • Include visual aids and additional examples • Discuss reality of genetic testing and education in PR (benefits vs. barriers, such as costs and availability of genetic counselors)
5) Early Detection in Cancer	<ul style="list-style-type: none"> • Simplify medical terminology • Include visual aids • Discuss importance of screenings • Replace barriers to care with local barriers and examples • Change title to “Cancer Early Detection”
6) Diagnostic & Cancer Staging	<ul style="list-style-type: none"> • Include visual aids • Simplify medical terminology
7) Beginning Steps in Cancer Treatment	<ul style="list-style-type: none"> • Remove “curanderos” • Include more alternative medicine examples as it relates to PR • Elaborate on side effects/treatments • Add table summarizing discussed treatments and side effects
8) Biological Samples & Biobanks	<ul style="list-style-type: none"> • Discuss importance of research before biobanking • Explain concept at broader level • Minimize science-heavy detail • Remove human subjects research issues that PR communities cannot relate to (i.e. Henrietta Lacks and Havasupai Indians) • Add Puerto Rico BioBank initiative • Change title to “How can I help find a cure for cancer?”
9) Cancer and Chronic Diseases	<ul style="list-style-type: none"> • Include PR statistics • Discuss how chronic disease affects population in PR • Discuss social determinants of health and environmental factors impacting PR chronic disease development
10) Support for Cancer Patients & Caregivers	<ul style="list-style-type: none"> • List local support groups • Replace “patient” with “survivor”

Module	Summary of Adaptations
	<ul style="list-style-type: none">• Change title to “Support for Cancer Survivors & Caregivers”

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Table 2

Comparison of Original and Transcreated *Cancer 101* Curriculum Modules after Revisions from an Expert Panel and Future Trainee Focus Group Sessions

Original Module	Phase 1	Phase 2	Phase 3	
	Panel Changes	Student Feedback	Final Revisions	Final Module
1) Cancer in the Hispanic Population	High	Needs improvement	Combine with Module 2	1) Cancer in Puerto Rico
2) What is Cancer?	Minor	Well-received	Combine with Module 1	
3) Possible Risk Factors in Cancer	Minor	Well-received		2) Possible Cancer Risk Factors
4) The Role of Genes in Cancer	High	Most problematic	Supplemental module	8) The Role of Genes in Cancer
5) Early Detection in Cancer	High	Well-received		3) Cancer Early Detection
6) Diagnostic & Cancer Staging	Minor	Needs improvement		4) Diagnostic & Cancer Staging
7) Beginning Steps in Cancer Treatment	Moderate	Well-received		5) Beginning Steps in Cancer Treatment
8) Biological Samples & Biobanks	Moderate	Most problematic	Supplemental module	9) How Can I Help Find a Cure for Cancer?
9) Cancer and Chronic Diseases	Moderate	Needs improvement		6) Cancer and Chronic Diseases
10) Support for Cancer Patients & Caregivers	Minor	Well-received		7) Support for Cancer Survivors & Caregivers