

Adaptation of a Multimedia Chemotherapy Educational Intervention for Latinos: Letting Patient Narratives Speak for Themselves

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Abstract

This study aims to adapt a video-based, multimedia chemotherapy educational intervention to meet the needs of US Latinos with advanced gastrointestinal malignancies. A five-step hybrid adaptation process involved (1) creating a multidisciplinary team with diverse Latino subject experts, (2) appraising the parent intervention, (3) identifying key cultural considerations from a systematic literature review and semi-structured Latino patient/caregiver interviews, (4) revising the intervention, highlighting culturally relevant themes through video interviews with Latino cancer patients, and (5) target population review with responsive revisions. We developed a suite of videos, booklets, and websites available in English and Spanish, which convey the risks and benefits of common chemotherapy regimens. After revising the English materials, we translated them into Spanish using a multi-step process. The intervention centers upon conversations with 12 Latino patients about their treatment experiences; video clips highlight culturally relevant themes (personalismo, familismo, faith, communication gaps, prognostic information preferences) identified during the third adaptation step. The adapted intervention materials included a new section on coping, and one titled "how to feel the best you can feel," which reviews principles of side effect management, self-advocacy, proactive communication, and palliative care. Ten Latinos with advanced malignancies reviewed the intervention and found it to be easily understandable, relatable, and helpful. A five-step hybrid model was successful in adapting a chemotherapy educational intervention for Latinos. Incorporation of video interviews with Latino patients enabled the authentic representation of salient cultural themes. Use of authentic patient narratives can be useful for cross-cultural intervention adaptations.

Keywords Chemotherapy · Disparities · Medical oncology · Hispanics/Latinos · Communication · Decision-making

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Introduction

Latinos are the largest minority population in the USA and are projected to comprise 30% of the population by 2050 [1]. Cancer is the leading cause of mortality among US Latinos, [2] yet they face significant barriers to receiving quality cancer care [3]. Communication inequities are an important, but overlooked cause of disparities in cancer care quality [4]. Latino cancer patients report high levels of dissatisfaction with patient-provider communication, [5] poor therapeutic alliance, [6] and dissatisfaction with their treatment decision-making and overall cancer care [7]. Similarly, oncologists report being dissatisfied with their ability to communicate effectively with Latino patients and support shared decision-making [8].

Communication challenges can be even more difficult in the setting of advanced cancer, where medical counseling intersects with highly personal and culturally informed values related to death and dying. Latinos with advanced cancers, particularly Spanish-speaking Latinos, have been shown to have limited understanding of their diagnosis, treatment options, and prognosis [9]. For example, in a large national cohort study, 91% of Latinos with metastatic colorectal cancer and 79% of those with metastatic lung cancer erroneously believed that chemotherapy might cure their cancer, far surpassing rates among non-Hispanic Whites [10]. These misconceptions are important because they contribute to preferences for life-extending care, [11] lack of advance care planning, [11] underutilization of hospice, [12] and receipt of intensive and burdensome medical care near the end of life (EOL) [13]. Unfortunately, few if any interventions have been developed to equip Latino patients with a more accurate understanding of their disease and treatment options.

A critical barrier to alleviating cancer care disparities is the dearth of evidence to guide the adaptation of health education interventions for Latino or other minority populations [14]. Extant literature on cross-cultural adaptations has focused primarily on linguistic aspects of translating measurement tools or intervention manuals [15] or on adapting psychological or care delivery interventions that are designed to be delivered by a person with intimate knowledge of the target population. Less attention has been paid to adapting tangible educational tools that can be easily deployed in real-world cancer care settings.

Given the need for tools to support treatment decisionmaking among Latinos with advanced cancers, we sought to adapt a multimedia chemotherapy educational intervention [16, 17] to meet the unique needs of Spanish and English-speaking Latinos. Here we present our framework, methodology, and adaptation experience.



Parent Intervention

Designed to support decision-making and patient education about palliative chemotherapy for adult, English-speaking patients, the parent intervention consisted of a suite of five educational videos and companion booklets, each reviewing a common chemotherapy regimen used to treat advanced colorectal cancer or advanced pancreatic cancer [16, 17]. The parent intervention presented balanced information about the risks and benefits of each chemotherapy regimen, highlighting the patient perspective by featuring video conversations with patients describing their experiences in treatment. Development involved multiple layers of iterative clinician and patient-stakeholder review with responsive revisions and has been previously published [16].

Adaptation Framework

Our goal was to adapt the parent intervention for English and Spanish-speaking Latinos in the USA with advanced GI cancers. The adaptation was informed by Viswanath's Structural Influence Model of Health Communication [4]. Our adaptation framework was based on the hybrid model used by Ko et al. to adapt a colorectal cancer screening decision aid for Latino immigrants [14]. The hybrid model avoids the poles of de novo intervention development and literal translation by using study team expertise and local stakeholder input to modify an existing intervention to meet a target population's needs. We modified Ko's adaptation process to include the following five phases (Fig. 1A): (1) creation of a multidisciplinary team with diverse Latino subject matter experts, (2) team appraisal of the existing intervention, (3) identification of key cultural considerations to guide the adaptation, (4a) revision of the parent English-language intervention materials, (4b) parallel development of a Spanish-language intervention materials, and (5) feedback from the target population with responsive revisions. Compared to Ko's framework, our adaptation process relied more heavily on input from professional stakeholders and Latino subject matter experts because specialized medical knowledge was required. Beyond interviewing the target population to solicit their advice or feedback, we made the voice of Latino cancer patients the core of the intervention by centering each video on conversations with Latino patients describing their treatment experiences.



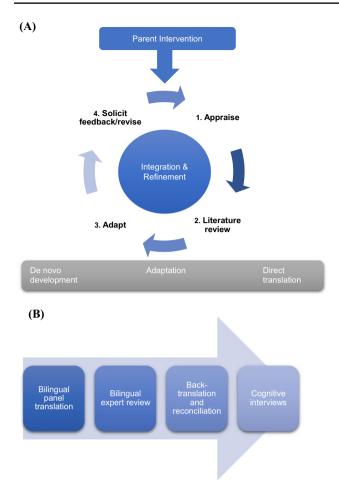


Fig. 1 Intervention adaptation and translation frameworks. **a** Adaptation framework; **b** multi-step translation framework

Phase 1: Building a Study Team

Funded through a disparities-focused, NCI-funded partnership (U54 CA156732) between a large academic cancer center and a local university located in the northeast USA serving a large Latino student population, the project was co-led by an oncologist/health services researcher (ACE) and a Latina public health researcher focused on Latino health (ACL). Leveraging the partnership's resources and infrastructure, we formed a multidisciplinary team of investigators, clinicians, and students with diverse knowledge of Latino culture and clinical expertise caring for this population. We also identified several external advisors with expertise in caring for Latinos with advanced GI cancers.

Phase 2: Appraisal of the Parent Intervention

The core study team evaluated the existing intervention through an iterative process that included individual review and in-person group meetings. External advisors reviewed segments of the intervention and joined meetings as needed. Critical appraisal was guided by group consensus around aspects of the intervention that needed general improvement and modifications required to meet our target population's specific needs.

Phase 3: Identification of Key Cultural Considerations to Guide Adaptation

We used two parallel research activities to identify themes that informed our intervention appraisal and adaptation: a systematic literature review and qualitative Latino patient/ caregiver interviews focused on cancer treatment decision-making and illness understanding. Complete methods and results of this research will be published elsewhere.

Following PRISMA guidelines, our team conducted a systematic integrative review on psychosocial, cultural, and communication factors influencing illness understanding and treatment decision-making among Latino cancer patients. Data were extracted and themes were analyzed through the lens of the structural influence model of health communication [4].

We also conducted interviews with Latino advanced cancer patients and their caregivers. Participants were recruited from the Dana-Farber Cancer Institute and Boston Medical Center (Boston, MA) and were eligible if they (or as caregivers, their loved one) self-identified as Latino, had advanced cancer (or were primary caregivers), had received chemotherapy, and could speak English or Spanish. All participants provided written informed consent according to institutional review boards (IRBs). Three trained, bilingual investigators (YM. AR. and GF) conducted semi-structured interviews focused on communication preferences and experiences during the diagnosis and initial treatment decision-making phase of their illness. All interviews were recorded and professionally transcribed in their original language. The team iteratively created a codebook informed by the social ecological theoretical framework, [18] and investigators dual coded each transcript and resolved disagreements through discussion and consensus. The study team identified overarching patterns and themes. They then identified a subset of most relevant themes and determined ways to incorporate them within the adapted intervention (see results).

Phase 4: Revision of Parent English-Language Intervention Materials and Development of Spanish Materials

The revision phase involved three steps: (1) Revision of content and structure of the English intervention, (2) Spanish translation, (3) Media production (film, print, and web) for English- and Spanish-language materials, and (4) post-production editing/revisions. We first revised the intervention's



content and structure to improve the intervention and to make it more relevant to Latino patients and families. We then translated the intervention into Spanish using a rigorous, multi-step process (Fig. 1B), described below ["Results" section, phase 4]. In the production phase, we recruited Latino patients with advanced colorectal or pancreatic cancer to be recorded (in Spanish and/or English), discussing their experiences in the relevant chemotherapy regimens. Filming occurred at four partnering cancer centers: Dana-Farber Cancer Institute and Boston Medical Center, Dana-Farber Cancer Care-Lawrence (Lawrence, MA), and Moffitt Comprehensive Cancer Center (Tampa, FL). We then partnered with a professional cross-cultural media production company to edit these materials into English- and Spanish-language videos and booklets. Finally, a firm with expertise in web-based behavioral health interventions developed a website to integrate written and video content. The study team and external advisors reviewed the draft materials and suggested changes iteratively until reaching consensus.

Phase 5: Target Population Feedback

We interviewed Latino patients with advanced cancer and their caregivers to solicit their feedback on the adapted intervention. After written consent, bilingual members of the research team (KM and AR) interviewed patients in English or Spanish (same eligibility criteria as phase 3) using a semi-structured interview guide and standard usability and cognitive interviewing techniques to assess their understanding of the material and its acceptability and perceived utility. We audio-recorded interviews and took notes during and after interviews. Feedback was summarized and reviewed by the research team, with common critiques prompting intervention revisions.

Results

Phase 1: Building a Study Team

The 13-member study team was comprised of clinicians and researchers with expertise in medical oncology, palliative care, nursing science, social work, Latino health disparities, sociology (with a focus on Latino culture), and Spanish-language film production. Most team members were first- or second-generation US Latinos, including two undergraduate nursing students and two social sciences graduate students. We also recruited several external advisors with significant expertise caring for Latino cancer patients (e.g., two first-generation Latino oncologists practicing in Latino immigrant communities, a Latina oncology nurse, and an

oncology social worker specializing in Latino patient/family support).

Phase 2: Parent Intervention Appraisal

The study team agreed to retain the video/booklet format of the intervention, and that the videos should remain centered around authentic patient interviews. Beyond needing English and Spanish versions of all materials, the team identified the need for a website to integrate written/video content in both languages. Beyond these structural issues, we identified five additional shortcomings of the parent intervention: (1) content was too long and complex, (2) it lacked interactive components, (3) it lacked Latino representation, (4) it required more attention to patient preferences around prognostic information, and (5) it lacked content on coping and palliative care.

Phase 3: Identification of Key Cultural Considerations to Guide Adaptation

Our systematic search of five databases yielded 55 articles that met inclusion criteria. Of these articles, 37 were quantitative and 18 were qualitative studies; 35 included multiethnic populations, while 20 included only Hispanics/Latinos; 23 focused on breast cancer, while 26 included patients with multiple cancer types. For the qualitative study, we interviewed 15 Latino advanced cancer patients and 23 caregivers (26 interviews conducted in Spanish, 12 in English).

Of the major themes identified within the systematic literature review and qualitative interviews, five were considered particularly salient to the project goals: (1) *personalismo*, the tendency to value person-to-person connection in health care interactions; [14, 19] (2) *familismo*, the tendency to place the family at the center of decision-making and care; [19] (3) faith and spirituality; [14] (4) communication gaps between clinicians and Latino patients and strategies to overcome these gaps; [7] and (5) variability in Latino patient preferences regarding disclosure of prognostic information [9]. These themes influenced the adaptation in several ways (Table 1). Notably, we identified video clips from Latino patient interviews that addressed these themes.

Phase 4: Revision of Parent English-Language Intervention Materials, and Development of Spanish Materials

Study team members revised scripted and written portions of the English-language intervention, considering issues of content, structure, and style. After revising the English materials, we translated them into Spanish using a multi-step process (Fig. 1B) [20]. First, two native Spanish-speaking, bilingual investigators (one oncologist, one social worker)



Table 1 Themes identified in literature review and qualitative interviews and how they were addressed in adapted intervention

Theme	How it was addressed within adaptation	Examples of patient video clips highlighting a theme*
Personalismo	 Video clips of Latino patients recounting both positive and negative interpersonal experiences with clinicians "B-roll" footage of patients having warm interactions with clinicians Video clips of Latino clinicians Clinician script highlighting warm, familiar clinician-patient interactions 	"I have the support of my family, and of the nurses who ask us how we are feelingThey are attentive of everyone. And that is so comforting to us"—Jose, aged 59 "Two doctors came in the room and I did not notice any compassion. They were very cold. I felt like another statistic. She was standing the whole time with her cklip board, no emotion. And she said 'You have cancer. Do you have any questions?' And I was shocked. Not by the news, but by her manners"—Sandra, aged 57, metastatic colon cancer
Familismo	Inclusion of video clips discussing the importance of family in coping with the disease and treatment Intervention targeted at patients and family members/caregivers Emphasize importance of family in care and decision-making	"Not every day is sunshine and rainbows. There are days I struggle to accept the reality of my situation. But I pull myself together. I stand firm. I know that my son still sees me the same way he did before I was diagnosed. So I try to see myself like that too"—Sandra, aged 57, metastatic colon cancer. Simply live life every day. I have my animals, my little chickens, my little roosters that distract meI feed them, give them waterI feel useful. I feel like I have my place in my family, within the family. And if any of them have problems, or something good to share, the come to me. They take advantage of my experience and I give them my advice"—Jose, aged 59, metastatic colon cancer "I know that my family supports me a lot. When I have something to do and cannot do it for whatever reason, because I'm sick. They are there for me every time probably that's why I feel so strong"—Edwin, aged 53, metastatic colon cancer
Faith/spirituality	 Including faith and spiritual activities as important coping strategies Use of patient narratives highlighting the role of spiritual coping and prayer 	"I have a strong belief in God, and I think that has helped me through. I've been very positive about it. He doesn't give you anything that you can handle. Okay? And so the way I looked at it, I said I either have a lesson to learn with this or a lesson for someone else to learn through me"—Linda, aged 65 "My first strength is GodI pray every night and ask God for one more day and for strength"—Adelaide, aged 66, metastatic colon cancer
Communication gaps	 Create English and Spanish versions of the intervention Lowered the literacy level Added a definition page Created infographics for conceptually difficult information Emphasized proactive communication, interpreter use, and asking questions within content and selected patient quotes Added a prompt list to help patients identify priority questions and encourage them to discuss with the care team 	"At first I didn't ask many questions, because I thought the doctor knows what he is doingbut you should ask questions, because it is your life!"—Jose, aged 59, metastatic colon cancer



Table 1 (continued)			100
Theme	How it was addressed within adaptation	Examples of patient video clips highlighting a theme*	0
Variability in prognostic information preferences	Variability in prognostic • Separated prognostic information into a sealed chapter of the booklet information preferences • Added a pause with a stop sign to the video prior to the segment on prognosis • "Decision aid" to help patients/families determine their desire for prognostic information • Present prognostic information in multiple ways	"I took it well. And I said okay, like you know I've got things to do, I've gotta check you know, I mean. What is my prognosis?"—Linda, aged 65, metastatic colon cancer "I asked the doctor, what does this chemo do and why? And she said 'this one prolongs your life, this one fights the cancer and so on.' It's very important to ask questions because it gives you perspective on what your situation really is."— Jose, aged 59, metastatic colon cancer "For people who have this cancer it's difficult to get healed because there is no cure. Know what I mean? what can be done is to exend your life for more time."— Angel, aged 60, metastatic pancreatic cancer	

Only English translations are presented

translated the English text into Spanish and reconciled differences. To ensure semantic and linguistic equivalence across dialects, the reconciled Spanish text was then reviewed by a bilingual panel, consisting of two oncologists, two social workers, and three students from 6 different Spanish-speaking countries in Europe, South America, and the Caribbean. Segments were then externally reviewed by several Latino community contacts, also with representation from Europe, South America, and the Caribbean, to ensure that they were accessible and understandable to Latinos from diverse regional, socioeconomic, and educational backgrounds. Two independent translators then back-translated the material into English. Any unintentional discrepancies were then reconciled by the study team. Finally, we tested the translated materials through cognitive interviews with our target population (see phase 5).

Overview of Adapted Intervention

The adapted intervention mirrors the structure of the parent intervention but is available in both Spanish and English. In addition to the suite of booklets and companion videos, a website serves as an integrated platform to host the intervention's written, video, and graphic content. The adapted intervention materials included a new section on coping, and one titled "how to feel the best you can feel," which reviews principles of side effect management, self-advocacy, proactive communication, and palliative care.

Video Adaptation

The predominant adaptation of the video was integrating authentic narratives and voices of Latino patients and clinicians in Spanish and English. We filmed Latino clinicians describing factual information about each chemotherapy regimen (Supp. Figure 1). A bilingual social worker interviewed 12 Latino cancer patients describing their experiences, using an interview guide designed to elicit information about their diagnosis, treatment decision-making, treatment side effects, benefits/lack of benefits (e.g., improvement in pain, tumor shrinkage), quality of life, and coping. Video interviews were transcribed to assist the team in selecting and editing footage.

We selected patient footage based on several criteria. First, to ensure an accurate and balanced portrayal of each chemotherapy regimen, we selected narratives that best conveyed the typical range of experiences with respect to side effects and treatment efficacy. Second, we selected clear descriptions and emotionally poignant stories. Third, we sought diverse representation with respect to age, gender, ethnicity/national origin, occupation, and socioeconomic status. Featured Latino patients included an orange farmer, a restaurant owner, a construction worker, a nurse,



a homemaker, and a musician. Finally, we selected narratives that highlighted cultural themes identified in phase 3 (Table 1). For example, to highlight *personalismo*, we included footage of warm interactions between Latino patients and clinicians and descriptions of strong therapeutic relationships. To address common communication gaps, we selected patient interview clips emphasizing the importance of proactive communication and working with professional interpreters—advice, which was also reinforced by clinician scripts.

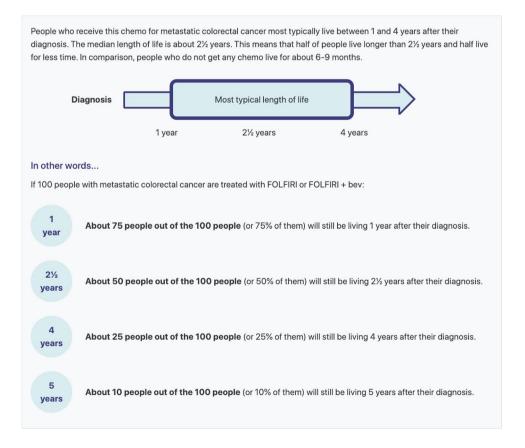
To promote a comprehensive description of chemotherapy experiences, we incorporated a small number of video segments from the parent intervention, dubbed into Spanish. We also added at least one Spanish-speaking patient (with subtitles) into each English-language video to better resonate with bilingual Latinos and to present a more diverse and authentic representation of the Latino voice. Translation of video dialogue involved three bilingual native Spanish speakers (YMC, PAH, and KM) independently translating patient interview clips and reconciling differences, with additional review by a native English-speaking oncologist (AE) to ensure accuracy of clinical information. Translation of patient interview footage posed some challenges. First, many patients mixed Spanish and English (i.e., "Spanglish"), which we chose to retain (without subtitles). Second, many idioms and nuances of spoken language required loose translations to best retain patients' meaning and sentiment.

Booklet Adaptation

In addition to language considerations, we made several major changes to the form and content of the adapted booklets. First, we simplified the text, decreased length, and added a page with basic definitions (e.g., cancer, metastasis, colon) and complementary diagrams. For conceptionally difficult information, such as response rates to chemotherapy, we created infographics (Fig. 2) to facilitate interpretation by patients with low literacy or numeracy. We also added pictures of Latino patients and clinicians throughout the booklets and highlighted culturally relevant themes (e.g., familismo, faith/spirituality) by integrating pertinent patient quotes (derived from videos) and by addressing faith and family support within written content about coping.

We added sections on coping, self-advocacy, and working with medical interpreters and adapted a question prompt list. To address the significant variability among Latinos in their desire for prognostic information, [21] we developed a list of questions to help patients and families decide whether they felt ready to review these segments. We simplified presentation of life expectancy statistics by adding an infographic that highlighted the "most typical range" of survival using

Fig. 2 Sample infographic describing potential impact of chemotherapy regimen on prognosis





the interquartile range of survival derived from clinical trials. We also included a discussion of the emotional impact of this information and how one might cope with it.

Website

The team collaborated with a health-focused website developer to adapt booklet content for web display, using collapsible/expandable lists, embedded links, and interactive visuals to enhance usability (sample website: www.chemovideo. org, userID = FOLFIRI). Users can toggle between English and Spanish. The website "splash page" presents the full video; tabs across the top present topics correlating with booklet segments (e.g., side effects, treatment process, treatment benefits) that also embed relevant video segments. The website features a "plug-and-play" library of chemotherapyrelated symptoms, with information about how patients can manage that symptom at home. We also added information about cancer-related financial concerns available through the National Institutes of Health. The website was designed in a modular fashion to enable future content revisions and the ability to scale to other regimens or diseases.

Phase 5: Target Population Feedback and Responsive Revisions

We conducted interviews with 10 Latino patients; 5 were USA born, 5 had immigrated to the USA (range of time since immigration, 1–37 years); 8 were male; 3 spoke Spanish only and 7 spoke both English and Spanish. Three participants completed post-secondary vocational school, college, or higher; 5 graduated from high school; and 2 completed some high school. Half reviewed the English and half reviewed Spanish materials. All participants considered the video and booklet to be easily understandable and identified no major problems in segments selected for review.

Participants' appraisals of the intervention were generally positive; several asked for access to the intervention at home and wished it had been available to them earlier in their treatment course. Participants particularly appreciated the presence of "basic" information such as definitions and how chemotherapy affects cancer and hearing directly from patients. One patient commented that patient stories made the material more relatable and helped him to feel less "alone." Criticisms related to minor technical issues (e.g., improving sound quality) or requests to add information about peripheral topics (e.g., dental health), which we incorporated where possible. Some participants suggested changes outside of the project scope, such as translating it into other languages or adapting it for pediatric populations. Participants affirmed the intervention's presentation of prognostic information. Their personal reactions to the information were mixed—one participant thought the information was "shocking and unnecessary," while most others found it to be appropriate, with comments including "very helpful" and "fair given the situation."

Discussion and Conclusion

Discussion

Here, we report the adaptation of a multimedia chemotherapy education intervention aimed at improving knowledge and chemotherapy decision-making among US Latinos with advanced cancer. We describe a rigorous and reproducible adaptation process designed to incorporate the perspectives of stakeholders and subject matter experts and that integrates authentic stories told by Latino patients in their own words to highlight culturally relevant themes.

Cross-cultural adaptation of patient educational interventions can be challenging with regard to language and culture, particularly for interventions aimed at Latinos. US Latinos come from multiple national backgrounds, each with its own set of cultural practices and dialects. Although there is no gold standard for cultural adaptations, many existing interventions have focused on linguistic translation and integrating important cultural values and concepts [22, 23]. Other interventions used scripted narratives by actors portraying patients and clinicians [14]. This approach has also been used by health communication interventions that use the telenovela format to discuss important and/or sensitive topics using dramatized stories [24]. These approaches allow interventions to be tightly scripted around core themes; however, they can lack authenticity and risk, presenting a monolithic, stereotyped representation of Latino culture.

Use of peer narratives and peer engagement has been another technique to adapt educational interventions [25]. Using this approach, we allowed patients to tell their own stories in their own words. While this approach sacrifices full control over messaging, the result is arguably more authentic, relatable, and understandable. Using patient narratives provided organic opportunities to highlight Latino culture as it related to patients' cancer care experience, potentially appealing to many Latino patients' desire for personal connection [19].

Additional strengths of our adaptation process included a diverse research team and grounding it in the existing literature and interviews with our target population. The Spanish language has considerable heterogeneity, and our rigorous translation process with review by persons of diverse national origins helped ensure that



the materials were broadly understandable and retained their nuance. Investigators could use similar methods for other interventions.

This intervention adaptation approach has several limitations. First, our process required a large team possessing significant linguistic, ethnic, professional, and disciplinary diversity. This was possible through the resources and infrastructure of an established inter-institutional partnership; however, it could be challenging and impractical in the absence of similar supports. Second, the oncology clinics we partnered with served predominantly Caribbean Latino communities, which limited patient diversity within our video intervention. Finally, our web-based videos may be inaccessible to those with limited technological literacy or without a stable internet connection. Alternative delivery strategies can be explored in future work.

Conclusions

In summary, a hybrid adaptation model allowed us to successfully adapt a multimedia chemotherapy education tool to meet the unique yet varied needs of the diverse US Latino population. Filming Latino patients describing their perspectives allowed us to represent cultural themes in an authentic and non-stereotyped manner. Future research will test the efficacy of such an intervention in improving information exchange and the quality of communication in Latinos with advanced cancer and their caregivers.

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Declarations

Conflict of Interest The authors declare no competing interests.

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