



Tailoring Content for Authenticity and Adoption: Community-Based Participatory Research and the Co-creation of Story-Based Health Communication for Underserved Communities

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Villar ME and Johnson PW (2021) Tailoring Content for Authenticity and Adoption: Community-Based Participatory Research and the Co-creation of Story-Based Health Communication for Underserved Communities. Front. Commun. 6:663389. doi: 10.3389/fcomm.2021.663389 This perspective presents concrete examples of how community-based participatory research can be used effectively to decolonize health communication through the co-creation of health communication content specifically tailored to minoritized and underserved communities. The authors describe how community members and researchers partnered to conduct community listening, observation and co-create stories to be used in fotonovelas (graphic stories), radio stories, serious games and community theater. Community members are experts on their experiences and can best translate those experiences into stories that ring true for target audiences from similar backgrounds. Truly participatory research grounded in community values can be slow and take unexpected turns, but it is critical to create health communication content that resonates with audiences and contributes to influencing attitudes and behaviors. When Community-Based Participatory Research (CBPR) is used in true collaboration with the community, marginalized communities, which were historically exploited by community researchers, can become the architects of their own health outcomes.

Keywords: non-traditional health communication, health content promotion, community-based participatory research, ethical community research, health promotion in underserved communities, fotonovelas, radionovelas

INTRODUCTION

Traditional science and health communication reflects the values and practices of dominant groups in society (Dawson, 2018). As such, communication for transformative change within underrepresented communities demands approaches outside of what is considered "traditional." This perspective piece will provide an overview of the research undertaken using non-traditional Community-Based Participatory Research (CBPR) within minoritized communities. This perspective is not meant to describe the intricacies of carrying out authentic participatory research, but rather to provide examples of how such engaged research can improve outcomes of story-based health communication approaches such as fotonovelas, radionovelas, community theater, and serious games.

There is robust research on Community-Based Participatory Research (CBPR) for health communication, and it increasingly addresses the importance of CBPR to tackle health disparities, intersectionality, and decolonizing health communication (Minkler and Wallerstein, 2003; Dutta, 2015; Brush et al., 2020; Nguyen et al., 2021) as well as the challenges of conducting authentic collaborative research that does not perpetuate the power structure between communities and researchers (Palmer-Wackerly et al., 2020).

As its most basic level, Community-Based Participatory Research (CBPR) is used to expand the reach of important messages and acceptance. Shiu-Thornton (2003), defines CBPR as:

a research approach that involves community members/partners in all phases of research ... seeks a collaborative approach that is equitable for all participants ... is grounded in the conscious recognition that historically, and particularly within ethnic minority communities, research has been done on (in contrast to with) communities of color by predominantly w researchers (p. 1362).

It is important to note that CBPR research has been used primarily by white researchers to benefit white researchers (Blumenthal, 2011). As such, campaigns did not often take into account audience characteristics beyond demographics such as race, ethnicity, gender, language, and geographic region. Other important variations including identities, collective narratives and understanding of health influenced by culture, dialect, ideology, literacy, and self-efficacy were not often included. To overcome these shortfalls, CBPR works best when the two-pillars concept is centered. Blumenthal (2011) describes the two pillars of CBPR that must be actively perpetuated:

The first [pillar] is ethical and responds to a history of exploitation of communities—especially minority and lowincome communities—in the name of research The second pillar—community empowerment—has roots that are often attributed to the writings of the Brazilian educator Paulo Freire ... [and] incorporates those activities that lead to community empowerment, such as social action and sharing of resources (Blumenthal, 2011, p. 2).

As CBPR is rooted in white researchers undertaking research in minority communities for their own benefits, the use of CBPR by minority communities for their benefit is strongly supported as a means of empowerment and community transformation. Applying principles of interpretative and critical research also benefits health communication as a process intimately tied to culture and collective narratives (Zoller and Kline, 2008; Sastry et al., 2021). Careful attention to these nuances is important to create messages that resonate with marginalized subgroups, which are often also the most at risk, in need of useful health communication and mistrustful of research and researchers (Smith and Blumenthal, 2012).

To truly engage the desired audience, approach, and source matter. The approach must be collaborative, respectful, inclusive, and broad in terms of stakeholders and resources. People in

general, and marginalized subgroups in particular, are more apt to trust their peers as sources of information. Knowing this, the Appreciative Inquiry/Boot Camp Translation Method fits well with CBPR to utilize the community's collective knowledge (Moody et al., 2019). Therefore, research that informs health communication content must come from the community and gathered through long-term observation, extensive listening and refining of the messaging and content. The deficit model, when local participants are seen as less "expert" than the researchers, can result in ineffective messaging, exacerbate inequalities (Delemos, 2006), and result in interventions that are nonsustainable (Wang et al., 2016). Community members know the culture, norms, and stigmas that will determine how the interventions will be received (Villar and Bauduy, 2014). This is where CBPR is critical; embracing community members as primary stakeholders, equal partners, and subject-matter experts results in the types of health behaviors that public health experts seek to influence.

APPLICATIONS OF COMMUNITY-BASED PARTICIPATORY RESEARCH

In this perspective, we will present examples of health communication methods undertaken with robust community participation that underscores the value of CBPR, and the two pillars, in co-creating interventions and assessing outcomes. The examples used in this perspective add to the conversation surrounding health communication and, while considered nontraditional methodologies, fotonovelas, community theater, and serious games are becoming more mainstream in health communication. As the key to CBPR is relationship-building, these projects took place over an extended period of time using a three-part, phased approach. In the initial phase, participants worked with the community to conduct research and learn as much as possible about the attitudes, beliefs, and practices of the target audience in relation to the issue. In phase two story, development sessions with community partners and other stakeholders were undertaken to identify common and relatable situations that could be used to challenge the stigmas associated with particular attitudes and behaviors. In the final phase, stories were produced as graphic novels, radio stories, community theater, or serious games, with community members piloting and refining the content until there was satisfaction that the stories were meaningful, accurate and appropriate representations of the target audiences.

MENTAL HEALTH SERVICES AMONG IMMIGRANT COMMUNITIES: GRAPHIC AND AUDIO STORIES

Fotonovelas for Latinx Community

The first set of projects focused on youth mental health services among immigrant communities. The methods used were fotonovelas and radionovelas to discuss how these challenges occur within their communities (Villar, 2021). Fotonovelas were adopted into practice in the U.S. as a method of disseminating

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health-related educational materials to underserved Latinx communities where literacy or English proficiency was lower (Cabassa et al., 2012). Fotonovelas are photos of scenes with simple word bubbles. Stories that use animations or comics have also increased in popularity for science education and communication (Farinella, 2018). The combination of visual storytelling and compelling narratives using cultural references increase the impact, effectiveness and appeal to a wider range of audiences (Farinella, 2018).

To develop stories within the Latinx community to create the fotonovelas, a great deal of community-listening came first. Researchers met with community members inside their neighborhood spaces and then went out into the community to talk to people. Researchers, designers and community members were equal participants in the development of the storylines, dialogue, and characters. With help from a graphic designer, photographs, and simple, short text bubbles were used to convey educational messages with a familiar, conversational tone. A cornerstone of the research and what made the community partnership so critical was the need to continuously debrief, edit, and reconfigure approaches and content based on the feedback received. The community's collaboration was especially meaningful in ensuring that word choice, and situational examples were culturally accurate and believable. In total, six fotonovelas were co-created and disseminated in Spanish and also translated into English for English-dominant community members (Villar et al., 2012).

Radionovelas for Haitian Community

As an offshoot of the fotonovelas, radionovelas were co-created for outreach to parents about youth mental health within the

Haitian and Haitian American community, with radio being substituted for graphic depictions. Bhatt and Kashyap (2015) highlighted that community radio is often utilized for opinion sharing, community participation and knowledge acquisition making it a unique and useful mode for the Haitian community in South Florida. This was due to the prevalence of radio usage in the Haitian community and an initial assumption that Haitian Kreyol was an oral language as opposed to written, based on marketing practices for that community.

The CBPR process with the Haitian community members closely followed that of the fotonovelas. The stories were audio recorded with voices of community members and disseminated online and through a local radio station. An unexpected community reaction after completing the radio stories perfectly illustrates the value of fully engaging and collaborating with the targeted community. When the finished radionovelas were shared with the community, feedback was very positive but there were requests for a printed version of the story that people could take home with them to read and share. Unlike previously thought, Haitian Kreyol is now taught in schools in Haiti and writing in Kreyol is more standard, especially among younger parents, which were largely the target audience for the messaging. This prompted a second round of cocreation to develop graphics to accompany the radio story script. A graphic artist worked with the team to develop drafts of the images depicted in the story, many of which were very culturally specific. For example, deciding on the appearance of the teacher, the priest, the grandmother, the cousin from New York, etc., involved intricate discussion of stereotypes, archetypes, and how the community wanted to be depicted. Discussing some scenes, such as a traditional medicine bath,



provided opportunities for the community co-creators to speak of their experiences and beliefs in a safe and welcoming setting. The result was a graphic story in comic book style that was also very well-received (Villar and Bauduy, 2014). These experiences demonstrate the need to engage community members in co-creation to ensure that the best method(s) of communication are used for maximum effectiveness (see **Figures 1**, **2**).

DOMESTIC AND SEXUAL VIOLENCE: FOTONOVELAS, COMMUNITY THEATER, AND SERIOUS GAMES

Intimate Partner Violence Fotonovelas

As part of a larger program to raise awareness about domestic violence in a majority Latinx community in Florida, several community organizations convened a group of women community members to develop culturally and geographically appropriate fotonovelas to discuss the stigma around seeking services for domestic and sexual violence. Through extensive community listening, they recounted situations that were then synthesized into fictional scenarios used for photos and dialogue. A key takeaway from the intimate partner violence fotonovelas was the occurrence of double victimization. In domestic violence situations, damaging gossip is spread that maligns the female victim both for not leaving her abuser and for not being able to "keep a man" once she escapes the abusive relationship. These details directly informed the discussion and content included in the fotonovelas as these characterizations of survivors of domestic and sexual abuse factor into the "cone of silence" and the perpetuation of abuse. This process also brought spousal abuse of men by women through bullying, threatening to block access to shared children, and removal of financial support (Villar et al., 2012). A series of six stories were written and made into fotonovelas with the help of a photographer and graphic artist. The benefit of the fotonovelas was in the ability for both community partners and the widespread community to see themselves in the situations, reactions and attitudes depicted in the graphic stories. Based on pilot evaluation results, the fotonovelas were just as effective in increasing knowledge as a traditional presentation, but generated more discussion, disclosure, and inquiries about services than the presentation format that included the same general content (Villar et al., 2012). Participants in the community discussion groups reported that they identified with the scenes, language, and felt that the stories reflected their experiences and made them think about how they would react in similar situations.

Cho!ces Sexual Assault Bystander Game

Serious games, which are role-playing activities and scenariobased simulations, were created to provide an opportunity to explore a serious issue in an interactive manner, safely. An example of co-creation with community youth is the Cholces social board serious game to raise awareness about bystander intervention in sexual assault. When playing a game, participants have the ability to try out different scenarios and decisions without real-world consequences and the opportunity to begin again, each time with new information and perspective. This layering of information and experience can foster selfidentification with the scenarios and issues of the game providing a deeper level of engagement and involvement (Wendler and Shuttleworth, 2019). The Cho!ces game was created (and named) by youth and is also based on scenarios drawn from community stories created by community participants that represent the target audience of the game. In preparation for the participatory research, youth participants aged 16-22 received preliminary training that included an introduction of the subjects of domestic violence, sexual assault and child sexual abuse, and games for social change. Participants then conducted their own community listening and met to report their insights, generating robust discussions and stimulating ideas for game designs. The final scenarios included commonly encountered elements designed to encourage discussion and bring awareness of the need for bystanders to become involved in instances of sexual assault. Through playing the game, players test and discuss different possible reactions, and ultimately reach a consensus on the best course of action. After pilot testing the game it became clear that some groups reached a consensus on a response that was not one of the game scenario options. Based on this insight, game rules were changes to allow for "other" options. Because of the input from the youth co-creators, stories referenced trends on social media, local socializing habits, use of rideshare services, and "typical" parent reactions. As with some of the previous examples, participants remarked about the realism of the scenarios, and that these were things that could happen to anyone in their community. The game simulations were especially beneficial because it allowed participants to safely think through the consequences of different actions, apply concepts of bystander intervention, and operationalize them into tangible actions and reactions should they ever experience, be told of another's experiences, or witness sexual abuse (Concha et al., 2020).

Por Nuestras Calles Game About Commercial Sexual Exploitation of Children

Like the Cho!ces social board serious game, simulations were co-created to develop a board game to raise awareness about commercial sexual exploitation of children and adolescents titled *Por Nuestras Calles* (Through Our Streets). This project

was initiated through law enforcement and tourism agencies in Colombia responding to growing concerns about the issue and low levels of awareness and concern by regular citizens. Different from previous methods, the partners and stakeholders came primarily from law enforcement and non-governmental organizations (NGOs) with community members acting as secondary resources (Wendorf Muhamad, 2018). Members conducted many interviews, observations and game trials to fine tune the stories. The creation of these stories had to be particularly nuanced, so that they would clearly depict how sexual exploitation of children happens, while avoiding graphic and possibly trauma triggering scenarios. It required crafting stories that did not shock or repel players with details that the targeted audience would be unable to relate to, tolerate or assimilate into tangible actions (Wendorf Muhamad and Harrison, 2017). While the aim of the game was to raise awareness, through the community research and creation of scenarios several central themes and attitudinal targets emerged. Specifically, it became evident that besides economic and social factors, an important barrier to community involvement in prevention of this kind of exploitation was apathy stemming from victim blaming and a misunderstanding of the practices and motivations behind child sex labor and the sex tourism trade. This became a guiding concept in the co-creation of stories, with different game scenarios intended to communicate different levels of sympathy, perceived risk, and perceived criminality.

¡No Más! Community Theater

Using the "theater of the oppressed" model (Boal, 2000), where community theater productions are developed by community members and stopped at crucial points for the audience to decide upon the next course of action, community partners co-created a script addressing unhealthy relationships. Throughout the process, the script/stories were written and rewritten to ensure that there was accuracy so that when the community members acted out stories on-stage, the audience would be empowered and inclined to participate and learn through the process of participation. When asked if the Teatro No Mas! (No More! Theater) helped participants in the community theater, the actors who were also the co-creators, reported that they learned more about what the issue looks like in their community, and how they can intervene and help others. By enacting situations of violence as it could happen in their own communities, they felt more aware and more prepared to prevent or respond. As is the case with the fotonovelas and games, community theater creates an opportunity to respond to a fictional scenario based on real stories, about which people can comment and also reflect on their own experiences. One Teatro No Mas! participant said they were "able to speak out loud about a life changing domestic incident that happened to me as a child. It helped me learn that I am stronger emotionally than I thought" (Concha and Azevedo, 2017). Participants also reported that working on the script with others "allows me the opportunity to express my thoughts and opinions on the subject," and made them engage more with their communities by "getting to know more people and learning their opinions" about how to address domestic violence (Concha and Azevedo, 2017).

DISCUSSION

Historically, CBPR has been undergirded by an inequitable power structure between researchers and the communities being studied (Palmer-Wackerly et al., 2020). Using CBPR without taking these power structures into account could perpetuate these disparities in way that could harm the communities. While CBPR has been successfully used in health communication, these examples illustrate that CBPR is especially effective in co-creating story-based health interventions for minoritized communities. Despite the positive outcomes, the challenges of achieving true engagement and trust should not be underestimated. Due to space limitations, we did not detail the logistics of engaging community partners and building trust, to achieve the research and communication goals. However, it is important to emphasize that these processes take time, and a mindset that values community members as experts and equal partners. Despite and perhaps because of - the time that it takes, CBPR is a highly effective method of gaining authentic feedback and ensuring that messaging is relevant and beneficial to the target population, particularly as it relates to health disparities (Chandanabhumma et al., 2020).

The examples detailed and their outcomes show that using CBPR methods were key to creating content that resonated with the community and allowed the creators to take advantage of visual forms of communication and storytelling. Thus, creating an environment of transference wherein the situations depicted were truly representative of "real life" people and situations. This representation empowered the communities to engage in a breaking down of barriers, an ability to more easily relate to and discuss the situations depicted and see themselves or others that they know in the stories. Stigma often relies on a sort of "othering" where "these things don't happen here" or that "it only happens to those people." By centering representative role models as the protagonists of the fotonovelas and radionovelas, a culture of awareness, empathy, and positive health behaviors could be cultivated, and the power reverts back to the community to create the methods of change (Blumenthal, 2011).

What is most telling about the effectiveness of the CBPR model and its use in engaging health communication, are the secondary takeaways that emerged during the process. Had the community not been as engaged and empowered to fully participate as partners in the process, these additional themes would be less likely to be uncovered, highlighted and added to the discussion. Of particular note, are the insights related to the format of radionovelas co-created with partners from the Haitian American community, and the need for open-ended outcomes in the sexual assault bystander game. Without the participation of those community members, the opportunity to connect more fully with the target audience would have been lost. Similarly, a key takeaway from the intimate partner violence fotonovelas was the emotional, cultural and social stressors faced by victims/survivors of violence. Incorporating these elements into the co-created stories led to a familiarity with the experiences, demonstrating empathy and awareness of situations that spoke to them directly.

CONCLUSIONS

Building upon the research of Dutta (2015), Nguyen et al. (2021), and Brush et al. (2020), this perspective piece contributes to the conversation about CBPR and health communication to reduce health disparities. A priority of community-based participatory research in health communication is to create content and deliver services that are fully cognizant and respectful of the cultural diversity, expert knowledge, and collective narratives of the community being served. The examples provided illustrate that meaningful, authentic community co-creation of health promotion content is feasible, and effective for the development of story, game-, and theater-based interventions. It is clear that community-led co-creation of health promotion content is transformative in its ability to make messages meaningful and directly applicable. Without community partnerships, health communication, and particularly health communication methods such as those detailed, could completely miss its mark through its inability to center the community and its members in the goals, approaches, processes, and narratives.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Mental Health Fotonovelas and Radionovelas: Approved through the Institutional Review Board at Florida International University. Por Nuestras Calles: Approved through the Institutional Review Board at University of Miami. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

PJ wrote the first draft of the manuscript. MV and PJ rewrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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