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Intentional Storytelling to Sustain Low-cost/Free Breast Cancer Services: A Latina Example of Community-driven Advocacy

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Abstract

Background: Community-based public health advocacy efforts are crucial to sustaining the low-cost/free breast cancer services that support underserved populations.

Objectives: We introduce two ways in which narrative theory may be a useful tool for developing advocacy materials and provide an example, using a community–academic partnership to promote Latina breast health in Chicago, Illinois.

Methods: Community and academic partners 1) engaged 25 Spanish-speaking Latinas in an advocacy workshop, 2) leveraged narrative theory to develop multi-media advocacy materials, and 3) disseminated materials to policymakers.

Lessons Learned: Our project highlights 1) that narrative theory may be useful to describe how Latinas engage policymakers in relation to their needs and cultural norms, 2) the importance of flexibility and offering community members multiple options to engage policymakers, and 3) the importance of leveraging partners' complementary strengths.

Conclusions: Narrative theory may be a useful tool for developing advocacy materials in community–academic partnerships.

Keywords

Breast neoplasms, health disparities, community health partnerships, community health research, Midwestern United States

Latinas' poor breast cancer (BC) outcomes¹⁻³ result from a lack of timely, guideline-concordant care uptake⁴⁻⁶ and partially reflect Latinas' greater exposure to poverty, lack of insurance, and limited English language proficiency.⁷⁻¹⁰ Low-cost/free BC services have been developed to address these problems.¹¹⁻¹⁵ A central advocacy strategy to support these services is meaningfully engaging past recipients in storytelling,¹⁶⁻¹⁹ including providing testimonials to policymakers from underserved community members through community-based participatory research (CBPR).²⁰⁻²⁵ In CBPR, community and academic partners work collaboratively to harness existing social capital, develop civic skills, and increase political self-esteem. This work empowers community members to act as storytellers for the area and the people community and academic partners serve.^{26,27} CBPR has been particularly important in policy development for health disparities by soliciting testimonials from populations that are disproportionately impacted by BC.^{23,28,29}

THE USEFULNESS OF NARRATIVE THEORY FOR CBPR-BASED ADVOCACY

A key challenge to using testimonials for policy change is enabling community members to tell their stories in a way that the story becomes resourceful to the listener (i.e., policymakers).^{30,31} Narrative theory may address this challenge because it provides a framework that systematically characterizes multiple sides of stories.³² There are three common story elements³³⁻³⁵: story of self, story of us, and story of now. A story of self communicates the narrator's values, goals, vulnerability, and choices.³⁶⁻³⁸ A story of us creates a sense of collective identity and communicates a community's shared values and collective experiences.³⁸ A story of now articulates specific strategies to address challenges.³⁷⁻³⁹ We provide two potential strategies in which narrative theory may be used to develop advocacy materials within the context of CBPR-based public health advocacy. Bidirectional engagement and in-depth discussions within community and academic partnerships are crucial to determining which strategy/combination of strategies is most helpful to achieve established goals.

First, narrative theory can be formally incorporated into advocacy training to teach persuasive messaging. Such training can focus on strategies that 1) align volunteers' testimonials with policymakers' interests (e.g., preferences for story of now),^{36,38,39} 2) convey how story elements persuade listeners (e.g., story of self and story of us leading to greater empathy),^{19,33,37} and 3) describe how story elements may be combined to produce targeted outcomes. A major benefit of this strategy is that the partnerships can maximize the incorporation of all community members' stories within advocacy materials that are subsequently used.

Second, narrative theory can be used as a tool to develop advocacy materials. In this process, volunteers are encouraged to share testimonials they believe are most important. Community and academic partners then conduct theory-driven analyses of testimonials to categorize how the three story elements (story of self, story of us, story of now) are represented. Decisions are jointly made by community and academic

partners to determine which story element, or combined elements, may be most important to include in advocacy materials. This process may be useful for characterizing how different story elements manifest across different communities. As well, this process can inform future quantitative studies that examine the relative prevalence of different story elements and their respective impacts on policy.

AN EXAMPLE: ADVOCATING FOR LATINA BREAST HEALTH IN CHICAGO, ILLINOIS

For the current manuscript, we exemplify the usefulness of narrative theory to develop advocacy materials. Specifically, we describe the process of implementing an advocacy workshop, evaluating resultant narratives, and disseminating information to policymakers in the context of a community–academic partnership to promote Latina breast health in Chicago, Illinois. We do not present the evaluation findings regarding the effectiveness of the advocacy workshop, which is part of a larger ongoing evaluation project. Nonetheless, this current manuscript offers important, relatively rare documentation regarding the development and dissemination of advocacy materials through a CBPR process.

Partners

En La Lucha a Sobrevivir (ELLAS) is an 8-year-old support group for Latina BC survivors within a local non-profit organization in West Chicago that leads bilingual health education workshops; navigates women to low-cost/free BC services offered throughout the city, county, and state; and leads BC-related civic engagement at city, county, and state levels.

Centro Comunitario Juan Diego (CCJD) is a 24-year-old non-profit organization in South Chicago whose staff leads bilingual health education workshops; navigates women to low-cost/free BC services offered throughout the city, county, and state; and actively participates in BC-related civic engagement at city and state levels.

DimeStore Films is a private video production company that has developed multi-media testimonial products for corporate and public sector clients for the past 8 years.

The University of Illinois Chicago (UIC) partners are well-known and emerging researchers in community–academic partnerships, BC equity efforts among Latinas, and community-driven health promotion (e.g., storytelling, train-the-trainer).

Partnership History

In 2015 and 2016, ELLAS, CCJD, and UIC began their collaboration through a National Institutes of Health–funded grant (K01CA193918).^{13,40} ELLAS and CCJD met the UIC lead (Molina) through introductions from members of the UIC Center for Clinical and Translational Science’s community engagement advisory board. They developed a successful National Institutes of Health–grant application to compare the effectiveness

of two approaches to promote screening mammography uptake among Latinas non-adherent to U.S. Preventive Services Task Force BC screening guidelines.⁴¹

Proposal Development and Project Design

In 2018, Molina (UIC) was invited to compete for a university-based fellowship for policy and civic engagement. Based on the relationships built through the National Institutes of Health–funded grant and the success of the partnership, Molina invited ELLAS and CCJD to collaborate on the fellowship project, which focused on developing and evaluating an advocacy workshop to support free/low-cost BC services offered throughout the city, county, and state. The application was successful, resulting in additional funds to pay ELLAS and CCJD partners' salaries and obtain material resources for the workshop. Table 1 depicts how each partner was involved in developing and implementing the workshop, analyzing testimonials, creating advocacy materials, and disseminating materials for the current project. All procedures described below were reviewed and approved by the UIC Institutional Review Board.

Workshop Development and Implementation

During January and February of 2019, ELLAS, CCJD, and UIC leaders developed the advocacy workshop content and procedures, which were based on ELLAS' past advocacy trainings with BC survivors and advocacy priorities identified through ELLAS and CCJD leaders' discussions with representatives associated with low-cost/free BC services offered throughout the city, county, and state.

During February and March of 2019, the team recruited women who had received low-cost/free BC services offered throughout the city, county, and state to participate in the advocacy workshop. ELLAS and CCJD first reviewed their community navigation databases for women who 1) identified as Latina, 2) were 40 years or older, and 3) had asked ELLAS or CCJD to be navigated to low-cost/free BC services offered throughout the city, county, and state. Staff called approximately 65 eligible women and described the workshop's three components, which are detailed below and in Table 2. Interested women received the time and location of the workshop and the phone numbers of ELLAS and CCJD leaders. Transportation was available for interested individuals.

In March 2019, our team (ELLAS, CCJD, UIC) led the approximately 4-hour advocacy workshop in Spanish within a community venue. All volunteers underwent the following three components of the workshop: 1) a multi-media presentation to introduce community members to available free/low-cost BC services offered throughout the city, county, and state as well as relevant information to identify which service they had previously used, 2) a multi-media presentation to introduce the various ways in which community members can engage policymakers, and 3) small group and individual activities to provide social support and maximize community members' willingness to participate in sharing their testimonials about BC with policymakers (Table 2). Group activities included discussions regarding what information to include in stories (e.g.,

“What about your BC experiences do you think is important for policymakers to know?”) and how to tell stories (letters, audio-recordings, videos). There were also optional role-playing activities for volunteers to practice their testimonials with each other. Individual activities included drafting, practicing, and completing written, audio-recorded, and video-recorded testimonials. Throughout the workshop, volunteers were made aware that 1) they could share whatever information that they felt comfortable disclosing, 2) they could choose whichever method to tell their story (letters, audio-recordings, video-recordings), 3) there was technical assistance available (e.g., writing letters for volunteers with limited literacy skills; handling audio/video recording equipment), and 4) they could stop participating and withdraw their materials anytime without any consequence. Finally, volunteers submitted the letters, audio-recordings, and video-recordings they wished to share.

Analysis of Testimonials

All verbatim transcriptions (audio-recordings, videos) and letters were partially de-identified by ELLAS (i.e., removal of volunteers’ names and identifying information), who stored Latinas’ stories. UIC staff translated letters and checked for accuracy. UIC staff used content analysis with inductive and deductive approaches to analyze data.^{42,43} For deductive codes, coders categorized stories by the three story elements (story of self, story of us, story of now).^{36–38} Volunteers’ testimonials were coded, such that specific texts were categorized by the three story elements. Thus, volunteers’ testimonials could incorporate more than one story element. Inductive codes that emerged from raw data were also applied. Two UIC coders independently read and coded each translated document and met weekly to ensure consistent interpretation/application of codes. Disagreement was resolved by discussing perspectives until consensus was achieved. Peer debriefing was held after initial coding was completed, wherein ELLAS, CCJD, and UIC leaders reviewed and contributed to subsequent coding, analyses, interpretation, and framing. Finally, Molina (UIC) analyzed similarities and differences in emergent themes by type of volunteer (e.g., BC survivor status) and type of storytelling (i.e., types of story elements across text, audio, and video testimonials). We did not quantify information regarding these data, given this analysis was not designed to enumerate associations. Providing percentages could have led to misleading counts for the identified themes.⁴⁴

Emergent Themes from Testimonials

All 25 volunteers identified as Latina, preferred Spanish as their primary language, and were at least 40 years old. Most women were Mexican/of Mexican descent. Five women were BC survivors. Women shared their stories using written letters ($n = 16$); audio-recordings ($n = 5$); combination of letters and audio ($n = 3$); and a letter with an audio-visual recording ($n = 1$). Table 3 provides illustrative quotes for each story element. Emergent themes did not vary appreciably by type of volunteer or type of

Table 1. Partners' Roles and Partnership Processes by Project Stage

Project Stage	Organizations: Roles	Community–Academic Partnership Processes
Proposal Development/ Project Design (2 weeks)	<p>ELLAS and CCJD</p> <ul style="list-style-type: none"> Consultation regarding responsive proposals that could be feasible within the time period, given existing resources/ assets Consultation to maximize inclusiveness of proposal Review of proposal <p>UIC</p> <ul style="list-style-type: none"> Development of proposal, based on ELLAS' and CCJD's recommendations 	<p>Meeting Frequency: Weekly</p> <p>Meeting attendees²: ELLAS-UIC, CCJD-UIC</p> <p>Meeting procedures</p> <ul style="list-style-type: none"> Group discussions regarding fellowship application and a responsive proposal design Disagreements resolved via prolonged discussion and collective decision making (e.g., plans to ensure ELLAS and CCJD engagement, despite travel and time barriers to meetings)
Workshop Development and Implementation (2 months)	<p>ELLAS and CCJD</p> <ul style="list-style-type: none"> Identification of service organizations and representatives who: 1) were partners/referral sites for ELLAS and CCJD clients and 2) would have knowledge regarding the diverse organizations' needs providing services Discussion with 2 service organizations and 3 directors of the 3 low-cost/free BC services throughout the city, county, and state to identify specific asks that service organizations need, which should be included in advocacy trainings (ELLAS only) Identification and recruitment of volunteers Lead on presentations (first workshop; ELLAS only) Facilitation of group and individual activities <p>UIC</p> <ul style="list-style-type: none"> Discussion with service organizations to identify specific asks Lead on presentations (second workshop) Facilitation of group and individual activities 	<p>Meeting Frequency: Twice a Month</p> <p>Meeting attendees: ELLAS-CCJD-UIC</p> <p>Meeting procedures</p> <ul style="list-style-type: none"> Group discussions regarding project design, based on service organization input (i.e., incorporating specific asks in the first workshop presentation), partners' experiences (e.g., available advocacy training materials/ protocols, priorities regarding constituent agency), and partners' preferred roles (e.g., leading presentations, facilitating groups) Disagreements resolved via prolonged discussion and collective decision making (e.g., multiple methods offered to allow for variation in community members' preferences)
Analysis of Testimonials (2 months)	<p>ELLAS and CCJD</p> <ul style="list-style-type: none"> Review of analyses, interpretation, and framing <p>UIC</p> <ul style="list-style-type: none"> Qualitative data management and analysis Review of analyses, interpretation, and framing 	<p>Meeting Frequency: Monthly</p> <p>Meeting attendees²: ELLAS-UIC, CCJD-UIC</p> <p>Meeting procedures</p> <ul style="list-style-type: none"> Group discussion regarding analyses, interpretation, and framing Disagreements resolved via prolonged discussion and compromises (e.g., sub-analyses to examine potential differences in message across types of volunteers)
Development of Advocacy Materials (2 months)	<p>ELLAS, CCJD, and UIC</p> <ul style="list-style-type: none"> Selection of stories Feedback on multi-media products Translation of stories (UIC only) <p>DimeStore Films</p> <ul style="list-style-type: none"> Creation of Multi-Media Products (initial, revised, and final products) 	<p>Meeting Frequency: Weekly</p> <p>Meeting attendees²: ELLAS-DimeStore-UIC, CCJD-DimeStore-UIC</p> <p>Meeting procedures</p> <ul style="list-style-type: none"> Group discussion to vote on testimonials and their order Disagreements resolved via prolonged discussion and compromises (e.g., shortening messages to fit within optimal 3- to 5-minute time frame of product) Summary of feedback to provide to DimeStore Films

Project Stage	Organizations: Roles	Community–Academic Partnership Processes
Engagement with Policymakers (2 months)	ELLAS and UIC Identification of relevant policymakers Delivery of electronic and physical materials Lead for scheduling/facilitating in-person meetings with policymakers Aggregate data collection (e.g., # of meetings, recommendations across meetings) UIC Development of English-based written materials (e.g., e-mails; introductory letters) Review and reporting of aggregate data	Meeting frequency: Weekly Meeting attendees ¹ : ELLAS-UIC, CCJD-UIC Meeting procedures Group discussion regarding assignment of roles based on resources (e.g., English fluency for written materials; existing relationships for scheduling meetings) Disagreements resolved via prolonged discussion and compromises (e.g., multiple routes to engage policymakers—e-mail and in-person)

BC = breast cancer.

¹ During certain project phases, ELLAS and CCJD were unable to attend the same meetings due to different schedules/time constraints (e.g., different days committed to meetings versus community service delivery). For these phases, ELLAS and CCJD offices were the meeting locations for ELLAS-UIC and CCJD-UIC meetings. Subsequently, each organization received a detailed summary of meetings they did not attend (i.e., ELLAS for CCJD-UIC, CCJD for ELLAS-UIC) via phone and provided necessary feedback. UIC summarized responses via e-mail and by subsequent conference phone meetings if there was disagreement for resolution.

² ELLAS-CCJD-UIC meetings were held in ELLAS or CCJD offices, wherein CCJD or ELLAS remotely attended by phone due to geographic/travel burden.

storytelling. However, BC survivors were slightly more likely to share their stories via audio- and video-based methods relative to other Latina community members who had received free/low-cost BC services offered throughout the city, county, and state.

Story of Self. Volunteers began their stories by 1) describing who they were (e.g., BC survivor), 2) sharing their perceived barriers to BC services uptake (e.g., insurance status) and how services addressed these barriers, 3) highlighting the quality of service (e.g., prompt service), and 4) describing their positive emotional responses to receiving BC services. BC survivors further appreciated how early detection services led to better treatment outcomes.

Story of Us. Some Latinas highlighted how these services were crucial for their communities, who experienced concentrated economic hardship and limited geographic access to healthcare. For example, volunteers described women in need within their personal networks and reported their active efforts in disseminating information to other women.

Story of Now. A few Latinas expressed gratitude to policymakers for existing free/low-cost BC services offered throughout the city, county, and state. They made respectful requests for continued support. Messages highlighted the collective need of underserved communities and, to a lesser extent, a call for policymakers to consider this cause in terms of their personal needs and motivations.

Development of Advocacy Materials

During April and May of 2019, team leaders from ELLAS, CCJD, and UIC reviewed and selected a subset of testimonials for multi-media products based on their

clarity and the emotional affect of storytellers. Testimonials did not include volunteers' names or identifying information. All BC survivors' stories were included in the final products. Final multi-media products, developed by DimeStore Films (HTN), showcased a heterogeneity of written and audio/video (approximately 3–5 minutes in length) testimonials. In line with narrative theory,^{33–35} products were designed such that story elements followed this order: story of self, story of us, and story of now.

Order	Facilitator (Organization)	Activity	Goals
1	Lucio (ELLAS)	Multi-media presentation on the available free/low-cost BC services offered throughout the city, county, and state: Participating clinics/hospitals Eligibility criteria (e.g., income and citizen requirements) and catchment area (city, county, state) Types of services offered (screening, diagnostic, treatment) Group activity to identify which service each woman engaged	To introduce community members to all available free/low-cost BC services and the importance of sustaining these services To provide community members with relevant information to identify which service they had previously used (e.g., via participating clinic)
2	Kling (UIC)	Multi-media presentation regarding Approaches for engaging policymakers (letters; calls; formal/informal in-person interactions; large/small groups) Community members' representatives at city, county, and state levels Other representatives involved in decisions regarding free/low-cost BC screening services	To describe the various ways in which community members can engage policymakers To introduce community members to policymakers whom they would engage as part of the workshop
3	Arroyo, Medina (ELLAS), Coronado, Garcia (CCJD), San Miguel, Torres (UIC)	Small group activities Introductions/Ice breakers related to breast health Decisions regarding preferred storytelling method (letters, audio testimonials, video equipment) Practicing testimonials (audio, visual) with other community members (based on community members' preferences) Individual activities with facilitators Drafting testimonials via index cards/bullet points in response to broad prompts (e.g., "What about your BC experiences do you think is important for policymakers to know?") Reviewing draft and practicing testimonials with facilitators (based on community members' preferences) Receiving literacy/writing support (based on community members' preferences) Completing final drafts of testimonials with facilitators' technical assistance (e.g., handling audio/video equipment, based on community members' preferences)	To provide social support and a sense of community to facilitate the process of storytelling To maximize community members' willingness to participate in sharing their testimonials about BC with policymakers via written letters, audio recordings, and video recordings (e.g., open-ended prompts; multiple methods and resources to address different needs and preferences such as limited writing ability, desire for anonymity)

BC = Breast cancer.

Table 3. Narrative Theory-driven Themes and Exemplar Quotes from Latinas' BC Services Testimonials

Theme	Exemplar Quotes
Story of Self	
Identities/Connection with BC	<p>"It was so terrible, so terrible for me to see my daughter have cancer . . . I didn't know about its magnitude!"</p> <p>"I am a resident of [geographic area], and I am a Mexican immigrant. I moved to this country 25 years ago."</p> <p>"I am an immigrant and cancer survivor."</p>
Barriers to BC Screening	
Access to health insurance barriers	<p>"I stopped getting mammograms 6 years ago because of my health insurance. It is the type of health insurance that has a very high deductible."</p> <p>"The barrier that kept me from getting a mammogram was not having health insurance."</p>
Transportation	<p>"Today, I write my testimony of having barriers [such as] not having transportation from my neighborhood to the other neighborhood where they offered mammogram services."</p>
Information about how low-cost/free BC services addressed barriers	<p>"They even did me the favor of providing me with transportation because at that time wasn't working and didn't even have health insurance, and didn't have money, and so they did that favor for me."</p> <p>"They helped me with the barriers of not having enough resources, not having health insurance nor transportation, and not knowing English."</p>
Promptness of low-cost/free BC services	<p>"The wait time is short; they tend to me quickly."</p> <p>"They helped me. They quickly attended [to] me."</p> <p>"[It was] Fast. They attended to me in the same week [that they scheduled me]."</p>
Positive emotional consequences	<p>"Today, I feel happy that I was able to get my mammogram."</p> <p>"My worry of [possibly] having or not having [cancer] went away."</p> <p>"Thank God everything went well. That helped me feel so much better because I didn't have to worry about whether my health was fine or whether it wasn't. Nor did I feel bad for not going to get my mammograms."</p>
Story of Us	
Low-cost/free BC services as a solution to collective hardship and challenges	<p>"It is very good here, the support they provide is very important, that way we [Latinas] are able to feel more confident in knowing that there are resources and people that are willing to help . . . I know a lot of women have benefited from these programs that provide free mammograms. And for me, these programs are very important to my community."</p> <p>"All of the people that worked in this program are marvelous in every aspect . . . I am very grateful to have found such amazing people, and I hope that they continue to help other people so that we could eliminate breast cancer and not have to suffer from it."</p> <p>"Because when we don't have health insurance, we tell ourselves, 'What are we going to do? I don't have a way of paying.' So, if we inform ourselves of the resources available, and if we also share information with other women who are going through the same things we are going through and even may also have cancer problems, more people will be motivated to seek out those resources."</p>
Story of Now	
Appreciation of existing low-cost/free BC services	<p>"Thank you for mammograms...and every person that helped."</p> <p>"Thank you for creating so many programs for women and for worrying about our health, and above all else, thank you for the help with our English, transportation, and health insurance. I hope that you can continue to help a lot of other women that live in [Geographic Area]."</p>
Advocacy for the continued support of low-cost/free BC services	<p>"To those who are the politicians, please place extra emphasis on this cause because we need a lot of help and support. Just like when you need our vote, we also need your help at the same time. Remember that you also have families as well."</p> <p>"My ask is that we keep supporting [these low-cost/free BC services] with its financial support because we are many women in my same situation, and we do not have resources."</p> <p>"It is very important to continue supporting these programs. It is sad to see people getting sick due to them not having health insurance and not having access to these programs that are so important. Please keep supporting these programs!"</p>

BC = breast cancer.

Engagement with Policymakers

During May and June of 2019, ELLAS and CCJD delivered an introductory letter and multi-media products via e-mail to 24 representatives who: 1) served Latinas' residential communities ($n = 12$), 2) led committees and caucuses pertaining to health ($n = 3$), 3) led committees and caucuses pertaining to Latino communities ($n = 2$), and/or 4) led committees or served in roles associated with budgetary decisions ($n = 7$). Next, ELLAS and CCJD distributed physical copies of materials and successfully scheduled in-person group meetings with 11 representatives. Thirteen policymakers did not respond to the team. Volunteers participated in 8 of 11 meetings. During meetings, ELLAS and CCJD leaders showed policymakers multi-media products. When asked for their responses/reactions to products by ELLAS and CCJD leaders, policymakers responded favorably, restating their commitment to continued support. Additionally, they suggested that advocates 1) provide specific asks regarding the BC services (e.g., increased funding/sustained funding) and 2) participate in budgetary planning.

LESSONS LEARNED

This project introduced two ways narrative theory may be useful for developing advocacy materials and offered an example via a community–academic partnership to promote Latina breast health in Chicago, Illinois. Below, we describe lessons learned that may inform future efforts to promote health equity through policy advocacy.

Lesson #1: Narrative Theory May Be Useful to Understand How Latinos Advocate

Emergent themes highlighted the usefulness of narrative theory for understanding Latino advocacy. Testimonials with story of self elements highlighted well-known barriers to BC services and clarified the acceptability of existing strategies to address them (e.g., prompt service).^{36,38} Testimonials with story of us elements elucidated how Latino norms may influence their description of important services, including community members' proactive efforts to disseminate information about available resources (e.g., *altruismo*, *personalismo*).⁴⁵ Finally, testimonials with story of now provided preliminary data describing which norms may influence how Latino community members make requests to policymakers (e.g., requests with gratitude, *respeto*; calls to invoke policymakers' *altruismo*).⁴⁵

Lesson #2: The Importance of Flexibility and Options in Advocacy Efforts

One of the key tenets of CBPR is to foster co-learning and capacity building by introducing feedback and flexibility/compromise into the process of engagement.^{26,46} Our project showcases the importance of flexibility and responsiveness to volunteers' diverse needs and experiences. We strove to maximize community members' agency as storytellers, including engaging a wide range of community members, offering different storytelling methods, and emphasizing that resources were available (e.g., technical assistance to address literacy challenges). This approach may be more

effective at promoting participation in advocacy efforts and civic engagement at large than more structured approaches.

Lesson #3: The Importance of Using Partners' Strengths and Collectively Addressing Challenges in CBPR-based Advocacy

We were able to achieve our goals because of the intentional integration of partners' diverse assets, skills, and experiences, including community partners' strengths in community-based BC promotion (ELLAS, CCJD), advocacy (ELLAS), and multi-media products (DimeStore) as well as academic partners' strengths in theory and research (UIC). This integration was built on several CBPR principles, including building on strengths and resources within the community (e.g., organizations' existing ties to community and advocacy) and promoting collaborative and equitable partnerships via cyclical and integrative processes.

Our partnership further highlighted the importance of CBPR principles in navigating emergent challenges and disagreements described in Table 1. For example, meetings occurred in ELLAS and CCJD offices; however, agencies serve geographically distinct Latino communities, resulting in a significant geographic burden. Simultaneously, ELLAS and CCJD requested separate meetings for most of the project due to competing demands (e.g., other health projects). We developed a meeting plan through collective decision-making, which allowed for iterative feedback across separate meetings that would enable participation based on ELLAS and CCJD leaders' different schedules.

Project Limitations

This project had several limitations. First, given the nature of this work (i.e., not research), detailed demographic and clinic data were not collected for workshop volunteers. Relatedly, no baseline data were collected, including volunteers' past experiences with civic engagement. Second, except for the 11 (of 24) representatives we visited in person, there was no way to verify that all the legislators listened to the stories, how they listened, or how the stories specifically affected their subsequent decision-making behaviors. Third, due to community partners' geographic and time constraints, the academic partner (UIC) was the only partner present at all meetings throughout the project's time. Relatedly, while our analyses did incorporate community partners' input during the peer debriefing phase, they did not directly analyze the data due to community partners' time constraints. These aspects of our project may have unintentionally shifted power dynamics, such that the academic partner had more power. Indeed, an important element of CBPR is co-learning, wherein partners gain skills and learn from one another. Unfortunately, due to contextual circumstances (e.g., partners' time constraints, limited funding), the opportunity to co-learn was limited.

Future Directions

Our project provided a promising example regarding the usefulness of incorporating narrative theory into CBPR-based advocacy efforts. Further, there are several important next steps for future theory-driven research and advocacy efforts.

1. Future work should explore and compare the different benefits and advantages of directly instilling narrative theory into advocacy trainings versus using narrative theory to guide the development of advocacy materials.
2. Future work should quantify the relative prevalence of story elements. For example, future studies that incorporate narrative theory into advocacy elements could examine which of the story elements are subsequently used by research participants.
3. Future work should quantify which story elements (or a combination thereof) are most persuasive to policymakers and most effective for policy change. Such work should be guided by extant communication and narrative theories. Regarding methods, future studies may consider pre-post assessments of quantitative metrics (e.g., funding for services) to evaluate the effectiveness of different advocacy efforts.
4. Future work is warranted to examine the usefulness of narrative theory to inform advocacy among other Latino groups (e.g., English-speaking Latinos, younger Latinos) and other populations. Such work, guided by sociocultural theories, may be particularly useful to clarify cultural differences in which persuasive messages are used and to compare the effects of different advocacy efforts on policy change.

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