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Community Engagement as a Process and an Outcome of Developing Culturally Grounded Health Communication Interventions: An Example from the DECIDE Project

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Abstract

Community engagement is a process often used in developing effective health communication interventions, especially in traditionally underserved cultural contexts. While the potentially positive outcomes of community engagement are well established, the communication processes that result in engagement with cultural groups are less apparent. The focus on the outcomes of engagement at the expense of describing how engagement occurs makes it difficult for methods to be improved upon and replicated by future studies. The purpose of the current manuscript is to illustrate the process of achieving community engagement through the development of a culturally grounded health communication intervention. We offer practical suggestions for implementing community engagement principles, as well as the benefits and challenges inherent in this approach to research. Key points are illustrated using examples from the DECIDE Project, a culturally grounded intervention for improving communication about clinical trials in the medically underserved Appalachian region.

Keywords: Cultural grounding, Community engagement, Rural Appalachia, Health interventions, Health disparities

Introduction

Community engagement (CE) is a process often used in developing effective health, education, and community psychology interventions, especially in traditionally underserved cultural contexts (Ozer et al. 2013; Trickett 2011). Theoretically and practically, there is strong support for engaging communities in interventions. First, community members are more likely to participate and remain in the research project when their needs are directly addressed with resources they might not otherwise have (Ozer et al. 2013). Second, individuals who are actively involved in developing interventions are predicted to be more motivated to pay attention to messages in the environment, consider them carefully, and take appropriate action (Braverman 2008; Greene 2013). Finally, in some cases, CE might also encourage individuals to share the intervention message with members of their social network, adopt a leadership role such as joining a health-related community coalition, or help facilitate organizational change (Roussos and Fawcett 2000).

Although CE principles and methods are well-established in the field of community psychology, it can be challenging to operationalize CE in research practice (Trickett et al. 2011). In all CE projects, community partners are involved in all phases of research for the purposes of achieving mutual benefit and disseminating findings among stakeholders; however, the degree to which the community is involved and engaged in key roles may differ (Smith et al. 2012). At one end of the "engagement" continuum is community-based participatory research (CBPR) (Hood et al. 2010), which is an intense collaboration between community stakeholders and academics in which power and decision-making are shared throughout the research process to change internal structures; build community capacity; and in a health context,

reduce health disparities (Israel et al. 2010; Israel et al. 1998; Smith et al. 2012). On the other end of the spectrum, communities are asked to participate in a study primarily conceptualized and designed by academic researchers with minimal input from community members (Hood et al. 2010). In the middle of the spectrum, communities are engaged in all phases of research for the purposes of achieving mutual benefit and disseminating findings among stakeholders; however, the degree to which the community is involved and engaged in key roles may differ (Smith et al. 2012). It is important to recognize that more participation is not always better; some community partners may not have the time, interest, or expertise to participate as equal partners in every stage of the research process (Hood et al. 2010). Within community psychology, cultural processes have long been central to CE interventions, especially CPBR (Trickett 2011). Community psychology researchers have primarily focused on the local cultures that have existed within communities (e.g., ethnic groups, urban populations, youth) (Andrews et al. 2012; Jacquez et al. 2013; Ozer et al. 2013), but have also begun to consider the culture of scientific research and the potentially conflicting goals and values that exist between the two (Trickett 2011). For example, interventions designed to make everyday activities, such as boiling water or engaging in sexual activity, safer may conflict with communities' core cultural values that render the interventions meaningless in certain contexts (Trickett 2011). Thus, within CE and CPBR, recognizing and incorporating cultural attitudes, beliefs, norms, values, and assumptions of all involved partners are critical to the success of community engagement (Trickett 2011).

While the positive outcomes of incorporating cultural processes in CE and CBPR are well-established within community psychology, the *communicative* processes that result in cultural community engagement are less apparent (Chen et al. 2010; Schensul and Trickett 2009; Viswanathan et al. 2004). For example, Trickett (2011) discusses the constant, long-term "struggle to make local culture central to our community intervention work" (p. 65). One way to address this challenge is to focus more attention on the theorizing of cultural engagement processes (e.g., choice, local practices, multiculturalism) during community interventions (Trickett 2011). We add to the current work in community psychology through the use of one such theoretical framework: the principle of cultural grounding (PCG), which theorizes the symbiotic relationship between developing culturally sensitive communication interventions and cultivating community engagement (Hecht and Krieger 2006).

The purpose of the current manuscript is to augment the community psychology literature on CE by using PCG to illustrate the specific communicative processes through which engagement occurs and how these processes influence outcomes using the development of a clinical trials intervention in a rural, Appalachian cultural context. Because the insights of community members are commonly enlisted in CE research in order to create interventions that are sensitive to the core values and identities of the audiences, a PCG perspective is a "difference of degree" because it privileges how identities are communicated, the role of narratives in sense-making, and styles of expression (Colby et al. 2013, p. 193). In doing so, the current manuscript answers Trickett's (2011) call for improving CE intervention research with diverse cultural groups by: (1) further documenting methods and process roles between research partners, which are useful for theory development in the engagement of cultural groups; (2) privileging the community cultural goal of "choice" over the scientific cultural goal of "change" (p. 65); (3) attempting to acknowledge the multicultural diversity within cultural groups; and (4) explicating processes which encourage the next generation of scholars to tackle the challenges and reap the rewards of community-involved research with cultural groups.

Specifically, the current manuscript illustrates the processes involved in developing a culturally grounded health communication intervention among an underserved, rural Appalachian population. We review literature from both community psychology and PCG to illustrate how the micro processes associated with cultural message development fit within the macro processes of CE and CBPR. We explicate these ideas with examples drawn from the DECIDE (Determinants of Clinical Decision-Making) Project, a culturally grounded intervention for improving communication about cancer clinical trials (CTs) in the Appalachian region. Finally, we conclude by discussing the implications of the practice of CE for advancing theoretical approaches to culturally grounded message design.

Community Engagement

The Centers for Disease Control and Prevention (1997) defines CE as the process through which "groups of people affiliated by geographic proximity, special interest, or similar situations" work collaboratively to improve wellbeing among and through these groups. Engagement can be conceptualized as a continuum consisting of five stages: outreach, consult, involve, collaborate, and shared leadership (CTSAC 2011). CE has been especially useful when considering the cultural influence on health. To implement behavior change, meanings must be understood and shared when talking about issues that influence health (Andrulis and Brach 2007; CTSAC 2011). For the DECIDE project, the first four stages were central to the success of the project, and we have potential to reach

the fifth stage, shared leadership, after piloting the intervention and assessing its feasibility and effectiveness. Through this framework, we illustrate how PCG can be incorporated into any form of engagement to enhance the focus on cultural norms and communication preferences.

Trickett (2011) suggests that academic researchers begin with "a focus on communities, not programs" (p. 65). The idea for the current study originated while the principal investigator (PI) was conducting another research project on social influence in the healthcare provider-relationship in rural Appalachian areas of Pennsylvania (Krieger et al. 2011; Krieger 2013). Various stakeholders in the community (e.g., community coalition members, cancer patients, healthcare providers) suggested a broader focus on improving both clinical and family communication about cancer treatment decisions, especially clinical trials. The PI approached academic and community partners in another region of the Appalachia Community Cancer Network (Ohio) and they confirmed an interest and need for improved communication about cancer clinical trials in Ohio's Appalachian region. The PI then began to work more closely with Ohio's regional ACCN office to build research partnership with health facilities in Ohio. These research partners then helped us create the materials through feedback and formative interviews. While the Ohio community partners were integral to the project because they assisted in the development of the intervention, the health care providers had limited time to devote to the study's direction and aims. Instead, they were instrumental in providing logistical assistance (e.g., scheduling of focus groups), information (e.g., consent forms, patient lists), and feedback on materials. Although CE in health communication interventions is important for the facilitation of research, it can also achieve theoretical goals of grounding the intervention in the salient identities of the target audience, an idea articulated by Hecht and colleagues as the principle of cultural grounding (Hecht and Krieger 2006; Hecht and Lee 2008).

The Principle of Cultural Grounding

The PCG has its theoretical roots in concepts such as cultural sensitivity and communication competence (see Hecht and Krieger 2006 for a review). At its core, cultural sensitivity refers to adapting communication practices for the purposes of enhancing communication with individuals from diverse cultural backgrounds, such as different norms, beliefs, values, expressions, and meanings (Kreuter et al. 2003). Resnicow et al. (1999) described cultural sensitivity as adhering to both obvious cultural features (e.g., people, food, language) and deeper cultural values and meanings (e.g., significance of beliefs and traditions). Building on this concept, Kreuter et al.

(2003) provided five strategies for effectively implementing cultural sensitivity in health interventions as ways to increase the acceptance of health messages among cultural groups: (1) peripheral strategies (e.g., obvious cultural features) to increase familiarity of the materials; (2) evidential strategies (e.g., data) to increase awareness of the health issue; (3) linguistic strategies (e.g. language) to communicate with words and meanings commonly understood; (4) constituent-involving strategies (e.g., experience of group members) to gain insight into cultural values; and (5) sociocultural strategies (e.g., in-depth understanding of cultural practices) to ensure that the intervention is meaningful to group members. These concepts focus on creating health messages that are informed by and therefore responsive to the values and beliefs of a particular culture (Resnicow et al. 2002).

Building on this literature, PCG has been offered as a theoretical approach to increase the effectiveness of cultural adaptation processes (Hecht and Krieger 2006). The challenge is to identify the 'cultural' practices as defined by the participants. As Colby et al. (2013) discuss, this concept is similar to cultural sensitivity in that it strives to match its language and meaning to the cultural group, but it differs in that group members are active, central participants in the design and production of the new health messages, thereby grounding the message design process in the cultural groups of the members. Researchers argue that members will be more likely to adhere to health messages because of "increased identification, liking, and perceptions of realism" (p. 194). As a result, PCG employs the symbolic representations, norms, and values of cultural identity groups to construct and communicate health messages that reflect members of the culture (Hecht and Lee 2008). Unlike many health campaigns, which often modify universal messages to 'fit' other cultures and might invalidate the experiences of traditionally underserved populations, cultural grounding engages the target audience by calling upon them to articulate their own meaning, codes, and identity (Hecht and Lee 2008). These culture-centered approaches emphasize the need to understand how participants articulate health by engaging in dialogue and mutual understanding, and stress the importance of addressing social, cultural, and environmental factors beyond a biomedical model (Dutta and Basu 2008; Thomas et al. 2004).

Principle of cultural grounding will not necessarily result in a culturally specific message, however. The messages derived from PCG reflect the "lived" reality of the population. If the lived reality of the target population is multicultural (e.g., range of ethnic and cultural backgrounds) then a multicultural message would emerge from the grounding process and be most effective in achieving behavioral outcomes (Hecht et al. 2003). One issue with targeted cultural messages is their limited

generalizability to an entire culture. The challenge then becomes identifying a cultural grouping that is broad enough to be practical but will still be seen a "local." Previous work suggests that multiculturalism or inclusion is effective when the issue is race or ethnicity (Hecht and Krieger 2006). However, there may be differences in a number of other areas that might define culture, including geographic region (Cohen 2009; Tebes 2010). Testing of the effectiveness of both targeted (culturally and geographically specific) and multicultural interventions will continue to advance a culturally relevant approach in health messaging.

In sum, PCG is particularly important because it is one way to address some of the criticisms of the dominant model of health promotion and behavioral change, which has largely drawn upon a Western-based individualistic conception of health risk while ignoring cultural and geographical context (Airhihenbuwa 1995; Lupton 1994). Thus, PCG is one theoretical and methodological mechanism through which CE (and CBPR) is accomplished (Hecht and Krieger 2006). Grounded messages require explicitly engaging members of the target audience to facilitate understanding of the cultural groups to understand the historical, social, psychological, and environmental variables, which influence the targeted health behavior (Colby et al. 2013). Our aim in the current project was to create a culturally grounded intervention about cancer clinical trials (CTs) in Ohio's rural Appalachian region. To accomplish this goal, we argue that interventions in rural Appalachia must be grounded in rural culture as well as the local community culture to increase informed decision-making about cancer CTs.

Health and Rural Culture

The Appalachia region, which includes 420 counties in 13 states along the Appalachian Mountain Range stretching from New York to Mississippi, is designated as medically underserved due to the high burden of disease among its inhabitants relative to the general population. It is important to investigate health disparities in the traditional sense of racial or ethnic groups but also broadly to include SES, urban or rural lifestyles, and geographic location. Appalachian areas where economic disadvantage has been most persistent over time are those characterized by low economic diversification, low employment in professional services, and low educational attainment rates (Wood 2005). Poor health outcomes have also been linked to socioeconomic disadvantages in these struggling areas (Braveman 2006; Schulz and Northridge 2004). Across the Appalachian region, recent studies have identified elevated morbidity and mortality rates for a variety of chronic conditions, such as diabetes, heart disease,

and cancer (Fisher et al. 2012; Hendryx and Zullig 2009; Serrano et al. 2007). The problems are so severe and persistent that the National Institutes of Health (NIH) has included Appalachia among its target priorities for the reduction and elimination of health disparities (Zerhouni and Ruffin 2002).

One important health inequity affecting this region is the significantly higher rate of cancer mortality (Huang et al. 2002). Appalachian states have a 7 % higher mortality rate for all cancers than non-Appalachian states. Within these Appalachian states, Appalachian counties have a 5 % higher mortality rate for all cancers than non-Appalachian counties (Blackley et al. 2011). Not only are rural Appalachians more likely to die from cancer, they are also less likely to participate in cancer CTs that provide access to state-of-science treatment (Friedrich 2002). Without adequate representation of rural Appalachians (as well as other medically underserved populations) in CTs, health inequities will continue to exist among various social groups and minimize the extent to which CT results can be generalized to the full range of people suffering from cancer (Di Maio and Perrone 2003).

Despite efforts to eradicate health disparities in rural populations, CT enrollment in these groups is sparse. Individuals living in rural areas are much less likely to enroll in a CT than their urban counterparts (Baquet et al. 2006). Given that CTs represent the state-of-science in medical treatment, this rural–urban disparity means that rural residents are receiving a lower quality of cancer care than other Americans. Low cancer CT enrollment in rural populations may be attributed to economic barriers (e.g., expense of examinations, time lost from work, distance traveled, childcare), personal barriers (e.g., lack of trust, problems with consent forms, unknown benefits, lack of interest, desire for other treatment), and provider barriers (e.g., discouragement from oncologist/family doctor, time constraints) (Lara et al. 2001; Paskett et al. 2002; Virani et al. 2011).

Another reason given for the lack of participation in CTs among rural populations is a lack of culturally appropriate communication to address patient concerns (Baquet et al. 2006). To address this inequity, CT information must be adapted to rural populations to reflect the unique culture of the region (Krieger et al. 2011; Krieger 2013; Colby et al. 2013; Ndiaye et al. 2008). Using a culturally sensitive and centered approach in the development of health interventions has been suggested in response to criticism that public health interventions have failed to sufficiently address health disparities (Dutta 2007). Thus, the current paper seeks to reduce barriers to CT enrollment by creating more culturally appropriate communication about CTs within Ohio's rural Appalachian region while also incorporating attributes of local identity when appropriate (Trickett 1996). The following sections give an overview

of our project and describe the process and outcomes through which we created a culturally grounded CTs intervention in Ohio's rural Appalachian region.

Project Background

The DECIDE (Determinants of Clinical Treatment Decisions) Project is a 2-year study funded by the National Cancer Institute, situated in the 32 counties designated as the Ohio Appalachian region. In order to reduce barriers to cancer CT enrollment among rural Appalachian patients, the DECIDE Project sought to create an intervention that grounded CT information in the cultural values, norms, and beliefs that were important to patients and their family members. To accomplish this goal, the project consisted of two creation phases: (1) formative interviews with cancer patients and their families, and (2) input and feedback from an intervention development group consisting of diverse representatives from the cultural community (e.g., doctors, nurses, and patients and their spouses). Considering the process of this study within the theoretical context of cultural grounding allows us to identify similar elements within a larger cultural group (e.g., rural culture) while also targeting patients at specific hospital sites and counties. Below, we describe the challenges and lessons learned (see Table 1) in creating a culturally grounded health communication intervention.

Meeting the Challenges of Community Engagement in Intervention Development

The following section describes our process in creating a culturally grounded intervention within a population that both experiences significant health disparities and is difficult to recruit. A defining feature of PCG is that group members are central to the design and production of messages. We outline how each of the first four stages of CE (i.e., outreach, consult, involve, and collaborate) contributed to the process of involving community members in the design and production of a clinical trials intervention (Clinical and Translational Science Awards Consortium 2011). Within each stage, we describe our methods (e.g., recruitment procedures) and results (e.g., challenges and lessons learned).

Outreach

The initial stage of engagement includes sharing information with the community and establishing communication channels between the community and researchers (Clinical and Translational Science Awards Consortium 2011). To access Appalachian patients for our project, we

Table 1. Summary of lessons learned from the DECIDE project

Stages of community engagement	Lessons learned
Outreach	Establishing reciprocity and trust with community partners is crucial.
	Creating initial partnerships is time consuming and should not be underestimated.
Consult	Creating individualized recruitment protocols based on clinic preference are helpful.
	Becoming familiar with each clinic's record-keeping reduces time and error.
Involve	Using social cues that emphasize the local focus of the research, such as a local area code and regional style of dress.
	Being flexible in place and time of interviews is needed.
	Establishing rapport in this population may be difficult due to barriers of researcher identity and the concept of cultural "otherness".
Collaborate	Using repetition and "real people" in materials enhances the credibility and trustworthiness of the research project.
	Tailoring materials that match the population's literacy levels increases interest in and comprehension of the research results.
	Encouraging family and friends to review the materials with the participant may help reduce reluctance to participate and facilitate conversation with the researchers.

sought to locate them through the clinics where they were receiving treatment. This effort included establishing relationships with four cancer clinics in Appalachian Ohio and our university's comprehensive cancer center (CCC), where Appalachian patients also receive cancer treatment.

The first step in gaining access to cancer clinics was to contact the program director at the CCC and the executive director of the Columbus Community Clinical Oncology Program (Columbus CCOP), a 25-year-old organization whose mission it is to support cancer CT programs in local communities. The study's principal investigator (Author) met with both of them to explain the purpose of the study and the need to recruit patients at as many clinic locations as possible. The university-approved IRB protocol and study summary were sent to CCOP for review and an Ohio cancer liaison physician affiliated with Columbus CCOP said that he would inform local hospitals about the project. The Columbus CCOP sent the

study summary to four regional cancer center liaisons, who wanted to speak to their medical directors in the Oncology Department before agreeing to participate. A relationship between the researchers and the CCC already existed, and the CCC agreed to send us the names of those patients who enrolled in a CT.

Challenges and Lessons Learned

Two main challenges were present in the outreach phase: (1) establishing trust with partners; and (2) length of time to create partnerships. When the PI first reached out to the Columbus CCOP, the executive director was initially wary of participating in the project due to previous experiences with academic researchers. Early in the process, the PI met with the executive director several times to understand what those previous experiences were and discuss strategies for ensuring a productive partnership in the current project. An important part of addressing organizational culture and developing community trust was working with an organizational and community gatekeeper to establish shared expectations about how community members could expect to benefit from the proposed project and how their effort and goals would be recognized. In these meetings, we collaboratively identified a number of ways the community could benefit from participation in the proposed project. One was immediate access to the results of the study, via a report to the CCOP organization and the community clinics once data collection was complete. Additionally, organizations that recruited patients who participated in the study would receive credit toward their Ohio Commission on Cancer (COC) Accreditation. Finally, patients and HCPs wanted to assist in the effort of improving communication around clinical trials to offer the best possible cancer care to future patients, reduce all possible barriers to future CT participation, and ensure that they are meeting patient needs.

Secondly, we underestimated the time it would take to establish initial partnerships with the community. Each step in the process took several weeks and required initially communicating through CCOP. For example, once the medical director at the first cancer clinic agreed to participate, he contacted the physician liaison, who then called the Columbus CCOP, who then contacted us. Once the clinics expressed interest, CCOP recommended that we wait to hear back from the clinics. CT nurses from two clinics called us immediately; however, only one responded to our return phone call. To attempt to reach the second nurse, we phoned and emailed over several months but did not receive a response until a press release was issued from another clinic describing participation in our study. She then called us and said that she wanted to participate because she felt like the level of publicity

would be beneficial for her clinic. The two remaining clinics took several months to recruit after conversations between health care providers, nurses, patient navigators, and communications staff. In sum, clinic agreement for participation in our project took 3 months for the first clinic, 4 months for a second and third clinic, 8 months for a fourth clinic, and 10 months for a fifth clinic.

Consult

The second phase in CE is consulting with the community, which includes increasing involvement with the community, seeking guidance from community, sharing information, gaining feedback, and developing connections (Clinical and Translational Science Awards Consortium 2011). Once clinics agreed to participate, we asked to recruit patients from their hospitals. This process required receiving their guidance on their recruiting preferences. In our initial IRB protocol, we were approved to recruit patients by asking health care providers to hand out a letter about our study to each cancer patient who either was considering a CT or who had participated in one in the last 2 years. The bottom of the letter had a detachable section where patients could provide their contact information to us and either (1) give them to the clinic to give to us or (2) mail it to us in a self-addressed envelope.

Challenges and Lessons Learned

Two primary challenges emerged in the consult stage: (1) adjusting our recruitment procedures to the preference of clinics; and (2) learning the differences in record-keeping for each clinic. The first challenge was presented when we approached the CCC and were told that asking clinic staff to send letters to patients on our behalf would be more burdensome than if we sent the letters ourselves. After receiving a letter from the CCC supporting this recruitment change, we applied for an IRB amendment to change recruitment to the preferences of the clinic. For patients at three clinics, a member of our research team prepared recruitment letters from their oncologists and emailed them to a clinic contact (e.g., CT nurse), who procured the oncologist's signature and mailed the signed letters to the research team. The researcher then compiled the envelopes and mailed the letters to the patients to reduce the administrative burden on the clinics. At the fourth clinic, the health provider's staff prepared the patient letters and envelopes, and a researcher picked them up to mail them. For these four clinics, follow-up phone calls were made by the research team to schedule interviews with interested patients. The fifth clinic preferred to keep patient names private and mailed the letters from their facility without disclosing their names and contact information to us. As a

result, no follow-up phone calls by the research team were made to that clinic's patients, and patients contacted us if they wanted to participate.

The second challenge involved learning the differences in record-keeping at each clinic. Initially, we sought to interview an equal number of patients who had accepted (*n* = 20) and declined (*n* = 20) a Phase III CT. Recordkeeping created four challenges. First, only two sites recorded the names of people who had both accepted and declined a CT; thus, we were not able to locate patients who declined a CT at the other sites. Second, some clinics overestimated the amount of patients they had on Phase III trials. Once the final lists were sent to researchers, patient numbers were fewer than researchers anticipated. Likewise, it was not always possible for clinic lists to be updated; thus, two patients were called who had passed away. Third, because clinic staff was busy, two clinics took several months to compile and send their patient list after they agreed to participate. Another clinic mistakenly sent a partial list of patients and once researchers noticed too few enrollees, they contacted the clinic, which sent an updated list a month later. Fourth, there was a miscommunication about the inclusion criteria for the study (i.e., patients offered a Phase III clinical trial). Some of the clinic lists included patients in Phase II studies or other types of research studies (i.e., tissue-banking studies, physician-monitored studies). However, this was not known until after the patients were interviewed, patients were confused about the questions, and their study status was later confirmed with the clinic.

Involve

We reached the third stage of CE when we began recruiting and interviewing patients. This stage involved participation and cooperation with the community, two-way communication between the community and the researchers, and increased visibility of partnership (CTSAC 2011). The purpose of recruiting patients was to conduct formative research in interviews with cancer patients who have considered a cancer treatment CT as well as their family members who had helped them in their decision-making. During this stage, we remained in contact with each clinic to receive new names of patients considering a CT, receive alternate contact information if phone numbers were disconnected, verify if patients were enrolled in a CT (e.g., versus a tissue banking study), and inform health care professionals about concerns about patients or questions from patients (e.g., questions about mental health services, concerns about a patient's coping ability, patient questions about finances). In total, interviews were conducted with 109 participants (i.e., 49 patients and 60 supportive others) from five Ohio cancer clinics.

Challenges and Lessons Learned

Two main challenges emerged in this third stage of CE: (1) recruitment issues and (2) interview issues.

Recruitment Issues — The first recruitment-related challenge involved reaching patients. Although our phone number was a toll-free number to allow patients to return the call free of charge when researchers called patients, the call was registered as an area code from a larger metropolitan area. Community members later informed us that the phone number may have contributed to the difficulty of reaching patients because people in the area often avoid answering unknown calls from outside the area. Patients were called two to three times per week at different times of the day and evening in attempt to reach people when they were home; however, only one voice message was left per week. Some patients returned phone calls within a few days; others took weeks or months to reach. Likewise, some patients had voicemail or answering machines while others did not, and some would pick up the phone only to hang it up immediately.

Upon reaching patients, several reasons were given for the lack of initial response: busy schedules between balancing work and family responsibilities with chemotherapy and radiation treatments; not feeling well enough to talk or return calls because of current treatment but wanting to participate later in the year after treatment was completed; not wanting to deal with "anything extra" other than coping with cancer; and the inability to understand the quick speech of the researcher in messages. Likewise, after interviews were scheduled, a few patients repeatedly canceled because of family, work, or treatment commitments. Although some of them eventually rescheduled, some did not. Thus, when recruiting in a rural, cancer context, future researchers should consider that patients may want to participate but may not answer phone calls for a considerable amount of time, may have difficulty scheduling, or may not actually want to participate even though they schedule with the research team.

Recruiting support individuals was also difficult. First, patients were reluctant to refer supportive others to the research team because of a protection of their loved ones' privacy, an unwillingness to burden them with an additional request for help, and emotional discomfort if the supportive others were to talk to us about the patient's cancer experience. To overcome the first challenge, we amended the IRB to recruit supportive others at the same time we recruited patients. If patients were reached, we would immediately explain that we were also interested in talking to others who had helped them with their CT decision. This request enabled us to arrange for family members to be interviewed on the same day immediately following each other while also making it more

convenient for them to share transportation and to schedule 1 day for interviewing. We also asked patients to refer those individuals who were "influential in their decision-making"; however, some patients bristled at "influential" because they interpreted it as a negatively valenced word to mean that we were suggesting others either made the decision for them or tried to manipulate, rather than help, them in their decision. In other words, the word "influential" was culturally interpreted as a threat to patients' independence and/or family identity. To overcome this barrier, we began asking to talk to others they had "talked to about their decision" in order to explore the different types of assistance (e.g., advice, listening, looking over paperwork) people had given during treatment decision-making.

While recruiting patients was difficult, it was possible primarily because the initial recruitment letter came from their cancer physician. For many patients, this letter signaled that their physician trusted us and approved of our study. Further, some patients told researchers that they would "do anything" for their doctor. This statement had several cultural meanings for patients, including feeling indebted to the doctor and the facility for the care they received, wanting to "give back" to research to express gratitude toward their doctor, and wanting to help their doctor in some way. As a result, we had to communicate that although our study might inform doctors of facilitators and barriers to CT enrollment, it would not directly help them. Also, they perceived the study to be in conjunction with their doctor; thus, we had to explain that although we were partners, the hospitals would only receive our findings, not view individuals' data.

Interview Issues — One difficulty in conducting interviews was scheduling a location to meet. Approximately half of all patients preferred to meet at their homes, while the other half preferred to meet in public places (e.g., hospital cafeterias and waiting rooms, coffee shops, community center). Some patients expressed embarrassment at having "someone from Columbus" come to their home. In addition, many participants had transportation difficulties (e.g., no car, lack of money for gas) and only agreed to participate once the researcher agreed to travel to them. However, some locations created barriers to establishing rapport once the interview started. For example, several participants wanted to be interviewed on the day they received treatment or while they received treatment; however, this created many challenges. Some of these challenges included continual interruptions by medical staff; interviews that had to be postponed because patients had to receive an unexpected test or because they experienced a reaction to the chemo treatment; low speaking tones and self-consciousness of patients because they did not want other people to overhear their interviews; loud background noise that obscured patients' voices; and limited time to speak to patients while waiting for appointments.

As recruitment continued, however, researchers learned to suggest a quiet, private location based on patients' suggestions (e.g., conference room in the hospital). Patients were satisfied with the convenience and comfort of the location and the researcher was able to hear the participant without being disturbed. However, sometimes this situation could not be arranged, such as if participants were adamant about meeting researchers at a local fast food restaurant. Thus, researchers thought that it was more important for the participants to feel comfortable in a loud space (e.g., no one knows them at this restaurant, or conversely, they feel comfortable at this restaurant where they know a lot of people) if they are willing to share intimate details of their personal and medical histories.

Another challenge during the interview process was establishing rapport. One barrier to rapport was that some patients did not remember being offered a CT and thought our study was the CT referred to in the recruitment letter. When this occurred, a researcher described a CT, its purpose, and asked if they remembered any alternative treatment offers to the one they chose. If they still did not remember, the interviewer asked about general treatment decision-making and followed up with the clinic once the interview was finished.

A second barrier occurred with identity and "otherness" in relation to rural culture. Although the interviewer was originally from an Ohio Appalachian county, some participants consistently viewed her as "that lady from Columbus." Her native affiliation with an urban area within an Appalachian county, however, assisted in establishing rapport with one participant, who was from the same county and was initially reluctant to participate because he did not view himself as living in Appalachia. Another identity issue occurred when participants were asked if they considered themselves to be "Appalachian?" Participant responses ranged from an immediate "yes" to an immediate "no". Most answers included responses, such as laughter, and were accompanied by questions, such as "Do you mean like hillbilly?", "You mean like from the country?", "I don't know, I have all of my teeth," and "I guess that's what they call us." Regardless of response type, all responses to this question signified awareness of negative cultural stereotypes while most responses indicated that Appalachian identity is a term given to them from others outside the community and one they do not use to describe themselves. As interviews continued, efforts were made to reduce barriers in communication and mirror participants' informal preferences, including wearing jeans and wearing less jewelry and make-up. Some participants even asked if the researcher would eat a meal with them before the interview

during which they could get to know her better, and she did so to make the participants more comfortable even if that meant that the initial conversation would not be recorded.

Some patients, however, readily established rapport with the interviewer. Although care was taken to explain the researcher role, some patients believed the interviewer to be a part of the medical team and this increased her credibility. Although the interviewer corrected these misperceptions, the connection between the researcher and a beloved healthcare professional or hospital created a halo effect. In other cases, the interviewer's outsider status enabled her to hear information (e.g., sexual dysfunction, mental health issues) that some participants were uncomfortable disclosing to the medical team or to community members because of a concern for privacy.

Collaborate

At this stage in CE, partners are integral to all project components "from development to solution" and communication continues to flow back and forth from both partners and researchers. At this stage, partners are building trust in each other and helping each other to accomplish their goals (Clinical and Translational Science Awards Consortium 2011, p. 8). We reached this stage of the process during Phase 2 of our project. The purpose of Phase 2 was to create an educational intervention with an advisory focus group. One hospital site was eventually chosen because of their active participation in Phase 1. Participants in the advisory group included 9 members: two cancer physicians, a nurse practitioner, a CT nurse, three cancer patients, and two spouses of patients. Three advisory group meetings were scheduled. The purpose of the first focus group was to ask for feedback on patient issues raised during formative interviews (e.g., timing of CT offer, information overload). The purpose of the second and third focus group was to receive input and feedback on the educational multi-media materials the research team created (e.g., interactive notebook, video) based on the results from the interviews and the first focus group.

Challenges and Lessons Learned

The major challenge in this stage was selecting and scheduling participants for the focus groups. We invited patients who had said "yes" and "no" to cancer CTs to have a representative sample; however, the patients who had agreed to participate in the focus groups all had enrolled in a CT. One patient who agreed to participate wanted his spouse to attend with him because she was equally involved in the decision-making. We then opened the group to family members in order to gain their perspective, which resulted in two spouses attending the meetings.

This inclusion was responsive to the cultural expectation that family members be considered in health decision-making (Hecht and Krieger 2006). All members were present at the first and third focus groups. For the second focus group, all members returned except a physician who had to attend an administration meeting.

During the first and second focus group, ideas were shared to create an intervention that would help patients in their decision-making about cancer CTs. The major suggestions included creating video and interactive workbook that would enhance credibility and trustworthiness of the materials. For example, participants stressed the importance of having "real people" instead of actors in the video to identify more with patients' experiences about CTs. They also wanted to see a more personalized version of paper-based information that included quotes from the health care team that they knew and trusted along with photos of these healthcare team members. Another example included using local visual cues for the cover of the paper-based, interactive workbook. Some suggestions included featuring the photo of the clinic, a calming nature photo of a nearby state park, or a photo of a handprint collage of cancer survivors that is showcased in the waiting room of the hospital to signal hope and serenity to patients. In the third focus group, participants suggested using a photo of the hospital clinic garden to combine depictions of nature with the clinic. Patients also indicated a preference for including quotes, photos, and identity descriptors (e.g., city of residence, religious preference, family member role, and personality adjectives) of other patients who had either enrolled in or declined a CT in the intervention materials to emphasize the local connection and relate with those individuals who made similar treatment decisions. These findings illustrate the importance of targeting some of the components of the materials to specific sites, sub-cultural groups, and communities within the Appalachian region in order to incorporate aspects of local identity and increase familiarity, identification, and comfort with materials (Barrera et al. 2011; Trickett 1996).

In addition, focus group members highlighted the importance of including information that discussed the challenges to CT participation. This suggestion, and its subsequent inclusion in the intervention, was given to privilege the community members' choice of cancer treatment over researchers' desire for change in CT enrollment (Trickett 2011). For example, although all community members who participated in the focus group wanted others to participate in CTs, they also realized that it was more important to validate community members' treatment decisions than increase CT enrollment. Thus, the goal of the intervention was renegotiated among all research partners: To increase informed decision-making, and decision-making satisfaction, among cancer patients offered a CT.

Another focus group finding was the importance of repetition and simplified organization in the notebooks to maximize understanding. When patients were diagnosed with cancer, patients and family members reported receiving paper work about their cancer and types of treatment, including a CT. However, most patients in the formative interviews reported feeling overwhelmed with the information while some reported they did not read the information at all. Building off of this finding, members of the focus group asked that paragraphs be short in length, bulleted to highlight important points, and include repetition between the notebook and video. These changes focused on matching patients' literacy level to the materials, allowing for patients and family members to view materials separately or together, and increasing their understanding and familiarity with the materials. Taken together, including the cultural group members in the design and production of the video and interactive workbook maximizes the possibility that these materials will be used as opposed to being immediately discarded like some of the more general educational materials. It is expected that a future experimental test of the materials will demonstrate that cultural grounding is an efficacious approach to designing CT interventions for traditionally underserved populations.

Discussion

Both theory and practice support the importance of fostering CE in health communication community interventions. Community psychology researchers have long incorporated local cultural preferences in developing community interventions and the current manuscript extends this tradition by emphasizing the communicative processes at work in CE through the theoretical application of PCG. We argue that CE should be conceptualized as a non-linear process, with loops and linkages among the stages. In doing so, this manuscript builds on the PCG literature by demonstrating how this theoretical approach fits into the larger literature on CE. It also contributes to the community psychology literature by emphasizing how communication is used to negotiate each stage of the CE process, potentially leading to CBPR. It illustrates the point that shared leadership can occur in one aspect of intervention (e.g., development of intervention materials), even when it is not possible for the overall project to achieve shared leadership given competing priorities for both community and academic partners. Finally, it describes cultural nuance associated with cancer clinical trials communication in rural Appalachia, a medically underserved population. Next, we consider the theoretical and practical benefits of integrating CE and PCG perspectives for developing community-based interventions.

Using the Principle of Cultural Grounding for Promoting Community Engagement

This manuscript fills a theoretical gap in the literature by demonstrating the potential for theory and research in the areas of PCG and CE to inform one another. Integrating these literatures demonstrates areas of substantial overlap as well as the distinctive strengths of each. Drawing on the strengths of both perspectives will help future scholars develop a more nuanced understanding of how community relationships with cultural groups are formed and develop greater awareness of how incorporating PCG principles can be used as a basis for developing relationships that result in various levels of CE (including CPBR).

Outreach

One fundamental tenet of PCG is that community members should be involved in all aspects of message design. However, PCG does not articulate the processes involved in this type of collaboration. The CE literature benefits understanding of PCG by articulating the various phases in developing community-academic partnerships that can result in culturally grounded interventions. Conversely, the CE literature specifies the importance of academic partners establishing connections with community members, but is generally nonspecific about the role of communication in this process.

A PCG approach emphasizes focusing on adapting to the identities and communication styles of the various constituencies within a cultural group. Thus, from a PCG perspective, the focus is not on the "community" as a singular entity, but an appreciation of the interplay of various identities that intersect in community-based research and the need for adaption to various communication styles represented. In the current project, our community partners included cancer patients and their families as well as administrators, healthcare providers, and members of community coalitions. Therefore, through the lens of PCG, outreach is not a discrete stage, but rather an ongoing activity as investigators interact with various types of community members. Adaption processes may look very different for each of these groups. For example, adapting to the communication styles of community gatekeepers such as administrators entailed allowing adequate time for relationship development before being granted access to professional and community networks that would help the project unfold and negotiating expectations for mutual benefit. Adapting to the communication styles of cancer patients and their families entailed changing our styles of dress and modifying questions to be more culturally appropriate.

Consultation

A second assumption of both CE and PCG is that questions related to the nature of the problem and efficacy of potential solutions must be identified through dialogue with target group members (Hecht and Krieger 2006). Engaging in dialogue with community members to define problems and potential solutions has the benefit of creating interventions that reflect the lived experiences of the communities they serve as well as demonstrating to communities that their participation in the research process is valuable. When CE and PCG are considered in concert, one of the key benefits of the consultation stage is that both academic and community partners become sensitized to the interplay of various identities with respect to a given topic.

To illustrate using the current project, there were several different aspects of identity that were salient among community members in current investigation. One was place identity, which was reflected in the suggestion that narratives used in the intervention materials include the name of particular communities where individuals lived. Another was illness identity, which was reflected in the desires that intervention narratives include the participant's specific cancer type (e.g., lung, breast) as well as stage at diagnosis. Relational identities were also emphasized, with participant's choosing to describe themselves as "wife/mom/ granny" and "dedicated to family" as a means of connecting with other patients who valued familism. Finally, personal identities were also at the fore, with participants wanting to connect with others around qualities such as, "outspoken," "upbeat," and "cautious."

There are also important challenges inherent in consultation, but these challenges and strategies for overcoming them are under-theorized in both the CE and PCG literature. One aspect that has received little attention is that not all individuals have the desire, time, or resources that involvement requires. In some cases, this may be due to experiencing some level of social disadvantage. For example, some potential patient participants declined to complete an interview because of limited time or resources due to living in geographically isolated areas, working several jobs, bearing heavy care giving responsibilities, being in poor health, or some combination of these factors. Similarly, some potential health care provider participants could not complete an interview due to heavy workloads. The time investment required by academic-community partnerships may not be valued by organizations and any contact with researchers may occur on personal, rather than work, time. Thus, outreach can be time-consuming and frustrating for researchers, but potentially even more so for community members.

Furthermore, the procedures and practices of organizations are designed to efficiently achieve the mission of the organization. When that mission does not involve research, academics may find it difficult to incorporate cumbersome procedures required by institutional review boards or methodological design into organization practice. For example, some of the administrative burden of subject recruitment in the current study fell on community partners because of federal regulations protecting the private health information of patients. At the same time, this was a burden that our partners were willing to endure because they would receive recognition in the accreditation process for enrolling patients in a behavioral research study. Nevertheless, the reality is that competing priorities, differential reward systems, and interpersonal dynamics add a layer of complexity not fully captured by simplistic characterizations of this important aspect of community-based research.

Involve

Both CE and PCG acknowledge the importance of community involvement in interventions. In PCG, this is reflected through practices that allow the target audience members to create their own cultural meaning, codes, and identity. For example, in the current study, involvement was demonstrated through in-depth interviews with members of the target audiences, including patients, family members, and healthcare professionals. Involvement can help both academic and community partners explore a given problem from a different vantage point. In addition, healthcare professionals provided insight to the research team about the organizational features that influence the low rates of cancer CTs (e.g., lack of nursing staff, increased costs associated with longer appointments and more medical tests). Similarly, the research team was able to share evidence with the health professionals about how certain types of language might alter understanding of the CT process and result in barriers to enrollment (e.g., randomization, risk, trial).

Collaborate

The final step in both the CE and PCG process is involving cultural group members as active participants in the design and production of messages. Through PCG, this phase involved the co-creation of the intervention by the researchers, oncologists, health educators/nursing staff, patients, and family members. In this way, all participants mutually negotiated both surface structures of the intervention, such as avoiding the color green for intervention notebooks because patients associated it with money and finances, to deep structures such as determining which information components were included and/or emphasized.

As with all the stages, certain challenges are inherent to collaboration. Although issues such as time are still important, negotiating power dynamics is a central feature of this stage. Power is most often discussed as a factor influencing the researcher-community member relationship. Although this is an important point, there are also power dynamics and differentials within the community that can influence collaboration. For example, it was essential to the current project that patients, family members, and health care professionals actively contribute to the design of the intervention. This is contrary to norms in most HCP-patient relationships, where the HCP provides the information to the patient. In the current project, this norm was overcome by asking everyone in the advisory group to share their personal narrative and asking questions based on their experiences related to cancer both in and out of the hospital context rather than focus solely on their roles of patient and provider.

Negotiation and Non-linear Relationship Development

Drawing on PCG, we also suggest a fifth stage: Negotiate. Once academic and community partners have co-created an intervention, it is important to acknowledge that the goals of community partners and academic researchers will diverge at some point. In the current project, the partnership was based on a shared desire to see help patients make informed cancer treatment decisions. From the perspective of community partners, it was important to disseminate the newly developed intervention as widely as possible. From the perspective of the academic partners, it was important to systematically study the efficacy of the intervention before full-scale distribution. The PCG approach helped mitigate these tensions. In the current project, the intervention was developed as a result of the academic partners contributing knowledge of theory and research design to the intervention development process and the community partners contributing medical and experiential knowledge. When the tension between dissemination and evaluation arose after the creation of the intervention, it was resolved through trust in our respective areas of expertise. Community partners agreed to wait on full-scale dissemination pending evaluation and the academic partners agreed to design an evaluation study that would enable the intervention to be used by patients at the clinic quickly and evaluated with minimal disruption to the clinic staff.

Although this project was originally conceptualized as a community-based participatory research project, part of the negotiation stage was that community members did not have the time or interest in sharing leadership of the overall project. Some degree of shared leadership was achieved in that academic and community partners co-created the intervention. For example, the goal of the intervention was renegotiated by all partners at the collaboration stage to include information that validated a patient's choice for cancer treatment, even if it was to eventually decline participation in a CT. Thus, we argue that negotiation is an ongoing stage that encompasses all levels of community engagement.

This is one area where PCG diverges from the CE model. This is not to say that shared leadership is inconsistent with PCG, but it is not a requirement for creating, administering, and evaluating culturally grounded interventions. Although redistributing power associated with implementing interventions in the form of shared leadership has intuitive appeal, this benefit is often not outweighed by the realistic challenges of the field. In many cases, community members are participating in academic research because they believe that the knowledge gained will improve overall well-being in their community. This type of altruism is what makes many academic-community partnerships possible. However, it is understandable that few community members may be interested in the responsibilities of shared administration of a project, especially when this labor is not compensated. Possible ways to overcome these barriers to shared leadership are (1) working the project administration into the daily schedule of the clinic with minimal interruptions to clinic staff and productivity and (2) creating opportunities for co-authorship in conference presentations and publications about the research.

The fact that many strong academic-community partnerships can vary in type and incorporate shared leadership in ways that best fit partners' needs (Schensul and Trickett 2009) illustrates that CE is not necessarily a linear process. A particular intervention may go through various stages in a linear process, or they may revert to previous stages as time progresses. Community members may initially be excited about a project and become increasingly engaged, only to reduce their level of engagement over time because time and resource pressures associated with the partnership become too great relative to their other responsibilities. Just as partnerships may unexpectedly decelerate, there may also be loops and linkages that accelerate the process. For example, particular relationships may be built in the outreach stage that enable an academic-community partnership to immediately move toward collaboration or even shared leadership.

Conclusion

The PCG approach prioritizes understanding how culture shapes communication and decision-making in specific environments over testing general principles in

de-contextualized settings. In this way, PCG requires researchers to move their research program from the safety of the laboratory into the less predictable field settings in order to address pragmatic problems in theoretically insightful ways. Doing so requires not only articulating a meaningful question to both researchers and community members, but establishing contacts within the community with individuals with direct experience relevant to that question. Our analysis of the process and outcomes in the DECIDE Project associated with using a PCG theoretical perspective within a CE model contributes to the current literature in two key ways. First, it explores the relationship between PCG and CE that results in an intervention that is targeted toward the norms, beliefs, and values of a larger regional population (e.g., inclusion of family members in decision-making) and the local community population through local narratives and identification practices (e.g., local HCP and patient perspectives about CTs) to increase the trust and credibility of CT information. Secondly, it illustrates the practical challenges and complexities of implementing the cultural grounding perspective within a population affected by systemic, geographic, cultural, and social barriers to health care. While grounding an intervention within a cultural group, the CE principles of outreach, consult, involve, and collaborate were essential to acquiring trust and building partnerships in the rural Appalachian population among researchers, patients, family members, and health care providers. Using a similar approach may assist future researchers in recruiting rural patients and establishing successful partnerships with rural health care facilities and traditionally underserved populations.

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