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Capacity Needs in Community-Based Organizations for Enhancing Translational Research in Puerto Rico

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Abstract

Background—In an effort to form and sustain community–academic partnerships (CAPs) to enhance clinical and translational research, an assessment of needs for selecting and implementing evidence-based programs (EBPs) was conducted among a group of community-based organizations (CBOs) throughout Puerto Rico.

Methods—The survey was based on an instrument developed by the Cancer Prevention and Control Research Network. It assessed specific service information, program selection/implementation processes, knowledge and perception of EBPs, funding venues, evaluation processes, and capacity and training needs. Recruitment consisted of contacting 100 nonprofit organizations in Puerto Rico that work or address specific health areas, namely, cancer, neurological disorders, HIV, and cardiovascular health.

Results—The survey revealed wide variability in understanding what constitutes an EBP. Training needs for building a productive translational research process also were identified. Prominent among these were securing funding for ongoing operations, utilizing data for decision making, developing collaborations, managing information, conducting community needs assessments, and program evaluation.

Conclusions—These findings point to important implications for promoting community–campus partnerships for advancing clinical and translational research.

Keywords

community–academic partnerships; evidence-based programs (EBP); translational research; needs assessment; capacity building; community-based participatory research (CBPR)

Starting with the National Institutes of Health Roadmap initiative in 2004,¹ the National Institutes of Health has made translational research a priority. Translational research is intended to foster the multidirectional integration of basic research, patient-oriented research, and population-based research, with the long-term aim of improving the health of

the public.² Woolf³ identifies two primary routes through which translational research is accomplished. One centers on the intersection between basic science and clinical medicine, in which knowledge generated by basic science is leveraged to yield new medical devices, drugs, and treatment alternatives for patients. The other emerges from a public health perspective, in which research knowledge is translated into practice by making sure that it reaches individuals and populations for which it was intended and is implemented consistently. At the heart of the public health perspective for translational research are EBPs and interventions.

EBPs are those that have been demonstrated effective based on the results of rigorous evaluations.⁴ For a program to be considered evidence based, it must have been tested in a well-designed and methodologically sound study (experimental or quasi-experimental) and shown to produce significant reductions in undesirable outcomes and associated risk factors. The Substance Abuse and Mental Health Services Administration indicates that EBPs consistently demonstrate positive outcomes, are reliable over time, and if implemented with fidelity, there is high confidence in their effectiveness.⁵

Although public health organizations are encouraged by their governing boards and funders to choose EBPs for implementation, a number of barriers impede their widespread use.⁶ Among the most common are inadequate knowledge about EBPs and how to identify them, limited training available on how to effectively adapt and implement EBPs, and various organization-level constraints.⁷⁻⁹ Moreover, failure to adapt existing EBPs to conditions on the ground, ignorance of local preferences, neglect of local data during adaptation efforts, and inadequate attention to implementation fidelity hamper the success of translational research efforts in communities.¹⁰⁻¹²

The Puerto Rico Clinical and Translational Research Consortium (PRCTRC) was established in 2010 as an initiative to advance translation of knowledge and to have an impact on health disparities in Puerto Rico.¹³ The PRCTRC is a multidisciplinary, collaborative effort between three academic health care institutions in Puerto Rico: The University of Puerto Rico Medical Sciences Campus, Central Caribbean University, and Ponce School of Medicine and Health Sciences. The program is inclusive, incorporating leadership from all participating institutions at several levels of administrative responsibility. It also provides a unique opportunity to incorporate resources and have an impact across a state-sized territory composed primarily of a minority population.

The Office of Community Research and Engagement (OCRE) is a key function of the PRCTRC. It serves as a venue for mobilization, capacity building, and collaborative research, involving a wide range of community partners and in concert with other PRCTRC key functions. One of OCRE's goals is to evaluate existing community capacity and resources to form and sustain CAPs to enhance translational research. As a first step, we conducted an assessment of needs for selecting and implementing EBPs among a group of CBOs throughout Puerto Rico.

Our choice to focus on CBOs as prospective partners is based on the notion that two stable anchor points are required for a successful translational research initiative to function: One

at the academic institution and one in the community setting. Both anchor points generate knowledge, and information is translated in both directions. However, in the absence of a stable community anchor point, efforts become diffuse and uncoordinated, leading to eventual failure. CBOs represent good anchor points because they already are embedded in the communities that they serve, have established connections, have built a positive track record and level of trust with community members, and have an established administrative infrastructure. We define CBOs broadly as registered nonprofits and service organizations, churches, neighborhood clinics, and local government offices.

The overall strategy of OCRE is to promote the formation of stable CAPs composed of a CBO and an academic research group as anchor points that are guided by principles of community-based participatory research (CBPR).¹⁴⁻¹⁷ CBPR requires that community and academic partners work together to design research, collect and interpret data, and disseminate results. An outcome of this collaboration is that community members should acquire skills and see tangible benefits from having participated.¹⁸⁻²⁰ CBPR is regarded as an effective method for transferring evidence-based research from clinical settings to communities that can most benefit, thereby improving health.²¹

Starting modestly with two anchor points that have a specific translational research focus increases the probability of initial successes. These help to establish a track record for the CAP, which in turn can be leveraged to generate interest among other stakeholders and interested parties at both anchor points through a Diffusion of Innovations process.²² However, a considerable amount of advance work is required to build a successful CAP.²³⁻²⁹ Because EBPs are at the heart of public health translational research efforts, we focused first on assessing knowledge, attitudes, and experience related to them among CBOs, with the overall objective of developing training programs to address areas of need that will better prepare CBOs to enter into CAPs.

Methods

study design

We used a two-stage approach to assess knowledge and attitudes related to EBPs, along with training needs for their implementation, in a broad-based sample of CBOs in Puerto Rico. The protocol consisted of an online survey as the primary data collection method. We followed this up with focus group sessions with a subsample of CBOs that were designed to broaden our understanding of the survey results, as well as to elaborate training needs and contextual factors associated with them. The study protocol was approved by the Institutional Review Board of the University of Puerto Rico, Medical Sciences Campus.

sample

The target sample for this study was identified through a compiled list of more than 1,000 registered CBOs and nonprofit organizations in Puerto Rico. Selection criteria were based on (1) a CBO having a focus on one or more of the health priority areas identified by the PRCTRC—cancer, HIV, neurological disorders, and cardiovascular health, (2) offering health-related services (prevention, promotion, education, clinical treatment or referral) or

that expressed an interest in expanding to offer them, and (3) agreed to participate in the needs assessment and had a responsible representative of the organization available to complete the survey within our data collection time frame. One hundred CBOs met the inclusion criteria.

Measures

The Puerto Rico Community-Based Organizations Service and Capacity Needs Assessment was adapted from an instrument developed by the Cancer Prevention and Control Research Network.³⁰ It assessed specific service information (e.g., services offered, target population, location), program selection/implementation processes, knowledge and perception of EBPs, and capacity-building and training needs. For the survey, EBPs were defined as programs that have proven to have a positive effect on the behavior or health of a population and in the context in which it was studied.⁴ The openness and divergence subscales from the *Evidence Based Practice Attitude Scale* also were included in the survey.³¹ The openness subscale assesses the extent to which the provider is generally open to trying new interventions and would be willing to try or use EBPs. The divergence subscale assesses the extent to which the provider perceives EBPs as not useful and less important than other experiences.³² The complete scale includes questions related to attitudes and decisions about the use of EBPs for decision making, along with push-and-pull factors, such as organizational setting and resources. Once the Puerto Rico Community-Based Organizations Service and Capacity Needs Assessment was finalized, an online version was created using Survey Monkey as the delivery mechanism.

data Collection

Initial contact of organizations identified as having a focus in one of the health priority areas of the PRCTRC consisted of a short phone call to verify contact information (telephone and email), establish eligibility, and explore their interest in participating in the needs assessment study. The unit of analysis for the study was the CBO, not the responsible representative for the organization that provided the information. Thus, a verbal consent to participate was deemed appropriate and approved by the institutional review board.

Approximately 10 days after recruitment, an email was sent to the sample of 100 eligible CBOs that included a link for the online needs assessment survey. Data collection was conducted from June 2011 to October 2011. Five weeks after the first survey participation notification, a second email was sent as a reminder to those organizations that had not yet responded. Telephone calls were made to further encourage participation of those organizations who had not answered the survey after these email communications. Eight organizations indicated that they were unable to complete an Internet survey because they lacked Internet access. This group received a visit by study staff to have the questionnaire administered in a face-to-face format. The response rate for the survey was 68%.

Once administration of the survey and preliminary data analysis were completed, we selected a subset of 20 organizations to participate in the second stage of the needs assessment. This selection was based on commonalities in their responses to training needs in the survey and their participation in previous capacity-building activities offered by

OCRE. To ensure attendance of the 20 organizations, these were divided into two focus groups offered on two separate dates. According to Rogers Diffusion of Innovations Theory, these organizations represented innovators and early adopters.²² Common training needs included identification of research resources and sources of funding, piloting and adaptation methodologies for EBPs, evaluation procedures, and administrative and organizational strategies. Focus groups sought to gain a more in-depth understanding of the expressed training needs and challenges that the CBOs faced in participating in collaborations. To encourage an open and honest discussion, focus groups were not recorded. Instead, two OCRE members made observations and took notes. The facilitator also transcribed his or her notes directly after the session was finished. Of those invited, 16 participants from 11 organizations attended the focus group sessions.

Analyses

Descriptive statistics using SPSS 19 (SPSS, Inc., Chicago, IL) were used to analyze survey responses and to characterize organizational infrastructure of CBOs, their processes for program development and evaluation, knowledge and attitudes about EBPs, beliefs about the importance of using EBPs, collaborations, and perceived needs for training on how to find and use EBPs. Focus group data were analyzed according to the procedures specified by Krueger and Casey.³³

Results

Characteristics of Respondents

Among the 100 invited organizations, 68 replied to the survey. From these, a total of 62 surveys were deemed sufficiently complete to be included in the analysis. A majority of respondents were executive directors of their organization (64.5%). For the remaining cases, this task was delegated to others, such as coordinators of community outreach or service programs who were deemed more knowledgeable about the content of the survey. Most respondents reported offering services related to HIV or neurological disorders; more than 70% ($n = 44$) reported providing services of education and health promotion. Only 10 of participating CBOs (16.1%) reported using an externally developed program for their services.

selection of Programs

Priorities for choosing a program for implementation, evidence-based or otherwise were (a) responds to the needs of the service population (87%), (b) consistent with the mission of the organization (85.4%), (c) easy to use (79%), (d) responds to the needs of their organization (77.4%), (e) consistent with the image of the organization (75.8%), and (f) cost effectiveness (70.9%). Prominent among the least selected responses was the existence of technical assistance (56.4%).

Knowledge About eBPs

A total of 37 CBOs (59.6%) reported knowing where to find EBPs and 32 CBOs (51.6%) reported having had some experience implementing EBPs. This was further contextualized during the focus groups, where CBOs mentioned that the federal government has required

the use of evidence-based interventions for HIV programs in Puerto Rico since 2004. Focus group participants acknowledged that adaptation and implementation of EBPs was a challenge, and that among the available EBPs, only one intervention had been developed in Puerto Rico. Participants also indicated that research findings from studies conducted by academic researchers in Puerto Rico or outside the islands seldom reaches their organizations and service communities.

Attitudes About eBPs

Our findings reveal that most CBOs have positive attitudes toward the use EBPs. Table 1 displays frequencies of positive and negative attitudes among CBOs. Positive attitude items were strongly endorsed compared with negative attitude items.

training Needs

Results revealed that training needs were related to the identification of research resources and sources of funding, adapting and implementing EBPs, evaluation methodologies, and administrative and organizational strategies. CBOs identified and prioritized needs: (a) Assistance in strategies for the development of EBPs (73.9%), (b) access to scientific studies (65.2%), (c) conducting community needs assessments (65.2%), (d) proposal development (65.2%), (e) program evaluation (65.2%), and (f) strategic planning (60.8%). In addition to access to current data, 21 CBOs (33.9%) expressed a need for training in using their own data, and that of others, to inform decision making. Some CBOs ($n = 16$; 25.8%) identified a need for information management services owing to the high cost of data collection and analysis equipment, and 11 (17.7%) expressed a desire to conduct a community needs assessment in their service area.

Focus group findings were consistent with survey results. CBOs indicated that the greatest challenge that they face, regardless of how long they have been in operation, is maintaining a steady funding stream. Administrative processes and procedures also pose a challenge, because accountability and reporting procedures have become more complex and labor intensive.

CBOs mentioned that although the U.S. Centers for Disease Control and Prevention has provided proposal preparation training in Puerto Rico in the past, these sessions have been short and have not met all of their needs. Participants suggested that hands-on training is needed that is targeted toward different levels of competency. Although they recognize the importance of using data, CBOs indicated that most data gathered by their organizations are anecdotal and not collected scientifically. At the same time, they exhibited a tendency to see their anecdotal data as sufficient to demonstrate evidence that their programs work. This emphasizes a need for instruction on what constitutes scientific evidence along with a corresponding training need on how use data from other sources to justify their proposals. However, access to current data also was identified as a challenge. CBOs in the focus groups expressed a need for training in identifying, interpreting, and using sources of data external to their programs. Compounding the problem, participants lamented not having access to results of research studies conducted in Puerto Rico or elsewhere. Finally, CBOs

emphasized the importance of identifying venues to share or publish their work that are more pertinent and flexible than scientific journals.

Collaborations

Nearly all organizations reported collaborating with at least one external entity; most reported more than one. The most frequent collaborator identified was the Puerto Rico Department of Health, which also is a major source of their funding. In general, CBOs identified several community-level needs that would help them to improve the scope of their work and services. Among the most common were strategies for community mobilization (61.3%), integration of services (59.7%), and development and analysis of public policies (53.2%).

A substantial number of CBOs identified a need for training assistance in establishing and maintaining collaborations. This was further clarified in the focus groups, where participants indicated that they lacked a concrete example of what a close reciprocal cooperative CAP would look like and function. Previous experience with academic institutions has been limited primarily to helping researchers recruit samples or provide space where interviews could be conducted.

Focus group participants added that it is easier to establish collaborations with other organizations than with academic partners. The challenge seems to center on finding potential academic partners and establishing collaboration agreements, rather than difficulties working with academic partners. Additionally, CBOs reported that they have greater success in establishing agreements with other organizations for the provision of specific services compared with more broad-based collaborations, because in the former each partner has a narrowly defined role. They expressed an overall resistance to engage in broad-based collaborations because of (1) a lack of legal expertise and experience in writing and implementing collaborative agreements, and (2) a lack of resources to contract experts in these areas to help them. At the same time, CBOs acknowledged the importance of partnerships and collaborations among organizations and indicated that the lack of them was a probable cause for service duplication in communities and less integrated public health approaches.

DISCUSSION

Our results demonstrate overall low usage of EBPs and indicate a dubious understanding of what constitutes an EBP. This conclusion is supported by a number of inconsistencies in survey responses. For example, about half of the sample reported some experience in implementing EBPs. However, only 10 out of the 62 CBOs reported using an externally developed program and a correspondingly large portion of the sample reported having developed their own programs. Calo and colleagues³⁰ encountered similar inconsistencies in their study of university and government agency initiatives involved in cancer control in Puerto Rico. They found that participants had relatively high levels of confidence in adopting EBPs, but simultaneously exhibited low levels of awareness and use of existing resources for EBPs. CBOs participating in our focus groups stated that they were aware of only one EBP developed in Puerto Rico, which would signify a necessity to identify and

adapt external programs. Nevertheless, data from our needs assessment do not support a conclusion that this is occurring.

Probing during focus groups revealed that CBOs often rely more on anecdotal evidence to guide their daily operations and tend to conflate anecdotal with scientific evidence. Thus, a CBO may interpret a program that they have developed as being evidence based because their experience suggests that it works, and relegate scientific evidence to an optional technical issue. We also found that CBOs seem to be under the impression that if they evaluate their programs, they are evidence based. In most cases, this is not true. Although evaluation is an integral part of program development and implementation, the type of evaluations conducted by CBOs in our study typically are centered on participant satisfaction and thus are not designed to provide the type of data that would demonstrate that a program is evidence based.

We emphasize that CBOs in our focus groups did not exhibit resistance toward using EBPs. On the contrary, they unanimously acknowledged their value. Factors associated with low usage seem to center on lack of expertise in developing or adapting them, coupled with inadequate time and resources to devote to the process. The reality for most CBOs is that programs have to be selected and implemented quickly. Thus, translating materials from English to Spanish tends to be the extent of adaptation initiatives.

A number of important training needs were identified, with securing funding, strategic planning, and establishing collaborations being prominent areas of interest. Securing funding was highlighted by CBOs in focus groups as their most pressing need. The significance of this should not be underestimated. Other needs, such as access to and interpretation of scientific studies, conducting community needs assessments, proposal development, and program evaluation identified in our study all have direct relation to it.

CURRENT AND FUTURE WORK

Securing funding relates to survival, and survival represents the main challenge that CBOs and academic researchers have in common. Both compete for funding in an environment of limited resources, albeit in different spheres. However, this common challenge often occupies the position of elephant in the room when academic researchers and CBOs approach each other to discuss a potential collaboration.

A number of authors have written about the issue of building trust between community and academic partners.³⁴⁻³⁶ However, our findings suggest that the trust established through traditional approaches will be tenuous at best if both parties are ignoring the primary challenge of survival that each faces. Accordingly, we have adopted an approach called *promoting empathy through transparency*, in which we address survival challenges at the beginning and throughout the partnership. Neither partner can devote 100% effort to the project. Both work under certain professional constraints and each answers to multiple constituencies. We ensure that all partners are fully aware of each other's ongoing challenges for survival. Additionally, key questions that we address with all potential partners are: What's in it for me? and What's in it for my organization/community/university? Understanding and accepting these factors from all sides at the beginning of the

partnership engenders an environment of mutual empathy and facilitates interaction, communication, and trust.

One of our primary priorities in establishing a new CAP is to offer technical assistance to the CBO partner in writing a proposal to secure additional funding for their organization that addresses a need that they have identified. Attaining early successes that address survival needs of CBOs identified in our needs assessment serve to solidify the CAP and increase the probability that it will be both successful and sustainable.

Focus groups indicated that CBOs would like to have a concrete example of how a productive CAP would function. To address this need, we have invested energy and resources into building a successful model CAP with a motivated CBO. Over the period of 1 year, we have launched several collaborative research projects with our model CAP, including a pilot randomized control trial of an evidence-based intervention to promote breast and cervical cancer screening and a study to test the effectiveness of an HIV prevention program that the CBO has developed. According to Diffusion of Innovations theory,²² this model CAP should serve as an incentive for other CBOs to become involved by virtue of showing them what is possible.

CBOs motivated by our model CAP would represent early adopters in Diffusion of Innovations theory and are be invited to participate in a comprehensive training program designed to build capacity in areas identified in our needs assessment. We currently have nine CBOs participating in the first cycle of this training. Simultaneously, the model CAP is being used to recruit interested researchers and enroll them in a parallel training program. Both the CBO and researcher training programs will converge toward the end of the training and opportunities to form CAPs explored.

A strength of our study is that it focuses on a broad, diversified sample of CBOs involved in health promotion and services in Puerto Rico. Use of a two-stage design enabled us to gain a deeper understanding of the needs and challenges of CBOs. For example, although our analysis of survey results did not reveal significant differences in CBO responses, probing in our focus groups revealed that differences do exist in several important areas of training needs. We also disseminated findings to all participating CBOs, took time to listen to input from CBOs that contextualized their responses, and then used the findings to inform our approach to building a stable and sustainable translational research infrastructure in Puerto Rico based on CAPs. Weaknesses of our study center on the use of an online survey format. Although convenient, this design significantly extended the data collection period and did not provide us with a reliable way to ensure that all CBOs were responding to questions with a common understanding of what constitutes an EBP. The online format also gave us less control over the responsible person identified to respond to the survey. Our priority was to have executive directors complete the survey, but in some cases directors delegated this to others in their programs. This could present a weakness to our survey. Additionally, because the unit of analysis for the study was the CBO and not individuals within CBOs, this hampered our ability to detect significant differences in responses.

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Table 1

Frequencies and Percentages of Items Measuring Positive and Negative Attitudes Toward Evidence-Based programs (EBPs)

Items	Frequency (n = 62)	%
Positive Attitude Items		
We are willing to use new interventions to help the population we serve.	40	64.50
We are willing to use innovative and different interventions developed by scientific investigators.	40	64.50
We are willing to use new interventions even if we have to follow a manual.	37	59.60
We will try to use new interventions even if they are very different from what we are accustomed to using.	34	54.80
Negative Attitude Items		
We know better than a scientific investigator the interventions/programs that our population needs.	17	27.40
The day-to-day experience with the population we serve is more important than EBPs.	14	22.50
Interventions based on evidence are not useful.	2	0.03
We will not use evidence-based programs.	0	0.00