Published in final edited form as:

Health Promot Pract. 2010 November ; 11(6): 876–887. doi:10.1177/1524839909335803.

Strategies for Assessing Community Challenges and Strengths for Cancer Disparities Participatory Research and Outreach

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Tampa Bay Community Cancer Network Community Partners

Abstract

Interventions involving community–academic partnerships must be driven by a participatory approach that is informed by a comprehensive understanding of the perspectives of communities or focus populations. Often research agendas of academics are different from perceived priority needs of community members. Successful and sustainable interventions are made possible with initial open dialogue among all collaborators so that roles are clearly defined and concerns are addressed. This article describes approaches used in the development of a participatory assessment of health and social issues as defined by community and academic partners, current findings, and lessons learned. The assessment is one initial activity of the Tampa Bay Community Cancer Network (TBCCN) to guide network directions through 2010. The TBCCN is one of 25 programs nationwide addressing cancer disparities through sustainable community-based participatory research, outreach, and screening activities.

Keywords

health disparities; community–academic partnerships; community networks program; community assessment; community-based participatory research

Community-based participatory research (CBPR) emphasizes the key concept that improvements in public health are most successful when community members are involved in the full spectrum of action: from problem definition, to intervention, to evaluation and when interventions address an array of social and economic factors (Baker, Homan, Schonhoff, & Kreuter, 1999; Minkler & Wallerstein, 2003; O'Toole, Aaron, Chin, Horowitz, & Tyson,

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2003). The goal of CBPR is to increase knowledge and understanding of a given phenomenon (i.e., address basic research questions) and to apply the knowledge gained to guide the development of interventions, policy, and social change aimed at improving the health of the community (Israel, Schulz, Parker, & Becker, 1998; Minkler, Blackwell, Thompson, & Tamir, 2003). This article details the application of CBPR to the process of community assessment through a unique academic–community partnership focused on the problem of cancer health disparities in the Tampa Bay area. Specifically, the article discusses the application of a CBPR approach to better understand community partners' expectations of the Tampa Bay Community Cancer Network (TBCCN) collaboration, the community partner–defined cancer concerns and priorities, and the partners' cancer education and training needs.

BACKGROUND

The TBCCN is one of 25 programs in the United States funded by the National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities with the focus of increasing community participation in preventive cancer screenings, improving education and awareness about cancer prevention and control, and developing CBPR projects with community-based organizations to address cancer disparities. This local network aims to positively affect cancer disparities by addressing critical access, prevention, and control issues that influence medically underserved, low-literacy, and low-income multiethnic populations in selected areas of Hillsborough, Pinellas, and Pasco counties in Southwest Florida.

Network Development

The TBCCN is composed of a variety of community-based organizations (CBOs), including grassroots organizations, health-focused nonprofits, faith-based organizations, adult literacy groups, and community health centers, that collectively provide an array of resources and services to local medically underserved populations. The TBCCN was formally developed in response to a funding opportunity issued by the NCI. Academic investigators at the cancer center became aware of the funding opportunity, and contacts with CBOs ensued to convene a gathering to gauge community interest prior to working on the grant application. Most of the CBOs approached for the new network already had established affiliations or working relationships with the cancer center but without a formalized structure.

Before TBCCN's formal creation, leaders of these organizations were invited to convene for an open-forum discussion at the cancer center about collaborating on community-based cancer intervention initiatives. At this forum, the academic partners explained in detail the proposal process for project funding and described the types of collaborative activities that could be funded by this mechanism. After this initial presentation, the floor was opened for questions from all meeting participants. Questions covered topics such as time and resource expectations from community partners, long-term objectives in attenuating health disparities in the communities served by the organizations, and health care access (e.g., screening and timely follow-up care) for community members who were under- or uninsured.

The ensuing discussion allowed for the development of a list of topics for the academic investigators to ask of the funding agency. Meeting attendees also discussed potential collaborative projects, which included outreach activities and community-based research with potential community benefit and impact of cancer disparities. Specific examples included developing culturally relevant and literacy-appropriate cancer education materials, cancer education delivery by community health workers, and community-based screening at health fairs. After the open discussion, all meeting participants were asked if they believed that a proposal should be submitted. Meeting participants agreed that funding should be sought but that collaboration should proceed regardless of project funding, as community need was significant. Meeting participants further agreed to meet on a quarterly basis for approximately

9 months prior to notification of the grant award. These initial meetings allowed for rapport to be developed, for organizations to know one another, and for outreach and education activities to be organized with both established and new community partners. Meeting minutes were kept for each meeting and distributed to partners in electronic and hard copies per their preference. Thus, based on positive feedback that was generated from these meetings, a common bond was formed to create the network for addressing the health disparities gap among the medically underserved in a tri-county area.

The project was funded, and meetings of community organization leaders and academic partners continued on a quarterly basis. A memorandum of understanding (MOU) between the cancer center and each community partner was required by the funding agency and outlined the minimal conditions for involvement in the network during the course of this 5-year project. In addition to helping consolidate and formalize the partnerships, the MOU provided clarity regarding co-equal participation of community partners and the cancer center. Conditions of involvement included taking part in at least three of four meetings per year and in the partner assessment, which had the goal of compiling descriptive and opinion-based information for each partner organization. An additional component was having someone from each organization attend the TBCCN Annual Retreat at the cancer center that gave all partners an opportunity to network with one another, to report on current activities and accomplishments, and (for the academic investigators) to report any communications from the funding agency.

During the 1st year of the project, a community partner assessment was completed to determine network priorities and felt needs. In keeping with the underlying philosophy of the TBCCN, the assessment was participatory in design. It focused on both strengths and challenges as perceived by community partners surrounding group-identified health and social service themes relevant to communities and to the broader task of addressing cancer disparities. The community partner assessment was a critical first step toward achieving TBCCN's broad, long-term goal to develop interventions, policy, and social change aimed at improving the health of the community. As the TBCCN grows, we anticipate that some partner organizations may join whereas others may take a less active role, as resources for nonprofit organizations constantly change. These transitions may be accompanied by new challenges (e.g., greater diversity in type of organizations, resources, and enthusiasm to participate), making consensus difficult. Thus, additional criteria and processes for conflict resolution may be needed. In the meantime, consensus is achieved through flexibility, inclusion, and focus on the important goal of reducing cancer disparities. We continue to use this successful approach, adapting it as needed, to ensure that consensus is reached among partner organizations to define future TBCCN activities and priorities. The following section describes how the community partner assessment was developed and implemented.

METHOD

Efforts to positively affect health disparities work best when community members are involved from inception to evaluation (Schensul, 1994; Travers, 1997; Wallerstein & Bernstein, 1994). Because discussion about cancer often invokes fear responses and avoidance of much needed education and awareness, it is especially critical that cancer disparities research and outreach efforts engage community members for program sustainability and improved community health outcomes (Baquet, Hammond, Commiskey, Brooks, & Mullins, 2002; Bigby, Ko, Johnson, David, & Ferrer, 2003; Institute of Medicine, 2003; Meade & Calvo, 2001; Wolff et al., 2003). Recognizing the importance of learning from the experiences of the TBCCN partners and existing data (population and health statistics, prior community needs assessments), the network used a two-stage approach.

The first step was to conduct an assessment of community partners to (a) develop a detailed profiling of each partner organization's mission, clientele, expectations, resources, and strengths; (b) identify the partner's perceived priorities and the needs of the community it serves; and (c) identify and prioritize the partner's cancer education and resource needs. The second step involved geographic information systems (GIS; Bell, Hoskins, Pickle, & Wartenberg, 2006) mapping of resource information obtained from community partners and health statistics from various existing data sources. GIS allows for mapping and spatial visualization of distribution and availability of cancer-related resources using maps that can precisely locate the available resources or show concentrations of populations, disease, or specific problems of interest in a geographically defined community (Bell et al., 2006; Glantz & McMahan, 2007). This step is currently under way and will be the focus of a future publication, but it is expected to provide a powerful tool for the network to visualize gaps in distribution of cancer-related services in medically underserved areas of the TBCCN collaboration.

We aimed to interview 20 key informants, including a representative from each partner organization. Key informants had strong social and cultural ties to under-served populations and were knowledgeable about the issues and needs in their community. The information gleaned from the assessment was expected to inform the next steps and decisions about future research, education, intervention, or policy initiatives aimed at addressing cancer disparities in the community.

Instrumentation

Congruent with a participatory approach, the draft interview guide instrument and procedures for the community partner assessment were based on review of the literature (Beverly, Mcatee, Costello, Chernoff, & Casteel, 2005; Mizoguchi, Luluquisen, Witt, & Maker, 2004) and developed with the co-equal participation (Israel et al., 1998; Macaulay & Ryan, 2003) of all TBCCN community partners during several face-to-face sessions to allow full input and participation of the community and academic collaborators. The draft instrument was pilot tested with four organizations (health care and non-health care) representing the diversity of the TBCCN partnership to make sure the questions were relevant and the interview instrument was of acceptable length. The resulting structured interview guide was composed of a combination of open-ended and closed-ended questions covering six general categories: organizational information and expectations, characteristics of client population, identification of community assets and strengths, perceived priority concerns, perceived education and training needs, and other relevant and important documents. Content validity of the interview guide was determined by consensus of the community partners and academic collaborators. Recognizing the diversity in community partners, the instrument allowed for skip patterns or opt-out options if questions were irrelevant or difficult for a specific organization to answer accurately. For example, some community advocacy organizations felt it was not feasible to provide an aggregate number of individuals served as their clients were often consortiums of organizations. The instrument allowed them to either state the number of organizations served or respond "not applicable," or provide qualitative responses. This flexibility in data collection was an important aspect of recognizing the diversity in partners and the inherent challenges and also served as a consensus-building tool. The open-ended question format also allowed us to capture the diversity of responses and different contributions of our diverse partners. The final instrument was reviewed and approved by the IRB before initiation of data collection by telephone interview with waiver of documentation of written informed consent.

Data Collection Procedures

In keeping with the participatory principles of CBPR (Macaulay & Ryan, 2003; Minkler, 2000; Minkler & Wallerstein, 2003; Mizoguchi et al., 2004; Robinson-Pant, 2001), the

methodology for data collection was developed collaboratively. The network determined that the key informant approach was best suited for this assessment and that at least one person in a leadership role from each organization should be designated as the respondent. Although in-person individual and group interviews were preferred by the academic partners, the community partners strongly preferred a telephone interview because of personal and organizational time constraints. Investigators accommodated community partners' needs and instead prepared a structured interview to be administered by telephone at a time convenient for each community participant. This method allowed for greater completeness of data (compared with self-administered, mailed questionnaires) while retaining the ability to audio-record the interview to improve accuracy of data capture.

The interviews were conducted by two teams of interviewers experienced in mixed methods research (qualitative and quantitative). Each interview was administered by either a faculty investigator or an experienced pre-doctoral researcher, accompanied by two trained research associates serving as recorders. The two research associates, both experienced data collectors trained in the specific procedures for this project, were graduate students in public health and participating members of the TBCCN project. After identifying the individual respondents (key informants) for each of the 20 community partner organizations, an introductory letter describing the purpose and logistics of the assessment was mailed (and e-mailed) to the potential respondents. A copy of the interview guide was included with the letter. The letter was developed with inputs from community partners and stressed on confidentiality, privacy, and ethical considerations related to data collection procedures and use of the data. Each interview was completed by telephone at a scheduled time convenient to the respondent. The respondents were encouraged to collect data in advance to facilitate the interview process. During the interview, the interviewer asked each question verbatim per the interview guide and the research associate wrote the responses directly onto the guide. The respondent was asked to have his or her copy of the interview instrument available and follow along as each question was asked. An audio recording of each session was made and reviewed to assist and improve data capture. The interviews lasted between 45 and 60 min. The interview team debriefed after each interview, and the audiotapes were reviewed. This debriefing meeting was essential to determine edits before the data were coded and entered into databases, which were developed and managed with the help of a biostatistician. The data were entered into two separate computer files, one containing open-ended questions (MS Word) and the other containing quantitative data (Excel).

Data Analysis

Responses from open-ended questions were organized by question and analyzed using content analysis procedures, including grounded theory (Bernard, 2006), by two experienced researchers. After reviewing responses and identifying common themes, the two researchers developed summary tables of the data for each question using a consensus approach by two researchers. Responses from the quantitative questions were summarized by tabulating the number (%) of respondents and graphical illustrations. SAS (v.9.3. SAS Institute, Cary, NC) was used for the data analysis. As a further check of the validity of the data, descriptive summaries of both qualitative and quantitative data (tables, graphs) were presented and discussed with the TBCCN partners on multiple occasions, including a half-day retreat.

RESULTS

This article summarizes findings related to community partner organizations' services and expectations, partners' perceived priority concerns, and partners' expressed needs with regard to cancer education and training. Nineteen of 20 community organizations completed the interviews. One organization did not complete the interview because of workload burden and

privacy concerns. Thus, we had a 95% response rate. The service profile of the organizations is summarized in Table 1. The areas of service these organizations focused on included primary health care (32%), health education (26%), advocacy (11%), cancer-related services (support groups, camps; 11%), and various other services (21%). However, the majority of organizations provided multiple services, including health education (84%), advocacy (68%), and primary health care (42%).

Organizational Expectations

The community partners expressed strong and consistent enthusiasm for their involvement in the TBCCN partnership. The following sentiments represent how one respondent felt about involvement: [TBCCN] is the “brain trust of the group. Each organization has own expertise. We can't all be experts in everything. We will learn from each other.” Other respondents expressed the following about involvement in the partnership: “to be made knowledgeable of other partners so that [*name of organization*] can collaborate with other partners to reach as many patients as possible.” “Exchange of ideas; it's a two-way relationship.” The organizations also articulated clear expectations (expected benefits from the network) and notable contributions to the collaboration. When asked how their organization expected to benefit from the TBCCN collaboration, two types of benefits—material and ideational—emerged. With regards to material benefits, the partners wanted to see improved access to clinical care, preventive screening, and follow-up. They also hoped to link to services provided by other TBCCN partners. Other material benefits are included in Table 2. Regarding ideational benefits, the partners viewed the TBCCN collaboration as a platform for knowledge and idea exchange among the partners. They expressed the sentiment that being one of several TBCCN partners provided them a sense of group solidarity and also the strength needed to reduce cancer health disparities in the communities they serve. For example, one community partner felt that the TBCCN collaboration allows for “building relationships to have one united voice, . . . strengthening older relationships and . . . better understanding of access issues in health care.” There was overwhelming agreement that the partners have critical contribution to the collaboration, with a rich knowledge of the community, long history of service, connectedness to existing social capital, and trusted reputation and expertise in their communities. Specifically, one community partner expressed the following: “[For] 30 years, [*name of organization*] has been in the community. We know what the needs of the community are, and also know the strengths. We can assist in [training] cultural sensitivity with this population to other organizations.”

Perceived Priority Concerns

Respondents were asked to identify and rank the importance of perceived (in their opinion and/or experience) priority concerns of the communities their organization served in three areas: general concerns (health and social), cancer-related priorities, and cancer information needs.

General concerns and priorities—The top general concerns were improving access to health care and services (42%), providing affordable health insurance (26%), and increasing the public's awareness of services offered in the community (21%). Cancer-related care was not specifically mentioned in these responses even after probing for additional concerns. For example, the most frequent services mentioned were dental health services, transportation, and language translator services. Results are summarized in Figure 1.

Cancer-related concerns and priorities—When specifically asked about their perceived cancer-related concerns for the community their organization serves, a pattern somewhat similar to that of general concerns emerged. The top priority areas of concern regarding cancer were availability of cancer-specific education (53%), improved access to cancer care and related services (32%), and access to affordable health insurance (11%). Regarding cancer-

specific education, the most frequently mentioned cancer types were breast, prostate, colorectal, and lung. Results are summarized in Figure 2.

Cancer information needs and priorities—Breast cancer–related information and materials and awareness for the general public emerged as the top (42%) area of cancer information needs. The other cancer information needs were related to increasing the public's general awareness and access to cancer information and materials (26%), followed by availability of literacy-appropriate and culturally relevant cancer information (16%) and education materials for cancer types (10%) other than breast cancer. These results are summarized in Figure 3.

In early discussions about possible ways to increase access to cancer education materials in the community, the partners proposed creating cancer information stations in the community at selected service sites of the partner organizations. The cancer information stations would be stocked with educational materials obtained from the National Cancer Institute's Cancer Information Service (CIS) and the American Cancer Society or produced by the TBCCN to fill special populations' linguistic needs (i.e., Spanish, Haitian Creole). A shared role for the cancer center–CIS research partnership was developed to provide enhanced access to these key resources, which allows for these materials to be obtained in a timely manner. The current assessment also sought to determine the level of interest in cancer information stations and whether space was available at the partner organizations' sites to house the cancer information stations. Sixty-eight percent of respondents were very interested in creating the information stations in the community, and 21% were somewhat interested. When asked about availability of space at their organization's community site, 35% reported that space was available and 47% said they would explore the possibility of making space available.

Perceived Cancer Education and Training Needs

Community partners were also asked to identify and rank in order of priority their interest in receiving specific cancer education and training to increase their organization's capacity to reduce cancer health disparities. Eight training and education workshops were identified as priority areas by more than 50% of respondents. The top three priority workshop topics endorsed by 74% of respondents were developing low-literacy materials, finding grant funding, and how to help the public access community-based cancer screenings. The next four priority cancer education workshops were grant writing (63%), followed by Cancer 101, new cancer treatments, and clinical trials education, each endorsed by 58% of respondents. The prioritization and ranking results are also summarized in Figure 4.

DISCUSSION

A fundamental goal of CBPR is to increase knowledge and understanding of a given phenomenon (i.e., address basic research questions) and facilitate solutions to problems facing communities (Minkler, 1997, 2000; Minkler & Wallerstein, 2003; Schensul, 1994). Through our TBCCN assessment, we were able to understand factors that may contribute to addressing cancer health disparities by answering three primary research questions concerning (a) community partners' expectations of the TBCCN collaboration, (b) defined cancer concerns and priorities, and (c) cancer education and training needs. This community partner assessment identified a clear need to increase availability and accessibility of services for underserved communities and highlighted distinct community capacity, education, and training needs.

Although collective data-gathering techniques (e.g., focused group interviews) might have yielded additional valuable information, we understood our community partners' time and resource constraints for in-person interviews and deferred to their requests for telephone interviews. Interview responses revealed recurrent common themes. For example, an

overarching and predominant theme from the current findings was the need to identify and make accessible services that benefit the community directly. The information obtained through this participatory assessment will serve as the basis of interventions, policy, and social change aimed at reducing the burden of cancer in underserved communities.

A focused, participatory approach in this assessment emphasized better understanding of the community partner's services, expectations, and contributions to the collaboration rather than focusing solely on deficiencies as in standard needs assessments. As stakeholders, community partners must be able to take part in the intervention process from problem definition, to implementation, to evaluation. This process helps build community capacity, foster ownership of data, and enhance collective community empowerment to effect positive social change, including attenuating health disparities in marginalized populations. This approach also allowed for identification and highlighting of positive community attributes to be brought into relief for addressing health disparities while also allowing community partners to define their most pressing perceived cancer education and training needs. This assessment approach also capitalized on the extensive knowledge of community partners as stakeholders, collaborators, and participants in the research.

Community Partner Expectations

Regarding partner expectations and potential contributions to the network, our findings have reinforced two important values of community–academic partnerships. First, TBCCN partners want to see improved access to services through a combination of new services provided by the TBCCN organization as a whole while also capitalizing on existing resources available through other partners within the TBCCN. Our findings are consistent with the cancer center's overall strategic plan for increasing access to underserved communities, which includes a focus on provision of culturally competent prevention and treatment and engaging community members in the process of intervention design, implementation, and evaluation to enhance outreach and screening effectiveness. In addition to enhancing its ongoing community outreach and education efforts, the cancer center has embraced these findings and is working on several new or expanded initiatives to improve access to a broad spectrum of prevention, screening, diagnosis, treatment, and aftercare services for medically underserved individuals.

Although the network embraces research, a clear and unequivocal goal is to improve access to clinical and preventive services. These findings align with the principles of distributive justice, wherein equal access to the benefits of health is a critical component of the social lives of community members. Thus, academic partners must frame and operationalize research objectives in ways that respect and achieve this goal—research that is important to and benefits the community directly.

Cancer Concerns and Priorities

To increase access to cancer-related services, the TBCCN is taking a multipronged approach. First, a referral directory identifying cancer education; preventive, screening, diagnosis, and treatment services; and follow-up care (support groups and other survivorship programs) and the logistics of how to access them will be developed and shared among current and future partners involved with medically underserved populations in the TBCCN geographic area. This initiative may ultimately lead to policy and evaluation research to assess the utility and efficacy of an established referral network on increasing access to and use of cancer-related services. Evaluations of the impact of the referral network directory and related efforts on reducing cancer health disparities have been carefully planned and integrated into these efforts. In addition, systematic GIS mapping of cancer-related resources in the tri-county area of the network is under way. Another NCI effort under way at the cancer center, the Patient Navigator Program (Freeman, 2006), includes partners who have expressed many of the same sentiments

about reducing disparities and meeting community needs. As such, the TBCCN and Navigator programs are in discussions to promote synergy in outreach, screening, policy, and research efforts.

Cancer Education and Training Needs

In the current assessment, the community partners identified education and training needs but also pointed out unique strengths as co-equal partners in the education collaboration. For example, some partners will contribute expertise in the development of literacy- and language-sensitive educational materials and will cofacilitate cancer education workshops when their expertise and resources allow. Current findings have directed the implementation of workshops on such topics as grant writing and development of low-literacy materials. It further led to the TBCCN's hosting of a Health Literacy town hall meeting in collaboration with the Florida Department of Health and Social Services.

The current findings also point to another important but underappreciated value of community-academic partnership—that communities have valuable experiences and resources that should be viewed as assets in these types of collaborations. Certainly, sustainability is more likely to occur when existing community assets and resources are recognized and community capacity is enhanced. Thus, the TBCCN network has identified several initiatives out of these findings. Another important perspective of our findings is the need to increase community-partner capacity through cancer education and training, and by enhancing information resources in the community. Addressing health disparities through community-academic partnerships requires significant capacity building for both community and academic partners.

The results of the current assessment provide many lessons that have direct implications for the TBCCN network and others involved in similar efforts nationwide. We summarize these lessons below and offer insight into how the network might proceed to develop practical solutions with direct implications for reducing health disparities. Despite the small number of respondents ($n = 19$), the current findings are robust in two ways: (a) the results are based on real-world cultural experiences of community partners committed to addressing the problem of cancer health disparities and (b) the potential solutions derive from similar levels of pragmatic enthusiasm to connect partners and maximize resources within the network. The network recognizes that no one organization alone can effectively address the complex challenges of health disparities without effective collaborations and partnerships.

Lessons Learned and Implications for Sustainability and Reducing Cancer Health Disparities

Much like any partnership endeavor (Kone et al., 2000), the TBCCN collaboration has experienced many positive lessons and challenges worth noting. However, for the purposes of illustration three key lessons learned in implementing the community assessment are summarized below. Although not an all-exhaustive list, these highlighted perspectives show how the TBCCN network embraced CBPR as a solution to the challenges of reducing cancer disparities. In addition, tremendous synergy between and among partners has emerged as demonstrated by the number of new interorganizational collaborations taking place.

1. Community partners as stakeholders, collaborators, and research participants—Our collaborative efforts in defining tangible roles, representation, and ensuring the involvement of community partners were critical to the success of this assessment as documented elsewhere (Kone et al., 2000). The involvement of community partners as collaborators and key informants in the assessment helped the network not only in understanding the partners' expectations, perceived priorities, resources, and assets but also revealed a sharp focus by community partners on the most fundamental aspect of the collaboration—to develop initiatives of importance and direct benefit to community. The

partners, serving as collaborators and key informants, remained thoughtful about the singular goal of reducing cancer health disparities by improving access to services. Therefore, as participants in the research (assessment) the partners were meaningfully engaged and steered the process in ways that could only maximize community benefit rather than only benefit the researchers or academic partner (Kone et al., 2000). Nevertheless, community partners also recognized the need to balance community benefit and the need for academic rigor, and the contractual and regulatory requirements that at face value seem to detract from service delivery. Most important in this balancing process was the patience of community partners as the project faced inherent delays related to funding processes, institutional review, instrument development, and the iterative co-equal participatory processes of CBPR. Perhaps the two challenges requiring the greatest learning curve were the memorandum of understanding (MOU) and the institutional review. Specifically, the academic partner gained greater appreciation of the complex and intricate nature of executing MOUs in the context of a research project involving numerous and diverse community-based organizations. Similarly, the MOUs presented an additional intriguing conceptual paradox between contractual expectations versus voluntary participation in research. By virtue of signing the MOU, community partners were consenting and were obligated to participate in the assessment according to the terms of the MOU. Yet on the other hand, the assessment was considered to be research not operations, thus requiring informed consent process. Thus, the network collaboration was faced with the question whether participation of community partners in the assessment was truly and meaningfully voluntary. Without question, the community is best protected when the informed consent process is followed and voluntary participation is achieved. Ultimately, both issues (MOU and informed consent) were appropriately addressed through IRB review and approval of the parent grant and assessment as a research project and when voluntary participation was upheld.

2. Where does cancer prevention and research fit with community priorities?—

To locate the priority of cancer health disparities prevention and research in the context of the community's most pressing priorities, the network developed a two-tier question. A basic objective was to determine how community partners perceived the significance of cancer in the bigger picture of community needs and priorities. This research supported our initial thinking that cancer health disparities was not a primary community priority. A key message from our findings is that the community wants cross-cutting solutions designed to address the fundamental access barriers fueling health disparities more broadly, not just cancer disparities. Thus, our findings pointing to the need for improved access to care require solutions that transcend the social, general health, and cancer-related sources of disparities. Essentially, the TBCCN collaboration will propose solutions that are rooted in a broader systemic context instead of narrowly directed fixes concerned only with reducing cancer disparities.

3. Should the academic partner (a comprehensive cancer center) do more in the collaborative?—

Perceptions of imbalance of resources between the community and the academic partners must be addressed honestly, fairly, and equitably. This includes discussing and sharing of the financial resources awarded by the grant as well as bringing to bear other existing resources outside the funded partnership grant. Specific to this context, the cancer center has joined resources with partners to assist them in obtaining their own grants. Improving access to funding for partner organizations through assistance with grant writing and connection to funding opportunities can only benefit and boost the network resources. In fact, the TBCCN was awarded monies from the Prevent Cancer Foundation that was distributed to network partners to produce and distribute relevant cervical cancer education for their client populations. Hence the cancer center's commitment and investment in these resources and leveraging processes are critical to the sustainability of the partnerships.

Another critical aspect of increasing access to services is the commitment by the cancer center to facilitate navigation of community members to education, screening, diagnosis, treatment, and follow-up care. Certainly, this does not entail that the cancer center bears the sole responsibility; rather, the navigation model should include access to cancer center and community-based resources as appropriate. The TBCCN partnership aims to develop or improve linkages to services where they already exist (to be meaningfully accessible to community members) or create new opportunities through expanded partnerships and resources, including promoting synergy with the Patient Navigator Program in place at the cancer center. These paradigms of increasing accessibility, acceptability, and affordability are not new but certainly require careful reexamination and thoughtful implementation in the context of new partnerships such as the TBCCN.

Summary and Future Directions

The TBCCN network has benefited from the partner assessment and specific findings and recommendations for improving access to services and resources for reducing cancer disparities. The network is moving forward with training, cancer education initiatives, and cancer information stations to improve community capacity. Similarly, initiatives are under way to develop GIS maps and implement resource directories with the specific goal of improving access to cancer-related resources for underserved populations. Additional efforts are required to better delineate future initiatives and to evaluate and realize their impact. Consistent with the research goals of the network, pilot projects are now under way and possible projects are being considered to develop interventions to improve access to cancer-related services. The strong focus on community benefit, co-equal participation, commitment of new resources and initiatives by the cancer center and some community partners, and new interpartner collaborations strengthen the prospects of sustainability of the TBCCN collaborative beyond the current funding period.

Community benefit from cancer education and related resources and services and sustainable infrastructure are direct measures of community empowerment resulting from this funding opportunity. An important element of measuring long-term outputs and benefits is the implementation of an elaborate evaluation data collection system in which all partners may meaningfully contribute. As such, durable measures of success (reducing cancer health disparities) and community empowerment may become evident from evaluation data over time, as the network endures and benefits from the new infrastructure and organization and as collaborative efforts are realized. Although our current efforts have attempted to build and enhance community competencies for cancer education and control to reduce disparities, the network could benefit from a more systematic assessment and attention to the organizational competencies required of the participants to ensure an effective outcome. Thus, future network assessments and evaluation data should include attention to empowerment and community competencies (Fetterman & Wandersman, 2004) required for effective and sustained impact on cancer disparities from both community and academic perspectives. This may entail collection of new data elements and delineation of additional items in the MOU documents.

In summary, the TBCCN partner assessment has provided practical lessons and outcomes for addressing cancer health disparities. Although much remains to be implemented and realized, the TBCCN network will use this assessment to move toward long-term community engagement in reducing cancer disparities.

Acknowledgments

The project described was supported by Grant U01 CA114627 from the National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities, Community Networks Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NCI.

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FIGURE 1.
Perceived Top General Community Concerns and Needs

FIGURE 2.
Perceived Top Community Concerns and Needs Regarding Cancer

FIGURE 3.
Perceived Top Community Cancer Information Needs

FIGURE 4.
Ranking and Prioritization of Partners' Education and Training Needs

TABLE 1Summary of Services Provided by Community Partners and Organizations ($N = 19$)

Service Type	Distribution of Main Focus, n (%)
Primary health care	6 (32)
Health education	5 (26)
Advocacy	2 (11)
Cancer-related services	2 (11)
Other services	4 (21)

TABLE 2**Partner Expectations for Collaboration Benefits**

Material Benefits	Ideational Benefits
<ul style="list-style-type: none"> • Improved community access to clinical care, preventive screening, and follow-up care and tapping resources of all partners • Desire to increase education and awareness in the communities they serve • Getting technical assistance for organizational development and grant writing and supportive help with their activities • Networking with other partners and volunteers 	<ul style="list-style-type: none"> • Platform for knowledge and idea exchange among partners • A sense of group solidarity and strength in numbers as partners of the Tampa Bay Community Cancer Network