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Community-Academic Partnerships: Approaches to Engagement

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Abstract

Current public health problems such as cancer have an expansive set of lifestyle and social circumstances that impact the cause and course of the disease. In response, over the past 7 years, the National Cancer Institute has recognized the important role that cancer centers play in their community and has gradually increased the requirements and stringency of these sections in the Cancer Center Support Grant guidelines to include a plan for community outreach and engagement. Developing sustainable community-academic partnerships is an essential factor for the successful dissemination and implementation of promising interventions and programs aimed at decreasing barriers and improving cancer outcomes. Understanding how best to facilitate linkages and collaboration can expedite translation of research knowledge into practice and allow more evidence-based improvements to be implemented into practice as well as influence research agendas. This paper will examine several examples of successful community-academic partnerships focused on cancer prevention and control and explore lessons learned.

Introduction

While increased attention has been paid to cancer disparities and their influence on patient outcomes, interventions to eliminate disparities have been largely limited in reach and sustainability.¹ One reason is that historically it was not common practice to tailor interventions to marginalized populations whose problems they are meant to address.² As a result, more community-academic partnerships have emerged in the past decade as a way to improve local health concerns and reduce health disparities.³ It is becoming clear that these types of partnerships and coalitions are necessary in developing lasting health promotion and wellness across communities because no single entity has the resources, access, and relationships to address the wide range of problems and social determinants of health.^{4,5}

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Tweet

An examination of successful community-academic partnerships focused on cancer prevention and control and lessons learned

Current public health problems such as cancer have an expansive set of lifestyle and social circumstances that impact the cause and course of the disease. Consequently, they require a multifaceted approach to address the complexities associated with cancer and its sequelae.⁶⁷

Academic research and programs often fail to be translated from university-based development to real world application. Alternatively, community organizations often lack an investment in academic research, stating different needs than those addressed by the researchers.^{3,8} The knowledge gap between research and community practice is evident. Thus, developing enduring community-academic partnerships is an essential factor for successful dissemination and implementation of promising interventions and programs, particularly for complex public health issues such as cancer prevention and control. Moreover, involving community partners has been shown to improve communication and trust, produce valuable innovation, and decrease marginalization of communities that have historically not benefited from research participation.^{4,9,10} Understanding how best to facilitate linkages and collaboration can expedite translation of research knowledge into practice and allow more evidence-based improvements to be implemented into practice as well as influence research agendas.

Although the importance of community-academic partnerships is apparent, and there has been a recent push by funding organizations (both national and local) to encourage community-based research, a successful partnership that is sustainable requires a systematic strategy and long term commitment that exceeds a simple community outreach strategy.^{3,7,9} The partnership must include academics, practitioners, patients, and community members who are committed to creating an environment of co-learning and capacity building in which findings and knowledge benefit all members. This paper will examine several examples of successful community-academic partnerships focused on cancer prevention and control and explore lessons learned.

New NCI Cancer Center Support Guidelines (CCSG) with a community engagement mandate for academia

Over the past 7 years, the National Cancer Institute (NCI) has recognized the important role that cancer centers play in their community and has gradually increased the requirements and stringency of these sections in the Cancer Center Support Grant (CCSG) guidelines.¹¹ Whereas previously community outreach and engagement were often overshadowed by the novelty and clinical impact of scientific programs at the center, in more recent years, lively discussions by external advisors and site visitors often focus on the extent to which the center defines and provides benefit to their catchment area. The idea of a population-based catchment area (CA) and its requirement was the initial step with the NCI mandate that centers define and justify the geographic areas they serve using census tracts, zip codes, county or state lines, or other geographic boundaries including the local area served by the center.^{12,13} Although the concept of CA would seem like an obvious component of a cancer center, in fact, this requirement challenged many centers at the beginning due to disparate access of underserved or rural communities to the center. More recently, the NCI has expanded this concept to a requirement for a 12-page section of the CCSG entitled

“Community Outreach and Engagement (COE)”. This section expects the center to not only define their CA, but to specifically articulate how they are conducting research relevant to their CA, for example, focusing on diseases and populations that are disproportionately affected, and to demonstrate their impact on cancer incidence and mortality, including among minority and underserved patients. Further, the center is anticipated to develop relationships with other health care delivery, state, and local health agencies to collect and disseminate findings and provide the evidence base for changes in cancer health policy beyond the CA. Examples of such efforts abound at centers across the country and include programs to promote and amplify efforts targeting Human Papillomavirus (HPV) vaccination, tobacco cessation, colorectal and breast cancer screening, obesity, and physical exercise, among others.¹⁴ A particularly challenging aspect of the CA is to demonstrate adequate enrollment consistent across the CA to therapeutic clinical trials, not just to tissue acquisition studies. This has led to an increasing awareness of racial and ethnic disparities in clinical trial participation, which fortunately is moving beyond description/definition of the problem towards development and deployment of evidence-based methods to better engage diverse populations.^{15,16} The review metrics for this new required COE section includes how well the center defines and justifies its CA; identifies and leverages the CA for relevant research questions, particularly addressing underserved populations; and how the center intends to expand its reach beyond the CA. In summary, these new NCI requirements formalize and consolidate efforts that have been integral to all NCI-designated Cancer Centers for decades, but by moving to the forefront have paved the way for continued development of COE programs and perhaps as the next step, appropriate metrics that centers can track for effectiveness.

Qualitative Patient Experience Data in Support of Community Academic Partnerships

While the previous section outlined some incentives for cancer centers to seek partnerships with communities, this section complements this discussion by presenting the voices of patients; thereby, further emphasizing the importance of these partnerships. As part of a larger community-academic outreach project¹⁷, the lived experience of African American women who did not engage in care for a breast tumor within six-months (and in some cases more than a year) following the identification of a breast abnormality were captured during a qualitative study. The implementation of this study allowed the primary investigator to engage in research and give a voice to women who are often under-represented in previous scientific studies and cancer center catchment areas, further informing existing models of community outreach and engagement.

Data collection for this study employed the use of an in-depth open-ended interview with participants. The method of phenomenology was employed and involved allowing narratives of lived experience to emerge as naturally as possible¹⁸. The principal investigator concentrated on what was shared as experience before following up with more specific questions about the phenomenon. According to the literature on phenomenological methodology, data is gathered around two general questions: What have you experienced in terms of the phenomenon (health decision making process as it relates to follow up care for

breast cancer)? And what contexts or situations have typically influenced or affected your experiences of the phenomenon (health decision making process as it relates to follow up care for breast cancer)?^{18,19}

Key findings suggest that engaging communities in health care decision making provide academic institutions a better understanding of social determinants that persist within socially-isolated and geographically-isolated communities. Exposure to chronic traumatic events (such as urban and rural poverty), life events (such as unemployment or under-employment or caring for a sick parent or child while working full time), or poor-quality built environment (neighborhoods with vacant buildings and areas of high crime), increases individual level distress. Individual level distress over time has been linked to mental health, isolation, morbidity, and mortality and health. Also noted was the influence of chronic traumatic events on psychosocial variables (such as self-efficacy, security, quality of life) and their mediating or moderating effects on help seeking behavior.

Women reported and took pride in providing a safe and secure home environment for their family. Several women stated that their accomplishments in the home are important to the present and future success of their families and treatment for breast cancer poses obstacles to this stability. Ms. Lynette stated,

With all that is going on up here (Ferguson, MO) who is going to take care of my boys. I'm all they have. I fight for them every day. If I'm too sick [from treatment for cancer] to get out of bed who will fight for them.

The women reported that health care professionals do not acknowledge these obstacles during the provider-patient interaction and yet this is essential in their ability to engage in care.

According to Ms. Cathy:

They (the doctors) wanted to know from me how could you take a bath every day and not notice that you had tumors protruding through your skin. But my children were fed, I took care of my grandmother who is living with me, I worked two jobs to make the rent and helped the kids with their homework. By the time I got in the bathroom to take a bath it would be after 10:00. I would jump in, shower and literally almost pass out being so tired because I worked full time so I didn't pay any attention to my own health because I was responsible for four other people. They didn't seem to care.

Ms. Velma, worried about her husband who is disabled, stated, "I can't afford to be sick. I have to take care of him [pointing to the bedroom where her husband is in bed]. He is counting on me. I have to think about that. It's not just me." While Ms. Helen, who suffers from a closed head injury and has worked part time at Good Will for more than 20 years, was afraid of losing her job if she started treatment. "I didn't know how I would pay for it. What if I lost my job? It was scary"

Women also reported wanting more resources in their communities about breast cancer treatment, side effects from treatment, and patient support services to deal with side effects,

but found none. Women reported having to make these health care decisions with very little information about the side effects of treatment and the availability of resources to help counter these side effects. Ms. Pat stated:

I guess you could say I went into this kind of blindly. I didn't ask enough questions. I found out by chance about reconstruction. I didn't know if I could afford it. No one around me ever talked about it.

These results indicate that future interventions aimed at engaging vulnerable communities in care decisions and improving time to treatment should take into consideration social determinants and include not only the patient and the providers but also the community. Community advocates provide academics with a level of knowledge of the particular needs of an area better than those who do not live there. The voices of the women in this study amplify the need for providers to partner with communities to address gaps effecting timely transitions of care.

While providers bring to the table evidence-based treatment plans, community leaders, non-profits, and primary care providers bring to the table the language and trust of the communities they serve. Incorporating these partnerships as a type of barrier-focused community-based intervention to assist cancer patients can increase a patient's self-efficacy and knowledge of resources and support and ultimately impact patient outcomes. Although the voices of the women in this study have highlighted the need for effective community-academic partnerships, there is a need to outline the important components involved in implementing effective collaborations. The following sections will discuss two community-academic partnerships that have led to sustainable clinical interventions and improved patient outcomes.

Examples of Community-Academic Research and Partnerships at Cancer Centers

1: Engagement with Rural Appalachian Communities to Improve Cancer Disparities

The purpose of this section is to highlight examples of academic-community partnerships focused on decreasing the cancer burden in Kentucky and its Appalachian region; building capacity and engagement among communities; and improving cancer control outcomes at the state and local levels. Notably, Kentucky has the highest rates of cancer incidence and mortality in the nation; these high rates for the state as a whole are driven by the Appalachian region of the state.²⁰ Indeed, the cancer burden for Appalachian Kentucky residents is disproportionately high compared to non-Appalachian Kentucky residents.^{21–23} This burden includes preventable and screenable malignancies (e.g., lung, colorectal, breast, and cervical cancers). The region faces myriad risk factors that range from behavioral risks such as high rates of tobacco use, poor diet, physical inactivity, and opioid abuse to access to health care issues that may result in lower rates of cancer screening, HPV vaccination, and receipt of quality cancer care to contextual barriers such as the rurality of the region and the unique geology of Kentucky resulting in elevated radon levels and exposure to carcinogenic heavy metals found in coal beds.^{23–27} In addition, the overall socioeconomic status of this unique geographic region is particularly low. Of the 54 counties in Appalachian Kentucky,

70% are classified as economically “distressed”.²⁷ The median income is \$20,000 less than the national average and the poverty rates exceed that of the nation as a whole. There is also a low percentage (14%) of college graduates in this region, which makes cancer-related health literacy even more important.²⁸

One of the first initiatives created by the University of Kentucky Markey Cancer Center (MCC) to alleviate the health disparities in Kentucky, and specifically Appalachian Kentucky, was the McDowell Cancer Network. Over 45 years this community-based outreach program has established statewide resources for cancer treatment, cancer surveillance, community-engaged research, and cancer education and awareness. These programs and resources include the NCI Surveillance, Epidemiology, and End Results (SEER)-designated Kentucky Cancer Registry; the Kentucky Cancer Program, a statewide cancer education program; clinical and research networks affiliated with the cancer center based at community hospitals across Kentucky; and several NCI-funded initiatives focused on capacity building, local coalition development, and community-based participatory research (CBPR) in Appalachian Kentucky, among others. The MCC utilizes a Community Advisory Board (CAB) to receive critical feedback from individuals that represent different constituent groups across the state; the CAB facilitates translation and implementation of science to the community and aids in evaluating our initiatives. Overtime this valuable partnership has led to collaborations with local health departments, federally qualified health centers (FQHC), primary care providers, faith-based organizations, emergency departments, cooperative extension, and pharmacies to deliver evidence-based programming across the cancer care continuum. Herein, we present two exemplars of academic-community engaged work and related partnership and cancer control outcomes across Kentucky.

In 1992, the Appalachia Leadership Initiative on Cancer (ALIC) was established and ran until 2000. The ALIC established community-academic partnerships and supported community-based coalitions that enhanced local cancer awareness and control in Appalachia. Building on ALIC’s foundation, NCI funding assisted in the establishment of the Appalachian Cancer Network (ACN) (2000–2005). ACN further enhanced the sustainability of community cancer coalitions, worked to understand barriers to clinical trial participation, and obtained community insights into increasing cancer awareness among Appalachian residents. ACN’s work lead to the subsequent creation of the Appalachian Community Cancer Network (ACCN) (2005–2015), which is a collaboration of investigators and community partners in five states including Kentucky, Ohio, Pennsylvania, Virginia, and West Virginia. The network promoted and enhanced community-based cancer education and awareness, conducted CBPR, and created mentorship and training opportunities to allow for more efficient and productive involvement between the community and practitioners.²⁹ This historical network provided continuity of engagement over 23 years and provided a foundation for subsequent multi-community, multi-state cancer control initiatives in Appalachia, including implementation of evidence-based cancer screening,^{30,31} obesity prevention,³² patient navigation,³³ and tobacco cessation interventions.³⁴

Another exemplar relates to Kentucky’s improvement in colorectal cancer (CRC) screening rates over a 15-year period. Specifically, CRC screening rates have risen from 34.7% in 2001 to 69.6% in 2016. In turn, CRC incidence rates also fell by 23% and the mortality rate

decreased by 30%. This success was due to a culmination of academic-community outreach and engagement efforts. For example, 15 District Cancer Councils across Kentucky, comprised of health care professionals, cancer survivors, and community leaders helped prioritize and guide local CRC screening activities based on KCR and behavioral and socioeconomic risk factor data along with a menu of evidence-based strategies to increase screening rates.^{27,35} Primary care physicians across the state were further educated on CRC screening modalities, including colposcopy and fecal immunochemical tests (FIT). Several initiatives specifically focused on community-based education and FIT distribution followed by navigation to further testing and treatment as needed.³⁶ Churches also served as an intervention site for CRC education and lay health advisors also promoted CRC screening among their clients in eastern Kentucky. Finally, state-level policies were passed due to strong support from the state's Centers for Disease Control and Prevention-funded comprehensive cancer coalition, the Kentucky Cancer Consortium. These policies included: 1) KRS 304.17A-257, which mandated coverage of CRC screening as a health insurance benefit; 2) KRS 214.540–544, which helped establish the Kentucky Colorectal Cancer Screening Project to provide free CRC screening tests to qualifying individuals via 14 health departments across the state; and 3) KRS 304.17A-257, which ensured coverage of “complete colon cancer screening” based on American Cancer Society guidelines without a co-pay or deductible.

Future MCC initiatives include a focus on the youth in Kentucky and on families more broadly through the development of the Appalachian Career Training in Oncology program for high school and undergraduate students from Appalachian Kentucky. This program is funded through the NCI's Youth Enjoy Science funding initiative and aims to provide students with cancer research experiences in addition to proactive mentorship, career training and coaching, and networking opportunities. Additionally, the program has a focus on training students to participate in community outreach and engagement activities in their home communities. Overall, the goal of the program is to facilitate development of a “pipeline” of future oncology professionals who will matriculate into professional and graduate school and to train students to be change agents within Appalachian Kentucky communities.

An expansion of school health programming is also planned. The *Get Fit. Be Smart. Don't Start.* Program, which launched in July 2015, offers smoking prevention, nutrition, and general health and wellness topics to children of all ages. Program goals are to educate young people on the impact their current health-related decisions may have on later cancer risk and to steer them toward healthy choices. The program also encourages students to take an interest in the health of their parents and grandparents, emboldening the youth to talk to their families about stopping negative health behaviors, such as smoking and eating healthy, and getting screened for various cancers. It is the belief that adults are likely to listen to the children, therefore utilizing their influence as a tool may allow for greater compliance with cancer prevention behaviors. Interactive discussions, educational displays, and cancer site-specific handouts are used in classrooms, school assemblies, health fairs, and summer camps to impart these messages. Since July 2015, the program has reached 2,361 students and 230 parents.

Although much work has been done across the state to decrease the significant cancer burden, the MCC has placed considerable emphasis on the Appalachian region. Designing and implementing evidence-based programs with community involvement and engagement as the primary foundation draws on the social assets and unique community strengths prevalent in the region. These programs have contributed to decreases in the health disparities in Appalachia and Kentucky as a whole.

2: The Role of Social Epigenomic Approaches in Addressing Underserved Populations in Urban Environments: The *Community to Bench* Model

The next example of a cancer center partnering with communities is that of the University of Illinois Chicago Cancer Center (UICC). The UICC is located in a large urban city and integrated within an academic health enterprise that owns and operates a network of FQHCs across this large densely populated urban community. Uniquely, the strategic oversight, direction and operational management for both, the FQHCs and the cancer center converge under one leadership team. As a result, community-academic partnerships are approached as natural extensions of our identity, rather than episodic or compulsory efforts to insert community into a standard framework. This integrated community-academic approach extends the “bench to bedside” language to include the community into the research (“bench to community”). More deliberately, it proposes a bidirectional approach that acknowledges the community as an equal expert as well as strategic thought partners that informs the development and execution of cancer research agendas.

The *Community to Bench* model is best explained through initiatives such as the center’s patient brigade (PB) - a group of community patient advocates and survivors convened to inform the center’s leadership and researchers on their cancer-related, patient-centered outcomes research. The PB also informs existing community-based cancer screening, prevention, education and navigation activities for future interventions; they engage in capacity and relationship building with key stakeholders to better serve “hard to reach” and marginalized populations such as under and un-insured, sexual and gender minorities and those differently abled (living with a disability).

The PB differs from many existing CAB models in that they guide the center’s strategic research planning and mission in addition to advising research foci, design, implementation, and dissemination. They are also unique in the diversity of its members, being truly representative of the populations that are served. However, a most salient, disruptive feature is that the PB was not an “out-reach” from the center to community members, but rather the responsive execution by the center from an “in-reach” of a cancer patient’s vision to be actively at the table, framing the problem. Her voice respectfully heard as an expert on herself and her community context. While individually succumbing to her disease, the legacy of this patient’s voice contributes to the rigor of science in the realization that upstream of the experimental design lies the identification of the problem. The job of identifying the problem is one to be done not by the scientists looking down into the community, but rather by the community informing the scientists.

Methodologically, this approach has two understudied advantages: first, it serves to minimize biases such as persuasion bias – the extent to which repeated exposure to an

opinion (such as that of a researcher) may have an effect on the agent's beliefs.³⁷ Second, it may generate "disruptive intelligence" (new, uninfluenced, information): the idea is that by minimizing the researcher's influence and potentially relaxing the expectations of existing frameworks, new community intelligence will surface that may inform existing research questions or may lead to new ones. Such considerations (how the researcher may influence how the community engages and the information they share) are not evident in most CBPR and other community engagement approaches. In our quest to elucidate the role of social epigenomics on cancer health disparities, a *Community to Bench* approach may be useful as a disruptive innovation to existing CBPR practices, leading to uninfluenced community intelligence to guide research agendas and shifting the power balance on "rules of engagement" back to the community, where it belongs.

Conclusion

As a complement to health behavior models, patient-centered care has become a national priority as a means of engaging patients in their care, improving treatment initiation, and enhancing health outcomes.^{38–40} The concept of patient-centered care, as opposed to provider-centered care, was widely circulated by the Institute of Medicine report, *Crossing the Quality Chasm*, as an integral component of the delivery of quality care.⁴¹ We are adding to the conversation that engaging marginalized communities in cancer care necessitates a space where providers recognize and respect the influence of life experiences of the patient and the social and economic conditions of communities in a systematic strategy to address transitions of cancer care and improve health outcomes. The authors of this paper argue that a good patient-centered model will include an informed and empowered patient; an accessible, well organized, responsive community environment; and health care providers who are willing to listen and incorporate experiences with social determinants in the clinical encounter.

Several insights emerged as a result of the above discussion. First, community-academic partnerships aid in focusing both university and local resources and increasing capacity among collaborators. One of the challenges academic institutions and community-based agencies face in isolation of the other is how to optimize reach while managing resources. By working together, and in some cases with city and state policymakers as illustrated above, the partnership can increase impact while maintaining rigor and high levels of community trust. In addition, community-academic partnerships encourage the facilitation of community-engaged cancer control research that integrates evidence-based health promotion practices with communities' existing knowledge and assets. Those that reside in are the experts on the needs of their community. An ongoing relationship with community partners affords academic institutions to tailor interventions in a way that meets the needs of that particular community. By partnering this knowledge with the scientific rigor of the academic partner, providers can increase the sustainability of interventions that influence patient outcomes.

Finally, community-academic partnerships support devising solutions that meet the distinct needs of each community and helps cancer centers achieve their mission of improving cancer outcomes among their constituents. Many of the isolated rural and urban geographic

areas with the highest rates of cancer consist of our most vulnerable communities. An important limitation of many interventions targeting disparities and the health of high-risk communities is that they tend to focus on genetics or individual-level factors rather than the influence of social and structural determinants of health. Risk factors such as isolated physical environment, limited access to quality health care and prevention information, and psychosocial experiences stemming from high stress social environmental factors also play an important role in sustaining health disparities. Therefore, partnering with community agencies affords academic institutions the opportunity to address the fundamental causes that perpetuate the incidence of disease.

With this paper we have identified and discussed several advantages associated with incorporating community-academic partnerships into strategies for community outreach and engagement focused on oncology; thereby ensuring the effectiveness and sustainability of mechanisms and pathways that effectively reduce health disparities within isolated rural and urban communities.

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Practical Applications

- Cancer centers are encouraged to initiate conversations with community organizations in order to nurture trust, convey respect, and create community defined prioritization of goals.
- The utilization of Community Advisory Boards (CAB) allows cancer centers to receive critical feedback from individuals that represent different constituent groups across their community; and aids in evaluating ongoing initiatives.
- The knowledge and trust gained by maintaining an ongoing relationship with community partners affords academic institutions the opportunity to tailor interventions to the needs of vulnerable community and thereby increases the sustainability of efforts that influence patient outcomes.
- The Community to Bench cycle serves as a disruptive innovation to existing community outreach and engagement approaches. This model may elicit minimally biased, maximally precise information from the community experts, not only about current research questions, but also potentially generate new questions.
- Current public health problems such as cancer have an expansive set of lifestyle and social circumstances that impact the cause and course of the disease. Therefore, partnering with community agencies affords academic institutions the opportunity to address the fundamental causes that perpetuate the incidence of disease.