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Community-Campus Partnership in Action: Lessons Learned from the DuPage County Patient Navigation Collaborative

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Abstract

Background—Using community-based participatory research (CBPR), the DuPage County Patient Navigation Collaborative (DPNC) developed an academic campus-community research partnership aimed at increasing access to care for underserved breast and cervical cancer patients within DuPage County, a collar county of Chicago. Given rapidly shifting demographics, targeting CBPR initiatives among underserved suburban communities is essential.

Objectives—To discuss the facilitating factors and lessons learned in forging the DPNC.

Methods—A patient navigation collaborative was formed to guide medically underserved women through diagnostic resolution and if necessary, treatment, following an abnormal breast or cervical cancer screening.

Lessons Learned—Facilitating factors included: (1) fostering and maintaining collaborations within a suburban context (2) a systems-based participatory research approach (3) a truly equitable community-academic partnership, (4) funding adaptability (5) culturally relevant navigation, and (6) emphasis on co-learning and capacity building.

Conclusions—By highlighting the strategies that contributed to DPNC success, we envision the DPNC to serve as a feasible model for future health interventions.

Keywords

Community-based participatory research; Community health partnerships; Community health research; Health disparities; Process issues

INTRODUCTION

Because community-based participatory research (CBPR) mobilizes a community surrounding a shared goal, it represents an especially powerful strategy for health improvement.¹⁻³ CBPR emphasizes equitable partnerships in all stages of the research process, successfully leveraging wide-reaching resources and knowledge to effect positive change. Though CBPR implementation often presents logistical, financial, and community-specific challenges, several strategies may aid in addressing such process issues. Herein, we detail the formation and implementation of the DuPage County Patient Navigation Collaborative (DPNC), a CBPR initiative within DuPage County aimed at supporting medically underserved women in achieving diagnostic resolution and subsequent treatment when necessary following an abnormal breast or cervical cancer screening. The DPNC was successful in increasing the proportion of women with diagnostic resolutions in DuPage County and the number of collaborations among community organizations in the county. By detailing the factors that contributed to these achievements, we envision that others may apply this community partnership model in future patient navigation and community-level behavioral health services interventions.

Cancer Health Disparities in DuPage County

Differential cancer health outcomes exist within the multi-layered context of cancer care including decreased screening, late presentation to care, and lack of treatment.⁴ Disparities in care are often compacted by numerous financial, structural, cognitive, and psychosocial barriers (Table 1).^{4,5} Factors associated with less likely or incomplete follow-up care include lower levels of income or education and lacking social and/or emotional support.⁶ Notably, in a review of 45 observational studies of diagnostic follow-up care following an abnormal cancer screening result, Yabroff et al. found that two-thirds of studies had follow-up rates below 75%, with follow-up greater than 90% in only a single study.⁶

While health disparities remain marked among urban poor populations, shifting demographic trends have resulted in exponential increases in health disparities in suburban environments, particularly in the inner-ring of suburbs surrounding large metropolitan areas. DuPage County, a border county to Chicago's Cook County, exemplifies these recent demographic shifts. Over the last two decades, Latinos, Blacks, and Asians in DuPage have increased by 253%, 173%, and 134%, respectively, while the percentage of DuPage County non-Hispanic Whites has declined by 9.6%.⁷⁻⁹ The percentage of DuPage County residents who reported speaking a language other than English at home similarly increased from 7.36% in 1990 to 25.5% in 2010.^{9,10} DuPage County population trends are estimated to continue, with additional increases of 39%, 29%, and 17% projected for 2020 among Latinos, Blacks, and Asians, respectively.¹¹

Though DuPage County is, on average, an affluent county, between 2000 and 2010, the percentage of DuPage County residents living 200% below the federal poverty level increased by 68%.^{8,9} Cancer-related health outcomes within DuPage County reflect numerous barriers faced by this patient population. Between 2001 and 2005, the mortality rate among Black female patients residing in DuPage was 53.3% compared with 35.5% nationally. Further, from 2004 to 2007, 58% versus 69% of women over age 40 (n=2,068)

reported receiving a mammogram within the last two years in DuPage and Chicago, respectively. Similarly, during this time frame, 63% versus 71% of women ages 18 and older (n=2,068) in DuPage and Chicago respectively, reported receiving a pap smear within the past three years.¹²

Overview of DuPage County Patient Navigation Collaboration

The DPNC was forged in 2006 as a partnership between Northwestern University's Feinberg School of Medicine (Chicago, IL) and Access DuPage, a collaboration of hospitals, physicians, local government, human service agencies, and community groups that provides medical services to DuPage County residents who lack access to healthcare. To address existing cancer health disparities, the DPNC is aimed specifically at increasing access to care for DuPage's underserved patients with an abnormal breast or cervical screening test through the use of patient navigation, a multifaceted strategy to improve barriers to timely diagnostic resolution and treatment.¹³ Because the DPNC project (1) builds upon the assets and strengths within the community, (2) facilitates participation and collaboration of community members and (3) utilizes partner knowledge and expertise to develop action-oriented research, it exemplifies the principles of CBPR.¹⁴ Notably, the DPNC represents the first time Access DuPage has housed a research project in partnership with an academic institution. Through the DPNC collaborative effort, the Access DuPage health system, Northwestern University, and numerous community partners uniquely intersect (Figure 1).

Northwestern University project partners approached Access DuPage for potential collaboration because of their shared dedication to improve health among uninsured, low-income and minority patients. After a series of meetings, project partners agreed that an academic-community partnership, anchored by Access DuPage's well-established community network, would be both a feasible and promising intervention for improved health. Thus, the DPNC identified a five-year National Institutes of Health (NIH) CBPR research grant that supported one of the top community priorities: reducing cancer health disparities, particularly among the growing sector of the county's population that is immigrant, Hispanic, and uninsured. The project was approved by Northwestern University's Institutional Review Board (IRB), the IRB of record for Access DuPage.

The county health department's Illinois Breast and Cervical Screening Program (IBCCP) and local community healthcare providers referred eligible patients with an abnormal breast or cervical cancer screening test result or new cancer diagnosis to the DPNC navigators. Patient navigators contacted patients following referral and written informed consent was obtained. Ethnicities represented among participants included Hispanic White (62%), Non-Hispanic White (29%), Non-Hispanic Black (6%), and Asian (3%). The majority of primary languages included Spanish (57%) or English (39%); additional primary languages included Albanian, Arabic, Bosnian, Cantonese, Farsi, Korean, Lithuanian, Mandarin, Polish, Portuguese, Russian, Tagalog, or Urdu.

The DPNC's navigation team comprises social workers and linguistically matched lay health navigators. Staff capacity was determined based on estimated IBCCP patient caseload and Access DuPage referrals. Patient navigators were selected to complement one another's area of professional expertise, from social work and case management to education and

communication. The patient navigation team received extensive training at the local and national level: on-the-job resource and administrative training at Access DuPage; case manager shadowing at the DuPage County Health Department; trainings facilitated through major community partners; and attendance at the three-day national NIH/American Cancer Society-sponsored patient navigation training, including topics such as the role of a navigator, cancer knowledge, and health disparities.¹⁵

Following consent, navigators assessed for patient barriers and guided them through diagnostic resolution (for those with a negative cancer diagnosis) or treatment completion (for those with a positive cancer diagnosis). Within the realm of cancer care, patient navigators aimed to increase timeliness of and adherence to medical appointments and offered culturally competent support and guidance.¹⁶ DPNC patient navigators performed appointment reminder calls; referred patients to community resources for emotional and financial support; supplied patients with information related to cancer facts, treatment, and pain management; provided patients with some interpretation services for appointment scheduling and during clinic exams and related procedures; and developed key bonds with local health clinics and community service organizations to improve patients' access to financial, social, and educational resources. Psychosocial questionnaires assessing potential predictors of delayed or non-compliance and patient satisfaction were administered at baseline and program completion. Given the CBPR approach to this project, patient navigators also facilitated focus groups with community stakeholders and low-income women from the community to ensure the needs of the target population were being addressed.

FACILITATING FACTORS AND LESSONS LEARNED

Collaborations within a suburban context

Implementing a navigation program in the suburban setting depended on the strength of community collaborations. Suburban settings are often marked by an absence of a traditional healthcare safety net system including federally qualified health centers and public hospitals. The DPNC addressed this concern by solidifying relationships with a full range of service provision organizations that matched the evolving demography of the suburban community. On-site patient navigators played a critical role in fostering and maintaining community collaborations by reciprocating referrals to cancer organizations, establishing a physical presence within the health department and local clinics, and attending community social service agency coalition meetings. With this integrated approach, patient navigators were able to reach more isolated communities with underserved and minority populations and serve as a central linkage in the suburban healthcare safety net system.

Systems-Based Participatory Research

When the CBPR principles are applied to a delivery system, it is known as systems-based participatory research (SBPR).¹ The DPNC extends beyond the scope of a singular hospital or practice-based clinic, including the thousands of individuals and hundreds of organizations within the Access DuPage health system—from community clinics, specialists' offices, and hospitals to local professional organizations and the DuPage County

Health Department. Because the DPNC defines a ‘community’ as including all those who are directly affected by a given health issue and working toward a common goal,^{1,17,18} it leverages an extensive and well-established resource network.

Of note, the project's close partnership with the county health department's IBCCP as well as the numerous local community healthcare providers have afforded both high volume and streamlined patient recruitment efforts. Further, given that the Access DuPage health system was established over a decade ago and currently serves over 13,000 patients, patient trust and familiarity with Access DuPage health delivery system has served to greatly strengthen DPNC implementation. The DPNC is, accordingly, afforded a built-in infrastructure for the implementation of a multifaceted and community-driven effort.

Equitable Partnership for CBPR Success

When considering the CBPR framework, it is important to emphasize that CBPR is not a research method, but rather an “orientation” to research, embracing power sharing to allow for increased community relevance.¹⁹ The DPNC represents a truly equitable partnership, involving community members, organizational representatives, and researchers in all aspects of the process. As such, both partners continue to be instrumental in shaping the study's development, implementation, analysis, and future direction.

Through the formation of a community advisory board (CAB), DPNC project partners have worked synergistically to guide project implementation. CABs comprise individuals who represent the community's interests, perceptions, and priorities²⁰ and, thus, function as an integral component to CBPR. Beyond instilling a community's stakeholders with project ownership, CABs advise on the study protocol design and implementation, facilitate community buy-in, help to provide resources, and disseminate findings.²⁰ The DPNC's CAB comprises community stakeholders that each brings invaluable expertise, including medical practitioners, lead social service professionals, and community professionals from organizations including the American Cancer Society, the county health department and the Federation for Human Services. Beginning in 2008, CAB meetings have occurred on a consistent basis, devoting efforts to ensuring patient recruitment and retention, refining research aims and the protocol as needed, reviewing data, and providing insight into strategies for project sustainability. Adding to the CAB's collaborative efforts, the DPNC has established data sharing agreements and memorandums of understandings, fostering partnerships among community care organizations, including primary clinical services, cancer support services, professional networks, and community support organizations.

CBPR Funding: Opportunities and Adaptability

The vast majority of research has historically been conducted on the 0.1% of patients receiving care at academic medical centers, resulting in research that was not readily translated into practice.^{13,21,22} In response, many researchers have moved their research practice into the community—a shift largely supported by a growing impatience among researchers with relevant funding opportunities²³ coupled with an accelerated NIH initiative to support community engagement research practices.²¹ Accordingly, the elevated interest at

the national level to fund CBPR programs such as the DPNC has been key in initiating sustained health improvement efforts in DuPage County.

Despite increased funding sources for CBPR-related projects, state-level budget cuts within Illinois impacted DuPage County Health Department staff members who we expected to be supported by the DPNC research grant. The DPNC adapted to these budget cuts, choosing to focus funding efforts to support lay health navigators versus nurse or social work navigators who are necessarily compensated at higher costs. In conjunction with these shifting efforts, patient navigators received basic clinical staff training and maintained close communication with health providers at local primary care settings, bolstering patient navigation efforts. As such, the ability of the DPNC to successfully adapt to these funding cuts was largely supported by the project's integration within the surrounding community through the Access DuPage health delivery system.

Culturally relevant services

Given that cultural background, language capacity, and socioeconomic status can affect patients' willingness to seek health services and readiness to participate in research studies,²⁴ CBPR provides a culturally sensitive framework for reducing health disparities among vulnerable patient populations.²⁴ DPNC patient navigators were culturally and linguistically matched with patients, greatly strengthening the availability of culturally relevant, peer-to-peer clinical support services. The DPNC's patient navigation team reflects the ethnic diversity within the DuPage community, including African American, Latina, and Arab patient navigators. Additionally, like many DPNC patients, patient navigators are bicultural, instilling navigators with greater insight into the cultural barriers faced at the community level. Equally important to culture and language, as natives and long-time residents of DuPage County, patient navigators understood the social culture of their community. Many navigators entered the program well trained in topics such as racism, homophobia, classism, and religious diversity from previous service in county agencies.

Though linguistically matched navigation services were available for a substantial number of DPNC study participants, we had not anticipated the volume of patients who remained ineligible for study participation due to language barriers. In designing future health interventions within the DuPage community, we aim to address this aspect of our study limitations by expanding study eligibility criteria to include a wider variety of languages and developing the study staff to support such efforts.

Co-learning and Capacity Building

Within CBPR, academic members become a part of the community and community members simultaneously become a part of the research team.² This co-learning and research capacity building is essential to the CBPR framework and greatly fortifies current and future project success. During the initial phases of the project, patient navigators and the county health department's IBCCP staff shadowed one another, prompting equal guidance and communication between the two teams and contributing to the refinement of the navigation process. The navigation team has garnered significant professional development through participation in numerous research opportunities related to the DPNC's implementation and

findings: national and local conference presentations and panel discussions; local media presentations; and DuPage County college presentations, serving to reinforce the pipeline of diverse students entering into science-related careers within the surrounding community.¹⁵ Through training opportunities with Northwestern University's IRB, the DuPage Federation for Human Services as well as DuPage community health workers, the navigation team has additionally nurtured their development as research scientists and gained valuable health information applicable to the medically underserved patients within DuPage County. Academic partners have similarly engaged in research and community-related training opportunities as well as numerous local and national presentations.

The DPNC has additionally utilized skills and knowledge to build dissemination projects and educational capacity that have directly stemmed from work on this project. By funding annual paid summer internships and offering extensive research- and community based-training opportunities for student interns, the DPNC has supported diverse student learners in developing immeasurable research, professional, and community-oriented skill sets. Further, a number of ongoing collaborative CBPR initiatives have been awarded to build dialogue around, implement, evaluate, and disseminate research within the DuPage community including projects designed to better understand potential improvements in connecting patients with affordable, quality care and to explore how caregiver training could impact the economic resilience of low-income families in DuPage County.

CONCLUSIONS

Considering the significant complexities of the U.S. health care system, patient navigation is an especially relevant strategy for communities such as DuPage that face significant barriers to care and rapidly increasing health disparities in the absence of an established healthcare safety net system that more often exists in urban metropolises. As noted by Schmitt diel et al., engaging a community's patients, clinicians, and other key stakeholders within a health system in a CBPR project, results in fewer barriers to translating research into practice and an increased likelihood that the research will be relevant and sustainable.¹ As the DPNC demonstrates, CBPR, particularly when implemented in partnership with a multifaceted health delivery system, holds immense potential for improving the health of a community. Moreover, conducting patient navigation CBPR within a suburban context may present both unique benefits and challenges; patient navigation may fortify the lack of a traditional healthcare safety net system, but to cultivate and maintain community collaborations, integration of on-site patient navigators is crucial. Furthermore, culturally-competent and linguistically-matched DPNC patient navigators have been invaluable in ensuring DPNC project feasibility and success.

Through this systems-based approach, the DPNC has established a community-wide partnership grounded in shared project goals and ownership. From project implementation and funding allocation to research presentations and pursuit of capacity building opportunities, the DPNC represents a truly equitable academic-community partnership. Looking forward, we plan to draw upon the lessons learned through the DPNC project, expanding patient navigation services to other chronic diseases such as diabetes and hypertension that are also highly prevalent among DuPage's growing poor populations. It is

our hope that others may also gain from the DPNC's lessons, using the program as a model for future health interventions aimed at decreasing barriers to care among underserved communities.

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Figure 1.

A visual representation of the *DuPage County Patient Navigation Project*, comprised of the Access DuPage Coalition, Northwestern University, and numerous community partners (Green: Community/Support Services; White: Cancer Support Services; Blue: Clinical Relationships; and Yellow: Professional Networks).

Table 1

Examples of financial, structural, cognitive, and psychosocial barriers to care^{4,5}.

Barrier Type	Examples
Financial	• Lacking or limited health insurance • Unable to afford needed medications • Forgoing recommended tests or treatments
Structural	• Limited transportation • Street safety • Lack of child care • Telephone access to providers • Structural characteristics of care including continuity of care, use of low performance hospital, no medical home, multiple locations for tests and specialists, operating hours of health care facility, and excessive wait times
Cognitive	• Knowledge barriers • Awareness of prevention facts • Awareness of health resources • Understanding of diagnosis and treatment • Health literacy • Availability of interpreter services • Language and/or racial/ethnic concordance • Cross-cultural communication skills
Psychosocial	• Limited feelings of control over health and body • Discomfort- and shame-related barriers • Lack of social support