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Patient Navigation Initiative: Executive Summary

Comprehensive Patient Navigation (PN) programs have the ability to significantly reduce gaps in breast cancer care, treatment, and prevention among groups of varying races, ethnicities, and socio-economic backgrounds. It is a patient-centered service delivery model that focuses on the movement of patients along the continuum of care, ensuring that patients receive proper services, timely follow up, and can overcome complex barriers to receiving care.

As one of the most racially and ethnically diverse areas in the United States, the communities within Komen Greater NYC's service area are often faced with barriers to accessing timely and effective breast cancer care.

In its 2015 Community Profile, Komen Greater NYC identified priority areas by their ability to reach the Healthy People 2020 targets: 1) Reduce women's death rates from breast cancer to 20.6 cases per 100,000 women; and 2) Reduce the number of breast cancers that are found at late-stage to 41.0 cases per 100,000 women. At least one of the counties, Bronx County, is classified as a medium high priority area, while four of the other counties are classified as medium priority areas. None of these counties will not reach these targets by 2020.

In addition, the Community Profile demonstrated that African-American women, Hispanic/Latina women, un/underinsured women, and undocumented immigrants experienced heightened disparities in cancer care delivery and availability. As a result, Komen increased its funding to support projects that focused on patient navigation services to overcome barriers to health care for these target populations. To deepen it's understanding of the impact Patient Navigators could make, Komen Greater NYC established a Patient Navigation Initiative (PNI) Committee in November, 2015. The committee's[1] purpose was to explore patient navigation programs that were working and propose solutions to the issues of disparities, standardization, and reimbursement that can expand access to care across vulnerable groups.

Patient Navigator & Barriers to Care

Patient navigators serve a variety of functions including enhancing patient-provider communication, advocating for patient's rights, facilitating decision-making, providing psychological supports and linkages, and providing culturally appropriate services. In providing these services, patient navigators can mitigate the barriers experienced by populations within the service area. For example, Black/African-American women and Hispanic/Latina women are more likely to be diagnosed at later stages of breast cancer. Additionally, death rates are particularly high among Black/African- Americans. These disparities can be linked to barriers such as lack of transportation, overcrowded hospitals, and language barriers, resulting in loss to follow-up and failure to receive screenings and treatment. With the inclusion of patient navigators, these barriers can be decreased by introducing services that can streamline the cancer care process and build trust with patients experiencing these difficulties in accessing care.

The Roles of Navigators

While many different roles in health care have a navigation component to them, it is important to distinguish the roles of patient navigators from these other unique positions. For example, the terms "community health worker" and "patient navigator" are often used interchangeably; however, they have distinct differences. Community health workers focus on disease prevention and wellness, while navigators focus on a single disease and assist patients through various phases of diagnosis and treatment. In addition to this confusion, patient navigators' roles vary across organizations, and they may enter the continuum of care for the patient at various points.

Cost-Effectiveness of PN

Studies have demonstrated that patient navigation is a cost-effective strategy for patients with cancer and for health care facilities. When navigation decreases the time interval in breast cancer diagnostic resolution by 6-months in comparison with usual care, the program can decrease lifetime breast cancer-attributable costs by $590. Patient navigation has also been found to be particularly cost-effective in women aged 50-54, especially when a mammography is the initial screening test. Another study analyzing the cost effectiveness and cost-benefit of colonoscopy patient navigation programs at three Health and Hospital Corporation (HHC) facilities in NYC demonstrated that with an increase in colonoscopies from the patient navigation program, there was a net financial benefit per additional colonoscopy. These studies demonstrate that patient navigation does not just play a role in assisting patients in overcoming barriers, but it is also a cost-effective method of bringing in financial gains for health care facilities as well.

Public Health Initiatives in Greater NYC

Komen has worked to reach patient navigation goals through its collaborations with various funding partners across the service area. Approximately 80% of grant funding focuses on patient navigation programs, with 20% of funding going to education and outreach programs that link individuals to breast cancer screening. In 2017, Komen Greater NYC funded 15 patient navigation programs. Additionally, NYSDOH's Cancer Services Program and Medicaid's Cancer Treatment Program work to reach uninsured and underinsured New Yorkers as well.

Analysis of Patient Navigation Services by Komen Grantees

In an effort to capture navigation metrics from 2014, 2015, and 2016, Komen Greater NYC developed a data collection tool. This tool was shared with 7 grantees who were funded consecutively for those three years: Open Door Medical Center, Peconic Bay Medical Center, Callen Lorde Community Health Center, Project Renewal, Long Island Jewish Medical Center, St. John's Riverside Hospital, and Staten Island University Hospital. The summarized findings were as follows:

- Lay navigators often did not have access to internal and external resources, patients' records, and resource guides that allowed them to provide a full range of services.
- There was a lack of standardized training for lay navigators.
- Health facilities gather their own data on patient satisfaction and employ it to address gaps in care.
- There are challenges in retaining lay navigators because of a lack of sustainable funding, and lay navigators often leave NGOs to join larger health facilities.

In addition to gathering information about the role of navigators, the tool also captured data on the services offered to communities. These are the key findings:

- There was a disconnect between one-on-one education services and the action of screening itself. For Blacks/African-Americans and Asians, more women received education services than screening services.
- 26% of clients were Black/African-American, but this population had the 2nd lowest proportion of screening services.
- Hispanic/Latina women were diagnosed within 30 days at the highest rates, followed by White women.
- Almost all women received a diagnosis within the first 60 days.
- 65% of respondents provided only outreach and education services, which may have impeded their ability to provide diagnostic workups and treatment services.
- Most patients (49%) who received patient navigation services were uninsured. 18% of these patients were navigated for further work ups on diagnosis.
- In recent years, services granted by the participating organizations have shifted. For example, some grantees now focus more on screening coordination, outreach activities, and support services to facilitate diagnostic work up, receive initial treatment and remove barriers. The number of grantees that primarily focus on education and survivorship have dwindled.

Patient Navigation Initiative (PNI) Conference

In November 2016, Komen Greater NYC and its committee partners launched *Patient Navigation: The Evolution of Patient Navigation in New York and Its Implications on Breast Cancer Care.* At this conference, more than 120 public health practitioners convened and shared their best practices and care models in cancer and chronic diseases. Breakout sessions were held to devise organized working groups that meet on a quarterly basis to discuss strengthening PN efforts.

Breakout Sessions

1. Disparities Working Group
    - In the Disparities breakout session, it was recommended that patient navigators be knowledgeable about and willing to attend to all types of disparities in addition to language, age, disability, education, ethnicity, etc. Additionally, health care providers should continue to build trust and strengthen their relationships with patients, never turning away patients in need of services.
2. Advocacy and Public Policy Working Group
    - In the Advocacy and Public Policy breakout session, participants discussed strategies to fund patient navigators, as grant funding is not a sustainable approach. It was recommended that experts from different professional backgrounds build a coalition that focuses on the reimbursement and certification of lay navigators. Additionally, institutions and health systems should actively take part in data collection, sharing, and utilization.
3. Standardization Working Group
    - In patient navigation, there is little standardization of the role of patient navigators across and within health systems. It was recommended that lay navigation services be standardized across the continuum of care and that hospital administrations bear the costs of trainings and certifications. Hospitals should also be responsible for the costs of recertification based on changes in screening guidelines and available resources.

PN Pilot Program

Komen Greater NYC plans to support a pilot patient navigation program that integrates the roles of nurse and lay navigators under the leadership of a project director at a breast health clinic. The purpose of this program is to enhance the services at each phase of the continuum of care, whether they are clinical or non-clinical, and ensure that women receive timely care and are followed up until the point of survivorship.

Conceptual Framework

Component	Description
Program Management	Managed under the leadership of the program director who will assist the cancer care team in program implementation, problem-solving, and evaluating the program.
Program Model	Professional and lay navigation model work collaboratively to assist patients from the point of screening to treatment and ensure timely follow up. This model is supported by the Oncology Nursing Society which states that “patient outcomes are optimal when a social worker, nurse, and lay navigator function as a multidisciplinary team.”
Screening, Diagnostic & Treatment	Services should support the women in receiving timely care from point of contact with navigators to the survivorship plan, as they are at the center of the program model
Data Management	Nurse navigators will have full access to patients’ data. Lay navigators will receive training on the use of the data at a capacity that will help to inform and evaluate the delivery of services.
Quality Assurance and Improvement	The project director will delineate health and non-health care determinants that result in delay of care or loss to follow-up. Navigators should foster relationships with their patients to enhance adherence to treatment plans.
Partnerships	Project directors should establish strong relationships with community partners as it is an effective strategy in identifying high risk populations, providing outreach services, and increasing referral services.
Professional Development	Hospitals should take responsibility for navigators and ensure that navigators are equipped with essential resources like cross-cultural communication tools, health insurance plans, knowledge of appropriate referral services, etc.
Evaluation	Plays an essential role in determining the factors that lead to the success of the program. Data collection and analysis should focus both on qualitative and quantitative information.

Recommendations

Komen Greater NYC and other funders should strategize their support toward maximizing the utilization of services in the community and reducing disparities in access to breast cancer care. The following recommendations can be implemented to ensure equal and personalized care through patient navigators:

(1) Komen Greater NYC should update funding priorities for every grant cycle to address the needs and barriers identified in accessing care among underserved populations. Actions to implement this recommendation are as follows:

   a. Collect and analyze data obtained from the grantees.

   b. Conduct a needs assessment survey every five years.

   c. Grants Education and Policy Committee revises the funding priorities.

(2) During data collection for this paper, we identified a huge challenge that our community partners face in providing information at each stage of the continuum of care. Most of our partners operate programs at the community level and refer the patients to larger health facilities for further diagnostic workups and completion of treatment. These community-based organizations are unable to obtain the data on the patients once they are referred to other health facilities due to HIPAA rules. Actions to implement this recommendation are as follows:

   a. Strengthen communication, data sharing, and collaboration within the organizations and among partners.

   b. Ensure lay navigators have access to patient health data to assist with seamless continuity of care within HIPAA guidelines.

(3) Data collection should be both quantitative and qualitative in order to assess the trends of the services and the patients' personal experiences. Navigators should be able to use the data to track patients who are lost to follow up, face delays in care, and do not have access to services due to barriers. Actions to implement this recommendation are as follows:

   a. Organizations develop a standard data collection system, which should be used by both clinical and non-clinical staff. The staff receive initial and frequent refresher trainings on how to collect and use the data.

   b. Staff address culturally sensitive topics in a respectful and effective manner to identify barriers in accessing the care.

(4) Komen Greater NYC and its grantees should identify best practices, challenges, and barriers in cancer care and address them in work plans. Actions to implement this recommendation are as follows:

   a. Identify one barrier in each quarter and work towards resolving the issue in collaboration with other partners in the service area.

   b. Komen Greater NYC and the grantees convene annually to present their success stories in overcoming the barriers to care.

    c. Komen Greater NYC collects best practices among community partners and disseminates the information.

(5) Lay and nurse navigators should work in close collaboration with the cancer care team. To avoid duplication of services and confusion of the responsibilities, lay and nurse navigators should have distinct and complementing roles. This emphasizes the importance of the standardization in care, delivery of services, roles and responsibilities, and competencies that navigators should attain. Actions to implement this recommendation are as follows:

    a. Lay and nurse navigators have clear job descriptions that define their specific roles.

    b. Lay and nurse navigators conduct regular meetings about the patients they receive and refer them for further workup.

    c. Lay and nurse navigators are able to complete application processes for the patients to receive appropriate services (for example, financial assistance, insurance plans, etc.).

(6) It is essential to review the core competencies and provide refresher trainings to the navigators and introduce new skills based on the needs. The goal of all patient navigation programs should focus on patient empowerment and assess their abilities in self-management. Actions to implement this recommendation are as follows:

    a. Lay and nurse navigators receive trainings in improving patient navigation competencies.

    b. Organizations hire bilingual and bicultural lay and nurse navigators to deliver culturally competent services and empower women to make safe and informed decisions.

(7) Breast cancer care programs should be evaluated to improve the quality of services and impact of the care. The evaluation process should be able to capture information about the efficacy and effectiveness of the programs at the delivering and receiving ends. Actions to implement this recommendation are as follows:

    a. Organizations develop a detailed process and impact evaluation plan and adjust the objectives based on the findings.

    b. Organizations evaluate patient navigation services both at patient navigator and patient levels.

(8) Most importantly, both nurse and lay navigators should gain knowledge in how to educate women about clinical trials and help them overcome myths and fears about participating in breast cancer research studies. Actions to implement this recommendation are as follows:

    a. Lay and nurse navigators have the knowledge to inform patients about different clinical trials and assist them in enrolling into research studies and genetic counselling.

b. Lay and nurse navigators encourage women of color to enroll in clinical trials through culturally competent approaches.

c. Patient navigators are aware of the myths and fears among women about clinical trials and assist them to overcome those barriers.

d. Patient navigators establish trust with patients to provide personalized care.

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[1] Icahn School of Medicine at Mount Sinai; Manhattan Cancer Services Program at New York-Presbyterian Hospital/Columbia University Medical Center; New York-Presbyterian/Lawrence Hospital; New York State Department of Health Cancer Services Program of Suffolk County; Laura and Isaac Perlmutter Cancer Center at NYU Langone Medical Center; and the New York City Department of Health and Mental Hygiene.