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Patient navigation and cancer-related care: Policy solutions to improve access to Pennsylvania's complex system of care



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ABSTRACT

In Pennsylvania, cancer patients experience disparate cancer-related health outcomes. Patient navigation, a patient-centered evidence-based approach effectively addresses barriers to care, and reduces cancer-related disparities and burden. We performed a literature search with specific inclusion and exclusion criteria to identify literature emanating from the United States which potentially described the development, efficacy and cost effectiveness of patient navigation across the United States and in Pennsylvania. The results from this review signified that, over last two decades there has been a rapid growth in the field of patient navigation programs across the United States which includes the state of Pennsylvania. However, despite the presence of these programs and navigators, Pennsylvania does not have state-wide guidelines which could define patient navigation and recognizes a patient navigators as well as roles and responsibilities. This paper calls for a policy-based approach to recognize and standardize patient navigation in Pennsylvania. We recommend the Pennsylvania Department of Health propose legislation which would help define patient navigation and patient navigator. We also urge various organizations, policy makers, state and private insurers, and funding agencies in Pennsylvania to recognize, acquire, and cultivate a culture of patient-centeredness through patient navigation.

1. Background

Despite cancer mortality decreasing by 29% from 1991 to 2017, cancer still remains the second most common cause of death in the United States (US), exceeded only by heart disease [1]. According to the American Cancer Society (ACS), more than 1.8 million new cancer cases are expected to be diagnosed in the US during 2020 [2]. In 2020 alone, approximately 606,520 US residents will die from cancer, which translates to about 1660 deaths per day [2]. Pennsylvania has the third highest cancer incidence rate nationally, and the second highest among states in the Northeast [3]. In 2020, Pennsylvania is estimated to have approximately 80,240 new cases and 27,860 deaths [2]. The medical costs and lost productivity from cancer in Pennsylvania are estimated to be \$7.3 billion each year [4]. Over the last two decades there has been significant advances in cancer screening and treatment which has resulted in overall reduction in morbidity and mortality among those diagnosed with cancer. However, there still exists disparities in receiving this recommended screening, care, and treatment [1,5–8].

1.1. Cancer-related disparities

Although there are significant medical and technological advancements afforded by the American healthcare system, the fractured infrastructure can make it difficult for patients to access and manage their care and treatment [9]. As per the National Cancer Institute (NCI), cancer disparities are thought to reflect the interplay of social, economic, cultural, environmental, diet, biological, and health system factors [8]. While the reasons for these cancer-related disparities are complex and not completely understood, research has identified numerous patient, provider, and health system barriers for these at-risk populations [10,11]. Across the US, these barriers include low health literacy, delays in early diagnosis and treatment, access to services, transportation, inadequate health insurance, and other structural, and personal obstacles to health care [2,6]. In Pennsylvania, residents of the 52 Appalachian counties experience excess cancer burden due to transportation and financial barriers, as well as limited availability of certified cancer screening facilities, oncologists and primary care providers [12]. There has also been a growing body of evidence which indicates that cancer-related barriers interfere with timely access to

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diagnosis and treatment and could possibly lead to negative health outcomes [6,13]. Hence, in recent years, reducing cancer disparities has become an overarching goal of policy-makers and researchers.

1.2. Patient navigation

Patient navigation (PN) has been demonstrated to be an effective and scalable intervention model to overcome these disparities and barriers [6,7,13–16]. Dr. Harold Freeman, a pioneer in PN, defined PN as, “a community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care” [17]. People who practice PN, are known by various names, including, but not limited to, patient navigator, nurse navigator, social worker, outreach worker, community health worker (CHW), and promotora (Spanish term for “CHW”). Patient navigators play an important role in addressing these challenges by educating people about cancer prevention and screening, connecting patients to healthcare providers, providing linkages to financial and community resources, and navigating patients through the healthcare system [9].

Over last two decades, there has been a rapid growth of patient navigation programs across the US [14]. However, despite the presence of these programs and navigators, there are many states in the US which do not have state-wide guidelines that define patient navigation and recognize patient navigators and their roles and responsibilities. Despite the presence of several PN programs, Pennsylvania lacks statewide PN guidelines. The objective of this paper is to address this gap, describe the existing literature on PN research and programs across the US and specifically in the state of Pennsylvania, and call for a policy-based approach to recognize and standardize PN in Pennsylvania. We recommend the PA Department of Health propose a legislation which would help define PN and patient navigator. Finally, we also urge various organizations, policy makers, state and private insurers, and funding agencies in PA to recognize, acquire, and cultivate a culture of patient-centeredness through patient navigation.

2. Methods

There have been several authors who have conducted full literature reviews of PN research and implementation programs across the US. The primary focus of the current paper is, however, not to conduct a literature review on PN research and programs. We aim to highlight the development of PN programs across US and more particularly in Pennsylvania so that, based on this available evidence appropriate policy recommendations for the state of Pennsylvania could be suggested. As part of the methodology, this paper followed a two-step mini-literature review process. In the first step, on-line resources such as PubMed, Google Scholar, and Penn State Library Resources were searched to find appropriate US based peer-reviewed literature with a limitation to English language. Searches were conducted using combinations of the following key words: “patient navigation”, “Cancer”, “policy”, “patient navigator” and “health disparities”. Previously identified key publications relevant and suited to the inclusion criteria were also used in the literature review.

In the second stage, we screened all identified references and categorized them in separate groups such as development of PN funding across the US, efficacy of PN, socioeconomic benefits of PN, and PN programs or studies conducted in Pennsylvania. Both qualitative and quantitative research were considered for this paper. The literature was restricted to the last three decades to stay current with government policy and studies on cancer PN. The literature selected included cross-sectional studies, randomized control trials, systematic reviews, brief reports, news articles, published program evaluations, policy briefs, and government and non-government organizations reports.

3. Results

3.1. Rise of patient navigation research & programs across the United States

Since 1990, PN has been a model of care that expanded rapidly in underserved communities and medical institutions across the US [13,14]. The National Cancer Institute’s (NCI) 2003 survey reported more than 200 cancer care programs across the US which provided some form of PN to cancer patients [18]. The first substantial research grant for PN came in the year 2005, when NCI along with the ACS provided \$25 million to 9 sites in the Patient Navigation Research Program (PNRP) initiative [19]. The purpose of this initiative was to evaluate the efficacy and cost-effectiveness of cancer-related PN [19]. Further, the federal legislative and executive agencies were also involved in the advancement of cancer-related PN across the US [20]. The Patient Navigator and Chronic Disease Prevention Act of 2005 further resulted in \$2.4 million grant from the Health Resources and Services Administration (HRSA) [20]. Six two-year demonstration programs were funded by the Health Resources and Services Administration (HRSA) in 2008 to support lay patient navigators who provide services that focused on a wide variety of health conditions (e.g., cancer, heart disease, diabetes, hypertension, obesity, asthma) [13,14]. By 2010, the number of PN demonstration projects funded by HRSA increased to ten [14].

Further, through their National Breast and Cervical Cancer Early Detection Program (NBCCEDP), the Centers for Disease Control and Prevention (CDC) provides PN services to overcome the barriers and help low-income, uninsured, and underinsured women gain access to timely breast and cervical cancer screening, diagnostic, and treatment services [21]. Currently, the NBCCEDP funds 70 grantees—all 50 states, the District of Columbia, 6 US territories, and 13 American Indian/Alaska Native tribes or tribal organizations [21]. Also, until 2018, the ACS had funded more than 80 patient navigation programs across the United States [22]. The increase in PN programs and research was directly related to the federal and private foundation funding [18]. Several studies across the US including Pennsylvania have described the efficacy of PN, and its cost effectiveness; we have summarized a few below to provide evidence for PN programs across the US and particularly in Pennsylvania.

3.2. Efficacy of patient navigation

Year after year this rising trend of PN programs across the US have benefited thousands of cancer patients. PN has shown to be effective in screening, diagnostic resolution, treatment and clinical trial enrollment [13,14,23].

3.2.1. Screening

The comprehensive Breast and Cervical Cancer Control Navigation Program (BCCCNP) of the Michigan Department of Health and Human Services (MDHHS) alone has provided breast and cervical cancer screenings to more than 656,439 women and diagnosed 4873 breast cancers and 6453 cervical cancers [24]. Since 2015, approximately 173,000 people across the US have relied on the PN program to help them through screening, diagnosis and treatment [2,25–27]. These PN programs were delivered by patient navigators from several educational backgrounds towards an increase in screening and early detection of cancer [13,14]. Two systematic reviews have reported that PN improved cancer screening rates in the range of 10.8%–17.1% for three major cancers namely breast, cervical and colorectal [13,14]. Besides, adherence to follow up visits following a screening abnormality have been reported to increase in the range of 21%–29.2% [13,14]. The evaluation of PNRP revealed that PN increased rates of resolution of abnormal cancer screening findings and decreased the time it typically takes patients to receive a diagnostic resolution [28]. The rates of treatment initiation were also increased among patients who typically

failed to begin treatment within 90 days of a cancer diagnosis [28]. In Texas, a three-year community-based PN program reported increased uptake and adherence for cervical cancer screening among Hispanic women resulting in a per capita gain of 0.2 years of life expectancy [29].

3.2.2. Diagnostic resolution

A randomized control trial conducted among racially/ethnically diverse inner city population in Boston, showed a significant decrease in time to diagnosis for subjects in the navigated group with a cervical and breast cancer screening abnormality [30]. The systematic review on efficacy of PN revealed that more than 25 articles focused on the effect of PN on the diagnostic resolution or timely follow-up of an abnormal test result and reported a favourable impact of PN interventions on diagnostic resolution in comparison with usual care [23]. These studies showed that compared with patients receiving usual care, patients in the PN group experienced a shorter length of time to follow-up and higher rates of completion of appropriate follow-up/attendance to scheduled appointments. Further, several systematic reviews have also covered other studies which were focused on medically underserved areas, uninsured populations, or rural Appalachian populations and overall even these studies suggested that PN was effective in increasing rates of diagnostic resolution consistently across diverse populations [13,14,23].

3.2.3. Treatment and patient satisfaction

Studies have also reported positive impact on cancer treatment, including a shorter time to treatment initiation, higher rates of treatment reception or adherence and increased patient satisfaction with cancer care [13,14,23]. PN can also contribute to enhanced relationships between patients and the health care team and may help increase patient satisfaction by reducing barriers and promoting patient-centeredness in the care process [31]. A qualitative study while highlighting the experiences of various patients through the cases presented found that, patient navigators tailored navigation strategies to guide each patient and aid them in overcoming the oftentimes fragmented, complex, or confusing system of care [32]. These tailored strategies ranged from researching affordable housing, transportation, and prescription options to helping patients apply for health insurance and developing critical bonds with local health clinics and community organizations to improve patients' access to resources. Additionally, PN has also been seen effective in improving the underrepresentation of racial and ethnic minorities in clinical trials [23,33]. PN increased enrollment into clinical studies in a county hospital setting serving minority and underserved population [34]. Other studies found that PN interventions resulted in higher rates of attendance to medical appointments, lower rates of hospitalization, and fewer intensive care unit admissions and emergency room visits [35].

3.3. Cost effectiveness of patient navigation

Apart from the early screening and treatment benefits, PN can also be an effective business strategy for cancer care. PN has the potential to increase top-line revenue in a fee-for-service (FFS) payment system and decrease costs in a bundled payment system [35]. Scientific literature clearly demonstrates a positive return on investment (ROI) for patients in a PN program in an alternative payment model systems, as well as in health systems operating in a FFS environment [35]. The University of Alabama study on cost effectiveness found that PN yielded a 1:10 ROI, with average costs for patients receiving PN declining by \$781.29 per patient per quarter and saving of \$19 million annually across the network [35]. Another study conducted at Michigan's Grand River Gastroenterology Institute identified that, only addressing the transportation barrier with the help of PN, the colonoscopy cancellation rate decreased by 54% and yielded an estimated annual saving of \$168,152 [36]. The Levine Cancer Institute (LCI), based in Charlotte, NC,

reported that for each disease subset, except melanoma, patients in the PN program had a reduction in health care usage in the acute care setting ($P < .001$) [35]. Another study reported 52% increased likelihood of a 30-day all-cause readmission among the patients who did not receive PN services ($P = .04$) [35].

Improved patient-related outcomes such as patient satisfaction, patient perceptions of PN, timeliness of care, care quality, adherence to screening, appointments, treatments and quality of life are also found to be cost-effective and contribute towards net financial gains [19,35,37]. One such example is Sarah Cannon, the Cancer Institute of HCA Healthcare which had a PN program that supported 65 hospitals across seven states [35]. These hospitals provided PN to more than 15,000 patients in 2018 and within a year, 59% growth in patient enrollment to PN program was observed, correlating with increased patient volumes. Additionally, another important quality measure at these hospitals was time from first diagnosis to first treatment, where the goal of less than 30 days was met across all disease sites. Another program at three hospitals in New York reported PN to be associated with a 61% increase in average monthly colonoscopy volume yielding a net financial benefit to the hospitals [38].

PN programs also significantly reduced medical treatment costs and potentially provided cost savings to the health care payer [39]. An economic evaluation of PN conducted at 3 community hospitals revealed that, PN helped in achieving a cancer diagnostic resolution which eventually resulted in decreased medical costs by \$511 to \$2080 per patient with breast cancer and by \$1192 to \$9708 per patient with colorectal cancer [40]. The average cost savings ranged from \$528 to \$781 per quarter per patient [39]. A pilot program at Northern California Healthcare Organization found that 35% fewer patients were lost to other health systems if they were in the PN program from the point of a suspicious cancer finding [35]. Lastly, PN programs reduced future incident cancer diagnoses and improved timely diagnostic resolution, and substantial future cost savings could be projected [41].

3.4. Cancer-related patient navigation programs and services in Pennsylvania

The Penn State Cancer Institute (PSCI) has been actively involved in training of patient navigators. They have trained more than 80 patient navigators across Pennsylvania [42]. In July 2017, the PSCI developed the Cancer Navigation and Survivorship Network (CaNSuN) to increase engagement among the community of navigators throughout Pennsylvania [42]. The purpose of this network is to create a platform for research, help disseminate best navigation practices, increase the knowledge base of navigation methods, develop a local network among navigators, and provide community support to navigators [42]. The PSCI also launched a Story Map, *The Story of Cancer in Central Pennsylvania* in 2018 [43]. This highly interactive educational tool can be viewed by individuals interested in learning more about the disease and how navigation can help patients overcome barriers to care. This data storytelling technology communicates important information to patients, navigators, and key stakeholders, while effectively aiding in the broader implementation of ground-breaking health care initiatives and research.

In addition, a group of investigators at Penn State College of Medicine has conducted a randomized study ($n = 60$) to test the feasibility of PN to overcome barriers to cancer-related care, for women with dense breast tissue. Women found to have dense breast tissue on a screening mammogram have 2–6 times increased risk of developing breast cancer. The study examined two questions: (1) whether a 12-week telephone-based navigation for women with dense breast tissue improves knowledge, attitude, and behaviours related to dense breast tissue, compared to usual care; and (2) if navigation changes the rate at which women receive supplemental breast cancer screening, compared to usual care. The study results suggest that PN is a feasible option to improve knowledge, attitude, and behaviours for women with dense

breast tissue, and that the navigation helped resolve the barriers that participants report; however, not every participant indicated that they had barriers to address.

At Penn Medicine, a retrospective and observational study ($n = 13,241$) conducted at three of their Health System hospitals reported that patients assisted by PN (22%, $n = 2996$) across all cancer types were 10% more likely to stay for treatment compared with those not in the PN program [35]. Further, the PN supported patients also reported an increased utilization of treatment services. Another study ($n = 125$) at Penn Medicine conducted to determine the feasibility, acceptability and use of the PN program reported that, 46 patients who completed PN-supported colonoscopy screening had at least one adenomatous (precancerous) polyp and of them 3 patients were later diagnosed with cancer [44]. Further, when the study evaluated the program satisfaction levels, overall 92% of the patients in this study were highly satisfied with the program and 36% of the patients who completed the program stated they would have been, “highly unlikely to have completed the colonoscopy without the patient navigator” [44].

In Western Pennsylvania, PN pilot programs in three hospitals found a 43% reduction in non-emergent emergency department use among frequent users [45]. In addition, the hospitals also showed 60% reduction in 30 days readmission across target diagnosis-related groups resulting in reduced financial penalties for readmissions. Given the costs associated with acute care and penalties for excess 30-day readmissions under the Centers for Medicare & Medicaid Services (CMS) Hospital Readmissions Reduction Program, these results indicate that, engaging navigators may help reduce hospital costs [35]. Also, Accenture in collaboration with Highmark Foundation has developed lay PN pilot programs in three Western Pennsylvania hospitals, targeting priority areas and patient populations based on the health needs of the communities [45]. PN is also a part of the University of Pittsburgh Medical Center (UPMC) and aims to provide individualized assistance to the patients, families, and caregivers throughout the health care experience [46]. The Fox Chase Cancer Center, Philadelphia, also receives funding from National Breast Cancer Foundation for its PN program [47]. This program provides cancer education, screening and outreach services to the community, with a special focus on reaching underserved populations [47]. In another project, Pennsylvania’s Healthy Woman Program trained and paid for two navigators to help immigrant patients ($n = 138$) over a 4-month period [48]. Among them, 88 were screened by the Healthy Woman Program and 40 made appointments on dates even after the project ended.

4. Discussion

4.1. Policy-based approach to cancer-related patient navigation in Pennsylvania

The scientific literature supports the effectiveness of PN in addressing cancer burden and disparities. However, despite the enormous evidence supporting PN across the US, including the state of Pennsylvania, there are no state-wide guidelines in Pennsylvania which defines PN and recognizes the patient navigator and their roles and responsibilities. Additionally, PN is not a consistently recognized profession in Pennsylvania and hence individuals with various backgrounds fill the navigator roles. Although individuals who practice PN may possess different sets of skills, training, and education, however, each one has valuable expertise to offer patients. Furthermore, given this heterogeneity in the background and role of the patient navigator, it becomes all the more difficult to identify guidelines applicable to various situations and individuals [49]. This identity crisis of the patient navigator in Pennsylvania could possibly be addressed through their formal recognition within our healthcare system. The policy for recognizing the work of patient navigators in Pennsylvania could further enhance their work and contribute towards bridging the gap between patients and the complex cancer-care system. This need for recognition

of patient navigators across all the states in the US has also been endorsed under the Patient Protection and Affordable Care Act (ACA), Public Law 111 – 148. The law recommends strengthening the role and formal recognition of patient navigators in the health care system of every state [49,50].

Apart from the recognition there are concerns over insurance reimbursement of patient navigators. Despite of a growing body of evidence from the US which supports the financial benefits of navigators to health systems including insurance companies, Medicare and many commercial insurance companies do not directly pay for PN services [35]. In fact, according to the Pennsylvania Department of Health, the state and private insurance companies in Pennsylvania may be over-spending on cancer treatment and rehabilitation [4]. If insurance providers cover the reimbursement for accessing PN among cancer patients, it could potentially in return receive benefits in reducing future treatment costs through increased screening uptake and early detection and treatment. In addition, this PN policy on formal recognition of patient navigators in Pennsylvania could potentially encourage hospitals and organizations to recruit a navigator work force to serve patients. This initiative could not only benefit patients, but could also provide a positive return of investment to the hospitals through increased screening rates and reductions in emergency and recurrent admissions costs [31,35,36,38,39,45]. This benefit has also been voiced by the ACA which recommends every state health insurance exchange to establish a “navigator program” to help individuals and insurance businesses [49]. After reviewing the literature on PN across the US and also more particularly in Pennsylvania, we recommend the following policy solutions for the continuum of cancer care in Pennsylvania.

4.2. Policy recommendations

This paper urges the Pennsylvania Department of Health, various health organizations, policy makers, state and private insurers, and funding agencies in Pennsylvania to recognize, acquire, and cultivate a culture of patient-centeredness through patient navigation. If each were to support in their respective capacity, Pennsylvania could benefit from the following policy recommendations.

- The Pennsylvania Department of Health is recommended to propose state legislation to define the term ‘PN’ & ‘Patient Navigator’ based on the definition provided under the Patient Navigator Outreach & Chronic Disease Prevention Act of 2005, 109, P.L. 18, 119 Stat. 340 [51]. It is also recommended to follow the same statute and enlist the duties performed by them and help patient navigators gain the essential recognition in the existing state’s health care workforce and state’s human health services. Once the standard criteria is formulated and the recognition has been established, licensure may be the next step.
- We urge state and private insurers to provide direct reimbursement for PN services and include it as an integral part of the health insurance programs.
- At an organizational level, we recommended that employers and funders recognize patient navigators’ contribution to the public health and healthcare infrastructure by compensating them at competitive wage levels. Navigators should also be provided employee benefits comparable to those received by other health professionals. Employers are also recommended to support PN career development and formation of state and local patient navigators’ networks and associations for purposes of mutual support, advocacy, and professional development.

Declaration of Competing Interest

The authors have no potential conflicts of interest to disclose.

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