Bridging the Healthcare Divide With Patient Navigation: Development of a Research Program to Address Disparities

Karen A. Schwaderer, RN, BSN, OCN®, and Joanne K. Itano, RN, PhD, OCN®

Americans who live in poverty as well as certain ethnic and racial groups have higher cancer death rates than other populations. Patient navigators have been identified as an important weapon against these disparities. Navigators can address insurance, financial, and logistical issues (e.g., transportation, appointment scheduling, child or elder care). They can provide understandable health education that may lessen fears of cancer diagnosis and treatment. This article describes the development and implementation of a multisite patient navigator program involving five cancer institutions in Western Pennsylvania. Navigator programs have great potential to enhance cancer care by reaching underserved populations and opening the door for future research.

A great deal of progress has been made in recent decades in the war on cancer. Technologic advances in screening and early-detection techniques, along with new treatments, have changed a previously dim outlook for many patients with cancer. Unfortunately, not all populations have benefited from this progress, with certain groups of Americans carrying a heavier burden of cancer than others.

Americans who live in poverty and specific ethnicities, particularly African Americans, have 10%–15% lower five-year survival rates than other populations (Freeman, 2004). According to Ward et al. (2004), male and female residents of counties in which at least 20% live below the poverty level (i.e., the threshold of income that varies by household size) have 13% and 3% higher cancer death rates, respectively, compared with counties in which less than 10% live below the poverty level.

Lower socioeconomic status, cultural beliefs, and social inequity can cause disparities among ethnic groups; however, poverty is the most important cause of disparities in Americans. Living in poverty often means residing in low-quality housing, making unhealthy lifestyle choices, and lacking knowledge about healthcare resources (Freeman, 2004). Lack of insurance and financial support as well as decreased access to health care prevent many Americans from receiving the preventive screenings and cancer treatments necessary to survive cancer (Freeman, 2004). Some populations’ cultural beliefs may create feelings of mistrust toward the healthcare system, and language differences may cause misunderstandings of medical terms. For Americans living in rural areas, geographic access and lack of transportation to community facilities may impede individuals from receiving appropriate cancer treatment.

At a Glance

- Patient navigation is a new concept in which trained personnel assist patients with cancer with access to care and impact outcomes.
- Barriers to care are comparable for rural and urban facilities, but the time to resolve barriers differs according to the community resources available.
- Patients and physicians report satisfaction with the use of patient navigators. However, the impact of patient navigation on clinical outcomes and its cost-effectiveness warrants further investigation.

African Americans comprised 13% of the U.S. population and 24% live below the poverty level (American Cancer Society, 2007). Thirty-three percent of working-age African Americans were uninsured in 2005 compared to 20% of Caucasians.
are more likely to be diagnosed with cancer at a later stage than Caucasians (American Cancer Society). Socioeconomic factors may deter African Americans from using preventive behaviors and seeking cancer screening services. In Pennsylvania, where this article’s program was implemented, the age-adjusted cancer mortality rate for African Americans showed an overall decline from 1992-2002; however, the cancer death rate for African American residents was 31% higher than that of Caucasian residents in 2003 (Pennsylvania Department of Health, 2005).

A minority group for which little cancer data are available is the Amish, a religious secular group. The largest Amish communities are interspersed throughout Ohio, Pennsylvania, and Indiana. A PubMed database search for cancer statistics among the Amish revealed three articles, with the most recent one published in 1988 (Hamman, Barancik, & Lilienfeld, 1981; Swift, Reitnauer, Morrell, & Chase, 1987; Trover, 1988). Typically known for their plain, simple lifestyle, the Amish have religious and cultural beliefs that prevent them from seeking insurance, medical care, and traditional cancer treatments. Although one survey reported that the Amish have a lower incidence rate of cancer than non-Amish, the disease still exists in this community (Ferketich, MacEachern, Shen, & Lemeshow, 2003).

Because healthcare disparities are so prevalent in rural poor and minority communities, including African Americans and the Amish, a program was designed to address those disparities in Western Pennsylvania. This article describes the program’s development.

Evolution of the Patient Navigator Concept

A simple concept to assist disparate populations in receiving timely cancer care has gained national attention since it was conceived in the early 1990s by breast cancer surgeon, Harold Freeman, MD, from Harlem Hospital in New York, NY. Freeman noticed that young African American women with breast cancer frequently were diagnosed with late-stage disease and began to examine the access-to-care barriers that the women faced (Hede, 2006). Freeman provided the women with a navigator, a person who was skilled in using community resources to remove barriers. As a result, the first patient navigator program was initiated, providing patients with a contact who could help them to navigate their way through a complex healthcare system.

Patient navigators are important weapons against the disparities that certain groups of Americans face (Dohan & Schrag, 2005). Navigators can assist patients with insurance, financial, and literacy issues as well as misinterpretations that may contribute to fears of cancer diagnosis and treatment. Logistical problems such as transportation, appointment scheduling, and child or elder care issues also may prevent patients from seeking diagnostic tests or treatment. Removing those barriers may help patients seek and access the medical care they need.

Since Freeman’s inaugural patient navigator program, more than 200 cancer programs throughout the United States have included some form of patient navigator concept (Hede, 2006). Navigator programs have been instituted throughout the cancer care continuum (i.e., prevention, screening, treatment, and survival) (Dohan & Schrag, 2005). Some programs’ navigators are lay community members, whereas others are professional nursing or social services staff. Programs can be disease or population specific (e.g., breast cancer awareness in outreach efforts for African American women, a clinic-based navigator who assists newly diagnosed Native American patients). Although many programs exist, patient navigation is understudied and documentation of the cost and effectiveness of patient navigation is inadequate (Dohan & Schrag).

Cancer Disparities Research Partnership

The National Cancer Institute (NCI) recognized inequality in the burden of cancer and committed itself to researching and reducing cancer care disparities. As a result, in 2002, the NCI (n.d.) Center to Reduce Health Care Disparities established a patient navigator program that provided a cooperative planning grant to the Cancer Disparities Research Partnership (CDRP). The CDRP, in turn, provided grant funding to six community institutions across the United States to confront the unequal burden of cancer within underserved populations. The community hospitals were challenged to develop patient navigator programs that addressed the frequency in which disparities occurred, the treatment that disparate populations receive, and the treatment outcomes of minority and low socioeconomic groups in their communities. Traditionally, grant funds were given to academic and university settings to filter programs to outlying communities that surrounded their service area; funding community institutions that actually provided the care for their neighborhoods instead of academic settings was a novel approach (NCI, n.d.).

Of the six community hospitals selected to participate in the CDRP initiative through a competitive process, two were funded in 2002 and four others received funding in 2003. Only one of the six awardees was a collaborative effort of multiple hospitals serving the rural and urban areas surrounding Western Pennsylvania. The other five awardees were single institutions.

Disparities in Western Pennsylvania

Western Pennsylvania once bustled with steel mills and industry. Most of the mills have closed, leaving a portion of the population poor and of lower socioeconomic status. According to the Pennsylvania Department of Health (2005), all five areas in Western Pennsylvania targeted for this study (i.e., Somerset, Johnstown, New Castle, and two urban Pittsburgh areas) have higher unemployment percentages than the state average of 5.6%. Pennsylvania has experienced an increase in annual age-adjusted cancer incidence rates compared with national averages and mortality rates. In 2005, the age-adjusted rate for

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a The six institutions were Rapid City Regional Hospital in South Dakota, Laredo Medical Center in Texas, Cantinela Freeman Regional Medical Center in California, New Hanover Regional Medical Center in North Carolina, Singing River Hospital in Mississippi, and the University of Pittsburgh Medical Center at McKeesport.
Radiation Oncology Community Outreach Group

Funded by the CDRP in fall 2003, the University of Pittsburgh Medical Center at McKeesport collaborated with another urban and three rural hospitals in Western Pennsylvania that spanned four healthcare provider systems. The collaboration was called the Radiation Oncology Community Outreach Group (ROCOG). One of the urban hospitals, the University of Pittsburgh Medical Center at McKeesport, was designated as the lead hospital. ROCOG was charged by the CDRP with developing programs to increase participation, especially among minorities, in clinical trials as well as developing a patient navigator program to reduce or eliminate the barriers that patients in Western Pennsylvania encounter when trying to navigate the healthcare system.

First Year of Funding

The grant proposal to NCI stated that, in addition to providing resources to underserved patients with cancer, the ROCOG navigator program would research its cost-effectiveness and impact on clinical outcomes. To achieve that goal, the navigator program was implemented in multiple phases. Two of the five institutions (one urban and one rural) initially began patient navigation and collected data about the program's impact for comparison with data from patients at the other three institutions who had received treatment without the services of a navigator.

The grant team began its planning year by building the infrastructure for research projects within a community hospital that had no previous grant activity. In addition to the planning and preparation for office space and reporting mechanisms, infrastructure was designed to access the NCI funds.

In the first year of funding, personnel were hired and prepared for the newly developed patient navigator role. Two navigators who each had a bachelor of science degree in health science and previous experience from internships and quality assurance management were hired as tumor registrars with an expanded job description that included navigator functions; one worked in the rural institution, and the other worked for the urban institution. The ROCOG navigator program was designed to enhance access to the healthcare system for patients who were identified as high risk of not receiving or completing treatments because of significant financial and societal barriers. Early entry would allow oncology nursing personnel to provide the teaching necessary for patient participation and understanding of the prescribed treatment plan. Policies that would guide and direct the navigator functions and the mechanism to track interventions and outcomes were developed during the planning phase.

The navigators were trained in the institution's tumor registry system to achieve early access to the patients. Access to the patients became a collaborative effort between the navigators and managing physicians. Within five days of receiving a pathology report diagnostic of cancer, the navigators would assess patients' risk level by reviewing insurance, financial, and demographic information. Patients undergoing any cancer treatment who had inadequate healthcare coverage, were age 80 or older, lived in known lower socioeconomic areas, or were non-Caucasians were considered for the program. The navigators contacted the managing physicians for approval to approach patients about the program. The policy for recruitment also included referrals from physicians who identified patients with barriers who were not located through the tumor registry system. The policy included a self-referral system; therefore, a brochure describing the program, along with navigator contact information, was developed. The brochures and self-addressed, prestamped envelopes were available in medical and oncologic clinics and physician offices. The physician and self-referral concept was deemed compliant with the Health Insurance Portability and Accountability Act (HIPAA) when reviewed by the institutional review board (IRB) at all locations.

Physicians who made a high number of cancer center referrals were identified by the navigator and oncology staff. The rural navigator met with 30 individual physicians' offices and their staff in meeting presentations and one-on-one sessions to inform them about the program. The urban navigator met with 5 low-income clinics and 10 private physicians' offices. The general response regarding the program from office staff and physicians was positive.

The need for a community resource directory, specific for the participating institutions, was identified early in the planning year. The original resource guide began as a hard copy, but as time lapsed, Internet guides became more useful. New agencies were identified to assist patients, so the navigators shared newfound resources with each other. Care was taken to ensure that credible companies and resources were used by checking Better Business Bureau records and by word-of-mouth recommendations from trusted sources.

Because of the different cultures located within the ROCOG service area, cultural diversity training for the navigators was an important priority. The Oncology Nursing Society (2000) Multicultural Tool Kit was used in the development of a diversity training manual specific to the cultures within the target region to assist the navigators in delivering culturally sensitive patient guidance. The manual was delivered by the navigator manager in a two-hour didactic session with the navigators. The cultural issues of African American, rural poor, and Amish populations were emphasized in the program.

Evaluation Process

One of the unique aspects of the ROCOG grant navigator program was the evaluation process. The navigator program was designed with a priori ideas about how patient outcomes could...
be influenced. A logic model was developed to communicate the hypotheses and evaluate whether the program met those objectives (see Figures 1 and 2).

A computerized database that was HIPAA and IRB compliant was developed to house patient demographic and diagnostic information as well as physician contact information. It also included the barriers to care identified by patients and navigators and the interventions used to resolve those issues. The number of attempts to contact patients was recorded. The time navigators spent dealing with patient access issues was recorded as an important measure in the evaluation process. The database also had a section for navigators to document notes about patients and the services they required. The content in the database was maintained by the navigators.

The database was later revised, adding a section for documenting the annual follow-up, which was built in to the navigator procedures. In the annual follow-up (i.e., the navigators contacted patients by phone), information about the patient’s health was requested as well as the treatments completed.

The navigators were required to complete a separate NCI database of patient activity and report any participation in clinical trials. NCI personnel conducted a training session to educate the navigators on data entry. The navigator manager completed periodic data entry verification checks on the information entered by the navigators and reported to ROCOG to ensure data accuracy. For purposes of evaluation, the database contents were collected every three months by a HIPAA-compliant third party who removed all identifying information prior to analysis.

Before the navigator program was implemented, IRB approval was required because data were collected about human subjects and the outcome results were to be published. The lead institution, the University of Pittsburgh Medical Center at McKeesport, was required to seek initial IRB approval, even though the program was being implemented in two other hospitals. After initial approval was obtained, each individual community hospital could seek approval through their respective IRBs. The approval process was one of the biggest challenges that the ROCOG staff faced during the planning year. The group allotted five months for completion of the process in all institutions so that the navigator program could be implemented in September 2004. However, the arduous process of completing submissions and making corrections to accommodate the requirements of the IRB was not anticipated. Fortunately, progress was made when the ROCOG grant staff began to work collaboratively with the IRBs in a proactive approach instead of responding to their comments. All patient brochures and consents were reviewed for accuracy and compliance with human subjects’ protection.

The lead institution’s IRB approval came six months after the process began, after which the program was submitted to the individual institutions for approval. That process took less time (i.e., three months) but delayed the start of the program by three to four months.

### Results

The navigator program was implemented in the rural hospital in January 2005 and the urban hospital in February 2005; however, early in the program, enrollment in the rural setting required more time because of the greater distance between the navigator and collaborating physicians. A random sample showed that 80% of the patients initially enrolled in the urban setting consented to the program within three days of eligibility determination compared to 45% of patients in the same time in the rural setting.

Thirty percent of the rural patients consented 20 days or more after eligibility was determined, whereas the remaining patients in the urban setting consented in 7–10 days.

Physician and patient satisfaction surveys were completed at three months, then annually. The satisfaction surveys included a five-point Likert scale that addressed specific navigator functions as well as results of interactions and a section for written comments. Using a scale of 1 (agree) to 5 (disagree), patients and physicians were asked to indicate how much they agreed or disagreed with statements regarding the services provided and overall concept of the navigator. All completed and returned surveys were included in the analysis.

### Potential Short-Term Outcomes

- For patients
  - Barriers to treatment are identified.
  - Environmental and miscellaneous barriers are removed.
  - Patients are more likely to get to treatment.
  - Patients are more likely to get medication.
  - Patients are motivated to seek treatment because barriers are removed.
  - Patients are referred to support groups.
- Hospital gets more reimbursement because
  - More patients are on Medicaid.
  - The hospital does not assume costs.
- The community and population are more informed about cancer screening and detection.

### Potential Intermediate Outcomes

- Patients are more likely to adhere with the full course of treatment and medication.
- Clinical trial enrollment increases over baseline.

### Potential Long-Term Outcomes

- Five-year survival is greater for those assisted by a navigator.

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**Figure 1. Radiation Oncology Community Outreach Group Navigator Program: Potential Outcomes**

**Figure 2. Study Measures and Indicators**

### Data Sources

- Patients
- Hospital records
  - Navigator database
- Community databases regarding outreach
- Tumor registry data

### One-Year Follow-Up

- Patients self-report regarding adherence.
- Sample hospital records to validate patient self-report compliance.

### Annual Follow-Up

- Determine whether patients died with disease, died without disease, are alive with disease, or are alive without disease.
physician and patient satisfaction forms were favorable on the Likert scale. Written comments showed favorable responses to interactions with the navigator. One survey included one unfavorable comment regarding the need for additional blankets in the radiation oncology department.

During the initial 17 months of implementation, the navigator program in the rural and urban settings assisted all 174 patients newly diagnosed with cancer. A greater number of African Americans were assisted in the urban facility (n = 34, 32.1%) compared to 14.7% in the rural facility (n = 10). The rural facility treated two Amish patients during the first year, and one chose to participate in the navigator program. The distribution of health insurance varied between urban and rural hospitals. More urban patients were enrolled in government-sponsored programs (Medicare = 38.7%, Medicaid = 31.1%). A higher percentage of patients in the rural facility (26.5%) paid for their care out of pocket compared to 21.7% in the urban facility (see Figure 3).

The main barriers identified in the rural and urban facilities related to inadequate insurance coverage, transportation issues, and high co-payment for prescription coverage (see Figure 4). Although more requests for transportation were made in the urban area, more time was spent on resolving the barrier in the rural setting. For example, on average, the navigator spent 57 minutes on a request for transportation in the rural facility compared to 27 minutes for the urban navigator to complete the same request. This finding indicates a direct correlation with the amount and type of resources that are available for use by the navigator. In the rural facility where public transportation is infrequent or nonexistent, providing services was more time intensive for the navigator to overcome the barriers. In fact, except for end-of-life care, all services provided by the navigator took longer for patients in the rural setting (see Figure 5).

After 14 months of data collection from the initial institutions, the navigator program was rolled out at the second urban hospital. Plans were made to include another rural hospital during that phase of implementation but were delayed because of IRB issues. The second urban institution began navigating patients in March 2006 and grew quickly. Three months after implementation, 27 patients consented to participate. The barriers noted in that institution were consistent with the other sites.

Next Steps in the Navigator Program

According to satisfaction surveys, physicians and patients believe that navigation is beneficial. Overwhelmingly positive responses support the need for assistance by certain populations in dealing with the complex and confusing healthcare system. But, how can patient navigation's impact on clinical outcomes be determined? The premise is simple: Removing barriers to care for patients to complete treatment regimes as prescribed will have a profound impact on clinical outcomes. The ROCOG navigator program was designed to answer that question. Fourteen months of data are available from patients who used the navigator system to adhere to treatment regimes. The clinical outcomes of those patients will be analyzed and compared to patients in corresponding institutions (i.e., rural-to-rural facility, urban-to-urban facility). The institutions have similar demographics regarding per capita income and state average unemployment rate. Patients will be matched according to age, race, gender, and disease, including prostate, breast, colon, and lung cancers. Information will be obtained from the tumor registry system such as date and stage of diagnosis, date of initial treatment, date of treatment's end, and yearly patient disposition.

Patient navigation was hypothesized to impact the amount of charity care or free care dispensed by institutions. Patients who are uninsured often receive care regardless of their ability to pay. A large portion of time was spent by the navigators

![Figure 3. Distribution of Patient Health Insurance at Time of Entry Into the Navigator Program](image)

**Note.** Data are from the first 17 months of the study.

![Figure 4. Patient-Identified Primary Barriers to Cancer Treatment](image)

**Note.** Data are from the first 17 months of the study.
assisting patients in obtaining state-funded medical assistance early in their diagnosis. A comparison of the use of charity care by the oncology department will be tracked over time and compared to use prior to the initiation of the patient navigator program.

Adherence to treatment will be measured by patient self-report. Annual follow-up phone calls will determine whether patients completed the intended treatment regime. A randomized check of patient records will verify accuracy of self-reporting.

Community outreach is needed to increase screening and early detection of cancer. Low socioeconomic communities and minority populations may have cultural beliefs and educational needs that prevent them from seeking preventive or diagnostic examinations. Patient navigators cannot assist patients if they stay in their communities without being diagnosed. Conversely, community outreach programs that promote cancer screenings in low socioeconomic areas must provide resources to deal with a devastating cancer diagnosis once it is made. Thus, community outreach programs are vital for patient navigator programs during the development phase.

Future Studies

Patient navigators have been well received as new members of the cancer care team. Their usefulness has been touted by physicians and the patients whose lives have been affected by navigators. Nurses who were interviewed informally believed that the program was beneficial. In addition, the concept of patient navigation received the attention of policy makers in Washington, DC. On June 29, 2005, the Navigator Outreach and Chronic Disease Prevention Act was signed into law, providing $25 million in funds to support patient navigator programs in community settings across the country that were linked to existing cancer screening programs (Winstead, 2005). However, patient navigation is still in its infancy, with the door to future studies wide open. Financially troubled community hospitals generally do not offer social services in their outpatient departments, leaving social service issues to be dealt with by the nursing staff. Can navigators fill that void and positively impact the workload of nurses while improving the quality of care received? Who would best fill the position—professional nursing staff with greater knowledge of oncology issues or skilled community members who are familiar with the community and its resources? Would navigators similar in ethnicity who speak the language used by patients in the community have a greater impact on care? Is patient navigation a cost-effective endeavor for community hospitals? What is the public relations value to a community where disparate populations may carry cultural beliefs of the healthcare system? Those questions need to be answered as patient navigator programs become implemented more widely.

Conclusion

Health disparities have existed for years but recently have been brought to the forefront when discussing national health care issues. The 2001 Cancer Panel Report to the President titled “Voices of a Broken System” concluded, “No person with cancer should go untreated. No person with cancer should be bankrupted by a diagnosis of cancer. No person with cancer should be forced to spend more time fighting their way through the health care system than fighting their disease” (Freeman, 2002, p. 5). Navigators will not only assist patients to achieve their goals by helping to guide them through a complex healthcare system but will make a difference in the outcomes of patients who might otherwise fall through the cracks.

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Author Contact: Karen A. Schwaderer, RN, BSN, OCN®, can be reached at schwadererka@upmc.edu, with copy to editor at CJONEditor@ons.org.

References

Call for Institutes and Open Sessions: 2008 ONS Institutes of Learning

The Institutes of Learning (IOL) Team invites ONS members to submit ideas for institutes or open sessions to be offered at the 2008 IOL. The conference will be held November 14–16, 2008, in Seattle, WA. The IOL Team will make decisions regarding institutes, content, and speakers at its January 2008 meeting. An institute provides three or six hours of intense training on a cutting-edge topic of interest, and the 90-minute open sessions focus on a variety of clinical and current healthcare issues. Selection of topics, content, and speakers is the sole responsibility of the IOL Team. Decisions of the IOL Team regarding content are based on identified ONS member learning needs.

Requirements: The IOL Submission Form requests the following: name of institute or open session, rationale, brief content outline, and identification of potential speakers.

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