

Implementing and Measuring the Impact of Patient Navigation at a Comprehensive Community Cancer Center

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The prevalence and incidence of cancer in the United States continue to increase. An estimated 1,479,350 new cases of cancer were diagnosed in 2009, and more than 500,000 Americans die from cancer annually (American Cancer Society [ACS], 2009). Pap smears, mammography, prostate-specific antigen testing, and colorectal screening are among the measures that have contributed to an increase in early detection and a dramatic decrease in cancer mortality overall (Freeman & Chu, 2005). Early detection and treatment also have decreased the burden of some types of cancers (ACS; Freeman & Chu). Although significant progress has been made in cancer cures and survival rates, a cancer diagnosis still elicits fear and other stressful emotional responses in patients and their families.

With the evolution of science and the pressure for evidence-based care, patient treatment plans for cancer have become very complex, making navigation of the healthcare system challenging and time consuming for patients and their families (Seek & Hogle, 2007). Patients with a cancer diagnosis often experience a disruption of daily functions, disorganization in their social processes, and emotional distress (Mills & Sullivan, 1999) when treatment decisions are needed in a short period of time. Multiple treatment options from multiple providers are available to patients and families, and some treatments are associated with severe side effects and carry increased risk (Lenhart, 2005). A lack of information and resources as well as deficits in healthcare literacy may affect adherence to treatment and negatively affect clinical outcomes (Adler & Page, 2008). In this context, the coordination of care and services, emotional support, and education become significant components of patient-centered care.

Patient navigation is an emerging trend to address the complexity of care in oncology. The Patient Navigation Research Program initiated by the National Cancer Institute defines patient navigation as the “support and guidance offered to vulnerable persons with abnormal

Purpose/Objectives: To determine whether patient navigation in a comprehensive community cancer center affects patient and staff perceptions of patient preparation for treatment, access to care, and overall satisfaction.

Design: Program evaluation with patient and staff surveys.

Setting: Comprehensive community cancer center accredited by the American College of Surgeons in the southeastern United States with 1,037 analytic cases of cancer in 2007; population of the main county served is about 177,963.

Sample: 48 patients (28 navigator and 20 non-navigator) and 26 employees, including physicians, nurses, and other support staff.

Methods: A 10-item survey with Likert scale format was sent to a stratified sample of 100 newly diagnosed patients with cancer. A five-item survey with the same format was sent to 40 staff working with the patients.

Main Research Variable: Patient navigation.

Findings: Patients who received navigation services responded more positively to survey statements. Statistical significance ($p \leq 0.05$) was identified in 7 of 10 statements when patient groups were compared. Provider responses indicated agreement with all five statements included in the survey.

Conclusions: Patients with cancer and oncology staff reported that patient navigation is effective in increasing patient satisfaction and decreasing barriers to care.

Implications for Nursing: Patient navigation is an emerging trend in cancer care. Patient navigators can play a significant role in assisting patients with coordinating services across the continuum of care. Continued research is essential in refining the role and eminence of patient navigators.

cancer screening or a cancer diagnosis, with the goal of overcoming barriers to timely, quality care” (Wells et al., 2008, p. 2007). Results of the Patient Navigator Research Program (Freund et al., 2008) published in October 2008 indicate that at least four primary measurable outcomes of patient navigation exist: time to diagnosis, time to initiation of cancer treatment, patient satisfaction with care, and cost-effectiveness.

The current study aimed to determine whether patient navigation in a comprehensive community cancer center affects patient and staff perceptions of patient preparation for treatment, access to care, and overall satisfaction after a cancer diagnosis. The first step in evaluating the patient navigation program was soliciting feedback from patients and staff to ensure that services provided were patient centered and effective in the opinion of those most qualified to judge.

Literature Review

A literature search of the CINAHL® and PubMed databases was conducted with the phrase *patient navigator*. A preliminary search with *patient navigator* combined with *oncology* yielded minimal results; therefore, the search was expanded to include *nurse navigator* and *care coordinator* combined with *oncology* to identify cancer-specific literature. The search produced a significant number of publications relative to patient navigation and other related terms; however, few identified sources reported current (conducted within the previous five years) investigations. Eleven relevant research studies were selected for inclusion in the review. The limited number of identified studies suggested that the evaluation of clinical efficacy and cost effectiveness of patient navigation in oncology has not been studied extensively (Dohan & Schrag, 2005; Wells et al., 2008). The investigations available for review were diverse in their purposes, methodologies, and sample sizes.

Barriers to Patient-Centered, Timely, and Effective Cancer Care

Patient navigation is an emerging trend in oncology care that aims to decrease cancer-related health disparities primarily by resolving barriers to care (Dohan & Schrag, 2005; Ell, Vourlekis, Lee, & Xie, 2007; Ford et al., 2004; Freeman & Chu, 2005; Goodwin, Satish, Anderson, Nattinger, & Freeman, 2003; Jennings-Sanders, Kuo, Anderson, Freeman, & Goodwin, 2005; Schwaderer & Itano, 2007; Steinberg et al., 2006; Vourlekis, Ell, & Padgett, 2005). Barriers to care vary by geographic area based on characteristics of the population, such as socioeconomic status, ethnic diversity, health system organization, services and resources, and patient-specific factors. Schwaderer and Itano studied rural and urban navigator programs in western Pennsylvania; findings indicated similar barriers, but time to resolve barriers varied based on available resources.

Barriers have been classified as financial and nonfinancial (Dohan & Schrag, 2005; Schwaderer & Itano, 2007). Among the financial barriers reported were absence of sources of payment, insufficient coverage for treatment, and lack of affordable transportation and child care (Freeman & Chu, 2005). Nonfinancial barriers to care identified

included cultural issues, such as a lack of trust in medical institutions or language barriers resulting in poor provider-to-patient communication; limited education, resulting in low literacy or healthcare literacy (Freeman & Chu); and conflicting information from multiple providers.

Navigation Programs

Although the general consensus defined patient navigation as a barrier-focused intervention, in practice, patient navigation has been operationalized differently depending on the setting of care. *Patient navigator* is used interchangeably with terms such as *nurse navigator* and *care coordinator*, and overlap is found with roles such as case manager. Likewise, those who provide services under the umbrella of patient navigation may be lay or community health workers; teams that include nurses, social workers, and lay staff; or individual nurses who vary in their educational preparation (Hede, 2006). Wells et al. (2008) concluded that interventions used by current navigators are similar to those provided by other models of patient assistance, and Freund et al. (2008) suggested that patient navigation is based on the care management or case management model of care. The most common approaches used by navigators often are based on individualized assessment and identification of patient-specific needs, resources, and barriers and include mobilizing financial assistance, coordinating services and appointments, providing education (Dohan & Schrag, 2005; Steinberg et al., 2006), and offering psychosocial support and advocacy (Wells et al.). Core components across programs include education, provider coordination, and patient advocacy (Costich & Lee, 2003; Sweeney, Halpert, & Waranoff, 2007).

Benefits of Navigation

Outcomes of patient navigator programs reported in the literature include an increase in timely screening services, promotion of timely treatment after a suspicious finding, improved adherence to treatment regimens, and increased patient satisfaction with care (Costich & Lee, 2003; Dohan & Schrag, 2005; Ell et al., 2007; Ford et al., 2004; Freeman & Chu, 2005; Goodwin et al., 2003; Jennings-Sanders et al., 2005; Schwaderer & Itano, 2007; Steinberg et al., 2006; Sweeney et al., 2007; Vourlekis et al., 2005). Patient navigation also has been associated in the literature with increased cost effectiveness of care and increased patient satisfaction (Dohan & Schrag; Freeman & Chu; Goodwin et al.; Jennings-Sanders et al.; Schwaderer & Itano; Sweeney et al.; Vourlekis et al.). Wells et al. (2008) reported on a synthesis of findings from 16 studies that evaluated the efficacy of a patient navigation intervention; most studies addressed diagnostic breast health services in particular, and different study designs were associated with different outcomes, none of which were comparable. In addition, only seven

studies used random assignment of participants or clinics to a patient navigation intervention or comparison group (Wells et al.).

In general, patient navigators have been reported to play a significant role in improving clinical outcomes through influencing timeliness between diagnosis and treatment and promoting adherence to treatment regimens by decreasing barriers to care (Ell et al., 2007; Goodwin et al., 2003; Schwaderer & Itano, 2007). Improved outcomes are accomplished by developing relationships with patients and other healthcare providers and providing patients with education related to diagnosis and treatment (Vourlekis et al., 2005). In addition, helping patients take advantage of governmental insurance programs has resulted in improved cost effectiveness (Schwaderer & Itano, 2007).

Methods

Setting and Context

The current study was conducted in a comprehensive community cancer center that is part of a not-for-profit, privately owned health system in a suburban area in the southeastern United States. Although the health system's service area includes eight surrounding counties, most patients come from the largely rural county in which the center is located. In 2006, the U.S. Census Bureau estimated the population at 177,963 (81.5% Caucasian and 16.9% African American) and the average household income at \$37,955 (Upstate Alliance, 2008).

The cancer center, which offers outpatient services exclusively, is accredited by the American College of Surgeons' Commission on Cancer as a comprehensive community cancer center. In 2007, 1,037 cases of cancer (85% Caucasian patients and 14.8% African American patients) were diagnosed and treated. Twelve percent of patients identified Medicaid as a primary or secondary payer source and 3.7% reported that they were uninsured, suggesting that most patients had limited financial resources.

The cancer center's executive advocated for a patient navigation program after having a personal battle with cancer and reading about national interest in the coordination of cancer care with navigation. The program was included in the annual strategic plan, and an RN patient navigator was added to the cancer center's support services in 2007. The position was funded by a three-year grant awarded by the Duke Endowment.

Program Description

The development of the patient navigator program was initiated in May 2007, and the position was fully functional by June 2007. The answers to four major questions shaped the development of the program.

- What is the ultimate goal of patient navigation for the center's population of patients with cancer?
- What subpopulations of patients with cancer would be served best by patient navigation?
- How does the patient navigator gain access to patients and vice versa?
- What individual processes and interventions should the navigator use to achieve positive outcomes for patients?

The navigator would provide the services of cancer care orientation, care coordination, patient education, resource identification, and referral for financial needs and other community-based services. No population was excluded because all patients could benefit from navigation services, regardless of primary cancer diagnosis or type of therapy. At the outset of the program, patient referral to the navigator was limited to physicians. However, the referral process was expanded about 90 days into the program to include self-referrals by patients, caregivers, and other support staff. The navigator met with patients one-on-one for an initial interview to develop a plan of action and identify the need for additional intervention.

Patient navigation has been operationalized broadly in practice settings and varies by resources available (Wells et al., 2008). To date, the current outpatient setting has one patient navigator, one RN case manager who follows patients with breast cancer from preoperative assessment through surgery (but not through surgery treatment), one master's-prepared counselor, 10 staff nurses whose primary role is to administer chemotherapy, and no social worker. As a consequence, patient needs that might be met by a social worker or case manager are addressed by the patient navigator. The demographics of the patient navigator's primary case load can be characterized predominantly as patients with inadequate resources, limited healthcare literacy, and unusually complex circumstances. The number of newly diagnosed patient referrals to the cancer center limits the navigator's relationship with the patient from the time of initial diagnosis to full treatment commencement and prevents extensive follow-up as treatment continues. The navigator follows about 80 patients at a time.

Study Design

After the patient navigator role was functional for about one year, patient and staff feedback regarding the program was solicited. A survey design comparing results from a group that received navigator services and another group that received customary treatment was chosen to enhance the credibility of the findings and add to the evidence base on patient navigation. In addition, a random sample of staff at the center was surveyed to determine their perceptions of the effect of navigator services.

Instruments

Two surveys—one for patients in the study group and one for staff working in the cancer center—were developed to measure responses to specific statements related to patient navigation. The patient survey consisted of 10 statements directly related to the goals of patient navigation that were derived from an extensive review of the literature. Patients were asked to rate survey statements with a Likert scale from 1 (indicating strong disagreement) to 5 (indicating strong agreement). Patients also could select “not sure” or “N/A” if the statement had no application or the patient did not understand the statement. The statements addressed areas significant to cancer care that can be strongly influenced by patient navigation, such as education for preparation of treatment, patients’ understanding of responsibility related to managing the effects of treatment, timely access to community resources for patients with cancer, financial assessment and mobilization of financial assistance, and overall satisfaction with the care received at the cancer center.

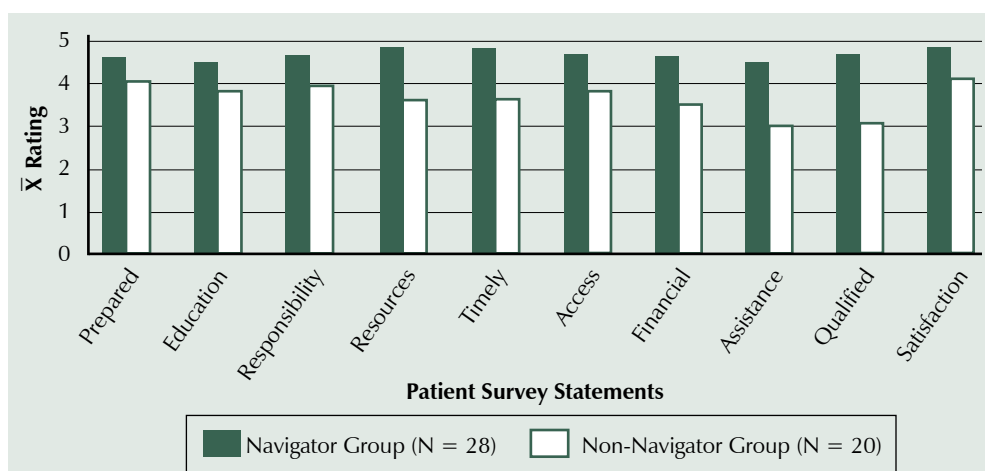


Figure 1. Mean Response Ratings on Patient Surveys

The provider survey was created to assess general knowledge and perceptions of the patient navigator program among staff working closely with patients served by the navigator. The survey consisted of five statements with the same Likert rating scale as the patient survey. The provider survey measured staff’s understanding of the navigator role, ability to distinguish between patients who had received navigation services and those who had not, whether patients perceived a decrease in barriers and an increase in preparation for treatment, and overall satisfaction with navigation services’ effect on patient care.

Content and face validity were established for both instruments by having them reviewed by doctors, nurses, and other appropriate staff. However, rigorous studies of validity and reliability were not performed on the instruments because they were developed for the evaluation of this particular program. A review of relevant literature guided the content of the instruments. Both instruments were formatted according to the organizational standard survey design of positively written comments to be graded by a five-point Likert scale and the ability to mark “N/A.” The instruments then were reviewed by three groups: oncology medical staff, administration, and nurses knowledgeable in cancer care. Feedback from the groups was incorporated into the final version of the instruments. The instruments were pilot tested with one patient and one staff member prior to distribution to determine readability (i.e., whether they were able to understand what was being asked).

Study Sample

After the organization’s institutional review board granted approval, a stratified random sample of 100 potential patient participants was selected for inclusion in the study. The navigator participants were

Table 1. Patient Demographics

Characteristic	Navigator (N = 50)		Non-Navigator (N = 50)	
	\bar{X}		\bar{X}	
Age (years)	55		54	
Characteristic	n	%	n	%
Race				
African American	12	24	3	6
Caucasian	38	76	47	94
Gender				
Male	13	26	27	54
Female	37	74	23	46
Primary pay source				
Self-pay	21	42	3	6
Medicare	6	12	3	6
Medicaid	1	2	2	4
Private insurance	22	44	42	84
Cancer diagnosis				
Breast	12	24	11	22
Colorectal	6	12	5	10
Genitourinary	8	16	10	20
Head and neck	4	8	2	4
Lung	7	14	7	14
Lymphomas or leukemias	7	14	7	14
Other	6	12	8	16

randomly selected from the navigator's records, and the non-navigator participants were randomly selected from the cancer registry. The number of patient participants who were older than 70 years or who had stage IV disease at diagnosis was limited to minimize the risk of selecting patients who were too ill, deceased, or cognitively impaired. The final sample (about 12% of the total number of patients seen by the organization in one year) was divided into a treatment group (n = 50) of patients who met with the navigator prior to initiation of treatment or early in the treatment process (i.e., within two months after treatment commencement on average) and a comparison group (n = 50) who received customary care and were not seen by the patient navigator during the course of treatment (see Table 1). Patient navigation was not discussed with the patient sample at the time the survey was administered. The navigator mostly worked with the underserved population, but the data show that other populations can benefit from patient navigation as well.

All participants were diagnosed and treated from June 2007–March 2008. Patient consent for participation was indicated by return of the survey. Though similar in age and type of cancer, groups differed in gender, ethnicity, and primary payer source; although the sample size was small, the authors believe this finding suggests that the navigator is more likely to receive provider and patient

self-referrals from patients who are most vulnerable and in need of support services.

The surveys were mailed to the participants with a postage-paid envelope. All surveys were stamped for return to the cancer center. A receptacle was available in the center for participants who wanted to return the survey while receiving treatment in the center. A second mailing to the same participants was conducted about one month after the initial mailing; participants were asked not to complete another survey if they had completed the previous one.

Provider surveys were hand delivered to 40 employees within the cancer center. Surveys were taken to each department and randomly distributed to staff working that day. Employees included physicians, nurses, and other support staff, all of whom were aware of the patient navigation program. Staff were instructed to return the surveys to the receptacle in the center.

Data Analysis

Data were entered in SPSS® version 14 for analysis by the investigator. Each statement on the surveys was assigned a one-word description, and the responses were assigned numeric values that correlated with the values on the survey. For no response and “not sure” or “N/A” options, values of 0 and 6 were assigned, respectively.

Table 2. Patient Survey Results

Survey Statement	One-Word Description	Navigator (N = 28)		Non-Navigator (N = 20)		p*
		n	\bar{X} Score	n	\bar{X} Score	
I was adequately prepared to start my cancer treatment (e.g., side effects of treatment, treatment schedule).	Prepared	25	4.56	16	4.06	0.1775
The education I was given prepared me for the side effects I experienced from my cancer treatment.	Education	25	4.52	16	3.81	0.0662
I understood what my responsibility was in managing the side effects of my treatment (e.g., when to call the doctor, how to use my nausea medicine).	Responsibility	24	4.63	16	3.94	0.0768
I was informed of resources within the community available to patients diagnosed with cancer.	Resources	26	4.85	17	3.65	0.0001
This information was given in a timely manner (within two months of diagnosis).	Timely	25	4.76	17	3.65	0.0011
There was someone available to address my concerns about financial issues related to my cancer diagnosis.	Financial	22	4.55	14	3.5	0.0336
After meeting with this person, I was informed of the financial assistance for which I was eligible.	Assistance	21	4.52	10	3	0.0085
If I qualified for financial assistance, I was assisted in gaining access to it.	Qualified	18	4.67	9	3.11	0.0075
Please rate your overall satisfaction with the care you received at the cancer center.	Satisfaction	28	4.82	16	4.12	0.0207

* Statistical significance based on $p \leq 0.05$

These responses were viewed as missing data and excluded from the analysis.

For the patient surveys, data were split to differentiate navigator versus non-navigator responses. The response rate was calculated for all groups. For the patient survey, statistical significance was assessed with an independent t test at a 95% confidence level, with a confidence interval (CI) of +/-5% for each statement and response. The provider surveys had no comparison group; therefore, only frequencies were measured.

Findings

Patient Surveys

After the second mailing, 48 of 100 surveys were returned by 28 (58%) navigator participants and 20 (42%) non-navigator participants. Fifty-six percent of navigator patients returned their surveys versus 40% of non-navigator patients. Figure 1 compares the mean response for each survey statement by group (navigator versus comparison group). Higher mean responses were obtained for the navigator group. Independent t test (CI = 95%) was used to determine whether the differences obtained between the groups were statistically significant (see Table 2). Statistically significant differences between the two groups were obtained for *resources*, *timely*, *access*, *financial*, *assistance*, *qualified*, and *satisfaction*. In the navigator group, the factors *resources* and *satisfaction* had no participant disagreement, and the other factors only had one or two. No statistically significant difference was obtained between the two groups for *prepared*, *education*, and *responsibility*; however, navigator participants indicated agreement with these variables at a higher rate than non-navigator participants.

Provider Surveys

Twenty-six of 40 staff surveys were returned for a response rate of 65%. Table 3 shows the percentage of staff agreement with the survey factors. Agreement was defined as a response of “agree” or “strongly agree.” *Distinguish* was the only factor with disagreement, and it was considered minimal.

Discussion

The results of this investigation indicate that patient navigation services are effective from the perspective of patients with cancer and staff, considering the factors of patient education, community resource referral, and mobilizing financial assistance, which impacts access to care and was an area of

interest on the survey. The results also indicate that patient navigation is associated with increased patient satisfaction with cancer treatment overall. Because no diagnostic, treatment, socioeconomic, or ethnic group was excluded, the findings suggest that patient navigation can positively affect all populations and should not be limited to specific socioeconomic or ethnic minorities. All patients have the potential to benefit from navigation services in the current healthcare system, which suffers from fragmentation. The findings are consistent with prior research; additional replication can assist in creating an evidence base that will allow generalization to other subpopulations of patients with cancer.

Limitations

Major limitations of the current study include evaluation by patients and staff at one site only, small sample size, and validity and reliability testing of the instruments. The sample size was limited because the patient navigation program had been fully operational only for one year and no power analysis was conducted. Using the cancer registry limited the identification of appropriate comparison subjects because data collection and entry can take up to six months to complete. In relation to measurement, the instruments were developed for the current study and have not been formally tested for validity and reliability. Survey designs also were limited in quality and reliability. Survey respondents were self-selected, and nothing is known about the nonresponders. In addition, respondents were not asked to report demographic data on the survey; as a result, correlation between demographic variables and item responses could not be assessed.

Table 3. Staff Survey Results

Survey Statement	One-Word Description	Agreement ^a	
		n	%
I understand the role of the patient navigator.	Role	20	76.9
I can distinguish patients who have received navigator services from those who have not.	Distinguish	15	57.7
The patient navigator has decreased barriers to care for my patients who have received navigator services.	Barriers	22	84.6
My patients who have received navigator services seem more prepared and tolerant for their cancer treatment.	Prepared	18	69.3
Overall, how satisfied are you with the impact the patient navigator has made on your patients who have received navigator services?	Satisfaction	21	80.7

N = 26

^a Indicated by “agree” and “strongly agree” responses

Implications

The results of the current study will be used to improve and expand the patient navigation program at the cancer center. The assessment of patient and staff perspectives was conducted as the first step of the program evaluation. An orientation program led by the patient navigator has been established with the purpose of improving orientation to the services offered at the cancer center and affiliated community agencies. Chemotherapy and radiation therapy education also are part of the orientation program. Patient orientation programs increase patient satisfaction and awareness of available resources (Deshler et al., 2006). Because no statistical difference was identified between the navigator group and the comparison group for the first three factors (*prepared, education, and responsibility*), interventions will be initiated to further address patient education related to management of side effects. Why this occurred is unclear because the goals of patient navigation impact these areas directly. The lack of statistical difference could have been caused by the small sample size or inappropriate survey design.

For oncology nurses, this research suggests that developing an appreciation for the complexity of the care continuum is essential. Nurses need to be able to appropriately assess patients with cancer and identify areas of need. For advanced practice nurses in areas without patient navigation services, market assessment and strategic planning should be conducted to determine whether a need for navigator services exists. A 2003 National Cancer Institute study found that only 200 of about 1,400 cancer centers in the United States offer some form of patient navigation, indicating an average of only four centers per state (Commission on Cancer, 2009; Hede, 2006). Limited research literature on patient navigation and the limitations of the current study suggest further research is warranted to

determine the effect of patient navigation on select demographic populations, types of cancer, stage at which cancer is diagnosed, adherence to treatment, quality of life, and cost efficiency. In addition, economic effects of patient navigation should be evaluated by determining whether such services reduce hospital admissions, emergency room visits, and duplication of services. Given the wide variation in providers of patient navigation reported in the literature, results based on type of provider in specific contexts also warrant additional investigation.

Conclusion

Patient navigation as a care coordination strategy is an emerging trend in cancer care. Although limited, published research as well as the results of the current study suggest the efficacy of patient navigation. Patient navigators can play a significant role in helping patients with cancer access care across an extremely complex continuum. Continued research is essential in advancing the role of patient navigators. The Institute of Medicine (2001) proposed that health care should aim to be safe, effective, patient centered, timely, efficient, and equitable to make significant improvements. Patient navigation can be used to affect all of these goals in caring for patients with cancer.

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