Patient Care Connect

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Lay navigators improve quality and reduce cost of care

Patient navigation is emerging as a significant patient care coordination and support resource to cancer patients. Navigation is recognized as an essential patient care service by the Centers for Medicare & Medicaid Services, the Commission on Cancer, the National Accreditation Program for Breast Centers, the Academy of Oncology Nurse & Patient Navigators, and other national organizations who see its potential to significantly improve patient outcomes and reduce unnecessary services.

The University of Alabama at Birmingham implemented a comprehensive patient care coordination program, Patient Care Connect, along with 11 community cancer center associate sites in Alabama, Georgia, Florida, Mississippi, and Tennessee. This article integrates prior Patient Care Connect program findings, focusing on the key learning points and critical success factors gained from our experience building this program. Organizations desiring to build or enhance a patient navigation program will gain a better understanding of what the University of Alabama at Birmingham has discovered to be the most important factors in serving cancer patients through navigation services.

Background

Cancer patients often have a long and difficult treatment journey with many possible complications along the way. According to the National Comprehensive Cancer Network, approximately one-third of cancer patients experience "significant distress," which can impact not only how the patient copes with the disease but also his or her strength and ability to fight the disease and to follow the recommended course of treatment.[1]

> Though the concept of patient navigation is not new, the use of lay navigation teams across the continuum of a cancer journey is a novel approach to care coordination. Integrating lay navigators into the healthcare team empowers the clinical team to work at a higher level within the scope of their training.

In July 2012 the University of Alabama at Birmingham Comprehensive Cancer Center was awarded a $15 million, three-year grant from the Center for Medicare and Medicaid Innovation to expand and enhance the cancer center's well-established, non-clinical patient navigation program and to extend it to the 11 associate sites in the University of Alabama at Birmingham Health System Cancer Community Network. The goals of the Patient Care Connect cancer patient navigation program are to proactively identify potential treatment complications, barriers to appropriate and timely patient care, and other causes of patient distress as early as possible and to avoid unnecessary duplication of services, prevent complications from treatment side effects, and minimize unnecessary costs to both the patient and the healthcare system.

The Need for Lay Navigation

Though the concept of patient navigation is not new, the use of lay navigation teams across the continuum of a cancer journey is a novel approach to care coordination. Integrating lay navigators into the healthcare team empowers the clinical team to work at a higher level within the scope of their training. These navigation teams are beginning to serve as a surrogate patient-centered oncology medical home model, which can provide a way to empower patients to more effectively manage their treatment and survivorship experience. Navigation teams also provide a foundation for disparate provider groups to join forces and provide a more integrated care delivery program, which will be attractive to insurance networks, accountable care organizations, and other value-based contracting entities in the future.

Most studies on disparity in cancer highlight that race and ethnicity are the leading variables contributing to a lack of early diagnosis and quality treatment. Statistics such as those generated by the National Cancer Institute demonstrate that minorities, specifically African Americans, have a higher rate of cancer diagnosis and a lower survival rate than other ethnicities.[2] Hershman et al. found that increased personal wealth was also associated with lower mortality, lower prevalence of chronic medical conditions, improved functional status, and reduced healthcare utilization and was correlated with racial differences in overall health.[3]

Due to such disparity, much research has been done to rectify this imbalance. Hendren et al. conducted a study to determine what factors led to newly diagnosed cancer patients needing more assistance from healthcare workers, a measure known as Navigation Time: "In univariate analysis, log Navigation Time was associated with race/ethnicity, education, income, employment, insurance type, health literacy, marital status, language, and comorbidity."[4] The most common barriers to care that were identified for all races include but are not limited to medical communication, a lack of social support, and medical insurance/financial concerns, with minorities experiencing these barriers at a greater rate.[4] Not only do minorities experience more barriers but they experience a more significant impact on care from those barriers and thus experience an increased need for Navigation Time.

The positive impact of the patient navigator role is quickly being seen and felt within the cancer treatment field, and an increasing number of organizations are adopting the initiative to better serve and treat patients. According to Braun et al., "A cancer patient navigator is an individual trained to help identify and resolve real and perceived barriers to care, enabling patients to adhere to care recommendations and thus improve their cancer outcomes."[5] Patient navigators have specifically been effective in helping poor, vulnerable, and underserved patients maneuver through the many barriers to care they encounter.[5] A study conducted by Donelan et al. on the follow-up of patients with abnormal mammograms demonstrated that patients who received navigation through the care process were significantly more likely to "definitely" understand what to expect in the follow-up appointment, receive appointment reminders, and feel welcomed.[6] A similar but more comprehensive study was conducted by Ferrante et al. in 2008 and focused on the effect that patient navigation had on urban minority women who received abnormal results from a mammogram.[7] The study tested the impact that patient navigation had on specific metrics such as improving timeliness to diagnosis, decreasing anxiety, and increasing satisfaction. The women who experienced patient navigation intervention had shorter wait times for diagnostic resolution by almost 18 days, and after 60 days only 6 percent of the patient navigation group was without a final diagnosis versus 22 percent in the control group.[7] When looking at anxiety, there was almost no difference in the baseline anxiety scores between the two groups; however, "after diagnosis, the mean anxiety index was lower in the intervention group (30.2) than in the control group (42.8; $p<.001$). Likewise, the change in anxiety index from baseline to follow-up was statistically different among the groups (decrease of 8.0 in intervention vs. increase of 5.8 in control; $p<.001$). In addition, the mean satisfaction score was higher in the intervention group (4.3) than in the control group (2.9; $p<.001$)."[7]

Racial and ethnic disparities are well documented in the diagnosis and mortality of colorectal cancer.[8] Research was conducted to determine the impact that patient navigation would have on a group of minority men and women over the age of 50 and who "had not had a fecal occult blood test within the past year, a sigmoidoscopy or barium enema within the past 3 to 5 years, or a colonoscopy within the past 10 years."[8] Similar to the other studies previously discussed, the patient navigation intervention group had a higher rate of compliance with physician recommended care and testing, demonstrating that patient navigation is successful in guiding minority patients through the barriers that can block or delay diagnosis and treatment.

Though efforts in healthcare reform to provide better access and availability to affordable healthcare are making an impact, more patient-centered help is needed. Nonclinical patient navigation is an innovative, proven, and effective initiative that helps cancer patients of all racial and socioeconomic types better manage the complex, emotional, and stressful journey of cancer treatment. Patient navigation provides patents with support, empowerment, understanding, and options to allow for better quality of care with the ultimate goal of healing.

The Patient Care Connect Program

The conceptual model behind the Patient Care Connect program is empowerment around improved health. Patients are empowered to become more engaged in shared decision making and self-managing many aspects of their care. Patient navigators are empowered to directly help patients overcome the nonclinical barriers to appropriate care. Clinical teams are empowered to work at higher levels within the scope of their professional training. The combined effects are better patient outcomes, more efficient care, and fewer unnecessary resources.

The Patient Care Connect navigation teams consist of a nurse leader surrounded by well-trained nonclinical ("lay") navigators. The lay navigator concept is based on more than 15 years of prior experience at the University of Alabama at Birmingham using community health advisors in a variety of community screening, low-income resource support, clinical trial navigation, and nurse navigation programs. The navigation teams typically have one to five nonclinical employees, depending upon the number of Medicare beneficiaries being served by each site. The Patient Care Connect program pairs a lay navigator with a new patient with the goals of empowering patients and helping them to:

- Overcome barriers to care.
- Make the most appropriate and informed choices for their treatment.
- Avoid the use of the emergency room.
- Reduce the use of unnecessary or repetitive services.
- Proactively consider and plan for advanced stages of disease progression.
- Maximize the appropriate use of healthcare resources.

These navigators follow patients through the entire continuum of their cancer journey.

The core workflow for the patient navigation team is centered on patient acuity stratification, continuous patient need assessment, and the proactive identification of significant barriers to improved patient outcomes. Over the course of the grant-funded program, Patient Care Connect served a regional population of approximately 31,000 Medicare beneficiaries. Because navigation teams are a limited resource, the program identified patients at the greatest need and/or risk of potential problems or barriers to care. All patients at the University of Alabama at Birmingham are eligible for support from our patient navigation team, but we proactively work with the highest need patients and prioritize the workload using a need-based triage process. To do this, patients are regularly administered a standardized distress assessment survey tool modeled after the National Comprehensive Cancer Network Distress Thermometer.[1] In addition, the navigators routinely searched through hospital census reports and other data to identify patients who had an unplanned visit to the emergency room or an unplanned admission to the hospital.

Approximately one-third of the patient population was triaged into active navigation services by the lay navigation teams. Patients who met the triage inclusion criteria for active navigation support were screened at least once per month, with more frequent contact based on patient needs. Those who did not meet the triage inclusion criteria were monitored in an "inactive" status mode. Patients in active status were proactively monitored and contacted at least monthly based on patient-reported distress, with those patients reporting higher levels of distress or identified as having higher acuity conditions being contacted more frequently.[9] Patients who reported low distress or who did not appear to have high-acuity conditions were contacted at least quarterly.[9] On average, patient navigators were assigned 152 patients per quarter, 91 of whom were identified as high acuity, and completed an average of 275 patient contacts per quarter.[9] Approximately 62 percent of these patient contacts were in a face-to-face setting.[9]

Navigators use the distress assessment tool to identify and prioritize the work for each patient. Clinical barriers are escalated up to the appropriate clinical resource, because lay navigators are not permitted to address clinical issues that would normally require a nurse's intervention. In 34 percent of the identified distress issues, patients requested help from the navigator to address their specific concerns.[10] Working directly with patients face to face and over the phone, navigators help identify possible solutions to overcoming nonclinical barriers to care by referring patients to the correct resource. In 92 percent of the cases, navigators were able to resolve these concerns to the patient's satisfaction.[10] Navigators cultivate and maintain relationships with a network of resources that may be able to provide appropriate assistance to the patients, including financial counselors, social workers, community resources, support groups, local charities, and advocacy groups. Navigators also have access to a limited pool of financial and community resources like transportation vouchers, discounted housing, and free food. Patient navigation is a limited resource but, when deployed correctly, it has been proven to significantly reduce unnecessary utilization and improve patient satisfaction.[11]

Beyond the continuous assessment of patient distress and barriers to care, the navigation team spends a large portion of their time identifying and coordinating various support resources for patients.

Together with our associate sites, the University of Alabama at Birmingham designed and developed all of the care protocols and pathways for the program, including a significantly enhanced distress assessment tool that forms the basis of the navigator's patient interview and assessment process. (Elements in this distress assessment tool are outlined in Figure 1, page 28.) Navigators receive extensive training on the continuum of cancer diagnosis, treatment, and survivorship, as well as training related to common geriatric health issues and complicated comorbid conditions. We also developed a custom software program to track all patient encounters. The software:

- Tracks levels of patient distress.
- Creates work lists as barriers are identified.
- Assists with referrals to other care providers.
- Provides follow-up intervention reminders.
- Serves as a team communication tool.

Note that many barriers to care such as pain or fatigue are common and may be continuous throughout the patient's treatment journey. Navigators may document pain as a common problem, but when the patient indicates that he or she needs help controlling the pain, it becomes a barrier that the navigator works to resolve until the patient is later assessed and reports that the pain is being appropriately managed and is no longer an uncontrolled barrier.

Following the formal distress assessment, navigators continuously assess their patients' needs in their ongoing work with their patients. These ongoing assessments are mostly partial distress assessments based on the identified barriers that the navigator is working on. These partial assessments are referred to as informal distress assessments. The continuous use and documentation of these informal assessments is at the core of the navigators' workflow. The Patient Care Connect program does not consider an identified barrier as having been addressed to the patient's satisfaction until the patient acknowledges in a documented formal or informal distress assessment that the issue has been satisfactorily handled.

Beyond the continuous assessment of patient distress and barriers to care, the navigation team spends a large portion of their time identifying and coordinating various support resources for patients. The navigators are constantly working on developing a broad network of internal and external resources to help patients with some of the more common barriers, including the need for:

- Disease-related information.
- Transportation to and from treatment.
- Temporary housing.
- Introductions to community support groups.
- Assistance with practical needs, because many patients live alone.

Navigators are also trained to help patients begin to think proactively about potential decisions they may face in the future. The Patient Care Connect navigators receive basic training in the Respecting Choices program, an evidence-based model of advance care planning aimed at identifying and honoring an individual's goals and values for current and future healthcare needs.[12] During distress assessments and patient interviews, navigators identify patient goals and values and encourage them to consider advance directives, open communication with family members and significant others about their wishes and other proactive planning issues.

Though navigators do many things for their patients, they also encourage the patients to identify barriers themselves and empower them to handle the situation independently. For example, if a patient identifies uncontrolled pain as a problem, rather than calling the nurse for the patient, the navigator may give the patient the nurse's name and phone number, tell him or her to call the nurse directly, and follow up in 30 minutes to make sure that the patient followed through. Over time, patients learn how to handle these situations proactively on their own and begin to need the navigator's coaching less and less. Of course, for patients who are not able to manage these tasks on their own, the navigators will assist them as much as is needed.

As important as it is to know what successful patient navigation teams do, it is even more important to understand what activities

(continued on page 30)

Figure 1. Elements in the Distress Assessment Tool

Date Administered: ___________	By: _____________________
Patient Name: ________________	MR# ___________________
Overall Level of Distress: 1-2-3-4-5-6-7-8-9-10	
PHYSICAL PROBLEMS:	
___Balance/Walking/Mobility	
___Bathing/Dressing	
___Body Sores	
___Breathing	
___Changes in Urination	
___Constipation	
___Controlling Bowel Movement	
___Controlling Urination	
___ Diarrhea	
___Dizziness	
___Eating	
___Fatigue	
___Feeding Self	
___Fever	
___Getting Around (inside home)	
___Getting Around (outside home)	
___ Hearing	
___Indigestion	
___Mouth Sores	
___Loss of Appetite	
___Moving In/Out of Chair or Bed	
___Nausea/Vomiting	
___Nose Dry/Congested	
___Opening Medication Bottles	
___Pain	
___Sexual Problems	
___Skin Dry/Itchy	
___Sleep/Insomnia	
___Substance Abuse	
___Swallowing	
___Swollen Arms/Legs	
___Talking	

(Figure 1 continued on next page)

Figure 1. Elements in the Distress Assessment Tool (continued)

PHYSICAL PROBLEMS:
___Tingling Hands/Feet
___Toileting
___Vision
___Weight Change
___Writing

PRACTICAL PROBLEMS:
___Ability to Use Phone
___Child Care
___Cooking
___Getting Groceries/Shopping
___Housekeeping
___Housing
___Insurance/Financial
___Manage Finances
___Transportation
___Work

INFORMATION CONCERNS:
___Alternative Therapy Choices
___Diagnosis/Disease
___Diagnostic Results
___Diet/Nutrition
___End of Life Issues
___Hospice
___Home Health
___Legal Issues
___Maintaining Fitness/Exercise
___Performing Medical Procedures
___Prognosis
___Scheduling
___Survivorship
___Side Effects/Treatment(s)
___Side Effects/Medication(s)
___Supportive Care
___Treatment(s)
___Treatment Decisions

EMOTIONAL PROBLEMS
___Adjusting to Changes in Appearance
___Adjusting to My Illness
___Boredom
___Concentration
___Coping with Grief and Loss
___Emotional Control
___Fear(s)
___Feeling Depressed or “Blue”
___Feeling Hopeless
___Guilt
___Intrusions
___Isolation/Feeling Alone
___Loss of Interest in Usual Activities
___Managing Stress
___Nervous/Anxiety
___Role Changes
___Sadness
___Self-esteem
___Worry

FAMILY PROBLEMS: Dealing with:
___Children
___Family Support
___Friends
___Partner

OTHER:
___Ability to Read/Write
___Cultural/Religious Needs
___Citizenship
___Lack of Social Support
___Language Barrier
___Post-op Care

SPIRITUAL/RELIGIOUS CONCERNS:
___Lack of Comfort, Strength or Hope from Spiritual Beliefs
___Facing My Mortality
___Lack of Support from Spiritual/Religious Group
___Loss of Faith
___Trust in God
___Loss of Sense of Purpose
___Meaning of Life
___Relating to God

(continued from page 28)

they do not do. Appropriate boundaries around the scope of a patient navigator's practice keep the entire clinical team working together most efficiently. At the University of Alabama at Birmingham, the navigators do not:

- Make any kind of clinical decisions or clinical recommendations about a patient's care.
- Replace nurses, social workers, or other clinical personnel.
- Steer patients away from appropriate care or toward inappropriate care.
- Inappropriately promote specific services, physicians, or facilities.
- Interfere with standard patient care activities.

Documented Results

Medicare provided comprehensive claims data on the beneficiaries enrolled in the Patient Care Connect program. In a retrospective matched study conducted by the University of Alabama at Birmingham, the pre-enrollment costs per beneficiary per quarter for beneficiaries who triaged into active navigation started higher but declined faster than the matched comparison group by $781.29 more per quarter per navigated beneficiary ($p < .001$), for an estimated $19 million decline per year across the network, ultimately becoming lower than the nonnavigated beneficiaries after six quarters.[11] Inpatient and outpatient costs had the largest between-group quarterly declines, at $294 and $275, respectively, per beneficiary.[11] The greatest mean quarterly cost declines were observed for inpatient costs, which decreased by $522 and $198, respectively, per quarter per beneficiary for navigated and matched comparison groups.[11] Quarterly reductions per beneficiary were also observed for outpatient costs ($473 for the navigated group and $194 for the matched comparison group) and physician visit (carrier) costs ($339 for the navigated group and $129 for the matched comparison group), and hospice costs increased ($39 for the navigated group and $36 for the matched comparison group) for navigated beneficiaries.[11]

With a cost decline of $781.29 more per beneficiary per quarter than among the nonnavigated beneficiaries, we projected a $475,024 reduction in cost annually for a navigator managing 152 beneficiaries throughout the year.[11] For a navigator with an annual salary investment of $48,448 (salary and fringe benefits), we estimated a return on investment of 10:1.[11]

We observed decreases in emergency department visits by 6.0 percent more per quarter among the navigated group than the matched comparison group (internal rate of return [IRR] = 0.94; 95% confidence interval [CI], 0.92–0.96; $p < .001$). Hospitalizations declined by 7.9 percent more per quarter (IRR = 0.92; 95% CI, 0.90–0.94; $p < .001$), and intensive care unit admissions were reduced by 10.6 percent more per quarter (IRR = 0.90; 95% CI, 0.86–0.94; $p < .00111$; see Figure 2, page 31). These findings were supported in an independent study conducted by Medicare that specifically evaluated patients at the end of life.[13]

Lessons Learned

Over the more than 20 years that the University of Alabama at Birmingham has been using nonclinical patient navigators to assist patients with overcoming the barriers to their care, we have learned many valuable lessons about how to make a navigation program successful. Through the Patient Care Connect program, Medicare has provided us with comprehensive claims data that have substantially enhanced our understanding and measurement of the key elements needed to support maximum effectiveness. Here are the top lessons learned from our experience:

1. *Clear and Compelling Objectives.* The most important factor for building a successful navigation program is to have clear and compelling objectives with clearly defined and tangible metrics for measuring program results. Clearly defined objectives keep everyone focused on specific goals. For Patient Care Connect, the compelling objectives are to reduce emergency room visits, unplanned inpatient stays, use of the intensive care unit, and chemotherapy in the last two weeks of life, as well as to increase the appropriate use of hospice care. These are all measurable outcomes that provide a clear picture of program results.
2. *Organizational Buy-in with Leadership from a Respected Clinical Champion.* Patient navigation can look like just another non-revenue-generating expense item on the budget. Without strong organizational buy-in and empowered physician leadership, the program will be weak and ineffective. When budgets become tight, weak programs are eliminated.
3. *Clear Clinical Team Role Definitions.* There is more than enough work for every member of the patient care team to do. Properly defined staff roles, especially for lay navigators, nurses, and social workers, are needed to drive patient engagement to the correct staff level. Unclear staff roles will lead to duplication of effort, arguments over turf, and gaps in patient care coordination. Additionally, a unified conceptual model that promotes interdisciplinary team engagement, strengthens role definitions, and helps to prevent scope creep will support a healthy program.
4. *Clearly Defined Navigator Competencies.* Clearly defined competencies for navigator recruitment, training, and ongoing development will provide a strong foundation for the navigation team's effectiveness. Team hiring is also strongly encouraged, because it will help to build team unity and minimize the hiring of the wrong skill sets. Table 1, page 33, outlines Patient Care Connect's lay navigation competency levels.
5. *Proactive Patient Engagement.* The use of a clearly defined triage process for proactively identifying the highest risk and highest need patient population will greatly enhance the focus and productivity of this valuable and limited resource.
6. *Continuous Patient Assessment.* The core of the Patient Care Connect program is having a structured process for continuously assessing and measuring patient needs.
7. *Easy to Use Navigation Tools.* Efficient navigation work is not possible without a well-structured, automated tool set with predictive analytics designed to support the navigation team. Navigators simply cannot be effective working from Excel spreadsheets or paper files. Automated tools need comprehensive data reporting that provides predictive ana-

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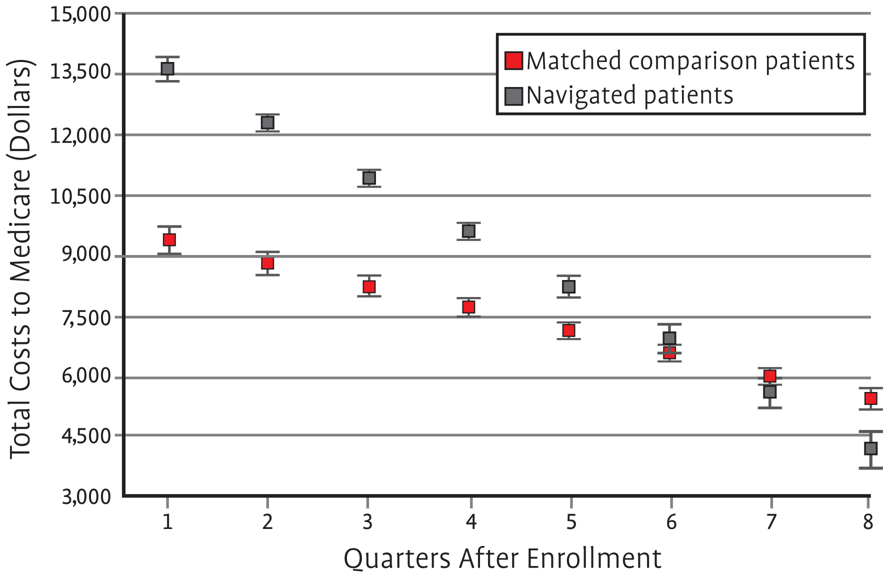
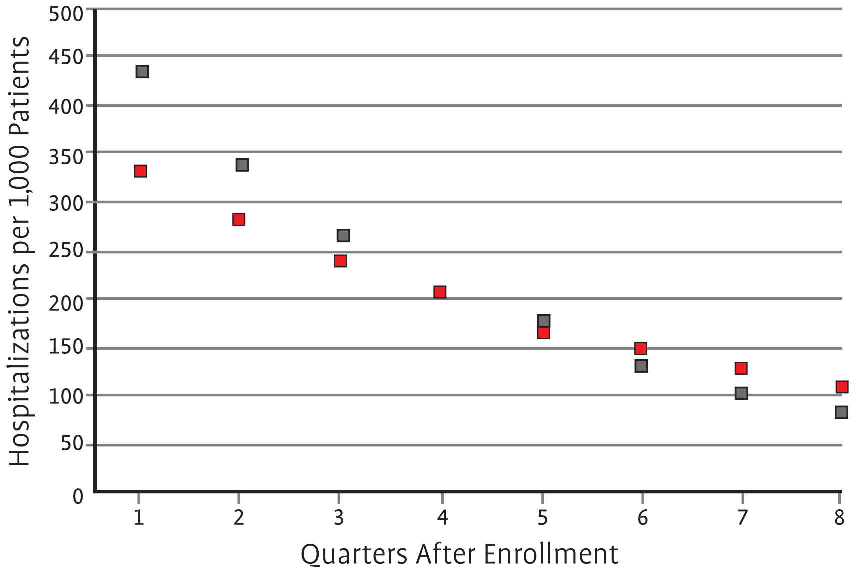
Figure 2. Model-Estimated Medicare Costs and Health Care Use After Enrollment for Navigated Patients and Pseudo-Enrollment for Matched Comparison Patients[11]

A Medicare costs



B Hospitalizations



ED = emergency department; ICU = intensive care unit

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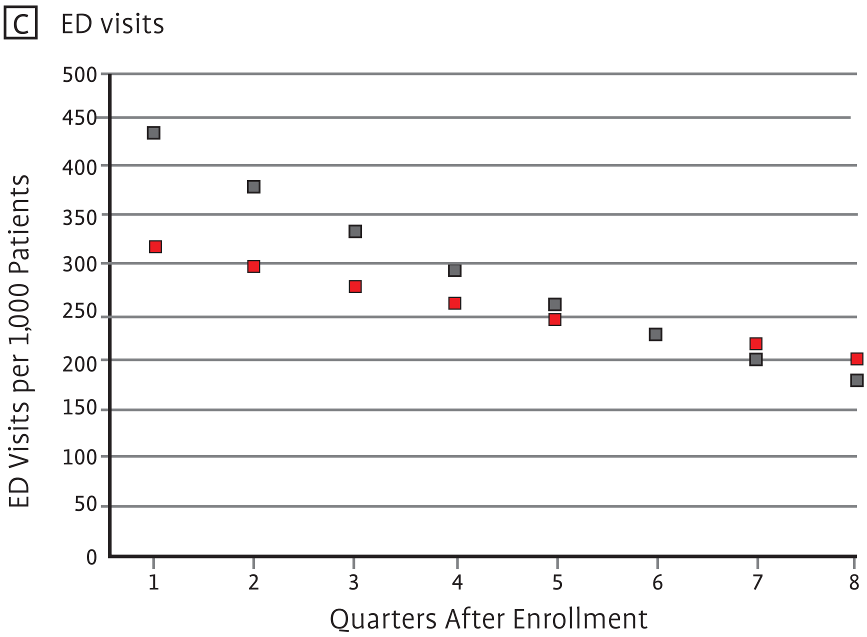
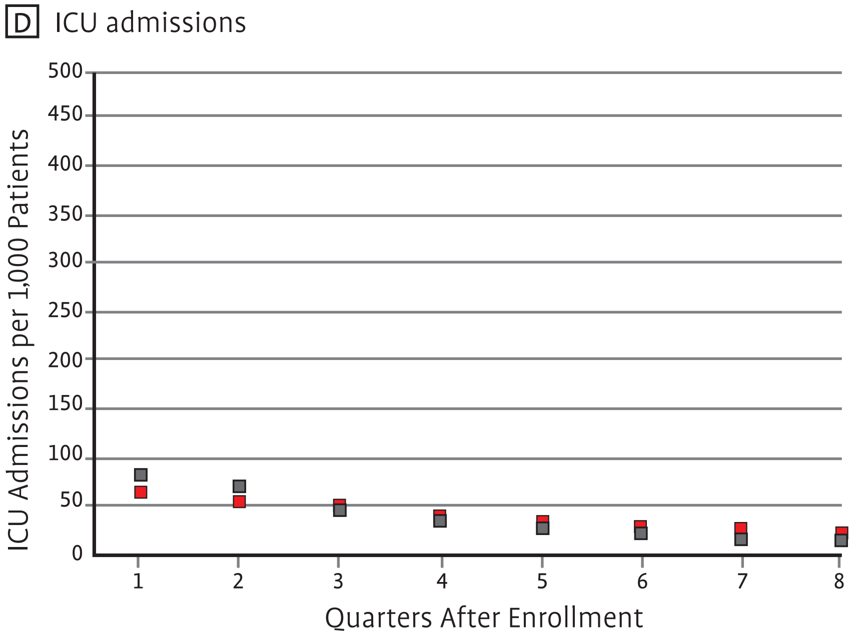
Figure 2. Model-Estimated Medicare Costs and Health Care Use After Enrollment for Navigated Patients and Pseudo-Enrollment for Matched Comparison Patients (continued)





ED = emergency department; ICU = intensive care unit

Table 1. Patient Care Connect: Lay Navigation Competency Levels

1	**Novice:** Beginner with no experience. Rule-governed behavior is limited and inflexible. Rules are context free, independent of specific cases, and applied universally. When an unexpected situation occurs, will get stuck.
2	**Advanced Beginner:** Demonstrates small degree of acceptable performance. May have gained enough prior experience in actual situations to recognize recurring meaningful components. Beginning to move from relying too heavily on the fixed rules. Can accomplish simpler tasks on own without supervision but has difficulty with identifying and eliminating problems.
3	**Competent:** Characterized by a sense of mastery and the ability to cope and manage as situations arise. Understands a situational component within the context of an environment. Able to identify and eliminate problems. Beginning to solve unique problems. Lacks the speed and flexibility of the proficient level. More aware of long-term goals. Gains perspective from planning own actions based on conscious, abstract, and analytical thinking and helps to achieve greater efficiency and organization. Able to complete work independently to an acceptable standard but may lack refinement.
4	**Proficient:** Perceives and understands situations as whole parts. More holistic understanding improves decision making. Learns from experiences and knows what to expect in certain situations and how to modify plans. Can achieve a high standard routinely.
5	**Expert:** No longer relies on principles, rules, or guidelines to connect situations and determine actions. Performance is now fluid, flexible, and highly proficient. High standard of decision making based on high level of critical thinking skills. Achieves excellence with ease. Easily integrates new information into catalogue of experiences. Able to determine relevant and irrelevant information.

(continued from page 30)

lytics and enhances the ability of the team to self-evaluate personal and program effectiveness.

8. *Internal Awareness and Communication.* It is critical that the entire organization be aware of the goals of the patient navigation team, what the organizational expectations are, how the lay navigators fit into the patient care team, and how this function adds value to the institution's goals.

Cancer patient navigation is a valuable resource that, when assigned correctly to the highest need patients, has the potential to significantly improve patient outcomes while reducing unnecessary utilization. The study and findings conducted by the University of Alabama at Birmingham in their Patient Care Connect lay patient navigation program serve as encouraging evidence that these types of programs should be implemented in every healthcare organization across the nation.[11]

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