An Oncology Nurse Navigator Program Designed to Eliminate Gaps in Early Cancer Care

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Although the burden of a cancer diagnosis for patients is profound, healthcare systems often fail to address patients’ and families’ psychosocial, information, and care coordination needs. The authors of this article designed an oncology nurse navigator program to proactively address these care gaps and tested the program’s effectiveness in providing high-quality cancer care through a randomized, controlled trial. The program’s model was informed by research synthesizing the perspectives of patients, families, clinicians, and experts throughout the country. The authors systematically incorporated feedback from participating clinical departments to improve the effectiveness of the program. This article details the intervention to help inform other systems interested in implementing an oncology nurse navigator program.

Medical treatment for patients with cancer has become increasingly complex. The process of diagnosis, staging, and treatment planning often requires assessment and recommendations across clinical specialties, as well as knowledge of evolving treatment protocols and best practices. The experience of patients and their families is equally complex and often confusing as they are asked to comprehend and make decisions about their care and become their own advocates and care coordinators. They must simultaneously handle the emotional distress of the cancer diagnosis. In response to the needs of patients and families, guideline authorities such as the Institute of Medicine and the National Comprehensive Cancer Network (NCCN) have promoted the need to provide cancer care that is of high quality from the patient’s perspective (Adler & Page, 2008).

In a previous study, Aiello Bowles et al. (2008) identified the barriers and facilitators of high-quality cancer care from focus groups with patients, family members of patients with cancer, and clinicians; site visits with cancer care providers and organizations in three communities in the United States; and interviews with experts in cancer care and policy. The findings from all of the sources indicated that the barriers to high-quality cancer care include delays in and lack of coordination of care, patient information gaps and passivity, and inadequate attention to psychosocial issues.

The fragmentation and uncertain accountability of early cancer care in the period before the initiation of treatment contributes to these issues. A solution was proposed by multiple sources: Patients and their families need an advocate or navigator to guide them through the maze of early cancer care (Wagner et al., 2010).

The role of navigation for patients with cancer has been variously defined and implemented (Freund et al., 2008; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). Although
it originally was conceived as a role for trained lay individuals to improve access to cancer screening for underserved populations (Freeman & Rodriguez, 2011), the role has spread and, today, professional organizations are in place and providing support to oncology nurse navigators (ONNs). The authors of this article posit that the aims and roles for these ONNs should be directly linked to the gaps in cancer care that patients and their families experience.

The role of the ONN is to provide targeted care management to patients recently diagnosed with cancer, a period characterized by an existential plight in which life and death concerns predominate and coping strategies are challenged (Weisman & Worden, 1976–1977). Evidence indicates that patients often feel overwhelmed and inadequately supported during this period (Adler & Page, 2008). The Institute of Medicine’s report Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (Adler & Page, 2008) proposed a model of high-quality, patient-centered cancer care developed by experts, frontline providers, and most importantly, patients themselves. The authors’ program was an implementation of this model.

Methods

The program was created as part of a National Cancer Institute–funded study. The aim of the randomized, controlled trial was to test the effectiveness of a 16-week ONN program compared to enhanced usual care to support patients with cancer early in their treatment. The enhanced usual care program consisted of providing newly diagnosed enrolled patients with a packet of educational materials and resources that were developed in partnership with a community advisory group. This group comprised current patients, family members, and community agencies, and all provided critical feedback on what the educational packet should include. For example, two patients developed a one-page quick guide booklet that illustrated the departments and procedures the newly diagnosed patient with cancer could expect as part of his or her immediate treatment. Patients (N = 251) from 11 participating primary care clinics were enrolled in the study from July 2009 to August 2011. Randomization occurred with primary care providers, and all patients from the same primary care provider were assigned to the same group. The ONN arm included 133 patients with the following three types of cancer: lung (n = 15, 11%), breast (n = 103, 77%), and colorectal (n = 15, 11%). Study outcomes include patient experience with care; quality of care; quality of life assessed by interview at baseline, 4 months, and 12 months; overall costs of care; and delays in treatment. The results are currently being analyzed and will be reported when complete.

The study was implemented at Group Health Cooperative (GHC), a not-for-profit capitated and integrated delivery system based in Seattle, WA. GHC provides medical coverage and care to more than 600,000 patients, and 2,600–3,000 patients with cancer annually. The patient population at GHC is generally representative of the region, including the proportion of patients with Medicare, Medicaid, and the state-sponsored Basic Health Plan program. GHC has a shared electronic medical record that facilitates communication among providers, including the ONNs.

Intervention

Figure 1 shows the flow of the ONN program. Direct ONN contact with patients varied throughout the 16-week intervention depending on individual patient needs, upcoming medical appointments, and patient availability. Patients had an average of 179 encounters with their ONN, and ONNs sent patients an average of 9.4 pieces of communication (electronic or letters) that mostly served to document their encounters and the next steps in the treatment plan.

The ONNs strived to meet each patient in person and attend one or more of their medical appointments with them. The ONNs believed that they were able to develop a more trusting medical relationship with patients who they were able to meet in person at least one time. Most weekly encounters were held via telephone calls. These nurse-initiated telephone calls assessed patient status and their needs. One of the ONNs also served as a clinic nurse in medical oncology. For her, the most significant difference between these two roles is that ONNs provided proactive care by asking patients about their concerns and problems during regularly scheduled outreach encounters, whereas oncology clinic nurses respond reactively to incoming queries from patients for immediate triage or problem solving. Table 1 lists the roles and responsibilities of an ONN.

The ONNs regularly used the NCCN’s Distress Thermometer, part of the NCCN’s cancer treatment guidelines, to identify problems patients were experiencing (Roth et al., 1998). Problems were categorized as practical, familial, emotional, spiritual or religious, and physical. For each area of distress identified, the ONN charted information about the patient’s perceived source of distress and then collaboratively devised a plan of action to diminish the distress. Action planning began with collaborative problem solving to evaluate solutions that were both doable and most likely to be effective. After development, plans were sent to patients through GHC’s electronic patient portal, or, if the patient was not active electronically, mailed to the patient’s home. Action plans often included other members of the patient’s clinical team, such as physicians. For example, plans may include scheduling an appointment with a primary care provider to discuss antidepressant medication,
or with a genetics counselor, or following-up with the oncologist about one of the patient’s medical questions. Those types of communication were documented in the patient’s electronic medical record.

Each ONN had a dedicated cell phone for patients to call or leave a message for a return call at any time. Cell phones were used because the nurses only worked part-time as ONNs. At the beginning of the program, the ONNs were concerned that patients may call the cell phones during off-hours or for emergencies, so the team mandated a voicemail message that clearly informed patients when to call the cell phone. When asked about this at the end of the program, the ONNs did not feel that patients used the cell phone contact inappropriately.

Table 2 describes the vital skills and attributes for successful ONNs identified in response to requests from outside programs interested in learning from the model. To corroborate the importance of these behaviors, the authors include quotes from patients collected during their 4- and 12-month interviews.

### Training and Support for Nurses

The ONN team consisted of three nurses from three different departments: medical oncology, general surgery, and breast cancer screening. Although this diverse makeup of the ONN team was unanticipated (the authors initially planned on including oncology nurses only), it actually became a strength of the program. The nurses were able to share medical expertise and process knowledge across departments, which ultimately improved their ability to care for patients.

Two nurses had been in practice for more than 30 years, and the third nurse was in practice for four years. All of the ONNs had bachelor of nursing degrees. The nurses maintained their work in their home departments and acted as ONNs for about 0.2 full-time equivalent (FTE), or eight hours, each week. The maximum number of patients that an ONN could manage was eight at any one time with that FTE level.

Before patients were enrolled, training led by the study team psychologist was conducted for the ONNs. The training reinforced their current skills and reviewed psychosocial skills such as empathic and motivational enhancement communication strategies, depression assessment, and behavioral activation and problem-solving strategies for addressing distress that they would not typically employ in their roles as nurses.

Community agencies that support patients with cancer were invited to join the training and share information about their services. Patients also were invited to meet the nurses and share their personal stories of cancer treatment. Together, the team developed protocols and guidelines for care, and an oncology nurse consultant reviewed the final protocol.

After enrollment was initiated, the ONNs discussed their cases weekly in a telephonic case review. Initially, all patients were discussed; however, as patient caseloads began to reach full capacity, only new and complex patients were discussed. The weekly telephone calls included all of the ONNs, the oncology department chief to answer cancer treatment questions, a clinical psychologist to support psychosocial skills, and program management personnel. When clinical and coordination questions surfaced, other staff were invited to join in on the telephone calls. Examples of people or representatives who joined the weekly conversations included lung cancer nurse navigators from a neighboring hospital, a staff member from GHC’s financial services department, a representative from GHC’s hospice and home health program, and a primary care provider/leader. These regular case discussions facilitated teamwork and the sharing of lessons learned.

### Case Studies

The following two case studies demonstrate the roles described in this article as well as critical behaviors for ONNs.

### Case Study: Karen

Karen is a 50-year-old Caucasian woman who came in for her annual screening mammogram with anxiety and the knowledge that her mother died at age 42 from breast cancer. Karen’s mammogram raised concern about a density in her right breast that, following a biopsy, proved to be infiltrating...
ductal carcinoma. An ONN was assigned to work with Karen and made the first of 16 weekly calls to her shortly after the diagnosis. During the initial interview, the ONN listened carefully for guidance, from Karen’s thoughts and responses, on how she would be best able to support Karen. The ONN had learned that each woman’s response to a diagnosis is unique, even if the pathology is similar. Karen had many questions about what this diagnosis would mean for her family, her work, the treatment path, and her survival. The ONN explained that the goal in working with Karen was to help her move through the experience as smoothly as possible.

Karen’s biopsy was done by a needle core sample, so the ONN explained that many of the answers to her questions would come from a layering of information as her workup progressed. The ONN shared that this process often is one of the most stressful phases because more unknowns than knowns are present. Karen began with a consultation with a surgeon who advised a staging magnetic resonance imaging (MRI) scan. The MRI revealed not only the known cancer in Karen’s right breast, but a second area of concern in her right breast and an additional density in her left breast. This news was very stressful for Karen, and the ONN explained that knowing the full extent of the disease was important before making surgical treatment plans. The recommendation that resulted from the MRI prompted an attempt to biopsy both areas by ultrasound guidance. The radiologist who performed the “technically challenging” biopsy of a vague density in Karen’s left breast was unable to find the second site in her right breast. The pathology revealed adipose tissue and six-month follow-up imaging studies were advised. Karen and the ONN felt that this course was somewhat inconclusive and a series of conversations were started between the ONN, Karen’s surgeon, the ultrasound radiologist, the MRI radiologist, and Karen. This added discussion and input led to an MRI-guided biopsy of both the right and left breast sites. Although the left breast site proved to be benign, Karen opted for bilateral mastectomy.

Results from the pathology showed multifocal disease in Karen’s right breast and atypical ductal hyperplasia (ADH) in her left breast. The ADH, a high-risk finding, would have led to close follow-up and Karen was relieved not to carry the worry associated with subsequent interval imaging studies. Karen was sent for a consultation with a genetics counselor because of her family history and age. She tested positive for a BRCA2 gene mutation, further confirming her decision to have bilateral mastectomy.

Karen has since consulted with a medical oncologist and finished her first round of chemotherapy. She will consult with radiation oncology, gynecology (because of her BRCA2 status), and a plastic surgeon for possible reconstruction. In the past four months, Karen and the ONN have discussed and problem solved a variety of concerns about finances, symptoms from chemotherapy, faith, family, and fear, as well as whom to call about certain health issues.

Case Study: Luis

Luis is a 59-year-old African American single man diagnosed with stage IV non-small cell lung cancer found, incidentally, on a chest computed tomography (CT) scan when he was admitted to the hospital for a stroke (transient ischemic attack).

The ONN had her first encounter with Luis by telephone and found out, among other things, that he lives on his own in a rented apartment in an urban setting, does not own a car, and uses the bus for transportation. He is a long-time smoker but a former marathon runner and semiprofessional athlete. He described himself as self-sufficient. Luis is afraid the disease “might do him in,” and wants to make sure he will receive truthful and

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<th>Critical Behavior</th>
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<td>Clinical expertise in medical, surgical, and radiologic treatment of cancer</td>
<td>“Her going with me to my appointments. She would explain stuff to me at the appointment if I didn’t understand it. Then she would explain it to my family.”</td>
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<td>Demonstrates knowledge and skills in oncology care, including symptom management, skin care, and nutrition support</td>
<td>“Just knowing I can talk to a person who knows so many different sides of treatment—she’s in contact with lots of patients, knows what other people are doing, like trying to alleviate symptoms. She could help determine if what I was reading on the Internet was valuable or not, very helpful.”</td>
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<td>Comfortable outreaching to patients</td>
<td>“I appreciated the [ONN] connection—a consistent and available resource.”</td>
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<td>Addresses personalized needs of patients, including psychosocial needs (ranging from financial concerns to extreme distress)</td>
<td>“I don’t think I would have felt half as comfortable without the ONN. You have so much information thrown at you; they help you figure out the best stuff for your cancer. The problem is that initially you are so frightened and she helped you and calmed you down. Helped clarify questions. Calming source.”</td>
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<td>Demonstrates the importance of active listening and converses with patients in a nondidactic manner</td>
<td>“The best part about the ONN is her vast experience and also her temperament, a good listener; she shared what other patients had experienced; that all helps. Just her very positive demeanor and attitude all the time.”</td>
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<td>Functions as first point of contact for many patient questions</td>
<td>“Single person that you could talk to about all aspects of your care. I did not have to call or e-mail many people. I could contact one person and she worked through the system for me.”</td>
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realistic information about his treatment plan and prognosis. He is worried he may become too debilitated by the treatment and not be able to care for himself or able to continue working and maintain his health insurance coverage. He worries that his family will be too overprotective on hearing this news and that he will lose his independence. The ONN offered to attend Luis’ first oncology consultation with him to act as a second pair of ears and an advocate because, otherwise, he had planned to go alone.

Luis is told that his disease is not curable but can be treated in a palliative fashion with IV chemotherapy. He asks and is told that he probably has a year to live. Luis asks the ONN for advice on how to let the people in his life know and they discuss ways in which he can inform his daughter, a brother he is closest to, and an administrator at his workplace.

Luis and the ONN begin a series of weekly telephone calls. He shares the news with his family and coworkers and has positive encounters with each. He speaks with his daughter briefly and asks the ONN to help bring his son-in-law home from Afghanistan so he can visit with him and his daughter at the same time to share this news in more detail. The ONN then helps to fill out the appropriate paperwork with the American Red Cross.

Luis has a cough that sometimes makes sleeping difficult; he is still smoking and he is very thin. The ONN discusses symptom management and possible treatment options and Luis begins wearing a nicotine patch and receives medication for his cough. Regarding treatment, Luis tolerates the chemotherapy fairly well except for fatigue. He makes plans for an extended visit with his daughter after one cycle of treatment and hopes to be at his best for her so he can discuss with her what is important to him now and for his future. He stresses that maintaining an independent lifestyle is a priority for him.

During the weekly calls with the ONN, Luis admits to having low feelings sometimes, but has a way of putting these feelings into a perspective that rallies him. He admits he sometimes feels afraid of dying, but he believes in an afterlife and takes solace in that. The ONN explains to Luis that these are natural feelings and that talking about them is a good thing. The ONN tells him about a local support group for people with cancer and how he might find it to be a place where he can discuss these feelings in more depth. The ONN also assures him that the clinical team will be supportive as he moves through this journey.

Issues start to arise at work for Luis. He does not want to further discuss his situation with coworkers and finds himself a bit estranged from his crew. His siblings also want to do more for him and he is feeling stressed from the attention. The ONN explains to Luis that he is well liked and that people naturally want to help him. The ONN suggests that Luis find small things for folks to do for him to make them feel better and to give him a better chance for more rest.

After three cycles, Luis is scheduled for a CT scan to check his progress and the scan shows shrinkage of the tumor. Luis is thrilled with the news, but is becoming more symptomatic now with increased fatigue and some shortness of breath on mild exertion. In addition, Luis is changing oncologists for a third time because of shifts in staff scheduling. The ONN is his constant in the healthcare team. He is scheduled for two more cycles of therapy and then an evaluation. He is comfortable with this plan and has talked with his family about giving him more space. However, Luis is expressing some anxiety about his prognosis and what is to come when treatment stops. He is surprised he has done as well as he has and is thinking about using a family home in North Carolina to rest and recuperate. He asks the ONN to accompany him to the appointment with the oncologist prior to his last treatment. At that time, he discusses his thoughts about skipping his sixth course and going south to rest and spend more time with his daughter. He is presented with some options, and says he will think about them.

Luis eventually decides to travel to North Carolina and cancel additional chemotherapy. He explains that he is feeling good now and wants to spend his remaining time with his daughter and the ones he loves most. He feels good about this choice and thinks it best for him. The ONN is grateful that she was able to help him along as he needed.

Lessons Learned

The two case studies demonstrate a number of themes and lessons the ONNs in the GHC program have learned during their two years in the role.

• The severity of the patient’s illness does not necessarily indicate the intensity of his or her distress. The patient’s personality, family support, financial situation, employment, and previous healthcare experiences affect how a patient handles his or her cancer.

• Healthcare providers should listen more and talk less. If you listen carefully from the start, patients will give you a good idea of what their needs are.

• By having weekly calls with patients, ONNs have the opportunity to reinforce their accomplishments and offer clinical and psychosocial support at the times they feel stressed or stuck by a particular problem.

• The intimacy of the relationship enables a level of understanding that a patient needs, which is unparalleled in usual care. This deep, patient-centered understanding is a positive contribution to clinical decision making.
Evolution of Knowledge and Skills by Nurses

The ONNs described their participation as a positive experience that deepened their skills and confidence and reinvigorated them about their profession. They appreciated the opportunity to connect and support patients undergoing an extremely difficult experience, as highlighted in the quotes from feedback provided at the end of the program.

The nurse navigator program helped me to mature as a nurse and as a person as it provided an avenue for me to spend ample time with patients on a weekly basis to discuss the whole patient, not just the disease.

This was an experience that will remain with me for the rest of my nursing career as it taught me how fragile life is but how strong the mind is when focused to heal the body. I will always remember that the first step to being a good nurse is to listen with compassion and empathy to really hear what the patient is saying, then to work with the patient to develop a plan that works for the individual patient.

I learned that teaching the patient how to problem solve while providing appropriate resources is, indeed, the best way to help the patient as they can take these skills and apply it throughout their cancer treatment.

The roles and functions for ONNs need to be articulated to understand their value in a healthcare settings. At present, the two national organizations supporting ONNs have to yet reach a consensus on these roles and functions, and this article is meant to provide input on the discussion. Simultaneously, many ONN programs are developed in the field with minimal evidence-based guidance because, to date, evidence is lacking. Although the effectiveness of this ONN model is currently being analyzed and prepared for dissemination, the authors hope that this article’s description of the key attributes of the model provide value to other healthcare settings preparing to develop their own ONN program.

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References


