



Assessing the Creative Application and Usefulness of NSider[®]: A Tactical Tool for the Oncology Nurse Navigator

Background

Oncology nurse navigators work in a variety of settings, including hospitals, outpatient clinics, oncology groups, and accountable care organizations (ACOs). Their patients have every conceivable type of cancer and a variety of treatment plans. Nurse navigators often follow patients from diagnosis through the entire spectrum of care. Their task has been to find the resources to help patients from diagnosis through care and recovery or relapse.

To this end, Eisai launched the NSider Patient Education Tool (NSider) in 2010. Eisai created NSider with a team of oncology nurses who had in-depth professional and, in some cases, personal experiences with cancer. NSider is an online nursing resource designed to help nurses provide patients and their caregivers with information tailored to their needs and situations associated with living with cancer. Nurse navigators can register at www.nsidernurses.com.

The objectives of NSider were to create a program that was at once comprehensive, but not overwhelming or impersonal, and to support the relationship between patients and nurses and underscore Eisai's commitment to humanizing healthcare. NSider permits nurses to assemble information based on cancer type, stage of treatment, type of treatment, and stage of disease. There are three ways to generate patient education materials using NSider—Fresh Start, Head

Start, and the Handout Wizard. Fresh Start allows you to preview and select content pages for the patient handout according to the phase of the patient's journey with cancer (first diagnosed, before treatment, during treatment, after treatment). Head Start provides previously created hand-

outs about the cancer type and treatment options that can be used intact or edited. Handout Wizard allows you to quickly generate handouts by selecting criteria from the menu options that match the patient's current circumstances (phase of patient journey, cancer type, treatment modality, expected side effects).

The Academy of Oncology Nurse Navigators (AONN) is the largest national specialty organization dedicated to improving patient care and quality of life by defining, enhancing, and promoting the role of oncology nurses and patient navigators. AONN recently conducted a survey to assess the usefulness of NSider for the nurse navigator community. This report will review the findings of that survey as

well as offer insights in the program from respected members of the oncology community.

The Oncology Nurse Navigator and the New Division of Labor in Cancer Care

The oncology nurse navigator specialty emerged almost spontaneously as an inevitable response to the downstream effects of the revolution in cancer care over the past decade. We are now in the era of biologicals

- "NSider makes [educating patients] an easy task."
- "It provides a great patient educational course."
- "Versatile – we can hand things out through different stages of cancer."
- "Helps patients come to grips with what they really need to know."
- "Helps streamline our work."
- "Helps us identify areas where we can be stronger in our presentations to patients."
- "Answers most of our [breast cancer] patients' questions. Most are middle-aged women who are focused on having information."

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transforming inevitably fatal cancers from acute disease states into chronic diseases, greatly increasing survival rates. As patients live longer, they require longer, more complicated management pathways. The oncologist workforce, rather than expanding with the larger patient base that will mushroom intensely very soon as the baby boomers attain geriatric status, is instead shrinking dramatically. Nuanced patient management was never the strong suit of physicians, but of nurses. Add to this scenario the emotionally charged nature of cancer, and it is clear why the role of nurses would expand in the oncology treatment team. This expansion led to the nurse navigator, who is charged with managing the new face of the cancer care treatment continuum.

The mission of AONN is to advance the role of patient navigation in cancer care and survivorship planning by providing a network for collaboration and development of best practices for the improvement of patient access to care and quality of life. NSider may help to provide systems support and eliminate redundant activities while embracing individualized treatment. Therefore, assessing the value of NSider is linked to the advance of personalized medicine in cancer treatment. According to cancer expert Dr Al B. Benson III, personalized medicine involves not only genomics but also managing the subjective, personal details the patient brings to the treatment process (eg, socioeconomic status, patient adherence and attitudes, caregiver support or lack of same, etc). Engaging the patient on an individual rather than a group basis is therefore critical for cancer treatment. Thus, NSider may engage, may help inform, and may help empower the patient, framing their expectations by illuminating their options and informing them of what to expect in situations that arise throughout the treatment process.

Survey on Usage

AONN conducted a survey on behalf of Eisai to determine the extent of awareness of the program among nurse navigators and how they used the program in its first 2 years. AONN initially elicited responses from 270 nurse navigators, 13% of whom had experience with NSider and used it for patient education (10%), to train members of their navigation team or for other navigators (5%), and for caregiver support (3%). The majority of these users (67%) agreed that NSider handouts increased patients' involvement in their own care.

AONN conducted follow-up interviews with 15 nurse navigators who had used the program to determine the depth of their experience with NSider and to elicit comments on its usability, usefulness, and effectiveness in their practices. The following report is based on real-world experiences of nurse navigators who use the tool to support patient education.

Survey Results

Work Setting

The nurse navigators who took part in the survey had held their positions for a median of 4 years (mean, 5.6 years). The majority of respondents were hospital based. Caseloads varied widely from 225 to 1400 new cases per year (median, 400; mean, 517), but this might have been a function of nurses reporting individual caseloads versus hospital caseloads. These were not differentiated.

Healthcare models varied and included ACOs, independent practice associations, acute care, and outpatient and inpatient hospital care. All respondents served as part of a care coordination team, but the nature and size of the teams varied from hospital to hospital, ranging from 4 to 7 individuals. All teams work together to coordinate care and use each other as resources.

NSider Usage

NSider was largely touted as a useful program for problem solving and meeting the needs of patients on their journeys through cancer care. One respondent personalized end-of-treatment summaries, including type of treatment, length of treatment, and treatment plan.

One nurse navigator created a book called *Our Journey*, using the Print Wizard for each of her patients. Each book incorporated the patient's healthcare provider contact information, type of cancer, stage of cancer, course of treatment, and current treatment regimen. It noted where in the stage of treatment patients were and what side effects they may experience or had experienced, as well as what to do in emergencies or when questions arose. The book also included resources required, including wigs and prosthetic devices or problems with insurance and resolutions. It outlined what to expect during treatment and what to do if certain side effects occurred. The

respondent noted that the book made patients feel secure, knowing that the information they needed was in one place. If other questions or problems arose, the nurse navigator added the appropriate pages to the book as necessary. Naming the book *Our Journey* reinforced the idea that patients were not in this alone, but that their physicians and nurses were always there with them to answer their questions and guide them through the difficult times.

Respondents use NSider during different stages of treatment and disease progression. Nurses who see new patients use NSider to describe the treatment process, mainly in the first stages of care ("as early as possible") and to describe the treatment plan.

All respondents used the Handout Wizard. One respondent used this area exclusively. Fresh Start was the second most favored section for patients who were newly diagnosed, but not for those with disease recurrence.

NSider Helped Nurses Standardize Information Provided to All Patients

- "It eliminates having to do extra research for each patient."
- "The team has access to the same material at the same time, which reinforces the message."
- "Written personalized instructions prevent having to review the same material over and over."

Common Problems in Care Coordination

- "Letting things slip through unnoticed. NSider keeps you on track and prevents lapses."
- "Giving too much information at any one time. NSider has helped prevent this. Patients can only process so much at any one time."
- "Overwhelming the patient. NSider provides a controlled amount of information."

Table Frequently Used NSider Topics

Fresh Start	Head Start	Handout Wizard
<i>First diagnosed:</i> Your care team Breast cancer*	Breast cancer basics All cancer types based on nurse specialty (breast, colorectal, lung, melanoma, prostate, leukemia, lymphoma)*	<i>Phase of journey:</i> First diagnosed* Before treatment
<i>Before treatment:</i> Surgery* Staying healthy	Preparing for surgery* What to expect after surgery*	<i>Tumor Type:</i> Chemotherapy* Radiation Surgery*
<i>During treatment:</i> Pain* Peripheral neuropathy (as needed)	Preparing for chemo* What to expect during chemo* Preparing for radiation* What to expect during radiation*	<i>Treatment:</i> Chemotherapy* Radiation Surgery*
<i>After treatment:</i> Your new normal Am I cured?	Support for caregivers	<i>Side Effects and Changes:</i> Blood counts Bowel changes Concentration changes Fatigue* Menstrual cycle Hair loss* Lymphedema Mood and emotional changes* Fertility changes Pain* Sexuality Nausea and vomiting Skin changes
	After treatment (both favorable and unfavorable prognoses)	
	Expected side effects* (as needed and depending on treatment)	

*Most frequently used topics.

NOTE: All handouts were provided exclusively for patients, not caregivers. The nurse navigators noted that caregivers received some information when patients were moved to hospice. Generally, the nurses do not maintain direct contact with hospice patients after they leave treatment.

All but one nurse navigator used the “Add Your Information” tab to customize patient handouts. Personalization was deemed especially important for describing medication regimens, treatment plans, and breast surgery changes. Names of physicians and dates for appointments were also included in most patient handouts.

None of the nurse navigators used the e-mail option. Hospitals and practices discourage and, in some cases, prohibit e-mails between patients and nurses or physicians. Some patients do receive e-mails from hospitals and prac-

tices, but through a separate system and only to receive lab and x-ray results. Patients cannot respond to these e-mails.

Impact on Quality of Care

One nurse noted that NSider increased patient satisfaction; fewer patients called back with questions after they received a handout. Nurses said it increased literacy, if not patient satisfaction with care. None of them had measured the effectiveness of the NSider program; however, one nurse did say she would do so within the next few months.

Several expressed surprise that NSider could be used to support quality improvement initiatives, such as measuring program impact on patient compliance, patient engagement, or patient satisfaction. One nurse did use NSider to track the time from diagnosis to treatment.

Two nurse navigators were using NSider for accreditation (ACS and NCQA) to demonstrate quality of care. Other nurses had not planned to use NSider for obtaining further accreditation or for measuring and improving performance (Standard 6: Element B), but would consider it.

Navigation Team and Care Coordination

While patients are able to interact equally with different members of the team, all nurse navigators agreed they were the patients' main contact. Although the materials assisted in clarifying the team approach to care, most did not share materials with other members of the care coordination team. One nurse navigator noted that it was the nurse's responsibility to educate patients.

All agreed NSider increased the efficiency of care coordination. One nurse appreciated that she could prevent patients from getting too much information at

First Impressions:

Thoughts on NSider From Dr John Fox

We sought the objectivity of one who is not a nurse navigator but rather an expert in the field of overall resource allocation. To that end we conducted an interview with Dr John Fox, Associate Vice President of Medical Affairs, Priority Health, to hear a payer's views on the utility of NSider and the environments in which it is used.

Dr Fox:

We're not going to have enough oncologists in the future, so we have to ensure that what the oncologists are doing are things that only oncologists can do. The nurse navigators can be very helpful in preparing patients to undergo cancer treatment and all that it entails, and in helping triage patients when they have issues. The ASCO Workforce Study is unquestionably sobering, and we need to entice more oncologists into the workforce. Yet this very fact is spurring long-needed efficiency measures for a team approach to patient care, the nurse navigator being one of them. Clearly, nurse navigators help improve the patient experience and patient outcomes by ensuring that patients are well prepared to be a participant.

What I like about NSider is its structure. It's broken out into the different stages of how a patient presents to oncologists: Newly Diagnosed, addressing what you can give patients to help them understand their disease; Before Treatment, about how you prepare a patient for treatment, and what they can expect. NSider is a tight, compact, yet customizable navigation guide through the process of cancer care: staying healthy during cancer treatment, outlining the workplace restrictions, what side effects to expect during treatment, what is the next phase, how to manage nausea and vomiting by yourself, and when do you call your physician if you have problems. And then there is what we call "survivorship planning": once you've completed your chemotherapy and are declared cancer free, what's next, how do you get on with life? It has anticipated the sequence of events confronting the cancer patient and

laid out a map to equip them to participate in their care. Health literacy is a crucial step toward efficiency in the future of healthcare.

I like NSider because it brings structure to the patient's program, which is then customized for individual patient needs. You can create your own custom content and select the information to give to a patient who is, say, newly diagnosed with metastatic melanoma or a number of other cancer types profiled in NSider tools – not all of them, but the most common cancers. It helps patients understand their diagnosis, some of the terminology that's used, and gets them ready for treatment. It counsels them on how to optimize their health during treatment, what to look for... and when to call their physician. Then it has a survivorship element to be used when patients are finished with chemotherapy. This element can be customized, with the nurse navigator selecting the information appropriate to each individual patient. And it is vital to have an equally robust system to handle patient calls when they come in, because it is that unnecessary trip to the emergency department we're trying to avoid.

But the other two key areas I think are around advanced care planning and making sure that the care we deliver is consistent with what the patient wants. In cancer care, patient preferences change over time. When you first present for treatment for cancer, most people want to try something to increase their likelihood of surviving, of beating cancer. But by the second or third time they fail chemotherapy, we're faced with what to do next. If we haven't taken the opportunity to ask patients about their preferences and priorities and had that discussion with the family, there's a significant chance we're going to overtreat patients. So that's a key element to the NSider program. And if we can provide what patients want, which is a better quality of life without chemotherapy or with palliative care therapy, or with better attention to pain management and dyspnea treatment, then we can eliminate waste.

any one time and could control what patients were given, and when.

Caregivers also appreciated the depth of materials patients were given, as it precluded their having to repeat or research information the nurse had given the patient. Having comprehensive material also eliminated caregivers from having to go online to possibly unreliable sites for further information. NSider provides a listing of references with electronic links to the sources, which include the American Cancer Society and the National Institutes of Health.

Worksite Setting

All agreed that one-on-one settings were the most productive and that the most productive setting was the private office, where it is relaxed and quiet. "The best setting is being alone with the patient and being able to determine their needs."

The least favorite setting was the hospital bedside, where nurses came in and out to do tests or provide medication, and where guests, televisions, phones, and other patients in the room interfered with privacy. "The hospital room is the scene of too many distractions and too many interruptions."

- "The busier you are, the less amount of quality time you can spend with a patient."
- "If you are prepared in advance (with NSider), you can offer the patient the best time and give them your full attention."

Using NSider in a Freestanding Ambulatory Clinic

NSider in this setting was used mainly to inform patients about the course of disease and treatment, and to answer questions they might have about their condition. As a variety of cancers are treated in this setting, the nurse navigators require a reliable and comprehensive source for all cancers at various stages of disease and treatment status. While helping to inform and educate patients about a variety of cancers in a variety of stages, NSider also helps to relieve the burden of other caregivers in the clinic. When questions arise, other practitioners and those in general nursing often refer their questions to the nurse navigator.

Using NSider in an Accountable Care Organization

NSider design appeals to those in the ACO environment, as it may reduce costs by reducing the need for redundant explanations of things to patients by the nurse navigator.

Patients in this setting usually represent uncomplicated cases in the first stages of treatment. NSider handouts are usually personalized with treatment plans, including expected length of treatment, that describe the journey they face and posttreatment information. Thus, Head Start is useful for this purpose in describing what to expect during chemotherapy and before and after surgery. Information on ports described by NSider has proved valuable, as most patients facing chemotherapy will require them. The material is usually presented in the clinic setting, where the nurse navigator can review material with each patient. It helps nurse navigators prepare for

appointments, while saving them time during the appointment to discuss issues affecting each patient. Any additional information the patient might require can be easily accessed.

In the ACO, the most important attributes of NSider proved to be saving the nurse navigator time, while allowing her to provide personalized information for each patient, and offering her ease of access to the system when additional information was required.

Summary Comments

The Handout Wizard was by far the most popular part of the program, followed by Fresh Start, as the latter required more time to develop patient handouts. All agreed that NSider was a "very comprehensive" program that "provides everything I need for my practice." Another was particularly fond of the landscape layout and the colors. "The fonts are easy to read," and "the words were easy to understand." "Even the photos are great."

The nurses attributed the following to NSider:

- Easy to use; navigable
- Language appropriate for any grade level; readable
- Patient friendly; easy to understand, especially for newly diagnosed patients and survivors
- High-quality information
- Concise
- Individualized
- Beneficial, especially after treatment

One nurse navigator thought the program should include more information on palliative and hospice care. None would actually change any part of the current program.



contents of the report.



About Eisai Inc.

Eisai Inc. was established in 1995 and began marketing its first product in the United States in 1997. Since that time, Eisai Inc. has grown rapidly to become a fully integrated pharmaceutical business. Eisai's key areas of commercial focus are neurology and oncology. The company serves as the US pharmaceutical operation of Eisai Co., Ltd, a research-based human healthcare company that discovers, develops, and markets products throughout the world.

Eisai has a global product creation organization that includes US-based R&D facilities in Massachusetts, New Jersey, North Carolina, and Pennsylvania, as well as manufacturing facilities in Maryland and North Carolina. The company's areas of R&D focus include neuroscience; oncology; vascular, inflammatory, and immunological reaction; and antibody-based programs. Further information about Eisai is available at www.eisai.com/US.