

Patient Navigation in Cancer Care 2.0
Guiding patients to quality outcomes

Navigating the Cancer Continuum

in the Context of Value-Based Care



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I. INTRODUCTION

Since the development of the 2014 *Pfizer Evolution of Navigation* slide deck, the healthcare environment—including oncology—has changed and continues to evolve. With the rising incidence of cancer, an aging population, and advances in the technology of treatment modalities, the cost of cancer is burdensome on both patients and society. The focus of healthcare is shifting to a landscape of value-based care, with health outcomes achieved per dollars spent.

Value-based care is the concept of improving quality and outcomes for patients by standardizing healthcare processes through best practices.¹ Navigation is integral to meeting these goals by facilitating effective interprofessional collaboration and promoting patient satisfaction and care quality, as well as the efficient use of healthcare

resources to decrease costs across oncology patient populations and healthcare settings.

Navigation, with its various models, has had to evolve beyond identifying barriers to incorporate core competencies, certification, and standardized metrics to help drive continuous quality improvement and value while identifying evidence-based best practices that elevate cancer care to a grander scale. Value-based care is the future of cancer management, and the competencies of navigation help ensure consistent delivery of optimized patient care across the care continuum and align and support this goal.

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II. PAST, PRESENT, AND FUTURE OF NAVIGATION

Past Initiatives in Navigation

Dr. Harold Freeman conceived and initiated the nation's first patient navigation program in 1990. This followed just over 2 decades of observation of more than 606 patients with breast cancer treated at Harlem Hospital Center; of these patients, 94% were African American. This population of disproportionately poor and uninsured patients had a high incidence of breast cancer mortality and often presented with more advanced stages of disease compared with patients living outside of this community.¹

Dr. Freeman's program focused on the window of opportunity that was critical to saving patients from cancer mortality, by eliminating barriers to timely care that were typically encountered between the point of a suspicious finding and the resolution of that finding by further diagnosis and treatment. For example, he observed delays in follow-up care after abnormal findings or cancer diagnoses, and therefore proposed that patient navigators from the community could help address and bridge the gaps and barriers that were prevalent between this patient population and the healthcare system. One of the major goals of what became known as the *Freeman Model* was to expand access to cancer screenings and clinical follow-up among the medically underserved through community out-

reach and the elimination of barriers to care. To that end, he offered free or low-cost breast examinations and mammograms coupled with one-on-one navigation services. As a result, 5-year survival rates increased among this population, from 39% before intervention to 70% following the initiation of his patient navigation program. Dr. Freeman was able to demonstrate that 5-year cancer survival rates can be improved with increased access to screening and patient navigation programs by addressing and working to eliminate issues presented by lack of health insurance, fear and distrust of the medical community, and cultural and communication barriers.¹ The scope of navigation, including nurse and patient navigation, has evolved from the Harold P. Freeman Patient Navigation Model of community outreach and prevention and can now span the entire continuum of care for oncology patients.¹

Although Dr. Freeman brought the patient navigation movement to the forefront of healthcare delivery in the 1990s, the nursing profession had its own movement that had been evolving since the 1970s. The goal driving the development of the utilization review movement in nursing included monitoring the use and delivery of services in the 1970s, which evolved into evaluating the appropriateness of medical care—including its need and efficiency—in the 1980s. The 1990s brought the focus to case

management and patient navigation/care coordination, with the goal of identifying and reducing barriers to care (**Table 1**).² With this evolution, the process of a multidisciplinary team approach, which centered on open communication, was developed to address the psychosocial distresses and financial concerns of patients, as well as coordinate care needs. The process of navigation cultivated the bidimensional care concept—patient-centered, to ensure continuity of care; and health system-oriented, to empower patients and their families—as oncology care moved to a predominantly outpatient setting.³

The navigation model currently in use was developed following several organizational and government reports and initiatives focused on decreasing healthcare disparities, eliminating barriers to care, and improving the overall patient experience. One such report, the American Cancer Society's *1989 Report to the Nation: Cancer in the Poor*, identified the 5 most critical issues related to cancer among the poor.⁴ The report identified the critical issues as: (1) poor people endure greater pain and suffering from cancer compared with other Americans, (2) poor people and their families must make personal sacrifices to obtain and pay for care, (3) poor people face obstacles in obtaining and using health insurance and often do not seek care if unable to pay

TABLE 1. Overview of the Evolution of Patient Navigation

Time Frame and Focus	Role	Relationship with Other Providers	Setting	Methodology
1970s: Utilization review	Monitor use and delivery of services	Adversarial	Inpatient	Retrospective chart review
1980s: Utilization management	Evaluate appropriateness, medical need, and efficiency	Adversarial	Inpatient	Concurrent chart review
1990s: Case management	Assess, plan, implement, coordinate, monitor, and evaluate	Collaborative	Involved in patient care	Hands-on care
1990s: Patient navigation	Identify and reduce barriers to access to care, diagnosis, and prescription	Collaborative	Underserved patients	Community outreach
2000-Present: Patient navigation	Identify and reduce barriers to access to care, diagnosis, and prescription	Clinical Collaborative	Across the continuum of care	Hands-on care and coordination of care

Source: Shockney L. Evolution of patient navigation. *Clin J Oncol Nurs*. 2010;14:405-407. Reprinted with permission. Copyright 2010 by Oncology Nursing Society. All rights reserved.

for it, (4) cancer education programs are culturally insensitive and irrelevant to many poor people, and (5) fatalistic ideas about cancer are prevalent among the poor and prevent them from seeking care.⁴ Additional reports and initiatives focused on addressing barriers to care include the US National Cancer Institute's report, *Voices of a Broken System: Real People, Real Problems*, which indicated that barriers to cancer care exist for people of all socioeconomic levels⁵; and the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, which ensured that navigators are accessible to all patients with cancer, to provide high-quality, coordinated care.⁶

Present Initiatives in Navigation

In 2012, the American College of Surgeons Commission on Cancer (CoC) released standards that reflected the goal of ensuring patient-centered care.⁷ One of the more recent standards

(Standard 3.1), which became effective in 2016, requires that cancer programs seeking CoC accreditation establish a process to identify and navigate potential barriers to care, and document that process each calendar year.^{7,8} The process must be driven by a community needs assessment (CNA) that is conducted at least once every 3 years.^{7,8} The CNA systematically evaluates processes currently in place within the facility and gathers information to identify the community being served, as well as any barriers to care that may exist within that community.^{7,8} Relevant data collection can include geographic locations served (urban, suburban, rural); socioeconomic characteristics of the sample population (eg, median household income, housing status, average education level, immigration status, employment status, availability of public transportation); race/ethnicity; median age; and behavioral and psychosocial health characteristics (eg, rates

of tobacco use, alcohol/substance abuse, and/or mental illness).⁸ The CNA should list resources available within the community, as well as point out disparities and gaps in resources.^{7,8} Taking these steps allows the program to identify priorities aimed at addressing barriers to care and implement programs, services, and/or partnerships to overcome them, thereby improving outcomes among the target population.⁸ To streamline this process and decide on a plan to overcome barriers, needs related to patients' access, education, treatment, monitoring, psychological support, and the overall patient navigation process would be considered (**Figure 1**).^{7,8}

Alternative Payment Models and the Future of Navigation

The complex healthcare landscape (including its payment system) has evolved over the past 4 decades and will continue to evolve in the future.

FIGURE 1. Requirements of a Community Needs Assessment (CNA)**The CNA Must Define/Identify:**

- The cancer program's community and local population(s)
 - Description of facility, number of patients with cancer served, range of cancer-related clinical services, prevention and detection programs
- Health disparities (numerous factors can contribute to disparities in cancer incidence and death rates, such as race, ethnicity, gender, underserved groups, and socioeconomic status)
 - Use local, state, and national resources to compile data
 - Compare cancer program data with national and regional data
- Barriers to care, which may include patient-centered, provider-centered, or health system–centered barriers
- Resources available to overcome barriers on-site or by formal referral
 - Perform internal and external resource mapping to examine existing resources
- Gaps in the availability of resources to overcome barriers
 - Create an action plan with SMART goals to address gaps

SMART indicates specific, measurable, achievable, realistic, and timely.

Sources: Commission on Cancer (CoC). *Cancer Program Standards: Ensuring Patient-Centered Care*. 2016 ed. Chicago, IL: American College of Surgeons. www.facs.org/quality-programs/cancer/coc/standards. Accessed June 13, 2018; and The George Washington University Cancer Center. *Implementing the Commission on Cancer Standard 3.1 Patient Navigation Process: A Road Map for Comprehensive Cancer Control Professionals and Cancer Program Administrators*. Washington, DC: September 2017.

In today's healthcare environment, key organizations drive the focus on quality, outcomes, and evidence-based practice. The Institute for Healthcare Improvement Triple Aim Initiative seeks to improve the patient experience of care (including quality and satisfaction), improve the health of populations, and reduce the per capita cost of healthcare.⁹ Value-based cancer care is a highly coordinated, patient-centered solution to address rising healthcare costs, ineffective duplication of services, and barriers to care.¹⁰ Navigation is integral to meeting these goals by facilitating effective interprofessional collaboration and promoting patient satisfaction and care quality, as well as the efficient use of healthcare resources to decrease costs across oncology

patient populations and healthcare settings.

The Center for Medicare & Medicaid Innovation (the Innovation Center) is developing new alternative payment and delivery models aimed at improving the effectiveness and efficiency of specialty care.¹¹ An alternative payment model (APM) is a payment approach that gives added incentive payments for the provision of high-quality and cost-efficient care. APMs can apply to a specific clinical condition, a care episode, or a population.¹² Among specialty models is the Oncology Care Model (OCM) launched in July 2016, which aims to provide higher quality, better coordinated oncology care at the same or lower cost as Medicare.^{11,13} The OCM is a 5-year model that combines financial

incentives, including performance-based payments, to improve care coordination, appropriateness of care, and access for beneficiaries undergoing chemotherapy.^{11,13} It targets oncology practices delivering chemotherapy treatment and the spectrum of care provided to a patient during a 6-month episode following the start of chemotherapy.¹³ The OCM is meant to shift reimbursement and payment to value-based quality care, which includes patient navigation as a foremost component.¹³ The Merit-Based Incentive Payment System (MIPS) is another payment mechanism instituted by the Centers for Medicare & Medicaid Services that will provide annual updates to physicians starting in 2018, based on performance in 4 categories: quality, resource use/cost, clinical practice improvement activities, and advancing care information.¹⁴ Using a composite performance score, eligible professionals may receive a payment bonus, a payment penalty, or no payment adjustment. The importance of care coordination is highlighted under the MIPS improvement activities.

The premise of value-based care is that better coordinated and connected patient care will improve outcomes and lower costs. Navigators play a critical role in the coordination of care and patient empowerment through education, patient-reported outcomes, and emotional support. Patients who have access to "easy to understand" information, education,

and self-care instructions are better prepared to adhere to treatment, manage side effects, and, ultimately, have the potential for achieving better outcomes. Navigators serve patients by acting as direct contacts to whom patients may report symptoms as they arise, as opposed to allowing the consequences of underreporting symptoms to escalate in severity, potentially leading to hospitalization.

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III. DEFINING NAVIGATION

The importance of navigation and the roles of nurse and patient navigators have been recognized by various organizations, such as the Commission on Cancer (CoC), the American Cancer Society, the Academy of Oncology Nurse & Patient Navigators (AONN+), and the Oncology Nursing Society (ONS). Although these organizations sometimes use overlapping terminology, they have

families, and caregivers to assist in overcoming barriers to receiving care and facilitating timely access to clinical services and resources. Navigation processes encompass prediagnosis through all phases of the cancer experience. The navigation services implemented will depend upon the particular type, severity, and/or complexity of the identified barriers."¹ AONN+ defines the navigation process as

Navigation is the process of “[h]elping patients overcome healthcare system barriers and providing them with the timely access to quality medical and psychosocial care from before cancer diagnosis through all phases of their cancer experience.”²

nonetheless each been significant in developing guidance, competencies, and standards for the profession of navigation. According to the CoC, “[p]atient navigation in cancer care refers to specialized assistance for the community, patients,

“[h]elping patients overcome healthcare system barriers and providing them with timely access to quality medical and psychosocial care from before cancer diagnosis through all phases of their cancer experience.”² In 2010, ONS, the Associ-

ation of Oncology Social Work, and the National Association of Social Workers developed a joint position on navigation. The position adapted an earlier definition of patient navigation in the cancer care setting from C-Change, modifying it slightly to consist of “[i]ndividualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience.”³

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IV. NAVIGATION CORE COMPETENCIES

Navigators serve in many roles as educators, care facilitators, counselors, and patient advocates by providing education and psychosocial support, coordinating care across the continuum of care and its disciplines, and assisting with financial needs. Navigators must demonstrate competence in oncology, as well as the psychosocial and spiritual aspects of care for patients and families. Based on the needs of the community and the navigation program, elements of the skill set should include knowledge in health promotion; past work or personal experience within the healthcare field; language skills to effectively communicate with the populations served; and capability in forming relationships, working well on a team, problem-solving, and demonstrating leadership when required.

The recently created National Navigation Roundtable (NNRT), sponsored by the American Cancer Society, is a national coalition of more than 40 member organizations and individuals who are dedicated to achieving health equity and access to care across the cancer continuum. Its goal is to advance navigation efforts that eliminate barriers to cancer care, reduce disparities in health outcomes, and foster ongoing health equity.¹ The NNRT website (www.navigationroundtable.org) will have updates and additions to the national work being done around training and education (competencies) for navigation.² The following are the 7 nationally

recognized domains of competency recommended by the NNRT for patient navigation:

I. Domain: Ethical, Cultural, Legal, and Professional Issues

Competency: Demonstrates sensitivity and responsiveness to a diverse patient population, including but not limited to: respecting confidentiality; organizational rules and regulations; ethical principles; and diversity in gender, age, culture, race, ethnicity, religion, abilities, sexual orientation, and geography.

II. Domain: Patient/Client and Care Team Interaction

Competency: Applies insight and understanding concerning human emotional responses to create and maintain positive interpersonal interactions leading to trust and collaboration between patient/family/caregivers and the healthcare team. Patient safety and satisfaction are priorities.

III. Domain: Health Knowledge

Competency: Demonstrates breadth of knowledge about health, the cancer continuum, psychosocial and spiritual aspects, and attitudes and behaviors specific to their patient navigation (clinical/licensed or nonmedical licensure) role.

IV. Domain: Patient Care Coordination

Competency: Participates in

the development of an evidence-based or promising/best practice patient-centered plan of care, which is inclusive of the patient's personal assessment as well as healthcare provider system and community resources. The navigator acts as a liaison among all team members to advocate for patients to optimize health and wellness with the overall focus of improving access to services for all patients. Navigators conduct patient assessments (needs, goals, self-management, behaviors, strategies for improvement) integrating patients' personal and cultural values.

V. Domain: Practice-Based Learning

Competency: Optimizes navigator practice through continual professional development and the assimilation of scientific evidence to continuously improve patient care, based on individual navigator gaps in knowledge, skills, attitudes, and abilities.

VI. Domain: Systems-Based Practice

Competency: Advocates for quality patient care by acknowledging and monitoring needed (desirable) improvements in systems of care for patients, from enhancing community relationships and outreach through end-of-life care. This includes enhancing community relationships and developing skills and knowledge to monitor and evaluate patient care and the effectiveness of the program.

VII. Domain: Communication/ Interpersonal Skills

Competency: Promotes effective communication and interactions with patients in shared decision-making based on their needs, goals, strengths,

barriers, solutions, and resources. Resolution of conflict among patients, family members, community partners, and members of the oncology care team is demonstrated in professional and culturally acceptable behaviors.

References

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V. NAVIGATOR ROLE DELINEATION

Clinically licensed navigators (ie, community health workers [CHWs], patient navigators, nurse navigators, and social work navigators) are 3 professional types of navigation specialists with overlapping yet distinct roles/responsibilities and competencies based on licensure. All 3 professional types of navigation are involved with individual or patient education, but the types of information provided can vary based on training or education and professional level. Although CHWs should have general knowledge on health issues such as cancer and chronic diseases, the oncology patient navigator should have knowledge of cancer screening guidelines, diagnostic processes, treatment options, and survivorship, as well as related physical, psychological, and social

issues that may confront patients with cancer. Working at the top of their licensure, a nurse navigator or social work navigator should have knowledge of the clinical impacts of cancer on patients, caregivers, and families, as well as the skills needed to intervene on their behalf (eg, assess functional and psychosocial health and manage symptoms).¹

Regardless of the navigator title, these 3 professional types must have a solid knowledge base and the expertise needed to perform job-related duties and tasks, including understanding one's scope of practice, supporting evaluation efforts, and identifying and exercising self-care strategies.¹ Although these professional types share the similarity of supporting evaluation efforts, they differ in the

type of evaluation based on their scopes of practice and licensure. During the course of their work, CHWs focus their evaluation on the community's needs and health behaviors. Patient navigators straddle the boundary between the community and the healthcare setting by evaluating barriers to care and health disparities within the community against quality indicators of the healthcare system. For clinically licensed navigators, such as the nurse navigator or social work navigator within the healthcare system, the focus of evaluation should be clinical outcomes and quality indicators.¹

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VI. MODELS OF NAVIGATION

Various models of navigation have evolved from Freeman's Patient Navigation Model, utilizing community members known as lay navigators. Navigators who assist patients may come from oncology programs, as well as from within the community itself. Current models of navigation include clinical nurse navigators (also known as oncology nurse navigators), social workers, patient navigators (also referred to as nonclinically licensed navigators), community healthcare workers as volunteers or advocacy/organizational employees, and financial navigators specializing in financial issues that impact care (Figure 1).^{1,2}

There are also hybrid models of navigation in which programs can implement one type of model or a combination of the various models of navigation to achieve the goal of eliminating barriers to care and enabling patients to move seamlessly across the care continuum. Institutions/oncology programs are able to develop and implement a useful navigation program based on their type of navigation model and the specific needs and goals of the program, as well as address the needs of the community served.

To effectively formulate the navigation process for a particular cancer program, the community needs assessment (CNA) is

key. Community is the population as a whole, including the medically underserved, low-income, or minority subpopulations within the geographic area served by the healthcare facility. The CNA helps identify the relevant healthcare disparities and barriers to care that exist within a community so that a plan can be developed to meet these challenges. The specific requirements of the target population will dictate the greatest service needs, and the skill set and model of navigation should align with these. For example, rural populations may find that the greatest service need is transportation to and from appointments, for which the navigator will focus

FIGURE 1. **Navigation Models**



on finding vouchers or resources to provide low-cost transportation. In addition, immigrant communities benefit from navigators who offer services in their language and possess a keen understanding of relevant cultural issues. Navigation programs can be focused on the nonclinical or lay navigator's perspective, with the navigator performing non-clinical tasks that include scheduling, interpreter services, and identifying and/or addressing financial needs. Other navigation programs may focus on the clinical nurse navigator, who has oncology-specific knowledge to provide education and resources to facilitate informed decision-making; is able to address symptom management and clinical aspects of care; and can provide psychosocial care. Based on the needs of the community served, navigation programs may incorporate social workers to assist with logistical needs, as well as provide psychosocial care and support.

How to Conduct a CNA³

Step 1:

- Establish a work group responsible for conducting and reporting the CNA
 - Multidisciplinary team approach
 - Create a timeline of activities.

Step 2:

- Collect and review data of the community
 - Demographic data of primary service area
 - Population trends
 - Poverty rates
 - Educational attainment

- Prevalence of health conditions
- Insurance
- Environmental factors
- Causes of death
- Sources of data
 - Cancer registry
 - Organization's marketing department
 - US Census Bureau
 - Centers for Disease Control and Prevention
 - State department of health
 - Centers for Medicare & Medicaid Services
 - American Cancer Society's *Cancer Facts & Figures* reports.

Step 3:

- Administer surveys
 - Patient, families, and caregivers
 - Healthcare professionals
 - Key stakeholders.

Step 4:

- Collect and analyze all data.

Step 5:

- Community Health Needs Assessment written report
- Report findings to cancer committee
- Discuss findings
- Formulate patient navigation process and discuss the process with the cancer committee.

Step 6:

- SWOT analysis
- Develop strategic implementation on how the organization plans to prioritize needs that were identified in the assessment.

See Appendix for Sample Work Plan for Community Needs Assessment.

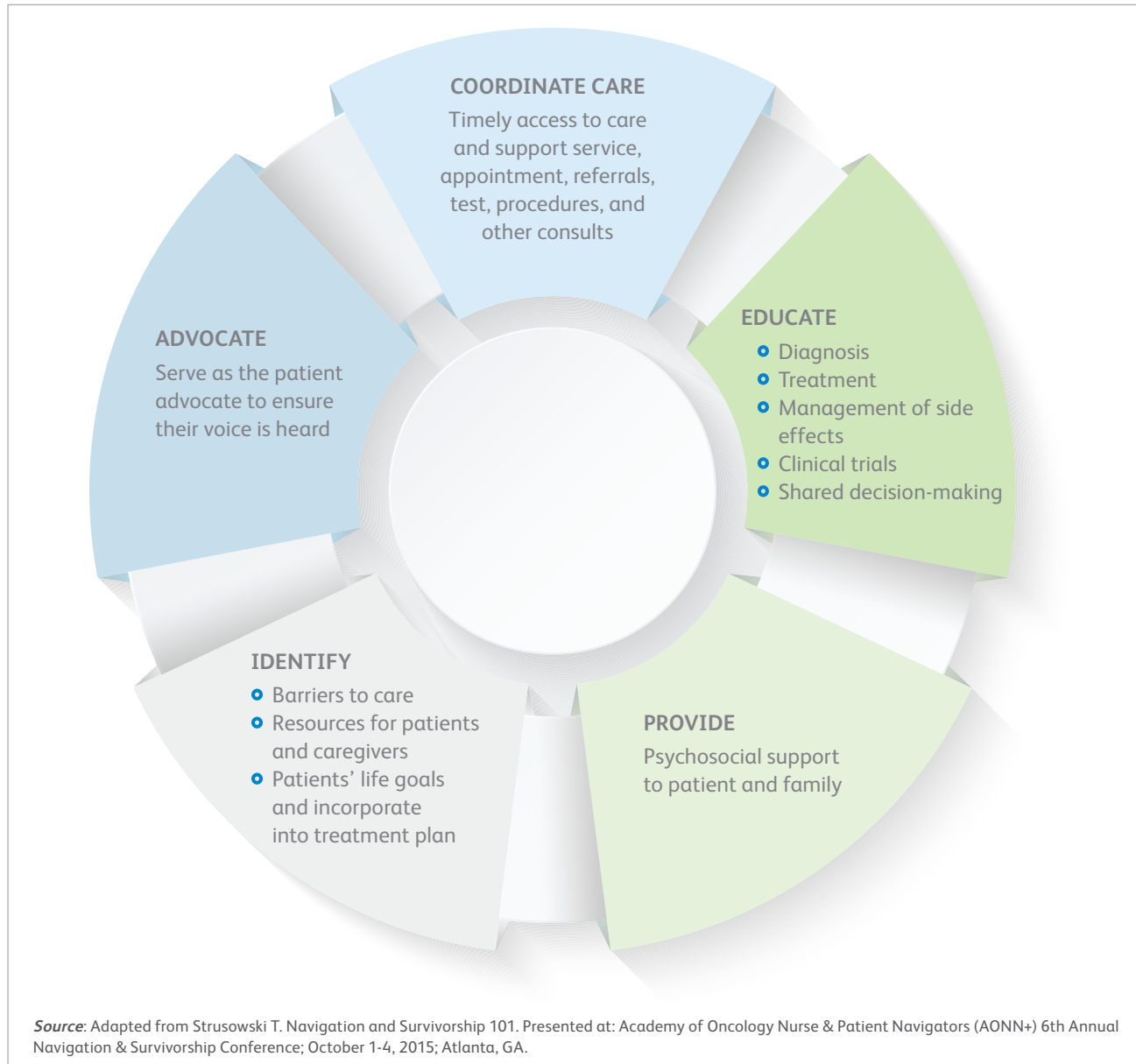
Goals of Navigation

Navigators may assist patients, their families, and caregivers in rural or urban communities or academic settings. Clinical nurse navigators may function as a tumor-specific navigator (eg, breast, thoracic, hematologic) or as a multisite/general navigator. No matter the setting or disease type, navigators share the same roles, responsibilities, competencies, and goals within their scope of practice. Their focus is to offer individualized assistance to the patient and family, reduce barriers, and increase access to medical and psychosocial care across the entire continuum.

Within the multidisciplinary team, the navigator works as an advocate, care provider, educator, counselor, and facilitator to ensure that every patient receives comprehensive, timely, and quality healthcare services.³ The goals of navigation can be described by 5 categories (Figure 2)^{1,4}:

- Coordination of care – Coordination of care involves ensuring timely access to support services, appointments, tests, and procedures
- Education of patients – Navigators provide patient-centered education to patients, families, and caregivers on the cancer diagnosis; treatment; side effects and management; and clinical trials, to ensure that they are informed and involved in the shared decision-making process
- Providing psychosocial support – Facilitating the

FIGURE 2. The Goals of Oncology Navigation



development of coping skills, and referral to psychosocial resources

- Identification of barriers and resources – Helping to improve access to needed patient resources
- Advocating for patients – Identifying and overcoming barriers to care by providing individualized assistance/

resources while ensuring as the patient's advocate that their goals, preferences, and voice are heard.

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VII. BARRIERS TO CARE

To effectively coordinate care, navigators must have an understanding of health disparities (ie, poverty, social injustice, or racial and ethnic biases) and healthcare barriers (ie, cultural, socioeconomic, geographic, and logistic) that patients may face. Although the term disparity is often interpreted to mean racial or ethnic inequalities, many dimensions of disparity exist in the United States, particularly in healthcare. If a health outcome is seen in a greater or lesser extent between populations, there is a disparity.

In phase I of the US Department of Health and Human Services' public health objectives referred to as Healthy People 2020, the term *health disparity* is defined as "...a particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health, cognitive, sensory, or physical disability, sexual orientation, geographic location, or other characteristics historically linked to discrimination or exclusion."¹

Barriers

Barriers to healthcare are obstacles that prevent vulnerable patient populations from getting the care they need or that cause them to get inferior healthcare

compared with other patient populations. Such obstacles can include financial barriers; communication barriers; healthcare literacy and healthcare system barriers; and fear and distrust. Many patients, particularly the underserved and uninsured, face significant barriers to receiving timely diagnosis and quality of care (**Table 1**).²

A key function of the navigator is the provision of tailored, culturally appropriate education to facilitate communication and collaboration based on findings of a learning needs assessment conducted to establish the patient's current health literacy, preferred language, motivation, and attitude.³

Barriers may be related to the patient, physician, or healthcare system. Socioeconomic barriers—including poverty, lack of health insurance, inadequate insurance/inability to pay out-of-pocket costs, poor education, and unemployment—can have the greatest impact on the existence of health disparities. The core principle of navigation is the elimination of barriers to timely, quality care throughout all phases of healthcare, including prevention, detection, diagnosis, treatment, and survivorship.

Increasingly, navigation programs have been used as a strategy to improve the timely receipt of needed healthcare services. During the time that

navigators work closely with patients and families, they develop a therapeutic and trusting relationship through open and honest communication, thereby helping ensure that patients and their families feel comfortable disclosing their specific needs and concerns related to care. Navigators should know the proper questions to ask to

elicit appropriate responses (eg, "What would keep you from getting or undergoing care?"). Navigators also conduct comprehensive assessments, such as distress screenings, to elicit information regarding physical, social, emotional, cultural, and spiritual needs. Based on the individual needs and specific barriers identified by the assessments, navigators collaborate with other healthcare professionals and members of the multidisciplinary team to develop a plan to address these issues.

Navigators must understand and practice cultural awareness in recognizing how culture can influence healthcare. A key function of the navigator is the

TABLE 1. Barriers to Care Addressed by Navigators

Barriers		Definition
<i>Patient Focused</i>		
Co-morbidity	Disability	Disability (physical or mental) that makes getting healthcare difficult
	Co-morbidity	Medical or mental health problems that make getting healthcare difficult
Financial	Insurance	Paying for direct aspects of healthcare is a problem
	Financial problems	Dealing with financial problems (not directly related to healthcare) is interfering with receiving healthcare (eg, not being able to pay food bills)
	Housing	Worrying about housing during healthcare
Attitudinal	Attitudes toward providers	Perceptions and beliefs about the healthcare providers who impact receiving healthcare
	Perceptions/beliefs about test or treatment	Personal or cultural beliefs that affect receiving healthcare
	Not a priority	Other issues take priority over healthcare
	Fear	Fear about any aspect of health or health-related care
<i>Other Focused</i>		
Transportation	Transportation	Difficulty getting from home to healthcare site
	Out of town/country	Out of area during healthcare
	Location of facility	Distance from healthcare facility even if transportation is available
Interpersonal	Social support	Lacks a person/community for assistance during healthcare
	Child care	Not having child care when needed during healthcare
	Adult care	Difficulty finding support for other family members during healthcare
	Employment demands	Work demands make getting healthcare difficult
System	Communication concerns with providers	Lacks understanding of the information provided by healthcare personnel
	Literacy	Difficulty understanding written communication from the healthcare system
	Language/interpreters	Not sharing a common language for communication
	System problems	Care provided is not convenient/efficient to patient needs (eg, waiting too long on the phone or in the office, days and hours of operation)

Source: Adapted from Katz ML, Young GS, Reiter PL, et al. Barriers reported among patients with breast and cervical abnormalities in the patient navigation research program: impact on timely care. *Womens Health Issues*. 2014;24(1):e155-e162.

provision of tailored, culturally appropriate education to facilitate communication and collaboration based on findings of a learning needs assessment conducted to establish the patient's current health literacy, preferred language, motivation, and attitude.³

Navigators must be competent in addressing, developing, and implementing plans/inter-

ventions to address barriers experienced by patients with cancer. In an effort to remove barriers, navigators connect patients to resources and support systems, assist in the healthcare provider interaction, and streamline appointments and paperwork. Navigator interventions can include arranging for logistical support (such as transportation, lodging, or child care), language inter-

preter assistance, referral to financial assistance programs (community, state, or national), advocating for appointments with oncology specialists and members of the multidisciplinary team, and connecting patients with available community and national support resources.

Resources that connect patients with available community and national services include

CancerCare® and Advocacy Connector. CancerCare® (www.cancercare.org/helpinghand) is a searchable, online database of financial and practical assistance available for people with cancer. Advocacy Connector (<https://advocacyconnector.com>) is a resource designed to help patients and caregivers

connect with relevant cancer advocacy group resources. (See **Navigation Resources** section for more information.)

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VIII. DISTRESS AND PSYCHOSOCIAL NEEDS

The cancer experience can have a life-changing impact on individuals, including the need to accept loss, a perceived lack of control in some situations, and fear of recurrence.¹ Psychological problems created or exacerbated by the diagnosis of cancer can include depression, anxiety, stress, and other emotional issues, which can be compounded by psychosocial aspects such as a lack of information or skills needed to manage the illness; a lack of transportation or supportive services; financial pressures; and disruptions in work, school, and family life. Distress encompasses the emotional, physical, and psychological aspects of facing a cancer diagnosis and its treatment. Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and includes appropriate information about psychosocial services in the treatment center and the community.^{1,2} The National Comprehensive Cancer Network® (NCCN®) defines distress as "...a multifactorial unpleasant emotional experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become dis-

FIGURE 1. Periods of Increased Vulnerability for Distress

- Finding a suspicious symptom
- During diagnostic workup
- Awaiting treatment
- Changing treatment modality
- End of treatment
- Discharge from hospital
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced cancer
- End of life

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abling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis."²

To deliver high-quality cancer care, the Commission on Cancer (CoC) Standard 3.2 incorporates distress screening into routine cancer care. The CoC recommends that all patients with cancer be screened for distress a minimum of 1 time during a pivotal medical visit such as post-surgical visits, the initial discussion of chemotherapy with a medical oncologist, at a routine visit with a radiation oncologist, or at a postchemotherapy follow-up visit. Pivotal medical visits that confer the greatest risk for distress could be given preference, such as at the time of diagnosis, transitions during treatment (ie, from chemotherapy to radiation therapy), or transitions off treatment. Other periods of increased vulnerability for distress among patients with cancer may include finding a suspicious symptom, during diagnostic workup, while awaiting treatment, changing

treatment modality, end of treatment, discharge from the hospital following treatment, medical follow-up and surveillance, treatment failure, recurrence/progression, advanced cancer, and end of life (**Figure 1**).² In addition, documentation of each patient's screening process and associated findings is encouraged, to properly assess psychosocial needs so that they may be addressed through tools, resources, and support services designed to improve patient outcomes.^{2,3}

A failure to acknowledge and measure distress stemming from clinical depression in patients can cause impaired functioning and decreased adherence to treatment and medication usage, which in turn may lead to poorer clinical outcomes.^{4,5} Depression is a common psychological symptom experienced by patients with cancer that, if left unchecked, can cause significant distress that may lessen quality of life.⁴ Many studies confirm that distress is often overlooked and

that many patients do not receive appropriate screening or treatment for it.^{4,6}

As early as 2007, the Institute of Medicine (IOM) highlighted the serious implications of unmet psychosocial needs faced by patients with cancer and their families in its report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. The IOM report emphasized the importance of screening patients for distress and conducting a psychosocial needs assessment to formulate the provision of high-quality healthcare. The report acknowledged that these tools can be used as part of standard clinical care and to enhance patient-provider communication. A variety of screening instruments were reviewed, many of which are brief and can be self-administered by the patient.⁷

In general, screening helps identify the risk for having psychosocial health needs. Needs assessment requires more time than screening and involves a more in-depth evaluation that confirms the presence of specific psychosocial health needs and describes their nature. Each yields personalized information that can be used to develop strategies to address an individual's psychosocial needs. Providing this type of emotional support to patients allows them to become active partners in the management of their illness and overall health.⁷

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management feature the **NCCN Distress Thermometer**, which was

developed as a visual analog tool for patients to indicate the level of distress they encounter in the week preceding a health-care-related visit. This tool is designed to screen for distress only and is not a diagnostic tool for measuring depression or anxiety.²

This single-page tool includes a visual representation of a thermometer with numbers ranked from lowest (no distress) to highest (extreme distress), and includes a list of potential problems at the right for patients to self-identify (**Figure 2**).² The Distress Thermometer can facilitate a conversation between the patient and healthcare provider to better elicit what is contributing to the patient's concerns and how these issues can be effectively resolved. Asking patients, "On a scale of 1 to 10 and including today, how much distress have you been experiencing in the past week?" opens a dialogue with the oncologist or navigator and gives permission for a discussion of emotions.²

According to the NCCN Guidelines®, patients should be screened during the initial visit and then as clinically indicated throughout treatment. Scores of ≥ 4 suggest a moderate to severe level of distress. If the patient's distress is mild (score is < 4), the primary oncology team may choose to manage the concerns by usual clinical support. If the patient's distress level is ≥ 4 , a member of the oncology team next looks at the problem list to identify key issues of concern and asks further questions to determine which resources (mental health, social work and

counseling, or chaplaincy services) would best serve the patient for referral.²

Screening for psychosocial distress along the cancer continuum allows navigators to address patients' perceptions of quality of life. Effective psychosocial care, consisting of a multidisciplinary team approach, has been shown to positively influence patient outcomes and quality of life.⁸ The NCCN Distress Thermometer has a secondary benefit of connecting many patients to services that might not otherwise have been identified. Distress screening provides patients an opportunity to partner with their healthcare team, overcomes patients' reluctance to ask for help, destigmatizes the issue and allows patients to share their vulnerabilities, and ensures timely referral to supportive services.

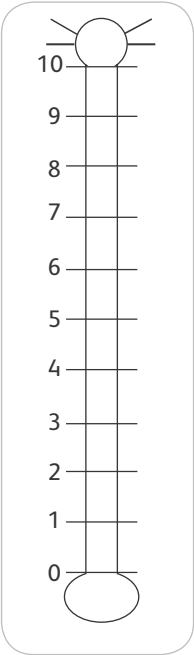
Evidence suggests that distress screening alone is not sufficient to improve patient outcomes. A critical component of a successful distress management program is making appropriate and timely referrals, and then following up with patients postreferral to gauge results of the experience and provide feedback as necessary.⁹ Navigators are instrumental in the development and implementation of a plan for psychosocial health services in their cancer programs that supports patients by providing personalized information, identifying strategies to address psychosocial needs, providing emotional support, helping patients manage their illness and health, linking patients

FIGURE 2. NCCN Distress Thermometer

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER
 Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST
 Please indicate if any of the following has been a problem for you in the past week including today.
 Be sure to check YES or NO for each

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
Family Problems			<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
Emotional Problems			<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Substance use
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other Problems: _____

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and families with psychosocial services, and coordinating psychosocial and biomedical care.⁹

Common barriers to physical and psychosocial care include lack of social support, financial and insurance concerns, and

problems with healthcare communication. Navigators can focus on resolving barriers to care, which can be assessed during interviews with patients, and gathering data on psychosocial, financial, and practical

issues. Regular interaction with navigators allows periodic evaluation of the success of interventions to reduce barriers.

The supportive role of navigation in addressing potential concerns that extend beyond coor-

dination of care and side effect management should help to alleviate issues related to distress as they arise. Navigators may strengthen physical and psychosocial adjustment to a cancer diagnosis by identifying and promoting effective coping strategies such as relaxation, meditation, counseling, education sessions, group social support, or exercise.

Case Scenario: Patient Distress

Stan is a 44-year-old divorced father with sole custody of 2 teenaged children. He is self-employed as a landscaper to support his family. After a 2- to 3-week history of abdominal pain and rectal bleeding, he was sent for a colonoscopy. A complete colonoscopy could not be performed, as Stan was found to have a neoplastic mass of the rectum narrowing the lumen to preclude advancement of the scope. An immediate oncology consultation was arranged. Upon meeting with the medical oncologist, Stan was sent for a PET scan, which showed intensive uptake spanning 12 cm of the rectum and uptake within a perirectal lymph node.

Based on the PET scan results, Stan discussed the treatment recommendations of neoadjuvant chemoradiation therapy with continuous infusion of 5-fluorouracil for 6 weeks, followed by surgical resection, and concluding with adjuvant chemotherapy. Stan met with the nurse navigator for chemotherapy and radiation therapy education, as well as for a psychosocial assess-

ment utilizing the NCCN Distress Thermometer. The nurse navigator instructed Stan on the role of the Distress Thermometer and encouraged its completion by having him mark problem areas relevant to his situation. Stan scored an 8 on a scale of 0 to 10 on the Distress Thermometer. In the areas regarding practical problems, emotional problems, and physical problems, Stan indicated that he was experiencing difficulty and distress. Based on Stan's self-reporting (score of 8 on the Distress Thermometer), the nurse navigator referred him to the oncology social worker, who contacted him within 48 hours.

Stan met with the oncology social worker and the nurse navigator to address the areas of difficulty he reported on the Distress Thermometer. An analysis of the screening revealed concerns with practical, emotional, and physical problems. Stan also reported difficulty with insurance/financial issues. As a self-employed landscaper and sole provider for his family, Stan lacked medical insurance coverage and expressed concern regarding his ability to pay medical bills related to his cancer treatment. The oncology social worker and nurse navigator referred Stan to the facility's financial counselor, state Medicaid outreach officer, and the local Social Security Administration office. The nurse navigator also referred Stan to the national financial assistance resources of CancerCare® and the Chronic Disease Fund®, and to the relevant pharmaceutical drug assistance programs.

On the Distress Thermometer, Stan reported difficulty with emotional problems in regard to treatment decisions and feelings of "sadness," "fears," and "worry." In his discussion with the oncology social worker and the nurse navigator, Stan expressed concern about his disease and its treatment, and the possibility that they may affect his ability to care for his family and contribute to loss of "normal life." Stan was encouraged to participate in the cancer center's Coping Skills program, which was facilitated by the oncology social worker to help patients with cancer develop skills to cope with the emotional and physical impact of cancer.

Under the physical problems portion of the Distress Thermometer tool, Stan reported difficulty with "constipation," "eating," and "fatigue." He also expressed concern regarding possible side effects of his planned treatment, including neuropathy, diarrhea, and neutropenia, and their effect on his livelihood and quality of life. The nurse navigator provided education on side effect management and referred Stan to the oncology nurse practitioner for supportive care/symptom management and to the facility's dietitian for nutritional support.

With the use of the NCCN Distress Thermometer tool, the nurse navigator and oncology social worker were able to identify Stan's specific needs and address them accordingly. The nurse navigator and oncology social worker utilized a multidisciplinary approach to address

Stan's specific needs. **Utilization of the distress assessment tool can effectively guide and assist the nurse navigator in providing high-quality, holistic, and patient-centered care.**

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IX. HEALTH LITERACY

In providing patient education, it is imperative for the navigator to assess a patient's health literacy in regard to their ability to obtain, process, communicate, understand, and act on health information. Barriers that could affect a patient's ability to comprehend health information include emotional distress, feeling overwhelmed with information, poor vision/hearing, certain cultural practices, low education level, financial concerns, and language. Useful tools for quick assessment of health literacy include the Rapid Estimate of Adult Literacy in Medicine, Short Assessment of Health Literacy–Spanish and English, Test of Functional Health Literacy in Adults, and Newest Vital Sign. These tools can be found at Health Literacy Tool Shed (<https://healthliteracy.bu.edu/all>), a database of health literacy measures. Navigators should understand the components of literacy, including:

- Print (reading and writing)
- Oral (speaking and listening)
- Numeracy (using numbers to make meaning).

The navigator should be able to assess the patient's preferred method of learning and language: written (print material summarizing key points), verbal (face-to-face conversation), pictorial (visual interpretation when presenting statistical information), and/or use of language translation services.

Teach-back is a way to confirm that the navigator has explained to the patient what they need to know in a manner that the patient understands. Patient understanding is confirmed when the patient explains it back to the navigator.¹

In educating patients, it is important for navigators to provide information using simple/plain language, presented in an organized fashion, and to use the teach-back method to demonstrate patient understanding. Education sessions should allow time for patients and their families/caregivers to ask questions, have their questions addressed, and to provide teach-back to demonstrate their understand-

ing of the material covered. The teach-back method, also known as “closing the loop” or the “show-me” method, can be used by healthcare providers to confirm that a patient (or caregiver) understands what is being explained. This involves having the person being taught to accurately “teach-back” (ie, reiter-

ate and explain) the information they just received. The teach-back method helps to close the gap in communication between provider and patient while enhancing the patient's knowledge and health literacy.¹

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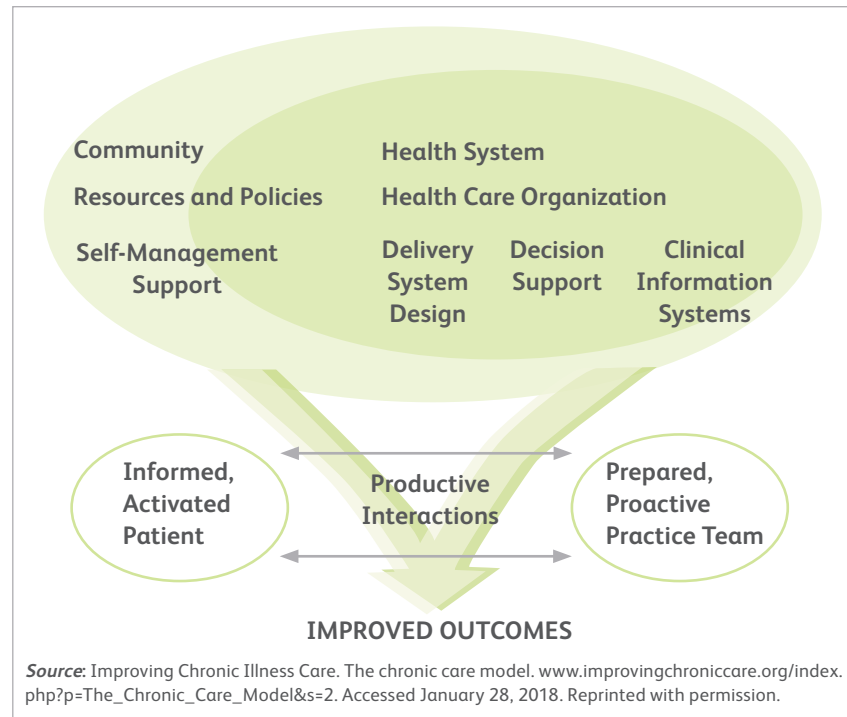
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X. THE CHRONIC CARE MODEL AND CANCER CARE CONTINUUM

Navigation and the coordination of care are integral components of an analog known as the Chronic Care Model, which summarizes the basic elements for improving care in health systems at the community, organization, practice, and patient levels. These elements include the community partnerships and resources to support and develop interventions for patients, health organizations to facilitate care coordination, self-management support to empower and engage patients in decision-making and outcomes, decision support of evidence-based guidelines to coordinate care and services across the delivery system, and the final element of clinical information systems for data collection, outcome metrics, and benchmarks. The elements working together create productive interactions between well-informed, activated patients and a prepared, proactive practice team that helps with care coordination resulting in improved outcomes (Figure 1).¹ The role of the navigator along the continuum of cancer care supports the Chronic Care Model, as it is bidimensional in nature. Specifically, because navigation has a patient-centered (advocate, empowerment with education, and psychosocial support) and health system (member of the multidisciplinary team) orientation, it is able to deliver timely, seamless care. In doing so, considering

FIGURE 1. The Chronic Care Model



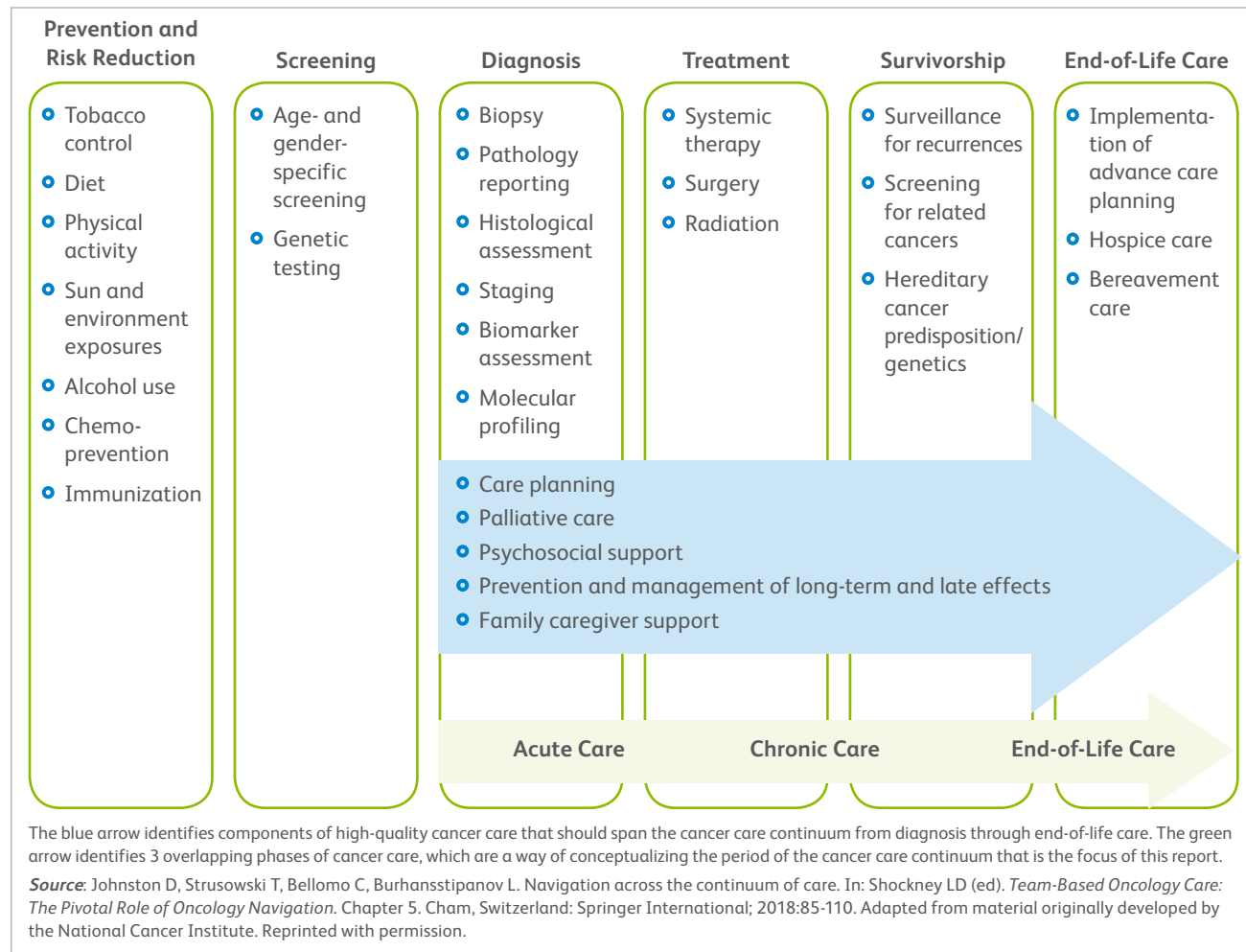
the needs of patients along with system characteristics promotes continuity of care.²

Depending on their work setting and role, navigators who work with underserved groups of patients throughout the cancer care continuum perform several key tasks to ensure that relevant care and services are understandable, available, accessible, and accountable. These tasks typically require that navigators pass through several phases along the continuum, which can include community outreach and education on the merits of early detection; screening; proper diagnosis/staging; securing timely treatment; survivorship;

and end of life (Figure 2).³ Sometimes a navigator will perform similar overlapping tasks (eg, offering education) among several or all phases of the continuum.⁴ Navigators may work in the outreach/screening entry of the care continuum and oversee nonclinical staff to increase cancer screening rates.^{5,6} They may also interact with patients at diagnosis, navigating them throughout the treatment phase and the transition into survivorship or end-of-life care.⁷⁻¹⁰

Across the cancer care continuum, the goals of the navigator are to identify and address barriers to care; empower patients with appropriate education and awareness of health

FIGURE 2. Domains of the Cancer Care Continuum with Examples of Activities in Each Domain



literacy so they can make informed decisions; offer psychosocial support and access to resources; advocate for the unique needs with cultural awareness of each patient regarding the use of facility and community resources; encourage patients to be engaged in their care planning; streamline care path transitions and logistical issues (diagnosis, treatment, survivorship, and end of life); and liaise between clinical and nonclinical specialists in the multidisciplinary cancer care team.¹¹

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XI. COMMUNITY OUTREACH AND PREVENTION

For many patient populations in various settings (eg, rural, community, academic), navigators play an essential role in community outreach and prevention along the continuum of cancer care (**Table 1**).¹ Outreach is the process of contacting, engaging with, and helping people to learn about and to use resources to improve their health and well-being. Outreach may be conducted with individuals, groups, organizations, and at the community level.² Outreach efforts can be conducted through culturally and educational level–appropriate media and printed materials, booths at community or cancer awareness events, or other public events. These outreach efforts allow navigators the opportunity to promote the value of early detection and prevention, and to explain how to access cancer resources and services available in the local area.

To be effective, navigators must have core knowledge of the early signs of cancer, genetics, and the current screening guidelines, as well as the available community and state resources for screening and diagnostics. Navigators must also be able to develop collaborative relationships with community partners and provide education to the community on the importance of cancer prevention and early detection for improving survival.^{1,2}

Navigation programs involved in community outreach must be tailored to meet the needs of

TABLE 1. Competencies of the Navigator in Community Outreach, Prevention, and Screening

- Finding community resources
- Community needs assessment
- Identifying barriers to care
- Interventions to remove barriers to care
- Community education on prevention and screening
- Population health
- Risk assessment
- Cultural awareness
- Behavior modification
- Genetics

Source: Bellomo C, Goetz P. Community outreach and prevention. *J Oncol Navig Surviv.* 2016;7:28.

the community identified through a comprehensive community needs assessment (CNA). The CNA provides a description of the community served, lists the top priorities for the community, and identifies health disparities and gaps. Through this, navigators can identify barriers to care, relevant interventions, and methods to link individuals to key resources.³

Cancer prevention may target people who are healthy and at normal risk for developing cancer; extend to populations at intermediate risk resulting from environmental and lifestyle factors, genetic predisposition, and precancerous lesions; as well as include previous cancer patients at risk for developing secondary cancers.³ Education on cancer prevention should address healthy behaviors such as diet, exercise, sun exposure, and smoking cessation, as well as

following cancer screening and vaccination guidelines to reduce the risk for cancer development. Effective communication strategies, such as motivational interviewing, help navigators to assess patients' readiness to learn and literacy skills, as well as assist patients in identifying personal goals related to adopting new, healthier behaviors.³ Navigators can partner with community resources such as local hospitals and clinics, community health departments, local health fairs and screening clinics, and local church and cultural groups to assess and educate the population on the importance of healthy lifestyles, cancer prevention and screening, and early detection.

Screening

Early detection of cancer is an important phase of the cancer care continuum. It greatly

increases the chances for successful treatment and improved clinical outcomes.^{4,5} Enabling care to be provided at the earliest stage possible is an important public health strategy in all settings.⁵ Early diagnosis is particularly relevant for cancers of the breast, cervix, mouth, larynx, colon and rectum, and skin.⁴

The 2 major components of early detection are education to promote early diagnosis (eg, teaching people to recognize possible warning signs of cancer) and screening.⁴ Cancer screenings may be offered through a variety of settings and strategies, such as community outreach health fairs, cancer awareness events, or other public events. Screening services may be provided at local health departments, local hospitals, through primary care physician offices, or even in mobile vans that travel to rural communities.³

No matter the setting, navigation services are essential for individuals with abnormal findings. The navigator reaches across the healthcare system into the community to facilitate care and seamless transitions. To do so, navigators must develop collaborative relationships with community partners to ensure that screening participants with abnormal findings have a medical home.³ Navigation has been shown to decrease the time to diagnosis and increase the number of individuals completing diagnostic procedures.^{3,6} The impact of the role of the navigator to facilitate timeliness of care from abnormal findings of screening to diagnostic work-

up and diagnosis can be measured utilizing the Academy of Oncology Nurse & Patient Navigators Standardized Evidence-Based Oncology Navigation Metrics (see **Appendix**).

It is important for the navigator to be familiar with the types of screening services within the community, funding programs offered to support the cost of screenings, and resources available for providing treatment. Navigators should discuss current cancer screening guidelines with individuals and recommend the test most appropriate to increase awareness and promote long-term health.³ With an understanding of genetics and its relationship to cancer risk, navigators are able to discuss and educate individuals on genetic risk assessment and refer to genetic counselors for testing that can lead to changes in medical management, such as increased screening or consideration of risk-reducing activities.^{1,3}

During the screening phase of the care continuum, navigators continue to assess, address, and remove barriers to cancer screenings, such as transportation, medical coverage, availability, cultural reasons, lack of understanding/medical knowledge, and fear. Navigators should strive to find proactive solutions to each barrier to screening. For instance, many people cannot afford to take time off from work to get screening tests performed. It would be pertinent for the navigator to identify facilities that can provide early morning hours or late hours that would not interfere with an

individual's work schedule. For individuals who have misinformation or are unaware of the cancer screening test, it is imperative for the navigator to provide education on the testing. Education and communication by the navigator can be proactive in addressing cultural barriers, as well as anxiety and fear. Every effort should be made to educate and reduce the barriers to screening, and to ensure that the navigator can assist the patient in being seen by the right clinician.³

Diagnosis

A cancer diagnosis is made through a combination of tests, procedures, and consultations with multiple healthcare providers, which can be very overwhelming to patients and their families. One key role of the navigator is to coordinate care among these different healthcare providers. As a member of the multidisciplinary team, the navigator works as an advocate, care provider, educator, counselor, and facilitator to ensure that every patient receives comprehensive, timely, and quality healthcare services. During the diagnostic phase, navigators can begin an assessment of patients' coping skills, provide emotional support, and refer to psychosocial services if necessary. Assessing and addressing issues of distress and barriers regarding their diagnosis can allow patients to focus on being able to make informed decisions and to be an active participant in their care.³

The Commission on Cancer Standard 3.2 specifies that pa-

tients must be screened for distress at least once during a pivotal visit when they are at greatest risk for distress, such as upon diagnosis, a preoperative or postoperative surgical visit, consultation with an oncologist, initiation of chemotherapy or radiation therapy, and transition into either survivorship or hospice care.⁷

Navigators should take the opportunity to ask questions and initiate discussions as they build trusting relationships with patients and their families or caregivers. It is important for navigators to establish their patients' preferences and goals with regard to their cancer care and life in general³:

- What is your understanding of your clinical situation?
- Tell me what you currently know about your cancer
- How much do you want to know about your cancer?
- Who do you want to include in discussions about your cancer and its treatment options?
- Do you want me to write down information for you regarding your cancer?
- What are you most worried about?
- Tell me what is important to you
- Tell me what you are hoping for.

Navigators should engage their patients directly by having straightforward conversations with them about their overall goals in life so that whenever possible, these life goals can be preserved rather than sacrificed to the cancer and/or its treatment. During these conversa-

tions is also an appropriate time for the navigator to provide information on advance directives, as well as listen to patients' questions and concerns. A patient's life goals and advance directives should be documented in the patient's medical record to help ensure that the oncology team is aware of these goals so that they are incorporated into the treatment decision-making process as necessary.³

With an understanding of a patient's goals and an assessment of their health literacy and understanding of their illness, the navigator can begin to provide patient-centered education on the disease process, the staging workup, treatment options, and clinical trials. During the education process, a key role of the navigator is to validate patients' understanding regarding their diagnosis and treatment options, including surveillance, surgery, radiation therapy, chemotherapy, and precision medicine.³ Precision medicine (also known as personalized medicine) uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat cancer.⁸ Precision medicine includes the use of biomarkers, molecular testing, and targeted therapies to deliver a personalized approach to cancer therapy through the use of molecular and genomic information about individual cancers.⁹ To be an effective member of the patient care team, a navigator must keep up to date on new knowledge that has direct implications for patient education and patient care. Naviga-

tors must be able to understand these requirements, and be able to explain to patients why additional testing is important and why not all types or stages of cancers are the same in molecular makeup.

As members of the multidisciplinary team and patient advocates, navigators play an important role in the coordination of multidisciplinary clinics and/or tumor board conferences.¹⁰ As a participating member of the tumor board, the navigator plays a role in expediting the patient's care based on knowledge of National Comprehensive Cancer Network guidelines and evidence-based practice, as well as advocating for the individual patient's needs, beliefs, values, and preferences to the members of the multidisciplinary team. Following the tumor board conference, navigators educate patients on the recommended treatment options and communicate to the treatment staff the information reviewed.¹⁰

When providing patient-centered, personalized care, the navigator facilitates coordination and scheduling of appointments/procedures and communication between the multidisciplinary team and the referring physician, often the primary care physician. Navigators can make appropriate referrals to other providers on the teams and ancillary services, such as dietary counseling, genetic counseling, rehabilitative services (for physical therapy/occupational therapy, lymphedema, or speech/swallowing), fertility preservation, and palliative care.

Navigators interact and communicate closely with various clinical and nonclinical specialists, including medical and radiation oncologists, surgeons, radiologists, pathologists, geneticists, pharmacists, and clinical trial research staff, as well as rehabilitation specialists, such as physical, occupational, and lymphedema therapists, dietitians, social workers, and financial counselors. Navigators are pivotal to facilitating communication and collaboration among the multidisciplinary healthcare team. This begins with the development of collegial and trusting relationships among the various oncology team members based on shared goals of providing high-quality cancer care and exceptional patient experiences through the coordination of care. The multidisciplinary team approach enhances safe, efficient, effective, timely, and quality patient-centered care.¹⁰

Treatment

The remaining phases in the continuum of care for patients with cancer following diagnosis include the transition to treatment, survivorship, and/or end-of-life care. Care transition refers to the movement that patients make between healthcare practitioners and settings as their condition and care needs change during the course of their disease, including treatment, survivorship care, palliative care, and hospice care.¹¹ Poor coordination of care during these periods of transition can lead to poor patient

quality of life, increased utilization of emergency department services and hospital readmission rates, duplicated tests, and medication errors, which lead to increased healthcare costs and suboptimal overall patient outcomes.¹² Navigators play pivotal roles in recognizing the stages of care transition, identifying patients at highest risk for gaps in care through assessment/distress screening and providing logistical support; empowering patients through education about anticipated events throughout the trajectory of care; and facilitating communication among providers and between patients and providers to result in better overall coordination of care. Navigators must recognize that patients' needs evolve as care progresses along the continuum, warranting the need for continued reassessment.¹³ Navigators must be familiar and knowledgeable to prepare patients for transitions in care in accordance with each patient's preferences and goals of care.

As the treatment phase gets underway, navigators should provide basic education to patients and their caregivers on the type and role of the treatment modality and the number of treatments to be received, when they will be administered, and the dosing schedule. In addition, navigators should have a discussion with patients and caregivers to review potential side effects related to treatment, how to recognize and report them to the healthcare team/clinic, and helpful strate-

gies to prevent and/or manage them. Patients and caregivers should also be educated on issues related to intimacy/safe sex and the proper handling of bodily fluids, safe handling of oral chemotherapy/targeted therapy, and the importance of nutrition, hydration, and activity during treatment.³

Navigators must be knowledgeable about the assessment and management of common treatment-related side effects and late effects to effectively coordinate care throughout the treatment phase. Such effects can include chemotherapy-induced nausea and vomiting, malnutrition, cancer pain, lymphedema, and fatigue. All of these can have a profound impact on a patient's quality of life and well-being. Navigators can assist patients with cancer by identifying those at risk for side effects and late effects through screening, assessment, and identifying barriers; by educating patients and families on coping skills, self-care skills, and symptom management; and by coordinating referral to specialists of the multidisciplinary team, palliative care, and community resources, to help patients improve their functional status.³

Clinical trials investigating new therapeutics and treatment paradigms are critical for advancing science and providing new therapies for patients. Navigators play a key role in clinical trial recruitment as they collaborate with clinical research nurses and physicians to identify patients who may be appropriate for a specific trial,

advocate for patient enrollment, educate and assess patient understanding of the clinical trial process, and address any barriers to patient participation.¹⁴ It is imperative that navigators have an understanding of clinical research with respect to the historical background; elements of good clinical practice ethics and guidelines for the protection of human research participants; informed consent; and the various types and phases of clinical trials. Navigators must also be educated on how to match patients to appropriate clinical trials, remain up-to-date on the status of ongoing clinical trials, and have an awareness of the strategies used to assist patients in understanding and participating in clinical trials. When patients receive proper education on clinical trials by navigators, they are able to participate effectively in the decision-making process, which can offer additional therapeutic options.¹⁴

Throughout diagnosis and treatment, it is important to always consider the patient's quality of life when determining treatment options. As patient advocates, navigators are in a position to help refer the patient to palliative care for symptom management and cancer rehabilitation to supplement their care. Palliative care, as specialized medical care for individuals with serious illnesses, is focused on providing relief from symptoms, pain, and the stress of illness with the goal to improve quality of life for both the patient and the family. The integration

of palliative care into standard oncology care allows for the prioritizing of pain and symptom management, emphasizes communication with patients and families, and establishes coordination of care.^{3,15}

Ideally, the navigator can intercede as early as at the time of diagnosis and across the care continuum and promote ways to maintain the patient's function and activity level, thus diminishing the impact of the side effect of deconditioning and preserving and/or restoring the patient's quality of life. Navigators can be proactive in identifying impairments and referring patients for cancer rehabilitation services to treat these impairments, such as exercise therapy, pain management, physical and occupational therapy, lymphedema, and speech/swallowing therapy. Navigation through a complex oncology care continuum, including cancer rehabilitation, is of utmost importance for the best possible outcomes for patients with regard to both quantity and quality of life.³ Competencies of the navigator with regard to the diagnosis and treatment of patients with cancer along the continuum of care and related care transitions are shown in **Table 2**.¹⁶

Survivorship

The American Cancer Society—in collaboration with the National Cancer Institute—estimates there were more than 15.5 million cancer survivors in the United States in 2016, and that the number will grow to

more than 20 million by 2026.¹⁷ The National Coalition for Cancer Survivorship defines a cancer survivor as an individual affected with cancer from the time of their diagnosis through the remainder of his or her life.^{3,18}

After the completion of active treatment, whether surgery, chemotherapy, or radiation therapy, patients may feel a sense of abandonment by the oncology team as they transition to the phase of survivorship. Cancer survivors have physical, social, psychological, and spiritual needs. Cancer survivors may experience a reduced health-related quality of life attributed to physical impairment and psychological issues. Many cancer survivors experience persistent physical symptoms and late or long-term effects of treatment. Often-reported, persistent symptoms of survivors of all types of cancer include fatigue, sleep-wake disturbance, pain, peripheral neuropathy, difficulty concentrating and remembering, and decreased physical functioning.³ Cancer survivors may also experience persistent physical symptoms and late effects related to the type of cancer and treatment, such as menopausal symptoms, bowel dysfunction, changes in sexuality and sexual function, and cardiac toxicity. They may also experience psychological issues, such as anxiety and fear of recurrence.³

In the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*, the importance of addressing the ongoing physi-

TABLE 2. Competencies of the Navigator with Regard to Continuum of Care/Care Transitions

- Understanding the Chronic Care Model
- Identification/intervention of clinical and service barriers to care
- Understanding the patient care process/cancer care continuum (prevention/screening, risk assessment, diagnosis, clinical trials, treatment, survivorship/end-of-life care) and providing referrals to appropriate disciplines and transitions across the continuum of care based on a comprehensive assessment
- Providing patient-/family-centered education (screening, diagnosis, treatment, side effects and management, survivorship/end of life)
- Identifying models of navigation
- Understanding and practicing cultural awareness
- Understanding and practicing health literacy
- Increasing communication among the healthcare team/multidisciplinary approach to care
- Participating in tumor board/cancer conference
- Understanding of National Comprehensive Cancer Network Guidelines, Commission on Cancer, Institute of Medicine, and other national standards in relation to oncology care
- Using evidence-based guidelines and tools in the assessment, intervention, and evaluation of patient care
- Understanding of clinical trials (eligibility, enrollment criteria)
- Understanding of and participation in performance/process improvement across the continuum of care
- Understanding of available institution, community, and state/national resources; collaborating with available community resources
- Providing psychosocial support and empowering the patient and family with treatment decisions

Source: Bellomo C, Goetz P. Continuum of care and care transitions. *J Oncol Navig Surviv.* 2016;7:30.

cal and psychosocial challenges of cancer survivors was emphasized to encourage the multidisciplinary approach to survivorship as a distinct phase of the cancer continuum. The IOM report noted the following 4 major components of cancer survivorship care^{3,19}:

1. Prevention of new and recurrent cancers and other late effects
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of late psychosocial and physical effects
3. Intervention for consequences of cancer and treatment
4. Coordination of care between primary care providers

and specialists to ensure all the survivor's health needs are met.

Navigators have an essential role in ensuring that quality survivorship care begins at diagnosis and continues throughout the balance of patients' lives. To be able to address the needs of cancer survivors and to provide patient-centered survivorship care, it is imperative for navigators to understand the issues that cancer survivors face. In "Seasons of Survival: Reflections of a Physician with Cancer," Mullan described a model for cancer survivorship in which survivorship begins at diagnosis and requires early identification and intervention to positively impact quality

of life and patient outcomes.²⁰ He identified the seasons of survival as comprising an acute phase (when the patient undergoes diagnosis and treatment), an extended survivorship phase (when the patient may be cured, in remission, on maintenance therapy, or receiving palliative care), and a phase of permanent survivorship (long-term survival or presumed cured).

In 2008, Miller and colleagues expanded on Mullan's paradigm.²¹ They incorporated the idea of a transitional season extending beyond the acute season, which they termed *transitional cancer survivorship*. In this season, patients are trying to adjust to the emotional, social,

and medical challenges that occur following the transition from active treatment to careful observation. The season of transitional cancer survivorship recognizes that a survivor evolves from a cancer patient who has just recently completed active treatment to a survivor who must now create a “new normal” or transition back into a precancer lifestyle. Several factors can affect a cancer survivor’s ability to adjust to the new situation, which can be disease-related, treatment/rehabilitation-related, or survivor-related. For example, survivor-related factors may include an individual’s personality, coping skills, beliefs, culture, and available support system.²¹

Miller and colleagues also divided patients living within the *extended survivorship* season among 3 groups: those in remission who are not receiving any ongoing maintenance therapy; those who appear to be cancer-free due to ongoing treatment with targeted therapy; and those who have been treated and are currently living with cancer as a metastatic or chronic disease.²¹ Within the season of *permanent survival*, 4 subgroups exist: survivors who are “cancer-free but not free of cancer”; survivors who are cancer-free but continue to have significant “fall-out” from cancer and its treatment, including psychosocial, medical, financial, or legal sequelae; survivors who go on to develop second cancers that may be unrelated to the first cancer or its treatment, or may be more likely due to genetic or environmental

factors; and survivors who later develop cancers that are secondary to the initial treatment.²¹

Throughout the seasons of survival—whether treatment is delivered for curative intent or for controlling a chronic disease—it is imperative for healthcare providers and navigators to continually offer the components of survivorship care in the forms of prevention through health and wellness promotion; surveillance for recurrence and strategies to deal with advanced disease; screening for new cancers and intervention for management of lasting physical and psychosocial effects; and coordination of care to cancer survivors.³

Maintaining the quality of life of a cancer survivor is a key component of survivorship care. The quality of life for a cancer survivor includes their physical well-being supported by control or relief of acute symptoms and late effects, as well as the maintenance of function. Psychological well-being is promoted by the ability to cope with illness. Social well-being deals with the impact of cancer on their roles and relationships, and spiritual well-being helps them to maintain hope and derive meaning from the cancer experience. Navigators, through their communication and open relationships with cancer patients and survivors, are instrumental in continually assessing quality of life. Navigators have a crucial role to play in education, assessment, and referral to the right resources to improve survivors’ function and quality of life.³

Two important components of survivorship care in which

navigators play a key role are referral to rehabilitation (to address late and long-term side effects) and utilizing survivorship care plans. The goal of cancer treatment includes preventing deconditioning and maintaining function in activities of daily living as much as possible during acute cancer treatments, so that less reconditioning is required after treatment is completed. Navigation through a complex oncology care continuum, including cancer rehabilitation, is of utmost importance for the best possible outcomes for patients with regard to both quantity and quality of life.³

Planning for survivorship care through the use of end-of-treatment summaries and survivorship care plans has been recognized by the IOM as an important part of the continuum of cancer care.¹⁹ The 2016 American College of Surgeons Commission on Cancer (CoC) includes “Standard 3.3 Survivorship Care Plan” as part of the requirements for accreditation.⁷ The treatment summary and follow-up survivorship care plan provide guidance for primary care physicians, the oncology team, other healthcare providers, and the cancer survivor who has completed treatment, in the coordination and continuity of care. The essential items in the survivorship care plan, as recommended by the IOM, include a follow-up care and management schedule, the providers responsible for follow-up, a list of symptoms of recurrence, and tests warranted for surveillance. In congruence with the IOM’s 4 goals of survivor-

TABLE 3. Competencies of the Navigator in Survivorship

- Establishing goal-setting, life goals
- Integrating survivor's goals/preferences into plan of care
- Providing survivorship education on late and long-term effects
- Coordinating plans of care
- Understanding of palliative and hospice care
- Understanding of Commission on Cancer Standard 3.3 Survivorship Care Plan
- Understanding of Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*

Source: Bellomo C. Survivorship/end-of-life care. *J Oncol Navig Surviv.* 2017;3:124-126.

ship care (prevention, surveillance, intervention, and coordination), survivorship care plans should provide^{3,19}:

- A summary of an individual's cancer diagnosis and treatment information (the treatment summary)
- An overview of both physical and psychosocial effects of diagnosis and treatment
- A detailed follow-up plan that outlines surveillance for recurrence and potential late effects, as well as recommendations for health promotion strategies
- Referrals and resources for physical, psychosocial, and practical needs.

The intent of the survivorship care plan is to help the survivor live a higher quality and longer quantity of life. The care plan serves as a guide for the survivor and the primary care provider by highlighting essential screenings and recommended lifestyle changes; identifies potential late and long-term effects of cancer and treatment; and assists in identifying and accessing needed resources. With the growing

shortage of oncology specialists in the United States, cancer survivors are no longer able to be followed long-term by their treatment team, and must transition back to their primary care physician for survivorship care. The navigator can be especially helpful to the transition process by educating patients on what it entails and by assisting in the development and implementation of the survivorship care plan.³

Resources can be found online through the American Society of Clinical Oncology (ASCO) and the Cancer Care Plan Builder Journey Forward to assist navigators and oncology programs in developing treatment summaries/survivorship care plans.^{22,23} ASCO offers a Cancer Treatment Plan, using an electronic form as a method to store information on a survivor's type of cancer, its treatment (ie, modalities and dosing), and follow-up care.²² A second form offered by ASCO, the Survivorship Care Plan, provides information about the given treatment, the need for follow-up care, the potential long-term/

late effects of treatment, and tips for survivors to improve their health.²² ASCO's Treatment and Survivorship Care Plan templates, which can be found at www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans, can be incorporated by navigators and oncology programs into their workflow and/or into their electronic health records system without seeking permission from ASCO.²²

The Cancer Care Plan Builder (Survivorship Care Plan Builder, Journey Forward) is a free tool for navigators and oncology professionals to assist in developing personalized treatment plans, treatment summaries, and/or survivorship care plans for patients.²³ Journey Forward's Care Plan Builder supports all the essential components identified by the CoC Standard 3.3 Survivorship Care Plan and the IOM recommendations on survivorship care.²³ The tool can be found at www.journeyforward.org/professionals/survivorship-care-plan-builder.

Competencies of the navigator in survivorship are shown in **Table 3**.²⁴

End of Life

End of life represents the time when cancer therapy is no longer effective and the disease progresses, or the patient chooses not to pursue further treatment. The coordination of care is transitioned to hospice care. Navigators also play an integral role in the transition of care to hospice care, which is a special-

ized branch of palliative care provided to patients who have a life expectancy of 6 months or less and who are no longer receiving cancer-specific treatment because their disease is deemed incurable. In the United States, the average length of time a patient receives hospice care is only 5 days, and approximately 21% of metastatic patients will succumb to their disease while hospitalized in an intensive care unit. These numbers can be attributed to poor or inadequate communication regarding advanced disease and end of life between the patient and the treating oncologists.^{3,24} Navigators should advocate for the use of hospice services by recognizing seasons of survival and changes in a patient's quality of life, as well as understanding that patients may have end-of-life tasks to complete. Statistics have shown that patients who enroll in hospice care at home sooner actually live longer with better quality of life than those who continue treatment until too ill to tolerate it anymore.^{3,24} Some insurance companies allow for "carve-outs," which allow patients on hospice to receive some treatment or procedures such as intravenous fluids, as long as they are related to palliative care.

During the transition to hospice/end-of-life care, navigators should continue to assess for and identify barriers, such as challenges with the healthcare system, financial concerns, health literacy needs, and cultural beliefs. Serving as the patient's advocate, navigators can help

TABLE 4. Competencies of the Navigator at End-of-Life

- Integrating patient's preferences into plan of care
- Coordinating plan of care
- Understanding of hospice care
- Support patient and family through informed decision-making

Source: Bellomo C. Survivorship/end-of-life care. *J Oncol Navig Surviv.* 2017;3:124-126.

support the patient and family by providing resources for planning legally, financially, and emotionally for end of life and making sure that the patient's voice is heard and supporting their goals for quality of life and a good death.³ Having a trusting relationship with patients/families/caregivers allows for navigators to have an open and supportive discussion to prepare for and orchestrate a good death. As a final phase at the end of life, the hope of a good death for patients is comprised of the following elements²⁵:

- Knowing he/she had purpose for living, and it was valued by at least 1 other person
- Leaving a legacy that is not related to leaving financial wealth
- Being pain-free
- Dying with dignity in an environment of their own choosing (most want to die at home with hospice care if asked)
- Giving forgiveness and receiving forgiveness
- Feeling confident he/she will be spoken of fondly after he/she is gone
- Having legal and financial affairs in order
- Leaving no financial debt behind for loved ones to pay that is associated with the

cancer and its treatment

- Feeling a connection spiritually to a higher power (which for some, comes closer to the actual end of life).

Navigators play a vital role in providing family/caregiver support, especially at the end of life. Navigators help to prepare the family/caregiver for what to expect and what they will observe during the patient's dying process, to discourage enabling behaviors that result in patients continuing to receive active treatment when they do not want to, and to promote closure for the family/caregiver with the patient. The navigator may be a source of consistency and support during this time.²⁵

Competencies of the navigator at end of life are shown in **Table 4**.²⁴

Case Scenario: Navigating the Continuum of Care

On a Saturday morning in November, Natalie, a thoracic oncology nurse navigator for a university-based medical center, participated in a community health awareness event. Natalie met with members of the community for outreach education/prevention to discuss the hazards of tobacco, resources for smoking cessation, and low-

dose computed tomography (CT) lung cancer screening. During the event, Natalie met Betty, a 56-year-old woman with a smoking history of 31 pack-years. Betty quit smoking 8 years ago and is asymptomatic but is concerned about developing lung cancer.

The institution provides low-dose helical CT lung cancer screenings based on the results of the National Lung Screening Trial, a lung cancer screening study that demonstrated a reduction in lung cancer mortality with the detection of early-stage tumors.²⁶ It was shown that high-risk patients—those with a strong smoking history—who received a low-dose spiral CT screening had a 20% lower mortality from lung cancer compared with patients screened with a chest x-ray.²⁷ Based on these data, the US Preventive Services Task Force²⁸ and the American Lung Association²⁹ recommend screening for current and former smokers based on specific guidelines.

After obtaining Betty's high-risk medical history, Natalie educated her on the lung screening guidelines recommended for current (>30 pack-year smoker) and former (<15 years since quitting) smokers who are apparently healthy and between the ages of 55 and 74 years, including an annual screening with low-dose CT. Betty wished to pursue the low-dose CT screening. The nurse navigator assisted Betty in the scheduling and completion of the low-dose helical CT screening.

Betty's CT scan results indi-

cated a 5-mm lung nodule. Based on the institution and the Lung-RADS™ guidelines for recommended follow-up,²⁸ Betty should continue low-dose CT screening every 12 months if there is no change.²⁶ When lung nodules do not require immediate diagnostics, the surveillance program of the institution is implemented. The abnormality was communicated to the patient's primary care physician, and the follow-up surveillance guidelines were coordinated by the nurse navigator and primary care physician.

Unfortunately, 24 months later, surveillance imaging noted progression in the size of the lung nodule. CT-guided biopsy was performed, with pathology identifying adenocarcinoma non-small cell. Natalie arranged for Betty to be seen in the multidisciplinary thoracic clinic, where she met with a surgeon, medical oncologist, radiation oncologist, social worker, and Natalie. During her consultations with the surgeon and oncologists, they discussed treatment options. Pretreatment staging workup of pulmonary function testing, bronchoscopy, and PET/CT was performed.

Based on test results, Betty was deemed well enough for surgery and elected to proceed with it. Betty met with Natalie to discuss next steps and address barriers to care. Natalie educated Betty on the recommended surgical procedure and postoperative care. In the preceding 24 months, Betty's socioeconomic situation had changed after she became unemployed

and was temporarily living with her daughter and 2 small grandchildren. Natalie therefore referred Betty to the financial assistance counselor and assisted her in preparing the documents she needed to bring with her (bank statements, income tax records, denials from Medicaid applicable, etc). Natalie also referred Betty to national financial assistance resources (CancerCare® and Chronic Disease Fund®), and considered pharmaceutical drug assistance. A social worker also helped Betty with decisions about employment and disability.

Betty underwent video-assisted thoracotomy with lower lobectomy and mediastinal lymph node dissection as the primary course of treatment. The surgical pathology identified a 3.7-cm, moderately differentiated adenocarcinoma with focal pleural involvement, clear surgical margins, and 2 positive lymph nodes. Betty's case was presented in the tumor board conference.

As the patient's advocate, Natalie shared with the board that Betty had continued to use supplemental oxygen most of the time since her surgery and had experienced some persistent chest wall pain. Natalie also shared that Betty was granted financial assistance from the hospital system for her treatment. Per National Comprehensive Cancer Network (NCCN) guidelines for stage IIIA T2N2M0, the multidisciplinary team recommended adjuvant chemotherapy followed by radiation therapy. The sequential rather than concurrent treatment allowed

Betty more time for her to recover from the surgery.

Betty met with the medical oncologist and Natalie to further discuss the plan for 6 cycles of combination chemotherapy. In meeting with Betty for her chemotherapy education session, Natalie provided information using simple language, presented in an organized fashion, to allow for teach-back to demonstrate Betty's understanding. Natalie referred Betty to the center's pulmonary rehabilitation program to assist her in regaining and maintaining pulmonary function following surgery. During the course of chemotherapy, Natalie continued to follow Betty, assessing and assisting with symptom management and barriers.

Upon completion of chemotherapy, Natalie met with Betty and the radiation oncologist to initiate the transition to adjuvant radiation therapy. Natalie educated Betty on the short- and long-term side effects and how to manage them. She then used the NCCN Distress Thermometer to assess Betty's psychosocial status, because the transition to radiation therapy is a pivotal crossroad. On the Distress Thermometer, Betty reported difficulty with emotional problems in regard to treatment decisions and feeling "sadness," "fear," and "worry." In her discussion with the oncology social worker and the nurse navigator, Betty expressed her concern about her disease and treatment affecting her ability to care for herself and a corresponding loss of "normal life." Betty was encouraged to participate in the

cancer center's "Coping Skills" program facilitated by the oncology social worker to help cancer patients develop skills to cope with the emotional and physical impact of cancer.

Following the completion of radiation therapy, Natalie met with Betty for her end-of-treatment visit. During the visit, they discussed Betty's treatment summary and survivorship care plan, thereby providing an overview of both physical and psychosocial effects of diagnosis and treatment, as well as the plan for follow-up medical management. Natalie educated Betty on possible late and long-term effects of non-small-cell lung cancer treatment. Natalie and Betty discussed the psychosocial issues that cancer survivors may experience, as well as health promotion strategies. Natalie referred Betty to the survivorship programs offered at the cancer center.

Nine months after completion of chemoradiation therapy, Betty reported to her medical oncologist that she was experiencing discomfort to her left flank region. PET/CT imaging indicated a mass to the adrenal gland suspicious for metastatic disease. The mass was biopsied and confirmed metastatic disease; molecular testing confirmed PD-L1 positivity, with the absence of *EGFR*, *ALK*, and *ROS1* indicators. Natalie met with Betty to educate her on the recommendation for further treatment with an immunotherapy agent. During the meeting, Natalie encouraged Betty to discuss her goals of treatment and her wishes for quality of life.

After 6 months of immunotherapy, Betty experienced difficulty with immune-related side effects, which decreased her quality of life. She expressed her desire to discontinue treatment. Natalie met with Betty and her daughter to discuss the transition to end-of-life hospice care. They discussed the role of hospice care and the services that can be provided. Natalie encouraged Betty to begin leaving her legacy for her daughter and granddaughters by writing cards, recording videos, and recording audiotapes of Betty reading bedtime stories. Natalie worked with the local hospice group to transition Betty's care, and encouraged Betty and her family to remain in contact. Natalie also requested that the local hospice group keep her and the cancer staff updated on Betty's status, reporting decline and death. The extended contact with Betty, the family, and the hospice group allowed Natalie and the cancer center staff to have a sense of closure.

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XII. NAVIGATION PROGRAM DEVELOPMENT

Standard 3.1

As the need and value of navigation in assisting patients with cancer and their families across the continuum of care and through the healthcare system became more evident, accrediting bodies such as the American College of Surgeons Commission on Cancer (CoC) required that a more formalized process be in place to support patients with cancer. The standards of the CoC are aimed at improving the quality of patient care across the cancer continuum by ensuring that cancer programs within CoC-accredited facilities offer their patients a full range of services and access to community-based resources.

CoC Standard 3.1 Patient Navigation Process, which became effective in 2015, reads as follows¹:

“A patient navigation process, driven by a triennial Community Needs Assessment, is established to address healthcare disparities and barriers to care [for patients]. Resources to address identified barriers may be provided either on-site or by referral [to community-based or national organizations].”

The navigation process is evaluated, documented, and reported annually to the cancer committee. The patient navigation process is modified or enhanced each year to address additional barriers identified by the community needs assessment (CNA).

Job Description and Orientation

Navigation program implementation involves developing the navigator's job description (based on skill set and licensure needed to meet the needs of the community assessment); outlining the orientation and training plan; and defining standard operating procedures, policies, and process flow maps that provide step-by-step guides of operational function for the navigation program. The navigation job description must include navigation core competencies, such as those of the American Cancer Society (ACS), Association of Oncology Social Work, and Academy of Oncology Nurse & Patient Navigators (AONN+) 8 domains of knowledge; responsibilities related to the CoC standards and the Institute of Medicine report findings; and specific responsibilities related to the navigator's role within the multidisciplinary team as they traverse the continuum of care. Examples of job descriptions for navigation can be found at the University of Colorado Cancer Center's website (www.patientnavigatortraining.org/course1/module3/index.htm) or the Association of Community Cancer Centers' website (www.accc-cancer.org/search-results?keywords=navigation).

For employees new to navigation or new to the oncology program, a strong orientation process is imperative to the successful implementation and sus-

tainability of a navigation program. The orientation process should include a detailed discussion of the following: navigation job description, review of national standards, the cancer program's CNA, ACS Navigation Core Competencies, AONN+ 8 domains of knowledge, internal and external resources for the program, health literacy, cultural awareness, guidelines from the National Comprehensive Cancer Network and other national guidelines, navigation and support staff policies and procedures (eg, referral process, managing transitions in care, etc), reports and metrics, and any specific institutional mandatory education.²

An annual evaluation of the navigation program is necessary to update the team on any changes in national standards or guidelines, policies, or procedures; updates on the CNA; and review of health literacy, new processes, updated cancer committee goals, and mandatory education.²

In the development and implementation of a navigator program, key stakeholders must agree on and ensure appropriate educational requirements, curricula for training, credentialing, and certification.²

See Appendix for Navigation Orientation Checklist, Navigation Annual Competency Checklist, and the AONN+ 8 Domains of Knowledge.

Involving Key Stakeholders

Another challenge for navigation programs is achieving “buy-in” from all stakeholders on the aim of and need for such a program prior to implementation. For navigators to be successful, they require champions to assist with their integration into the healthcare system, as well as engaged administrators to define and monitor the tasks and activities that the navigators provide, maintaining an appropriate scope of work.² The following key stakeholders are essential to a successful program³:

- Navigators and cancer center staff
- Cancer center administration (buy-in from administration is necessary, as navigation is not a direct revenue-generating program)
- Physician and other healthcare provider involvement. Physician support is important, particularly in specialty areas, such as medical, surgical, and radiation oncology; rehabilitation; palliative care; and hospice.

In addition, to successfully implement the navigation program, it is vital to garner institutional support by building consensus with referring physicians, advocacy groups, and community support networks.

The integration into the healthcare system is much more likely to occur when each member of the healthcare team understands his or her roles and responsibilities, as well as those of other members of the team. Careful delineation ensures that navigators are not

performing the tasks better allocated to either clinicians or administrative support already present with the care team, and ensures that clinical systems develop so that navigators and clinicians are aware of and can coordinate their work. Although delineation of roles is necessary, it is also vital for administration to be engaged with the team and to instill in the team the need to communicate through morning team meetings and huddles.² Multidisciplinary meetings (including navigators, social workers, nursing, outreach, and other team members) that provide education on respective roles and referral processes, as well as serve as arenas for open communication and collaboration, are also helpful to build successful, sustainable navigation programs.²

Because it is crucial for a successful navigation program to have key stakeholders, navigators must also be champions for the program. It is very important for navigators to be able to articulate their role as defined by the CoC standards and navigator competencies from their national organization. Navigators should be able to communicate their role to the members of the healthcare system, as well as to the community population they serve.

See Appendix for Communicating Your Role: “30-Second Elevator Speech.”

Navigation Processes: Entry Points/Referral

Upon identifying the components of the navigation program, the process of naviga-

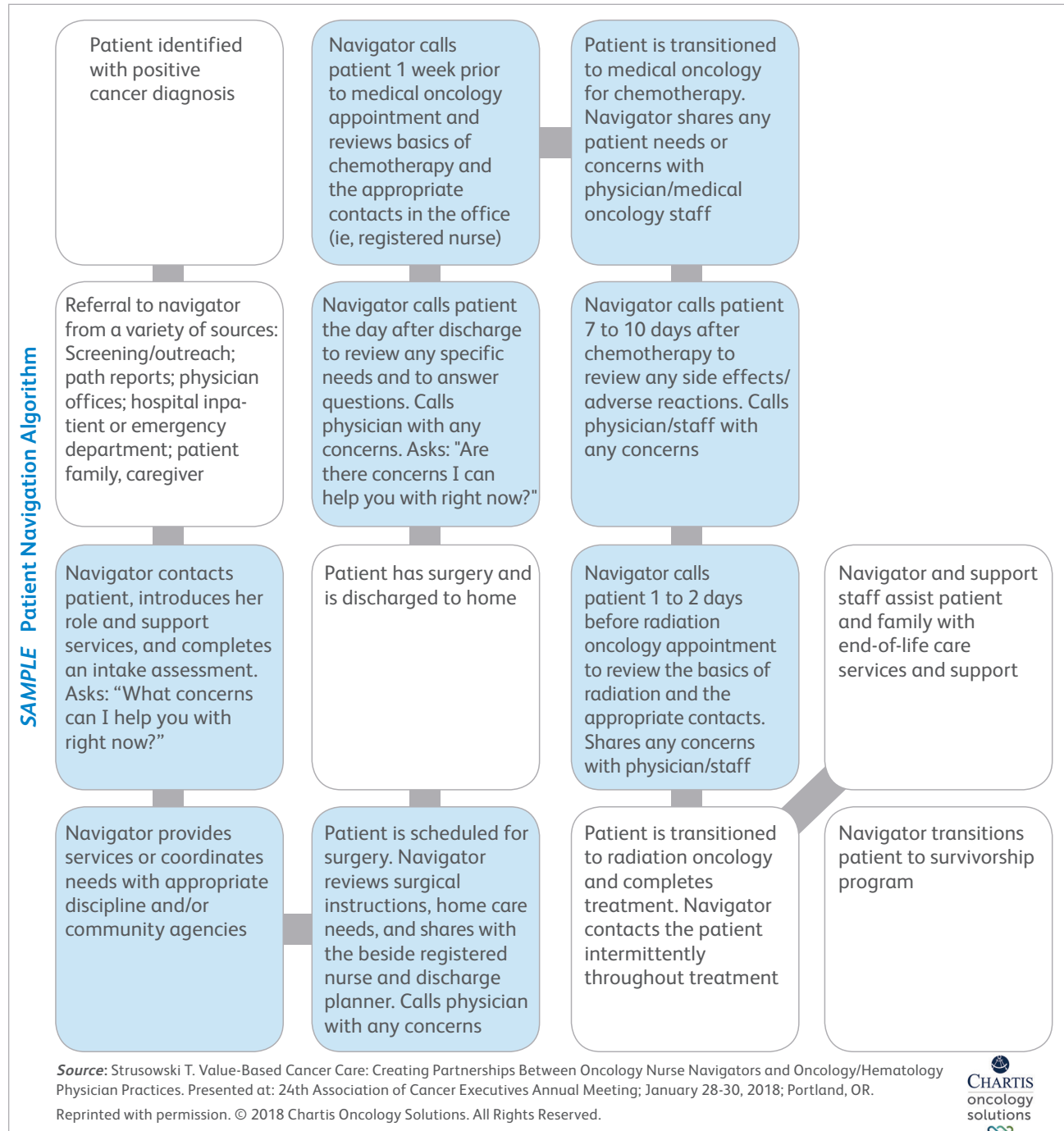
tion—including the entry of the navigator, touch points of care, and the actions to be taken by the navigator within specific time frames—must be determined and assigned so as to provide timely, coordinated, and efficient care to patients and families. As the navigator role is bidimensional in nature—being patient-centered and healthcare system-oriented—it is critical for navigators to view the healthcare system through the eyes of the patient, document the workflow, and identify ineffective processes, communication gaps, and areas of improvement. A workflow diagram can illustrate the care process, including who provides care for the patient (members of the multidisciplinary team), where services are performed, when and how aspects of care are completed, and why each element is needed (**Figure 1**).⁴

It is essential for navigators to be oriented and connected to the healthcare system, as patients may be referred to navigation services through a variety of entry points. Blaseg identified 4 entry portals: physicians; other staff from the facility; hospital reports, such as laboratory and admission lists; and physician schedules.⁵ Additional patient entry points may include referrals from community agencies, survivors, or caregivers.

Navigation Processes: Intake Assessment

Upon referral of a patient to navigation services, it is essential for the navigator to assess whether the patient is ready for

FIGURE 1. Example of Workflow Diagram



a discussion about navigation, support services, and the cancer journey. The initial interaction can set the tone for what follows, highlighting the importance of the following steps of

the assessment⁶:

- First, provide support
- Let the patient and his or her family take the lead in the conversation
- Listen. Active listening is a

special way of reflecting back what the other person has expressed to let him/her know you are listening, and to check your understanding of his/her shared information.

TABLE 1. Components of a Well-Crafted Intake Assessment Tool

- Role of the navigator and the support staff at your cancer center
- Mini assessment of immediate support service needs
- Preferred learning style for education
- Open questions that prompt a conversation on what the patient knows about his or her cancer
- Open questions to elicit from the patient specific concerns, goals, and family concerns
- Family, medical, and surgical history
- Mini symptom and behavior risk assessment
- A listing of national and community resources

Source: Strusowski T. Creating a navigation intake assessment tool. www.accc-cancer.org/ACCCbuzz/blog-post-template/accc-buzz/2017/07/26/creating-a-navigation-intake-assessment-tool. July 26, 2017. Accessed June 13, 2018.

Active listening is a re-statement of the other person's communication—both the words and the accompanying feelings (eg, nonverbal cues, tone of voice, facial expression, and body posture). By providing support and utilizing active listening, navigators are able to assess the needs of the patient and family while developing a trusting relationship

- Ask. Then, based on your assessment, ask the patient and family if they are ready to review the support services and their specific needs. Once you receive their permission, you can then initiate the intake assessment process.

Each cancer program should have a consistent process for assessing and educating patients and families about the cancer program and support services. The navigator's assessment process is an opportunity to begin the discussion about goals of care and/or goals of

treatment—a pillar for providing patient- and family-centered care. Furthermore, identifying the preferred learning style and using it across the continuum sets up the patient to be successful in understanding their cancer and treatment plan. Gathering this essential information at the time of the navigator's initial visit with the patient will establish a strong foundation for the multidisciplinary team. As the patient's advocate, the navigator can share this information at tumor conferences, multidisciplinary meetings, and huddles. A well-crafted intake assessment tool, which can be used for all cancer disease sites and all aspects of the cancer continuum, should include all the components outlined in **Table 1**.⁶

An assessment tool is a key component for a consistent foundation to navigation. It supports the primary navigator in educating the patient and family, and can be used as a reference for navigators who may be called on to cover for a col-

league. The inclusion of health literacy training and patient education teach-back methods further contribute to staff success in educating patients and families. Therefore, assessing the immediate needs of the patient and family while providing education and support establishes a patient-centered approach and lays the groundwork for a strong bond between the patient, family, navigator, and support services.⁶ (See also www.accc-cancer.org/ACCCbuzz/blog-post-template/accc-buzz/2017/07/26/creating-a-navigation-intake-assessment-tool.)

See Appendix for Patient Navigation Intake Form and <http://aononline.org/education/navigation-tools>.

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XIII. NAVIGATION PROGRAM MONITORING AND OUTCOME MEASURES

As discussed earlier, the community needs assessment (CNA) is the cornerstone for navigation program development. The Commission on Cancer recommends that a CNA should be conducted every 3 years to identify changes in cancer incidence, changes in culture, or socioeconomic shifts within the population, as well as to address healthcare disparities and barriers to care for patients. Based on the triennial CNA, navigation programs will have to reflect the changes occurring with the community and utilize the information to establish objectives for

growth and improvement.¹

Once established, a navigation program should be assessed annually to evaluate successes; identify areas of unmet need, new barriers, and ongoing challenges; and establish objectives for expanding and advancing the program. Using the metrics and outcome measures established for the navigation program, data collected can be compared with the baseline and analyzed to determine areas needing additional attention and those requiring further development to promote program viability and evolution. The National Cancer

Institute Community Cancer Centers Program's Navigation Assessment Tool can be used to establish a baseline assessment of a navigation program and to provide a framework for setting goals and establishing benchmarks for evaluation and monitoring of programmatic growth and quality improvement.²

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XIV. METRICS

As evidence guides practice, it is essential for navigation programs to identify core metrics and standardize data collection to clearly demonstrate program outcomes. Collection of data in regard to specific outcomes can be helpful in creating a workflow for the navigator, assisting in program development, maturity and sustainability, and providing a mechanism for resource allocation to the most needed and beneficial program components.¹ Monitoring outcomes can provide valuable information on community needs and guide future discussion of program offerings. Quality improvement and program evaluation enable navigators to provide the highest quality of care and support by anticipating and mobilizing available resources. Program outcomes and metrics should be reviewed annually to ensure they are realistic, reflective of progress, and supportive of the program goals and patient needs.¹

Metrics and quality measures as defined by the Centers for Medicare & Medicaid Services (CMS) are tools to “measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high quality healthcare and/or that relate to one or more quality goals for healthcare.”² Metrics are methods used to evaluate the success of the navigator role (accurately measuring performance) in cancer programs

to improve the care of patients by monitoring and measuring outcomes. Metrics for evaluating navigation programs must include measures that assess reductions in barriers to care and improvements in the delivery of timely, effective, and equitable cancer services.¹

the navigation program. Therefore, what type of reporting is best suited to communicate patient navigator efficacy? The answer is clear: data and metrics. The challenge is that while navigation programs have existed for decades, standardized national metrics to measure programmat-

Metrics and the Oncology Navigator Professional Practice:

It is imperative that oncology nurse and patient navigators understand that active participation in data collection, analytics, and reporting outcomes *is not added responsibility* but is already a part of the professional role.

Source: Sein E, Johnson D, Strusowski T, Bellomo C. Measuring the impact navigation has on patient care by supporting the multidisciplinary team. In Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 14. Cham, Switzerland: Springer International; 2018:291-314.

Although several articles and research projects have discussed various measures that can be used to capture the impact of navigation, most of these discuss time-to-care metrics, patient satisfaction, and measures that assist with care for the underserved; few discuss the broad range of measures that validate the role of navigation in all areas of oncology patient care.³ It is the expectation that each navigation program is developed to meet the needs of the patients and the institution where the program is being created, and those indicators to measure the success of that program must be tailored to

ic success had yet to be created and standardized. After a comprehensive literature search on the topic of navigation metrics, 3 main categories of metrics were identified: patient experience, clinical outcomes, and business performance/return on investment (ROI). To be able to support continuation or perhaps even expansion of patient navigation services, cancer programs will need to collect quality metrics in all 3 of these categories.^{1,4}

Patient Experience Metrics

The “patient experience” is increasingly emerging as a more

enhanced method for measuring navigation success. The 2013 Consumer Assessment of Healthcare Providers and Systems cancer survey results revealed that patients' expectations were exceeded when they felt their healthcare provider actively listened and incorporated their personal psychosocial goals into the treatment plan. The results of this survey also confirm the importance of ensuring navigators and support staff know how to provide the appropriate level of education. Asking patients about their experience(s) and encouraging patients' active participation in their treatment discussions increased the level of understanding and satisfaction of the patient and their family. As the focus on cancer treatment broadens to include the entire continuum of care, navigators, as patient advocates, increasingly have opportunities to enhance the patient experience from outreach and screening through survivorship and/or end-of-life care. Especially as patients complete active treatments, the focus will have to shift to prevention and wellness, as well as implementing a successful surveillance plan in the outpatient setting for the balance of their lives. Patient experience interventions are not difficult to create for a navigation program, but patient-centered care methodology must always be applied to create appropriate metrics.^{1,5}

Clinical Outcomes Metrics

Clinical outcomes metrics are much more familiar to health-

care providers, because clinicians have used these to assess patients' clinical outcomes and the provision of quality patient care. Navigators can have an impact on clinical outcomes through measuring their services and interventions. These navigation metrics include distress screening, pathway compliance, and timeliness of care. Clinical outcomes measurement should include assessment of the psychosocial domain (quality of life and patient/family satisfaction) for the continuous evaluation of the navigation program.^{1,4}

Business Performance Metrics

Business performance metrics—unlike patient experience or clinical outcomes—are much less familiar for navigation programs, yet this category is becoming increasingly important as cancer program administrators question the ROI for navigation services.¹ Navigation programs have been incorporated into cancer programs over the past 2 decades to support the Institute of Medicine report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, and the Commission on Cancer's (CoC's) Cancer Program Standards.^{6,7} Administrators now must measure the ROI for the navigation program and report metrics and outcomes to ensure sustainability of the program. Navigators focusing on business performance metrics may require additional training or education on such measures.^{4,8} Resources that provide navigators with additional

information on business performance metrics include the Association of Community Cancer Centers at www.accc-cancer.org, CMS at www.cms.gov, and the Academy of Oncology Nurse & Patient Navigators (AONN+) at www.aonnonline.org. To fully understand the “what” and “why” of business metrics, navigators should be knowledgeable about business-related cancer topics, including⁸:

- Value-based cancer care
- Federal healthcare reform and reimbursement
- CMS quality measures
- Affordable care organizations, oncology medical homes, and bundled payments
- Future reimbursement models for medical care based on quality measures rather than fee for services
- Population management and the initiation of penalties for readmission.

Navigators can have an impact on ROI through measuring their services and interventions. Five major areas in which navigation can have an impact and support program ROI are⁹:

- Remove barriers
 - Allows for patients to undergo diagnostic/staging, workup, and treatment
- Promote treatment adherence
 - This demonstrates cost-effectiveness, as navigators can impact treatment adherence through patient education and promoting shared decision-making
 - Increases continuity of care
- Enhance revenue
 - Navigators can impact

TABLE 1. The AONN+ 8 Domains of Knowledge

- Community Outreach and Prevention
- Coordination of Care/Care Transitions
- Patient Advocacy/Patient Empowerment
- Psychosocial Support Services/Assessment
- Survivorship/End of Life
- Professional Roles and Responsibilities
- Operations Management/Organizational Development/Health Economics
- Research/Quality Performance Improvement

Source: Johnston D, Sein E, Strusowski P. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation program. *J Oncol Navig Surviv.* 2017;8:220-237.

revenue by facilitating referral to downstream revenue-generating services, monitoring “no shows,” and decreasing outmigration

- Decrease preventable emergency department (ED) visits
- Decrease preventable hospital admissions
 - Through education and early intervention, navigators can help keep patients from frequenting the ED or being readmitted to the hospital for avoidable reasons (constipation, nausea, vomiting), allowing healthcare to become more cost-effective.

AONN+ Standardized Metrics

With standardized metrics, navigation and cancer programs can demonstrate their success on a national level. By utilizing the same metrics, navigators can truly partner and be on the same page, with the same mission and vision to enhance the care of all oncology patients and families through the development of national

benchmarks.⁴ These metrics should align with national standards such as those of the CoC, National Accreditation Program for Breast Centers, Quality Oncology Practice Initiative, and value-based care. National standards help drive continuous quality improvement and value, as well as identify best practice programs that elevate cancer care to a higher level.¹ The integration of performance improvement methodologies and data analytics drives quality outcomes and reimbursement.

The goal of the AONN+ Standardized Metrics project was to develop a set of standard metrics supported by strong source documents and national standards that can be used by all organizations and models of navigation as a baseline to prove the efficacy and sustainability of their programs.⁴ As it is essential for the metrics to support and correlate with the goals of individual navigation and cancer programs, each navigation program will determine which standardized metrics are

essential to measure outcomes specific to their program, and perhaps will have additional metrics they must capture to suit the needs of their own programs.

The AONN+ 8 Domains of Knowledge were utilized to develop a set of standardized metrics in the areas of patient experience, clinical outcomes, and ROI (**Table 1**).⁴ The domains of knowledge provide a comprehensive list of all areas in which navigators practice along the continuum of care to provide quality patient care and financial stability for their organizations.⁴

For a comprehensive review of the AONN+ Standardized Metrics Task Force’s development of the Standardized Evidence-Based Oncology Navigation Metrics, see the following 2 sources:

- Johnston D, Sein E, Strusowski P. Standardized evidence-based oncology navigation metrics for all models: a powerful tool in assessing the value and impact of navigation programs. *J Oncol Navig Surv.* 2017;8:220-237⁴
- Strusowski T, Sein E. Standardized Metrics Source Document: www.aonnonline.org/metrics-source-document⁵

See Appendix for National Comprehensive Cancer Control Program Navigation Matrix (www.accc-cancer.org/docs/Documents/oncology-issues/supplements/ncccp-navigation-matrix-tool).

See Appendix for AONN+ Standardized Evidence-Based Oncology Navigation Metrics for All Models.

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XV. PROFESSIONAL DEVELOPMENT

Professional Organizations

Several professional health-care associations and societies are dedicated to the education and support of navigators. These organizations include the Academy of Oncology Nurse & Patient Navigators (AONN+), Oncology Nursing Society (ONS), and Association of Oncology Social Work (AOSW).¹⁻³ These organizations offer evidence-based guidelines to ensure the high-quality, standardized care of oncology patients. AONN+ and ONS lead groundbreaking research and initiatives related to patient-centered care. Navigation training programs, such as the Institute for Patient-Centered Initiatives and Health Equity (formerly the George Washington University [GW] Cancer Institute), aid in navigation program development.⁴

The mission of AONN+ is to advance the role of patient navigation in cancer care and survivorship care planning by providing a network for collaboration and development of best practices for the improvement of patient access to care, evidence-based cancer treatment, and quality of life during and after cancer treatment. As cancer survivorship begins at the time of cancer diagnosis, the philosophy of AONN+ is that one-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life. In addition, navigation should en-

compass community outreach to raise awareness targeted toward prevention and early diagnosis, and must encompass short-term survivorship care, including transitioning survivors efficiently and effectively under the care of their community providers. The vision of AONN+ is to achieve, through effective navigation, patient-centered, superior quality cancer care coordination from prediagnosis through survivorship/end of life.¹

ONS is a professional association of more than 39,000 members committed to promoting excellence in oncology nursing and the transformation of cancer care. Since 1975, ONS has provided a professional community for oncology nurses, developed evidence-based education programs and treatment information, and advocated for patient care, all in an effort to improve quality of life and outcomes for patients with cancer and their families. Together, ONS and the cancer community seek to reduce the risks, incidence, and burden of cancer by encouraging healthy lifestyles, promoting early detection, and improving the management of cancer symptoms and side effects throughout the disease trajectory.²

AOSW is a nonprofit, international organization dedicated to the enhancement of psychosocial services to people with cancer, their families, and caregivers. Created in 1984 by social workers interested in oncology,

AOSW has become the world's largest professional organization entirely dedicated to the psychosocial care of people affected by cancer. AOSW membership is comprised of an international set of professionals and students who practice in hospitals, cancer centers, home care agencies, hospice, community-based oncology practices, community programs, patient advocacy organizations, educational institutions, and other settings.³

The mission of AOSW is to advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through networking, education, advocacy, research, and resource development. AOSW envisions a global society in which oncology care meets the physical, emotional, social, and spiritual needs of all people affected by cancer.³

The Institute for Patient-Centered Initiatives and Health Equity (formerly the GW Cancer Institute) was inaugurated in 2003, chartered by the university in 2004, and rechartered for 2014 through 2019. In 2015, the Institute for Patient-Centered Initiatives and Health Equity became part of the GW Cancer Center. The GW Cancer Center is a collaboration of George Washington University, George Washington University Hospital, and the GW Medical Faculty Associates to expand GW's efforts in the fight against cancer. The GW Cancer Center also incorpo-

TABLE 1. Benefits of Certification

Benefits of Certification	
Individual	Greater confidence in providing care/services
	A heightened ability to discern complications
	More effective education of patients
	Enhanced collaboration with peers, colleagues, and team members
	Personal satisfaction
	Career advancement
	Increased earning potential
	Acknowledgment of achievement by peers and employers
	Recognition of efforts to improve knowledge and skills
	Validation of qualifications, knowledge, and skills
Employer	Knowledge that the professional work environment includes advanced professional employees
	Greater retention of employees due to professional and personal satisfaction
	Reduced exposure to risk
	Enhanced care for patients and client to distinguish them from competitors
	A way for employers to sort through resumes at a primary level
Patients & Families	Assurance that provider of care is qualified and competent at more than a basic level
	Improved quality, safety, and accuracy of care by advanced skilled professionals
	Expanded knowledge to be shared about choices and treatment options
	More empowerment in decision-making
	Knowledge that the professional has shown the desire to improve their quality of patient care and service delivery

Source: National Consortium of Breast Centers (NCBC). Breast Patient Navigator Certification (BPNC). Why should I get certified. www2.bpnc.org/why-should-i-get-certified. Accessed June 28, 2018.

rates all existing cancer-related activities at GW with a vision to create a cancer-free world through groundbreaking research, innovative education, and equitable care for all. The GW Cancer Center's mission and focus is to foster healthy communities, prepared patients, responsive healthcare professionals, and supportive healthcare systems through applied cancer research, education, advocacy, and translation of evidence into practice. The values of the GW Cancer Institute anchor the work of the Institute

for Patient-Centered Initiatives and Health Equity: credibility, transparency, inclusivity, innovation, and patient-centricity.⁵

The GW Cancer Institute created core competencies for nonclinically licensed patient navigators using a highly collaborative, multistage process from January 2013 through August 2014.^{4,6} With the competencies established, the GW Cancer Institute developed comprehensive competency-based training for oncology patient navigators.⁶ The training uses interactive, web-based presentations

to discuss evidence-based information and case studies to prepare patient navigators to effectively address barriers to care for cancer patients and survivors.

Certification

Professional certification reflects a navigator's achievement beyond licensure requirements and a basic level of knowledge required for general practice. Through certification, navigators can validate specific skill sets, specialized knowledge, and experience to provide enhanced care and services for

patients. Professional certification has both tangible and intangible benefits. Certification benefits not only the professional who earns certification but also the certified individual's employer, clients, patients, and the families of those for whom care and services are provided (Table 1).⁷

AONN+ certification is unique to the field of navigation. The establishment of baseline competencies for oncology navigators centered on their roles, responsibilities, educational level, and evidence-based best practices will help ensure consistent delivery of optimized patient care across the care continuum. AONN+ offers generalist certification for both oncology nurse navigators (ONN-CGSM) and, in collaboration with the GW Cancer Center, oncology patient navigators (OPN-CGSM). The organization also offers certification to clinical nurse navigators working specifically in the thoracic specialty (ONN-CG[T]SM), and is looking to develop certifications for other tumor type-specific navigation.⁸ The AONN+ website offers

information regarding the requirements for certification, as well as learning guides and modules for certification exam preparation (www.aonnonline.org/certification).

The National Consortium of Breast Centers (NCBC) offers the NCBC Breast Patient Navigator Certification Program. The program offers 6 types of Breast Patient Navigator Certifications: The Certified Navigator—Breast Imaging (techs); Management/Social Worker (all social workers and managers of navigators); Advocate (volunteers/lay navigators); Clinical (medical assistant, technicians, licensed practical/vocational nurses); Provider (all breast care diagnosticians, nurse practitioners, physicians, physician assistants, breast care PhDs); or Nurse (registered nurses). The exams are specific for the 6 types of certification, and developed based on specific licensure.⁹ The NCBC website offers information regarding the requirements for certification (<http://www2.bpnc.org/certification>).

Membership and certification information for these organizations can be found at:

AONN+ – www.aonnonline.org

AOSW – www.aosw.org

GW Cancer Institute – <https://smhs.gwu.edu/gwci>

NCBC – <http://www2.bpnc.org>

ONS – www.ons.org

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XVI. NAVIGATION TOPICS FOR PROFESSIONAL DEVELOPMENT

Communication Tips for Difficult Conversations with Patients

As the patient's advocate, it is essential for navigators to have an open relationship built upon trust and communication—not only with the patient, but with their families and caregivers, as well. As they move along the cancer care continuum, navigators must often have difficult conversations with patients regarding their disease, its prognosis, and treatment options. It is vital for navigators to pay attention to how they set up a conversation, as this will improve the comfort level for all parties involved and allow for successful communication. Suggested tips for having difficult conversations with patients are listed in **Table 1**.¹

The Ask-Tell-Ask approach is one of the best methods for assessing knowledge and understanding, sharing information, and educating patients and their families. This principle is based on the idea that education requires knowing what the learner already knows and building on that knowledge.² The Ask-Tell-Ask approach also works as a way to build a relationship, as it shows that you are willing to listen and that you care.

- **ASK** the patient to explain their current understanding of the purpose of the conversation (their diagnosis, prognosis, treatment plan, and palliative/hospice care). This

allows for assessment of their level of knowledge, emotional state, and degree of education. *“What is your understanding of palliative care? It is helpful for me to know what you already know.”*

- **TELL** the patient in easy-to-understand words the purpose of the conversation (eg, diagnosis, prognosis, treatment plan, palliative/hospice care) and your role through their entire continuum of care. Information should be provided in short, digestible chunks, and in plain language.
- **ASK** the patient if she/he understood the information given. This allows for assessment of their understanding. Ask them to repeat what you reviewed with them and clarify any misunderstandings. Review and reiterate as needed. *“When you tell your family what we have talked about today, what will you say?”*

Shared Decision-Making

Shared decision-making is a vital component of patient-centered care that enables and encourages patients to play a role in the medical decisions related to their care and health. It is a process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values. Shared decision-making

is especially important when there is more than one reasonable option, such as screening or a treatment decision, when no one option has a clear advantage, and when the possible benefits and harms of each option affect patients differently.³

Shared decision-making benefits both patients and providers. Patients learn about their health and understand their conditions; recognize that a decision must be made and are informed about the options; understand the pros and cons of different options; have the information and tools needed to evaluate their options; are better prepared to talk with their healthcare provider; collaborate with their healthcare team to make a decision right for them; and are more likely to follow through on their decision. In addition, healthcare providers report that both patients and providers benefit from the lasting and trusting relationship that is formed in the process of shared decision-making, with high satisfaction overall.³

As members of the oncology team and as the patient's advocate and educator, navigators are in a prime position to help with the shared decision-making process by inviting the patient to participate, letting them know that they have options, and explaining that the patient's goals and concerns are important. In the role of educator, navigators can assist patients by providing

TABLE 1. Suggested Tips for Difficult Conversation

Create a comfortable/private environment	
Sit at eye level	
Ask permission	Before discussing difficult information, assess how the patient wishes to receive the information. “Is it ok if we talk about some difficult information?”
Start the conversation	Always start the conversation with addressing the patient’s agenda, concerns, and goals. “ <u>Let’s start with what’s been the biggest concern for you.</u> ” This demonstrates that you respect and honor the wishes of your patient and their family through compassion and superb listening skills. In discussing their goals, agree on the big-picture goals before specific treatment/medical interventions
Track emotional information	Track and pay attention to the <u>emotional information</u> that you are receiving from the patient, as well as the <u>cognitive information</u> , while moving the conversation forward one step at a time using <u>open-ended questions</u> to identify concerns
Reiterate the communication	Reiterate the communication and clarify what you can do to assist before you discuss what you are not able to do. Repetition may be necessary, as stressful situations can inhibit retention

Source: Adapted from Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-311.

information on their options; helping to evaluate those options based on the patient's goals and concerns; and assisting patients with following through on their decisions by addressing any pertinent issues and barriers to care.

Resources for shared decision-making can be found at Mayo Clinic: <https://shareddecisions.mayoclinic.org>.

Compassion Fatigue

Every day, navigators provide care to patients and their families who rely on them not only for their physical care but also for their emotional and spiritual needs. In their work, navigators expend a tremendous amount of energy and concern over the long-term as they care for patients who may or may not recover from their illnesses. During this time, close relationships are forged among navigators, patients, and families, and

the navigator might find themselves unprepared for the emotional challenges, such as death, a moral or ethical dilemma, or a difficult family situation. These challenges—on top of daily duties and obligations—can leave a navigator feeling physically, emotionally, and spiritually drained.

Charles Figley, PhD, a trauma specialist, defines *compassion fatigue* as a state experienced by those helping people in distress; it is an extreme state of tension and preoccupation with the suffering of those being helped to the degree that it is traumatizing for the helper.^{4,5} The helper, in contrast to the person(s) being helped, is traumatized or suffers through the helper's own efforts to empathize and be compassionate. Often, this leads to poor self-care and extreme self-sacrifice in the process of helping. These, in turn, result in compassion fa-

tigue and symptoms similar to posttraumatic stress disorder.^{4,5}

Compassion fatigue develops over time—taking weeks or sometimes years to surface. It may begin as a low-level, chronic clouding of caring and concern for others but over time the ability to feel and care for others becomes blunted and eroded through overuse of compassion (**Table 2**).^{5,6}

Compassion fatigue can have far-reaching effects that extend beyond the navigator to the entire organization. Compassion fatigue can result in increased or chronic absenteeism; increase in safety issues and workers' compensation claims; high staff turnover rates; and friction among employees, staff, and management/administration.⁵

For navigators, combating compassion fatigue starts with recognizing the symptoms and making changes that lead to personal transformation. It is im-

TABLE 2. Symptoms of Compassion Fatigue

Excess blaming	Recurrences of nightmares or flashbacks
Bottled-up emotions	Chronic physical ailments
Isolation	Apathy, sadness, no longer finding activities pleasurable
Receiving unusual amount of complaints from others	Difficulty concentrating
Complaining excessively about administrative functions	Mentally and physically exhausted
Substance abuse	Preoccupation
Compulsive behaviors	In denial about problems
Poor self-care	Legal problems, indebtedness

Source: Gamblin K, Francz S. Compassion fatigue: when caring takes its toll. *Oncology Nursing News*. www.oncnursingnews.com/publications/oncology-nurse/2011/sepember-2011/compassion-fatigue-when-caring-takes-its-toll. September 21, 2011. Accessed June 12, 2018.

portant for navigators to reflect on why they have chosen the profession, their mission, and overall goals as they relate to life, themselves, and their families. Navigators should develop a self-care plan with techniques to incorporate into their lives to avoid or improve symptoms of compassion fatigue. Simple practices that can help include finding time to recharge one's batteries each day, committing to an exercise regimen, eating healthier, connecting with family and close friends, and taking

breaks throughout the day to breathe properly. Speaking with peers, managers, family, and friends can also help alleviate symptoms of compassion fatigue. Navigators should seek professional assistance (eg, from a trained counselor) when the symptoms of compassion fatigue become overwhelming.⁵

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XVII. CONCLUSION

The framework of a navigation program must be structured on an evidence-based clinical practice model. Whereas navigation programs may be diverse in organizational structure, the goals of navigation in regard to patient and clinical outcomes must be standardized to establish benchmarks of care. Standardization of navigation programs includes

consistent requirements for navigators in regard to experience, certification, standardized orientation and mentoring programs, and documentation. Diligence in measurement of goals, baseline performance, patient experience, clinical outcomes, and return on investment is imperative to demonstrate the impact and sustainability of the navigation program.



XVIII. NAVIGATION RESOURCES

Professional Organizations and Societies

Academy of Oncology Nurse & Patient Navigators – www.aonnonline.org

Advisory Board Oncology Roundtable: Navigation Program 2017 – www.advisory.com/research/oncology-roundtable

Agency for Healthcare Research & Quality – www.ahrq.gov

American Cancer Society – www.cancer.org

American College of Surgeons Commission on Cancer – www.facs.org/cancer

Association of Community Cancer Centers – www.accc-cancer.org

Association of Oncology Social Work – www.aosw.org

Institute for Healthcare Improvement – www.ihi.org

National Coalition for Cancer Survivorship – www.canceradvocacy.org

National Comprehensive Cancer Network – www.nccn.org/index.asp

National Consortium of Breast Centers – www2.breastcare.org

Oncology Nursing Society – www.ons.org

Program Development and Training Programs

Association of Community Cancer Centers: Patient Navigation Resources and Tools for the Multidisciplinary Team – <http://oi.accc-cancer.org/resources/PatientNavigation-Overview.asp>

EduCare – <https://educareinc.com>

Harold P. Freeman Patient Navigation Institute – www.hpfreemanpni.org

Institute for Patient-Centered Initiatives and Health Equity at the GW Cancer Center – <https://smhs.gwu.edu/gwci>

Joint Commission Cultural Competency Training – www.jointcommission.org/assets/1/6/aroamapforhospitalsfinalversion727.pdf

Patient Navigator Training Collaborative – <https://patientnavigatortraining.org>

US Department of Health & Human Services Health Literacy Training – <https://health.gov/communication/literacy/quickguide/default.htm>

Resources to Address Patient Barriers

Advocacy Connector – <https://advocacyconnector.com>

CancerCare: A Helping Hand – www.cancercare.org/helpinghand

