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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ACADEMY OF ONCOLOGY NURSE & PATIENT NAVIGATORS: MISSION AND VISION

The mission of the Academy of Oncology Nurse & Patient Navigators (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. Cancer survivorship begins at the time of cancer diagnosis.[1] One-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life.[2] In addition, navigation should encompass 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.[3]

The vision of the Academy of Oncology Nurse and Patient Navigators (AONN+) is to achieve, through effective navigation, patient-centered superior quality cancer care coordination from pre-diagnosis through survivorship/end of life. https://aonnonline.org/mission-and-vision

The endorsement mark certifies that the information presented in educational seminars, publications, or other resources is considered by AONN+ to be reliable and credible.

PFIZER ONCOLOGY: OUR COMMITMENT

Pfizer Oncology is a committed partner in the cancer care community, dedicated to humanity's quest for longer, healthier, happier lives. Our goal is to improve the life of every patient with cancer and positively impact all who deal with this disease. One way we demonstrate our commitment to this goal is through our support of the patient navigation movement occurring throughout the United States.

Ask your Pfizer Oncology Account Manager about Patient Navigation in Cancer Care 2.0 to support your commitment to making a difference in the lives of patients and in shaping the future of cancer care.

Additional information regarding this program can be found at www.patientnavigation.com.

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I. INTRODUCTION

The healthcare environment—including oncology—continues to evolve. With the rising incidence of cancer, an aging population, and advances in treatment modalities, the cancer burden has become costly for both patients and society. The focus of healthcare is shifting to digital care; person-centered and personalized care that address the gaps in accessibility and equity; creative changes that expand the availability of healthcare workers; and value-based care that demonstrates evidence of improving care, which ultimately delivers the best patient outcomes.[1]

Navigation is integral to meeting the demands of this shift as it helps the community to access healthcare services, facilitates effective interprofessional collaboration, promotes patient satisfaction, quality care, and efficient use of resources to decrease costs across oncology patient populations and healthcare settings.

Navigation, with its various models, has evolved beyond identifying barriers to incorporating cancer core competencies, certification, standardized metrics, and professional standards that help drive continuous quality improvement and value while identifying evidence-based best practices that elevate cancer care to a grander scale. Value-based care, the future of cancer management, is the concept of improving quality and patient outcomes by standardizing processes through best practices.[2] The competencies of navigation help to ensure consistent delivery of optimized patient care across the healthcare continuum, thus aligning with and supporting value-based care.

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II. PAST, PRESENT, AND FUTURE OF NAVIGATION

Past Initiatives in Navigation

The concept of patient navigation developed after the findings of the American Cancer Society's (ACS) National Hearings on Cancer in the Poor, which were conducted in 7 American cities in 1989.[1] The report identified the following critical issues: (1) people with insufficient income endure greater pain and suffering from cancer compared with other Americans, (2) people with insufficient income and their families must make personal sacrifices to obtain and pay for care, (3) people with insufficient income face obstacles in obtaining and using health insurance and often do not seek care if they are unable to pay for it, (4) cancer education programs are culturally insensitive and irrelevant to many people with insufficient income, and (5) fatalistic ideas about cancer are prevalent among people with insufficient income and prevent them from seeking care.[1] As a response to this report, Dr Harold Freeman implemented the Harlem Cancer Education and Demonstration Project (HCEDP) to develop and pilot a patient navigation program in 1990.[2] This followed just over 2 decades of observing more than 606 patients with breast cancer treated at Harlem Hospital Center. This population, 94% of whom were African American, consisted of a disproportionate number of people with insufficient income and no medical insurance. They had a high breast cancer mortality rate and often presented with more advanced disease.[2]

Dr Freeman's program focused on the window of opportunity for saving patients from cancer mortality by eliminating barriers to timely care that were typically encountered between reporting a suspicious finding and resolving 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 community patient navigators help address the barriers and bridge the gaps that were prevalent between this patient population and the healthcare system. One of the major goals of the program was to expand access to cancer screenings and clinical follow-up in the medically underserved through community outreach and 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, the breast cancer 5-year survival rates increased in this population, from 39% before intervention to 70% after he initiated his patient navigation program. Dr Freeman demonstrated that the 5-year cancer survival rates can be improved with increased access to screening and patient navigation programs because they address issues such as lack of health insurance, fear and distrust of the medical community, and cultural and communication barriers.[2] The HCEDP patient navigator model established the idea that patient navigator staff members, who had no nurse or social worker licensure, could help to reduce health disparities.

Another patient navigation program around the same time as Freeman's work was the Wai'anae Coast Cancer Control Project in the Pacific Islands.[3] Papa Ola Lokahi, a native Hawaiian community-based organization was awarded a National Cancer Institute cooperative agreement to test how effectively a cancer control intervention increased breast and cervical cancer screening rates and enhanced knowledge attitudes, and behavior scores among participants. The design was centered to take advantage of the rural native Hawaiian social and family networks and their sense of "Kokua", which means "to help without being asked to help." Navigators helped the community members move successfully through the healthcare system. The program succeeded as women were educated and brought into healthcare settings for breast and cervical cancer screening. Again, the focus was on a patient navigator and not a nurse or social worker.

Although Dr Freeman brought the patient navigation movement to the forefront of healthcare delivery in the 1990s, nurses had the utilization review movement, which has evolved since the 1970s. The goal of this movement in the 1970s was to monitor the use and delivery of services, and in the 1980s, the goal evolved into evaluating the appropriateness of medical care—including its need and efficiency. The 1990s shifted the focus to case management and patient navigation/care coordination, and identifying and reducing barriers to care (**Table 1**).[4] With this evolution, the process of a multidisciplinary team approach, which centered on open communication, was developed to address the psychosocial and financial concerns of patients, as well as coordinate their 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.[5]

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.

The basis of current navigation models was influenced by several organizational and government reports and initiatives focused on decreasing health care disparities, eliminating barriers to care, and improving the overall patient experience (**Table 2**). The U.S. National Cancer Institute's report, *Voices of a Broken System: Real People, Real Problems,* indicated that barriers to cancer care exist for people of all socioeconomic levels.[6] The Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, ensured that navigators are accessible and can provide high-quality, coordinated care to all patients with cancer.[7] This Act not only supported the training and employment of patient navigators who had direct knowledge of the communities they served, but it also promoted outcomes such as coordination of care and referrals, community organization involvement in supporting patient needs, enrollment in clinical trials, assistance in obtaining

TABLE 2. Evolution of the Oncology Patient Navigation Profession

2008
33rd Annual Oncology Nursing Society (ONS) Congress – Implementing the Nurse Navigator Role
National Coalition of Oncology Nurse Navigators (NCONN) incorporated (annual conference 2010, 2011, 2012, 2014). Dissolved the organization in December 2014.
2009
Academy of Oncology Nurse Navigators (AONN) incorporated (annual conferences since 2010)
The National Accreditation Programs for Breast Centers had a Patient Navigation standard in place
Association of Community Cancer Centers Cancer Care Patient Navigation: A Practical Guide for Community Cancer Centers
10th Annual Oncology Nursing Society Institutes of Learning presentation acknowledged nonclinical versus clinical navigators
2010
Journal of Oncology Navigation & Survivorship®(*JONS*) was published
ONS/Association of Oncology Social Work (AOSW)/National Association of Social Workers (NASW) Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation
2011
National Patient Navigation Leadership Summit. Measuring the Impact and Potential of Patient Navigation. *Cancer.* 2011;117(S_15):3535-3636.
First book published by Jones & Bartlett on navigation – *Becoming a Breast Cancer Nurse Navigator* by Lillie Shockney
2012
Patient Navigator Research Program (PNRP) results published in *Cancer Epidemiology, Biomarkers & Prevention*
Commission on Cancer Patient-Centered Standards phase in for 2015
Standard 3.1: Patient Navigation Process
Standard 3.2: Psychosocial Distress Screening
Standard 3.3: Survivorship Care Plan
2013
AONN changed name to Academy of Oncology Nurse & Patient Navigators (AONN+)
ONS releases Oncology Nurse Navigator Core Competencies (updated in 2017)
2014
AONN+ released Nurse Navigation Domains of Knowledge
ONS published *Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum*

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TABLE 2. Evolution of the Oncology Patient Navigation Profession *(Continued from page 9)*

2015
George Washington Cancer Institute published Core Competencies for Oncology Patient Navigators in *JONS*
AONN+ initiated development of standardized navigation metrics focused on patient experience, clinical outcomes, and return on investment.
AONN+ was granted membership in the American College of Surgeon's Commission on Cancer
AONN+ launched *CONQUER™: the patient voice*
AONN+ started Local Navigation Network (LNN) development
2016
AONN+ launched certification exams at the 7th Annual AONN+ National Conference; (AONN+) Foundation for Learning (AONN+ FFL) was established in the future as the certification arm.
2017
The National Navigation Roundtable (NNRT) launched
ONS published *Oncology Nurse Navigation Case Studies*
ONS updated Oncology Nurse Navigator Core Competencies
2018
AONN+ released a book *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation.*
2020
AONN+ in collaboration with the ACS, released the Navigation Metrics Toolkit.
The American National Standards Institute National Accreditation Board accredited AONN+ Foundation for Learning national accreditation to offer national certification to Oncology Nurse Navigator-Certified Generalist (ONN-CG℠) and the Oncology Patient Navigator-Certified Generalist (OPN-CG℠).
AONN+ FFL achieved national recognition from the American College of Surgeons Commission on Cancer confirming the Oncology Nurse Navigator–Certified Generalist℠ demonstrates compliance under Standard 4.2 titled "Oncology Nursing Credentials."
2022
The Professional Oncology Navigation Task Force released Oncology Navigation Standards of Professional Practice.

coverage by public programs or private insurance, and tackling barriers within the healthcare system to ensure prompt diagnosis and treatment.[7] A project that provided funding to 9 sites, titled the Patient Navigator Research Program (PNRP), was supported by the National Cancer Institute and the American Cancer Society in 2005. Its goal was to develop operationally effective and cost-effective patient navigation interventions that would eliminate barriers to timely delivery of cancer diagnosis and treatment services with a focus on breast, cervical, colorectal, and prostate cancers.[8] Key outcomes from the PNRP program were as follows[9]:

- Patient navigation increased rates of resolution of abnormal screening findings as well as the time for patients to receive a diagnostic resolution.
- Patient navigation increased rates of treatment initiation.
- Navigated patients reported increased satisfaction with cancer care compared to non-navigated patients and thus improved quality of life.
- Identified barriers to healthcare access were financial problems along with medical/mental health comorbidities and a barrier to abnormal screen resolution was language/interpreter issues

As a recognized profession, the role of oncology patient navigation has flourished and evolved since the late 2000s.

National Standards in Navigation

The first organization to include a standard for oncology navigation was the National Accreditation Program for Breast Centers (NAPBC).[10] Standard 2.2 states that "a patient navigation process is in place to guide the patient with a breast abnormality through provided and referred services."[11] The standard does not dictate who the navigator is as it acknowledges the process may involve different individuals at each point of care and can take on different forms in various communities as determined by the needs of the patient, family, and the community.[11]

In 2012, the American College of Surgeons Commission on Cancer (CoC) released standards with the goal of ensuring patient-centered care.[12] Standard 3.1, which was effective between 2016 and 2020, required cancer programs seeking CoC accreditation to establish a process for identifying and navigating potential barriers to care, and document that process each calendar year.[12,13] The process was driven by a community needs assessment (CNA).[13] In 2020, the CoC navigation standard was designated as Standard 8.1–Addressing Barriers to Care. A CNA was no longer a requirement but could be used as a resource to analyze strengths and weaknesses of existing program.[13] Standard 8.1 states that the cancer committee should focus on at least 1 patient-, system-, or provider-based barrier for the year, identify resources and processes to address the barrier, and evaluate and report the solution(s) selected to address the barrier.[14] As oncology care evolves, navigation standards will continue to promote quality of service by addressing unacceptable variations in the principles of treatment and care.

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 today's healthcare environment, key organizations drive the focus on quality, outcomes, and evidence-based practice. The Institute for Healthcare Improvement's Triple Aim Initiative seeks to improve the patient care experience (including quality and patient satisfaction), improve the health of populations, and reduce the per capita cost of healthcare.[15] Value-based cancer care is a highly coordinated, patient-centered solution to address rising healthcare costs, ineffective duplication of services, and barriers to care.[16] 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 resources to decrease costs across oncology patient populations and healthcare settings.

The Center for Medicare & Medicaid Innovation (CMMI) is developing new alternative payment and delivery models aimed at improving the effectiveness and efficiency of specialty care.[17] An alternative payment model (APM) is a payment approach that gives incentives for high-quality and cost-efficient care. APMs can apply to a specific clinical condition, a care episode, or a population.[18] The Oncology Care Model (OCM), launched in July 2016 aims to provide higher quality, better coordinated oncology care at the same or a lower cost than Medicare.[17,19] The OCM model combines financial incentives, including performance-based payments that improve care coordination, appropriateness of care, and access for beneficiaries undergoing chemotherapy.[17,19] It targets oncology practices delivering chemotherapy treatment and the spectrum of care provided to a patient during the 6-month episode following chemotherapy.[19] Its aim is to shift reimbursement and payment to value-based quality care, which includes patient navigation as a foremost component.[19] A Participants' Perspectives report, collected during the first 4 years of the OCM, showed that a combination of navigators, lay and/or nurse, were employed by the OCM-affiliated hospital or practice.[20] Depending on their role, the navigators closed referral loops, addressed transportation or lodging needs, conducted well-check calls to lower-risk patients, met with new patients, saw patients during clinic appointments, and followed up by telephone. Their role reflected higher ratings on communication from patients. The Enhancing Oncology Model is the next performance-based payment component for the CMMI as it is distinct and built on lessons learned from the OCM.[21] The Merit-Based Incentive Payment

System (MIPS) is another payment mechanism instituted by the Centers for Medicare & Medicaid Services that has provided 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.[22] Using a composite performance score, eligible professionals receive a payment bonus, a payment penalty, or no payment adjustment. The important role of navigation with care coordination is highlighted under the MIPS improvement activities.

The premise of value-based care is that patient care that is better coordinated and connected improves outcomes and lowers costs. Navigators are critical in coordinating patient care and 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 achieve better outcomes potentially. Navigators are direct contacts for patients to report symptoms as they arise, as opposed to allowing unreported symptoms to escalate in severity, potentially leading to hospitalization.

The ongoing work of AONN+, NNRT, other professional oncology navigation groups such as the Patient Oncology Navigation Taskforce that created the Oncology Navigation Standards of Professional Practice, were a foundational basis for the 2024 Medicare Physician Fee Schedule (PFS) final rule, which provides payment for principal illness navigation services to help patients and their families navigate cancer treatment and treatment for other serious illnesses.[23] This navigation milestone included reimbursement of the American Medical Association CPT codes for clinical oncology navigation services provided by licensed registered nurses or clinical social workers that went in effect November 2023.[24] The four new Healthcare Common Procedure Coding System G-codes were part of the PFS rule for principal illness navigation (PIN) services provided by certified or trained auxiliary personnel under the direction of a physician or other practitioner that were effective January 1, 2024 and were applicable to non-licensed navigators but licensed navigators can also be covered.[25] The key to G codes is the training of non-clinical personnel who perform PIN services. They must meet applicable state requirements, including licensure or in states with no applicable requirements, auxiliary personnel providing PIN services must be trained or certified in the core competency domains listed in the PFS rule.[26] All PIN services are under applicable state laws and regulations. This funding source is a start in patient navigation sustainability and will evolve and grow over the coming years.

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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+), the Oncology Nursing Society (ONS), and the National Navigation Roundtable (NNRT). Although these organizations sometimes use overlapping terminology, nonetheless each has been significant in developing guidance, competencies, and standards for the process of navigation. According to the CoC, "[p]atient navigation in cancer care refers to specialized assistance for the community, patients, families, and caregivers [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] The CoC focuses on the navigation process and not the type of navigator employed to understand the health disparities among populations and reduce barriers to care. AONN+ defines the navigation process as "[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 Association of Oncology Social Work (AOSW), and the National Association of Social Workers (NASW) developed a joint position on navigation. The position defines patient navigation in the cancer care setting as "[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] The NNRT navigation process definition is the same as the joint statement from ONS, the AOSW, and the NASW.[4] This consistent definition from the professional organizations was recognized by the Professional Oncology Navigation Task Force when creating the Oncology Navigation Standards of Professional Practice.[5] As patient navigation has evolved through the past decades, it has been consistently recognized as an effective intervention that increases access to cancer screening, and promotes complete screening and treatment in populations affected by healthcare disparities.[6-8]

NOTES FOR NAVIGATORS

To support the navigation process definition, there are 9 principles of patient navigation[9]:

1. Patient navigation is a patient-centric healthcare service delivery mode.
2. Patient navigation virtually integrates a fragmented healthcare system for the individual patient.
3. The core function of patient navigation is to eliminate barriers to timely care across all segments of the healthcare continuum.
4. Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers.
5. Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through each phase of the care continuum.
6. Patient navigators should be determined by the level of skills required at each phase of navigation.
7. In each system of care, the point at which navigation begins and ends should be defined.
8. Patients should be navigated across disconnected systems of care, such as primary care sites and tertiary care sites.
9. Patient navigation systems require coordination.

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IV. NAVIGATION CORE COMPETENCIES

Navigators serve as educators, care facilitators, counselors, and patient advocates who provide education and psychosocial support, coordinate care across the cancer continuum and its disciplines and assist with financial needs. Navigators must demonstrate competence in oncology, as well as the psychosocial and spiritual aspects. Based on the needs of the community and the navigation program, elements of their skill set should include health promotion knowledge; past work or personal experience within the healthcare field; language skills to effectively communicate with the populations served; and the ability to form relationships, work well on a team, problem-solve, and demonstrate leadership when required.

The Navigation Roundtable (NNRT), sponsored by the American Cancer Society, is a national coalition of more than 80 member organizations dedicated to achieving health equity and access to care across the cancer continuum.[1] Its goal is to advance navigation efforts that eliminate barriers to cancer care, reduce disparities in health outcomes, and foster ongoing health equity. The NNRT uses Task Groups composed of experts from partner organizations to collaborate on projects around evidence-based promising practices, policy, workforce development, and public awareness and communications.[2] The Workforce Development Task Group built consensus on various national oncology patient navigation program competencies and derived 7 competency domains for any patient navigation program.[3] The following are the recognized domains of competency recommended by the NNRT for patient navigation:

NOTES FOR NAVIGATORS

Navigators serve as educators, care facilitators, counselors, and patient advocates who provide education and psychosocial support, coordinate care across the cancer continuum and its disciplines and assist with financial needs.

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 includes the patient's personal assessment as well as those of the healthcare provider system and community resources. The navigator acts as a liaison among all team members to advocate for optimized patient health and wellness with the overall focus of improving access to services for all patients. Navigators conduct patient assessments that (needs, goals, self-management, behaviors, strategies for improvement) integrate the 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 the systems of care for patients, from enhancing community relationships and outreach through to end-of-life care. Develops 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 and 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 by professional and culturally acceptable behavior.

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V. NAVIGATOR ROLE DELINEATION

Patient navigators, nurse navigators, and social work navigators have overlapping yet distinct roles/responsibilities and competencies based on their licensure. All 3 are involved in patient education, but the information they provide can vary based on their training, education, and professional level. Community health workers (CHWs) provide community education, and they should have general knowledge of 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. With 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 skills needed to intervene on their behalf (eg, assess functional and psychosocial health and manage symptoms).[1]

NOTES FOR NAVIGATORS

Consensus-Based Role Definitions[4]

Professional Navigator
A trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of oncology navigator. Positions that fall under the professional navigator category include oncology patient navigators and clinical navigators. Clinical navigators comprise oncology nurse navigators and oncology social work navigators.

Oncology Patient Navigator
A professional who provides individualized assistance to patients and families affected by cancer to improve access to healthcare services. A patient navigator may work within the healthcare system at the point of screening, diagnosis, treatment, or survivorship; or across the cancer care spectrum; or outside the healthcare system at a community-based organization; or as a freelance patient navigator. A patient navigator may be employed by a clinic or a community-based organization and work throughout the community, crossing the clinic threshold to continue to provide a consistent person of contact and support within the healthcare system. A patient navigator does not have or use clinical training.

Clinical Navigator/Oncology Nurse Navigator
A professional registered nurse with oncology-specific clinical knowledge who offers individual assistance to patients, families, and caregivers to help overcome healthcare system barriers. Using the nursing process, an oncology nurse navigator provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum.

Clinical Navigator/Oncology Social Work Navigator
A professional social worker with a master's degree in social work and a clinical license (or equivalent as defined by state laws) with oncology-specific and clinical psychosocial knowledge who offers individual assistance to patients, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social work navigator provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum.

Regardless of the navigator's title, they 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 they all support evaluation efforts, they perform different evaluations based on their scopes of practice and licensure. CHWs focus their evaluation on the community's needs and health behaviors.[2] 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. Clinical navigators, like nurse or social work navigators within the healthcare system, should focus their evaluation on clinical outcomes and quality indicators.[1]

In 2022, the Oncology Navigation Standards of Professional Practice were released by the Professional Oncology Navigation Task Force (PONT).[3] PONT included representatives of navigation professional practice organizations and individuals who previously served on the Biden Cancer Initiative Patient Navigation Working Group. The standards provide oncology nurse, social work, and patient navigators with clear professional practice guidance and agreed upon definitions, and role delineation. This includes the knowledge and skills all professional navigators should possess to deliver high-quality, competent, and ethical services to people impacted by cancer. These standards also provide benchmarks for use by healthcare employers and information for policy and decision makers, health professionals, and the public to understand the role of professional oncology navigators. The standards are intended to provide guidance and may be applied differently, as appropriate, in diverse settings.

Below is an example of 1 of the 19 standards to support the profession of oncology patient navigation (**Table 1**).[4]

TABLE 1. An Example of an Oncology Navigation Standard of Professional Practice From the Professional Oncology Navigation Task Force

Standard 13: Psychosocial Assessment and Intervention **Oncology navigators assess, assist, and/or provide clinical services to best support the psychosocial needs of patients and caregivers throughout the cancer continuum.**	
All navigators:	Utilize empathy, patient-centered interviewing and listening skills, and methods appropriate to patients' capacity and cultural practices. Provide anticipatory guidance and manage expectations to assist patients in coping with the diagnosis of cancer and its potential or expected outcomes. Demonstrate knowledge of psychosocial issues and resource referrals to address patient needs and interests. Administer evidence-based patient-reported distress screening to identify patient barriers to care and provide appropriate referrals. Remain current on standardized instruments helpful in identifying and responding to patient needs and concerns. Screen for distress.
Clinical nurse navigators:	Provide psychosocial assessment and support and facilitate appropriate referrals for patients, families, and caregivers, especially during periods of high emotional stress and anxiety.
Clinical social work navigators:	Conduct ongoing biopsychosocial assessments with patients to determine the needs, assets, and priorities of the patient. Provide clinical psychosocial diagnostic, assessment, and treatment services to support patients' identified social and emotional needs. Sit on institutional boards and committees that implement and monitor psychosocial assessment and intervention.

(Continued on page 19)

TABLE 1. An Example of an Oncology Navigation Standard of Professional Practice From the Professional Oncology Navigation Task Force *(continued)*

Standard 13: Psychosocial Assessment and Intervention **Oncology navigators assess, assist, and/or provide clinical services to best support the psychosocial needs of patients and caregivers throughout the cancer continuum.**	
Patient navigators:	Refer to clinical navigators to answer questions regarding psychosocial information and to clinical social workers, clinical social work navigators, or other licensed mental health professionals for more specific psychosocial information and treatment.

Source: Franklin E, Burke S, Dean M, Johnston J, Nevidjon B, Simms Booth L. The Professional Oncology Navigation Task Force. Oncology Navigation Standards of Professional Practice. *J Oncol Navig Surviv*. 2022;13:74-85. Reprinted with permission. Copyright 2022 by Academy of Oncology Nurse & Patient Navigators®. All rights reserved.

The standards that define the specifics of a profession are reflective of the collective voice of oncology patient navigator professional organizations, stakeholders, and any interested party that participated in the open comment period to create this foundational document to solidify high-quality navigation services that are applicable to healthcare systems, but flexible to fit population and community needs. This standardization is a logical and critical step to serve as a foundational document for navigation sustainability.

NOTES FOR NAVIGATORS

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.

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VI. MODELS OF NAVIGATION

Oncology navigators are important in establishing a patient navigation process and addressing patient, provider, and system-related barriers to ensure patient satisfaction and timely access to care.[1] The current Commission on Cancer (CoC) 2020 Standard 8.1–Addressing Barriers to Care is a revamped version of the CoC 2016 Standard 3.1–Patient Navigation Process.[2] The updated standard focuses on the barriers to care themselves rather than the navigation process and the navigator role, but navigators remain an instrumental part of identifying and addressing these barriers. CoC 2020 Standard 8.1 does not require but continues to emphasize the importance of a community needs assessment to help identify the relevant healthcare disparities and barriers to care that exist within the community so that a plan can be developed to meet these challenges.[3] The specific needs of the community will dictate the service and skill set required, and the navigation model should align with these needs. For example, rural populations may find that the greatest barrier or service need is transportation to and from appointments, and the navigator will then focus on finding vouchers or resources to provide low-cost transportation. Immigrant communities will benefit more from navigators who offer services in their language and possess a keen understanding of relevant cultural issues. The standard is relevant to patient, nurse, and social work navigators in diverse settings such as hospitals, community clinics, rural and reservation clinics, and community organizations that provide patient navigation services.[4]

Different navigation models have evolved from Dr Harold Freeman's Patient Navigation Model, which used community members known as lay navigators.[5] Presently, navigation recognizes patient (those without a clinical license), nurse, or social work navigators (**Figure**).[6,7] The current navigation models are tailored to the individual needs of the community that the cancer center serves, the patient referral base (urban/rural), geospatial community health assessment, racial and ethnic diversity, and health-related socioeconomics.[8] Navigation models and processes may be based upon the skill set of the navigator, setting, point of entry into the continuum of care, and disease type. They can also be blended models.

Models Based Upon Skill Set

Oncology Patient Navigator

As defined by the Oncology Navigation Standards of Professional Practice, an oncology patient navigator is a professional who provides individualized assistance to patients and families affected by cancer to improve their access to healthcare services.[6] As the patient navigator does not have or use clinical training, they focus on performing nonclinical tasks that include scheduling, interpreter services, and identifying nonclinical barriers to care such as communication, information, medical system, practical and social-emotional, and/or addressing financial/resource needs (financial navigator/cancer resource coach). George Washington University offers free online training on identifying barriers to care and linking patients to resources based on core competencies for oncology patient navigators.[9]

Financial Navigator (subset of Oncology Patient Navigator)

The advances made in treating cancer can come with higher costs, which are then shifted to patients through increased out-of-pocket responsibilities (premiums, deductibles, coinsurance, and copays). This cost shift causes financial toxicity for patients that can affect their treatment adherence. The COVID-19 pandemic, with its impact on jobs and insurance, has thrown a new spotlight on the financial toxicity in healthcare–an area where financial navigators can have a positive benefit.[10] Financial navigators focus on treating and preventing financial toxicity by guiding patients through the complex healthcare system and helping them to gain access to care by reducing financial barriers. Financial navigators use resources of co-pay assistance and patient assistance programs when patients are prescribed medications that come

FIGURE. The Goals of Oncology Navigation

Source: Adapted from Strusowski T. Navigation and Survivorship 101. Presented at: Academy of Oncology Nurse & Patient Navigators (AONN+) 6th Annual Navigation & Survivorship Conference; October 1-4, 2015; Atlanta, GA.

with high out-of-pocket costs.[11] They liaise with payers/providers/pharmacies and patients by providing cost and coverage information that supports shared decision-making, treatment adherence, and patient satisfaction, thus mitigating patient and institutional financial toxicity. The Association of Community Cancer Centers (ACCC) has a Financial Advocacy Boot Camp, a self-paced eLearning program consisting of 9 modules designed to build the knowledge and skills of financial navigators, nurses, social workers, and other healthcare professionals.[12]

Clinical Navigator/Oncology Nurse Navigator (ONN)

Navigation programs may focus on the clinical nurse navigator. Their expertise and clinical skill set related to the cancer care continuum, including risk reduction, diagnosis, treatment, survivorship, and end-of-life, is what differentiates the ONN from patient and social work navigators.[13] Whereas oncology nurses often work in silo–chemotherapy infusion, inpatient oncology units, radiation, or other select roles, nurse navigators use their operational management knowledge to track patients along the care continuum, record steps to reduce barriers, ensure that cancer care meets standards of care, and focus on care coordination between the different oncology departments.[14]

Nurse and patient navigators can be essential in clinical trials. Literature on clinical trial participation cite numerous barriers that could impede patient participation, particularly for minority populations. They include cost, family commitments, time, lack of social support, transportation, and an inadequate understanding of clinical trials.[15] Using their understanding of the healthcare system and resources, navigators can assess and address logistical/financial barriers. As members of the multidisciplinary team, navigators can collaborate with the clinical trials coordinator/team to help the patient understand clinical trials better including the eligibility criteria, costs, and appointments.

Clinical Navigator/Oncology Social Work Navigator

Based on the needs of the community served, navigation programs may incorporate oncology social work navigators. With their clinical psychosocial knowledge, oncology social work navigators can provide psychosocial assessment, resources, and coping skills for patients, families, and caregivers. Social workers can counsel patients and their families, facilitate support groups and educational programs, refer patients to community counseling and social safety net programs, and consult with them regarding their workplace or educational options.[16]

Models Based Upon Setting

Navigation models and processes can be based on work setting. Clinical nurse navigators and social workers usually work in a clinic or hospital-based cancer center where they use their skills and knowledge to coordinate quality, patient-centered care through effective communication with the interprofessional cancer care team. In the community setting, patient navigators can assist patients to get screened and address any barriers to screening. Many patient navigators use their understanding of the culture of the community they represent to liaise between the healthcare team and community resources, thus ensuring seamless delivery of care.[17] They link patients to primary care providers, health information, health screening, financial assistance, or transportation. Of note, one community radiation oncology program creatively addressed transportation barriers with a rideshare program that increased patient satisfaction and reduced no-shows.[18]

Models Based Upon Point of Entry Along the Continuum of Care

Models of navigation may focus on the point of patient entry to the continuum of care. Community engaged patient navigators in an outreach setting focus on addressing health education and screening needs while assisting individuals in the community to get into the healthcare system. Typically, nurse navigators assist patients during diagnosis or treatment and address any barriers to seamless treatment and supportive care coordination. Posttreatment, patients may work with survivorship navigators to address the challenges that patients encounter during and after the transition from active cancer treatment.[17] When cancer therapy is no longer effective, the patient's disease progresses, and/or the patient wishes to stop active treatment, the coordination of care is transitioned to hospice care. Navigators are integral in the transition of care to hospice because they serve as the patients advocate and address barriers, financial concerns, and health literacy needs.

NOTES FOR NAVIGATORS

Many patient navigators use their understanding of the culture of the community they represent to liaise between the healthcare team and community resources, thus ensuring seamless delivery of care.

Models of Disease-Specific Navigation

While models of navigation may vary by point of entry, they can also vary by focus or disease-specific type. Dr Harold Freeman's Patient Navigation Model focused on breast cancer.[19] Common types of disease-specific navigation programs focus on lung, breast, cervical, and prostate cancer. Facilities with larger oncology navigation programs can often offer a wider range of disease-specific navigators. Today, the use of navigators for patients with chronic illness and complex care is rising.[20]

Blended Models of Navigation

A navigation program's aims will determine if the navigation team should consist of just 1 type of navigator or a combination. Blended oncology navigation models can include nurse, social worker, and patient navigators. Clinical and nonclinical staff working in tandem to support patients in the navigation process is beneficial because it allows clinical staff to focus on clinical aspects of navigation while having nonclinical tasks assigned to patient/lay navigators. Clarifying of roles/role delineation and setting of priorities for the navigation process is critical in a blended model to ensure the most effective use of resources, decrease confusion and duplication of efforts, and maximize the benefit to patients.[21]

Clinical Trials and Navigation

With the basic goals of the navigation model being directed to individual community needs, each navigator can play an essential role in clinical trials. The American Society of Clinical Oncology (ASCO) and the National Cancer Institute (NCI) both recommend navigation as a strategy to evaluate and improve patient enrollment in clinical trials.[15,22]

NOTES FOR NAVIGATORS

Navigators can build a trusting relationship between patients and the healthcare system by attending to misconceptions, addressing logistical concerns, and introducing clinical trials as a care option early in the treatment process.

Clinical trial participation is a process that starts in the outreach continuum of care as patients need to be aware of clinical trials in general and understand and trust the medical purpose of research. If they are willing to participate, barriers such as transportation, lack of insurance, and other out-of-pocket expenses must be addressed. Navigators can build a trusting relationship between patients and the healthcare system by attending to misconceptions, addressing logistical concerns, and introducing clinical trials as a care option early in the treatment process. A synergistic relationship between research staff and nurse navigators can decrease barriers as the patient begins clinical trial participation and raise healthcare provider awareness of specific patient needs or concerns. Oncology patient navigation is a solution for the standard that the National Comprehensive Cancer Network (NCCN) emphasizes in their guidelines "the best management of any cancer patient is in a clinical trial."[23] As patient navigation models emerge and evolve, evidence of the difference it makes within the clinical trial process as well as outcome measures to evaluate program effectiveness are growing.[24]

Considerations for Using Navigators in Clinical Trials

AONN+ can leverage established partnerships to increase the awareness and acceptance of the use of navigation in clinical trials.

- The deployment of relevant education and resources would support navigators in their efforts to enhance clinical trial patient access, retention, and adherence
- The creation of a robust clinical trial navigator community would equip navigators with relevant clinical trial resources and provide opportunities to facilitate best practice sharing

Navigators can glean additional best practices in clinical trial navigation by connecting with the AONN+ clinical trial national committee at AONN+ .org. In 2022, AONN+ explored the potential of expanding the role navigators play in clinical trial recruitment and retention and created a brochure with the findings and considerations as a resource for navigators and their administrators.[25]

Conclusion

As the healthcare market continues to evolve and provide cost-effective, high-quality care, models of navigation will also continue to evolve to meet the needs of communities, patients, and the health system. This was evident during the COVID-19 pandemic, which resulted in telehealth service expansion. With the variety of navigation models, the responsibilities of the navigator may include educating patients on the disease or health system, removing medical system barriers, assisting with insurance coverage, addressing additional financial barriers, aiding in coordinating care, referring patients to community resources, and providing emotional support. No matter the model of navigation, the goal is to provide resources to support patients emotionally, inform and educate patients, expand access to care, facilitate coordination and continuity of patient-centered care, and improve cancer outcomes.

Resources

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VII. BARRIERS TO CARE

To effectively coordinate care, navigators must understand social determinants of health (SDOH) (ie, safe housing and neighborhood, racism, education, and access to nutritious foods). SDOH contribute to healthcare disparities (ie, race or ethnicity, sex, sexual identity, age, disability, and socioeconomic status) and barriers (ie, culture, language, insurance status, geographic location, and logistics) 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. It exists if a health outcome is seen to a greater or lesser extent between populations.

Healthy People 2030 has a goal to reduce new cases of cancer and cancer related illnesses, disability and death having noted that, "[d]eath rates are higher for some cancers and in some racial/ethnic minority groups."[1] These disparities are often linked to SDOH including education, economic status, and access to health care."

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 system literacy, fear, and distrust. Many patients, particularly the underserved and uninsured, face significant barriers to receiving timely diagnosis and quality of care (**Table**).[2]

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 health disparities. The core principle of navigation is to eliminate barriers to timely and quality care through all phases of healthcare, including prevention, detection, diagnosis, treatment, survivorship, and end-of-life. Increasingly, navigation programs have been used as a strategy to improve the timely receipt of needed healthcare services.[3]

As navigators work closely with patients and families, they develop a therapeutic and trusting relationship through open and honest communication, thereby ensuring 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 and SDOH screenings to elicit information regarding physical, social, emotional, cultural, and spiritual needs as well as other barriers that may impact care.

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.

NOTES FOR NAVIGATORS

A key function of the navigator is to provide tailored, culturally appropriate education that facilitates communication and collaboration based on a learning needs assessment, which establishes the patient's current health literacy, preferred language, motivation, and attitudes.[4]

Navigators must understand and practice cultural awareness and humility by recognizing how culture can influence healthcare. A key function of the navigator is to provide tailored, culturally appropriate education that facilitates communication and collaboration based

TABLE. Barriers to Care Addressed by Navigators

Barriers		Definition
Patient Focused		
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
Other Focused		
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.

on a learning needs assessment, which establishes the patient's current health literacy, preferred language, motivation, and attitudes.[4,5]

Navigators must be competent in addressing, developing, and implementing plans/interventions to address barriers experienced by patients with cancer. To remove barriers, navigators connect patients and caregivers to resources and support systems, assist in healthcare provider interaction, and streamline appointments and paperwork. They can provide logistical support (such as arranging transportation, lodging, or childcare) and language interpreter assistance, refer patients to financial assistance programs (community, state, or national), facilitate appointments with oncology specialists and members of the multidisciplinary team, and connect patients with available community and national support resources.

Resources that connect patients with available community and national services include CancerCare®, Triage Cancer and Advocacy Connector. CancerCare® (www.cancercare.org/helpinghand)is a searchable, online database of financial and practical assistance available for people with cancer. Triage Cancer (https://triagecancer.org) helps with practical and legal issues. Advocacy Connector (www.cancer.com) is a resource designed to help patients and caregivers connect with relevant cancer advocacy group resources. (See **Navigation Resources** section for more information.)

NOTES FOR NAVIGATORS

"Navigators may take the time to gain a deep understanding of patients' perspectives of their illness. These patient-centered actions begin dialogues about culture-informed viewpoints critical to the provision of culturally competent care"[5]

References: 1. U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Goal: reduce new cases of cancer and cancer-related illness, disability, and death. Healthy People 2030. Accessed July 10, 2023. https://health.gov/healthypeople/objectives-and-data/browse-objectives/cancer **2.** 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:e155-e162. **3.** Dixit N, Rugo H, Burke NJ. Navigating a path to equity in cancer care: the role of patient navigation. *Am Soc Clin Oncol Educ Book*. 2021;41:1-8. **4.** McDonald C. A first-hand look at the role of the breast cancer nurse navigator. *Care Manag*. 2011;17:11-13, 27-28. **5.** Phillips S, Villalobos AVK, Crawbuck GSN, Pratt-Chapman ML. In their own words: patient navigator roles in culturally sensitive cancer care. *Support Care Cancer*. 2019;27:1655-1662.


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VIII. DISTRESS AND PSYCHOSOCIAL NEEDS

The cancer experience can be life-changing. Individuals deal with loss, a perceived lack of control in some situations, and fear of recurrence.[1] Psychological problems created or exacerbated by a cancer diagnosis 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 undergoing treatment. Patients, families, and treatment teams should be informed that management of distress is an integral part of holistic medical care. It should include appropriate information about psychosocial services in the treatment center and 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 fear, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis."[2]

As part of delivering high-quality cancer care, the Commission on Cancer (CoC) Standard 5.2 incorporates distress screening into routine cancer care. The CoC recommends that all patients with cancer be screened for distress at least once during the patient's first course of treatment.[3] NCCN recommends that, "[i]deally, patients should be screened for distress at every medical visit as a hallmark of patient-centered care. At a minimum, patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (ie, remission, recurrence, progression, treatment-related complications)."[2] 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, at the end of treatment, at 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 important to ensure that psychosocial care is coordinated and needs are identified and 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 function and decreased adherence to treatment and medication, which may lead to poorer clinical outcomes.[4,5] Depression is a common psychological symptom experienced by patients with cancer. If left unchecked, it can cause significant distress and 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]

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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NOTES FOR NAVIGATORS

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.

In 2008, 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 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 patients with psychosocial health needs.[2] Needs assessments require more time than screening and involve 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 healthcare-related visit. This tool is designed to screen for distress only and is not a diagnostic tool for measuring depression or anxiety.[2] It 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 that better elicits issues contributing to the patient's concerns and how they 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]

Using this tool, 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 looks at the problem list to identify key concerns and asks further questions to determine what type of referral or services would be helpful.[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, allows patients to share their vulnerabilities, and ensures timely referral to supportive services. Many patients are new to healthcare and are unaware of what services exist to help them along the cancer care continuum.

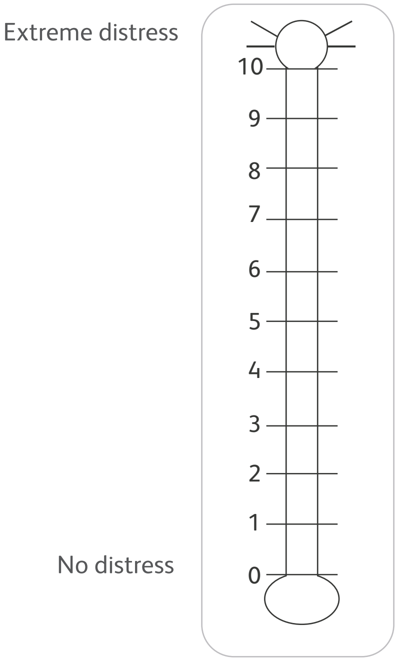
Evidence suggests that distress screening alone is not sufficient to improve patient outcomes. A critical component of a successful distress management program is appropriate and timely referrals, and post referral follow-up to gauge results of the experience and provide feedback as necessary.[9] Navigators are instrumental in developing and implementing a plan for psychosocial health services in their cancer programs that supports patients by providing personalized information, identifying strategies to address

FIGURE 2. NCCN Distress Therometer

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.



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
☐	☐	Child care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school
☐	☐	Treatment decisions
		Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children
☐	☐	Family health issues
		Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities
☐	☐	**Spiritual/religious concerns**

YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry/itchy
☐	☐	Sleep
☐	☐	Substance use
☐	☐	Tingling in hands/feet

Other Problems: ____

____

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psychosocial needs, providing emotional support, helping patients manage their illness and health, linking patients and families to 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 in reducing barriers.

TABLE. 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. “Let’s start with what’s been the biggest concern for you.’’ 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 emotional information that you are receiving from the patient, as well as the cognitive information, while moving the conversation forward one step at a time using open-ended questions 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.

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 also with their families and caregivers. As patients move along the cancer care continuum, navigators must often have difficult conversations with them about the 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 the **Table.**[10] 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.[2,11] The Ask-Tell-Ask approach also builds 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 one to assess the patient’s 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 they 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 medical decisions related to their care and health. It is a process where clinicians and patients work together to decide on 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 in screening or treatment decisions where no one option has a clear advantage, and when the possible benefits and harms of each option affect patients differently.[12] Shared decision-making benefits both patients and providers because 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 that is 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 following shared decision-making. Both groups report high satisfaction overall.[12] 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 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. Shared decision-making resources are found at Mayo Clinic's Knowledge and Evaluation Research Unit (https://carethatfits.org).

The supportive role of navigation in addressing potential concerns that extend beyond coordination of care and side effect management should help to alleviate issues related to distress as they arise. Navigators may strengthen the 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 (a hypothetical patient) is a 44-year-old divorced father with sole custody of 2 teenaged children. He is a self-employed landscaper. 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 because a neoplastic mass of the rectum, which narrowed the lumen and precluded the scope from advancing, was found. An immediate oncology consultation was arranged. Upon meeting with the medical oncologist, Stan was sent for a PET scan that showed intensive uptake in the rectum spanning 12 cm and uptake within a perirectal lymph node.

Based on the PET scan results, Stan and his oncologist discussed the recommended treatment of neoadjuvant chemoradiation therapy with continuous infusions of 5-fluorouracil for 6 weeks, followed by surgical resection, and then adjuvant chemotherapy. A nurse navigator educated Stan about chemotherapy, radiation therapy, and the role of the Distress Thermometer. Stan was encouraged to complete it and mark relevant problem areas. He scored an 8 on a scale of 0 to 10. In the areas regarding emotional and physical problems, Stan indicated that he had 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.

NOTES FOR NAVIGATORS

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.

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 was concerned about his ability to pay the cancer treatment bills. The oncology social 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 regarding treatment decisions and feelings of "sadness," "fear," and "worry." As they discussed with the oncology social worker and the nurse navigator, Stan expressed concern about the disease, its treatment, and being unable to care for his family, which would contribute to the loss of a "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.

NOTES FOR NAVIGATORS

Use of the distress assessment tool can effectively guide the nurse navigator in providing high-quality, holistic, and patient-centered care.

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 used a multidisciplinary approach to address Stan's specific needs.

Use of the distress assessment tool can effectively guide the nurse navigator in providing high-quality, holistic, and patient-centered care.

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IX. HEALTH LITERACY

Definition

According to the World Health Organization (WHO), health literacy is an individual's ability to obtain, communicate, process, and understand basic health information and services, make judgments and relevant decisions regarding their own health, and then act on them in their daily lives.[1] Each of these components of health literacy is needed to effectively manage one's health and navigate the healthcare system. This includes knowing how to describe symptoms, where to find help for health issues, how to understand medical information, and how to safely manage medication. Health literacy is one of the strongest psychosocial determinants of health outcomes, and it explains a range of health inequalities based on age, ethnicity, and socioeconomic position.[2] Societal factors associated with inadequate health literacy include lower educational accomplishment, poverty, minority status, race or ethnicity, and older age.

Barriers to Health Literacy

Poor health literacy is not a new problem and has been highlighted in the past. Research shows that about 80 million adults in the United States have limited health literacy.[3] The National Assessment of Adult Literacy survey found that the problem more profoundly affects those 65 or older, with a higher percentage considered having below basic or basic health literacy.[3] For older adults, navigating complex healthcare information is even more challenging, especially for those suffering from cognitive decline or sensory problems, such as vision or hearing loss that hamper communication.

NOTES FOR NAVIGATORS

Language barriers have a negative impact on the quality of healthcare, patient safety, health outcomes, and the satisfaction of medical professionals and patients.

Health literacy barriers can be related to the individual/patient, healthcare provider, and the healthcare system. Based on information from Koh et al, individual/patient-related health literacy barriers include physical and emotional state, previous medical experience, fear of questioning, cultural or spiritual practices, and family influence; healthcare provider-related health literacy barriers include overestimation of patient's health literacy, use of medical jargon, time constraints (lack of quality interactions), and lack of cultural competence; and healthcare system-related health literacy barriers include noisy atmosphere, logistics of multiple appointments, poor signage, and understaffing.[4]

Language and communication are key factors of health literacy. For individuals with limited English proficiency or a preferred language different from their healthcare provider, language barriers can make the delivery of quality healthcare challenging due to miscommunication of information and lack of language/translator access. Language barriers have a negative impact on the quality of healthcare, patient safety, health outcomes, and the satisfaction of medical professionals and patients.[5]

For the hard of hearing and deaf American Sign Language (ASL) users, barriers in communication can reduce their access to healthcare messages and healthcare communication thereby placing them at high risk of inadequate health literacy.[6] Barriers to communication for the hearing impaired and ASL users are associated with reduced access to essential healthcare services, health information, and poorer health outcomes. It is important to remember that deaf individuals communicate through visual language and learn visually. So, visual-based information sources should be used to communicate information and address health literacy gaps.

Impact of Low Health Literacy—Reflection of Gaps During the COVID-19 Pandemic

Unfortunately, inadequate communication and health literacy may lead to poor outcomes such as increased medication errors, increased hospital readmissions, and increased use of emergency services resulting in increased healthcare costs. Inadequate communication and health literacy can contribute to decreased disease prevention, screening, medication adherence, and pain management resulting in poor health management.[7] Improving health literacy is an effective strategy in health promotion, disease prevention, and control.[8]

The COVID-19 pandemic exposed weaknesses of healthcare services in several countries including the United States. Deficiencies such as overcrowding of hospitals and lack of supplies and professionals to combat the disease contributed to chaos as agencies tried to establish rapid intervention measures and disseminate information regarding transmission and prevention guidelines. The uniqueness of the virus and the knowledge uncertainty contributed to unclear messaging. Despite technological advances and information dissemination, it exposed gaps in the health literacy levels of the world's population as the exponential increase in the number of confirmed cases and low rates of social isolation evidenced people's difficulty in understanding basic prevention guidelines.[8] A study in Australia revealed that people with inadequate health literacy had poorer understanding of COVID-19 symptoms, were less able to identify behaviors that prevent infection, and experienced more difficulty finding information and understanding government messaging about COVID-19 than people with adequate health literacy. People with inadequate health literacy were less likely to rate social distancing as important, reported more difficulty with remembering and accessing medicines, and were also more likely to endorse misinformed beliefs about COVID-19 and vaccines than those with adequate health literacy.[2] For hard of hearing and deaf individuals, barriers to communication were amplified with mandates such as physical distancing and the use of masks, which although necessary to prevent respiratory transmission of SARS-Cov-2, obscured access to facial features used in lipreading and sign language.[9]

Reflecting on the COVID-19 pandemic, improving the world's basic health literacy may help with how people behave and acquire new information. People's understanding of infection transmission can reduce disease transmission and help people to understand the reasoning behind recommendations, which allows for better compliance. Improved health literacy would also allow people to evaluate the information they receive better and avoid spreading misinformation.[10]

Role of Navigators in Health Literacy and Interventions

Healthcare providers, including oncology navigators, are important providers of health information to patients and families. They can improve the health literacy of patients by how they organize, present, and communicate information. It is imperative for all healthcare providers to be aware of the range of effective strategies they can implement to improve the health literacy of patients through effective interpersonal communication, health materials in written and visual formats, and health literate environments that improve health outcomes, respect the needs of patients, and provide safe care.

Universal Precautions

Research has identified that healthcare providers including nurses often overestimate an individual's health literacy level.[11] Often patients and their families are reluctant to admit that they don't understand and feel compelled to follow the instructions/recommendations as they understand them, rather than seek clarity. To minimize misunderstandings and improve clarity of communication, it is strongly recommended that all healthcare providers adopt the "Universal Precaution" approach to health literacy and assume that all patients may have difficulty understanding information or navigating the complex healthcare environment. They should create an environment where individuals of all literacy levels can thrive.[11]

Interventions designed to address health literacy focus on areas of verbal communication, written communication, and patient engagement. Some basic health literacy strategies for verbal and written communication include[11]:

- Use plain language to communicate health information, instructions, and choices by limiting medical jargon
- Speak slowly in short sentences that are clear, concise, and well-organized
- Provide "need to know "rather than "nice to know" information and provide information in 3 to 5 small segments in each section ("chunking")
- Repeat information at every visit
- Use essential information first and by itself
- Use an active voice, announce topics, make visits interactive, and call the patient by name
- Use visual aids, illustrations, and infographics to present numerical or statistical information
- Use visual information sources for predominantly visual learners and the hearing impaired
- Use professional healthcare translators for individuals with low English proficiency or those with a preferred language other than English

Ask Me 3

Effective interpersonal communication between healthcare providers and patients is fundamental for engaging patients, improving their health literacy, and providing them with safe and high-quality care. Ask Me 3 is a validated tool developed by health literacy experts at the Institute for Healthcare Improvement (IHI) that encourages patients to ask 3 simple questions each time they talk to a healthcare provider. The questions are designed to improve patient–provider communication and promote shared decision-making.[12]

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Using the Ask Me 3 tool, oncology navigators proactively answer patient's questions and provide them with verbal and written information that focuses on what they need to know versus what is nice to know. To ensure that patients have all their questions answered, welcome them to ask questions throughout the visit rather than leaving them until the end of the visit. For effective communication, it is important for healthcare providers to use open-ended questions such as "What are your questions?" or "What questions do you still have?" to help encourage questions rather than "Do you have any questions?", which can lead to a close-ended response.

NOTES FOR NAVIGATORS

Effective interpersonal communication between healthcare providers and patients is fundamental for engaging patients, improving their health literacy, and providing them with safe and high-quality care.

Teach-Back

Regardless of a patient's health literacy level, oncology navigators should ensure that patients understand the information they have been given. The teach-back method is a way of checking understanding by respectfully asking patients to state in their own words what they need to know or do about their health. It confirms if the navigator has clearly explained things in a manner the patient understands and provides an opportunity to clarify any misunderstandings if needed. The teach-back method helps to close the gap in communication between the healthcare provider and patient while enhancing the patient's knowledge and health literacy.[13]

Conclusion

The COVID-19 pandemic has highlighted the importance of health literacy. Better health literacy potentially improves community trust, alleviates health disparities, improves immediate pandemic response and health outcomes.[10] To enhance patient involvement in their care, to provide safe care, and to improve health outcomes, it is imperative for healthcare providers and oncology navigators to understand the concept of health literacy, to respect the health literacy needs of all patients, and to implement evidenced-based strategies that improve the health literacy.

Resources

Ask Me 3 (www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx)

Plain Language Planner (www.plainlanguage.gov/resources/checklists)

ACCC Health Literacy & Clear Communication eCourse delivers a deeper understanding of health literacy effective practices and simple methods to improve patient-provider communications. (www.accc-cancer.org/projects/health-literacy/clear-communications-ecourse)

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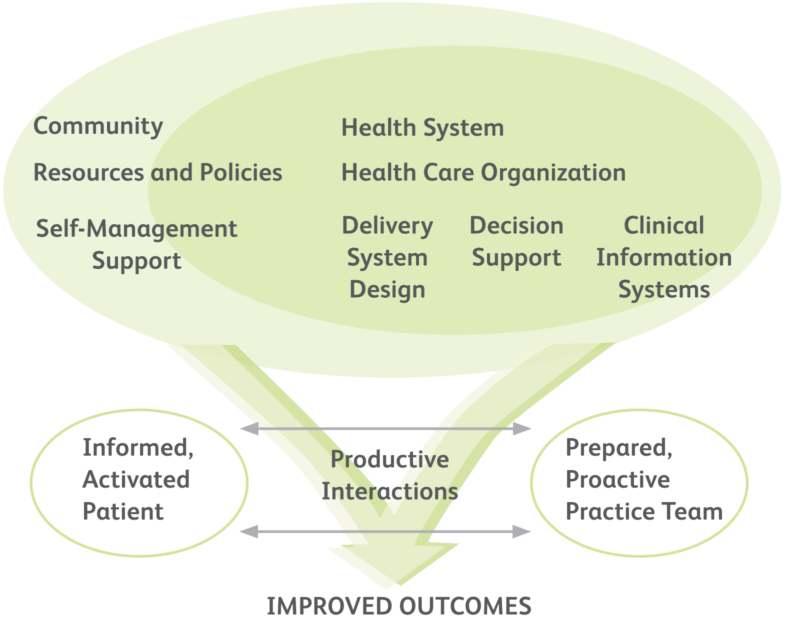
X. THE CHRONIC CARE MODEL AND CANCER CARE CONTINUUM

Navigation and the coordination of care are integral components of an analog known as the Chronic Care Model (CCM), which summarizes the basic elements for improving care in health systems at the community, organization, practice, and patient levels.[1] These elements include 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; support of evidence-based guidelines to coordinate care and services across the delivery system; and clinical information systems to collect data, outcome metrics, and benchmarks. Together, these elements create productive interactions between well-informed, activated patients and a prepared, proactive practice team that helps with care coordination, which results in improved outcomes (**Figure 1**).[2] Navigation, which is bidimensional in nature, supports the Chronic Care Model along the continuum of care. Because it is patient-centered (advocate giving education and psychosocial support) and health system (member of the multidisciplinary team) oriented, it can deliver timely and seamless care. Considering patient needs alongside system characteristics promotes continuity of care.[3] For more than 2 decades now, CCM has remained relevant because of adding artificial intelligence and telemedicine services to support decisions, using wearable devices to plan patient care, embedding electronic health records in the clinical information system, and focusing on value-based care.

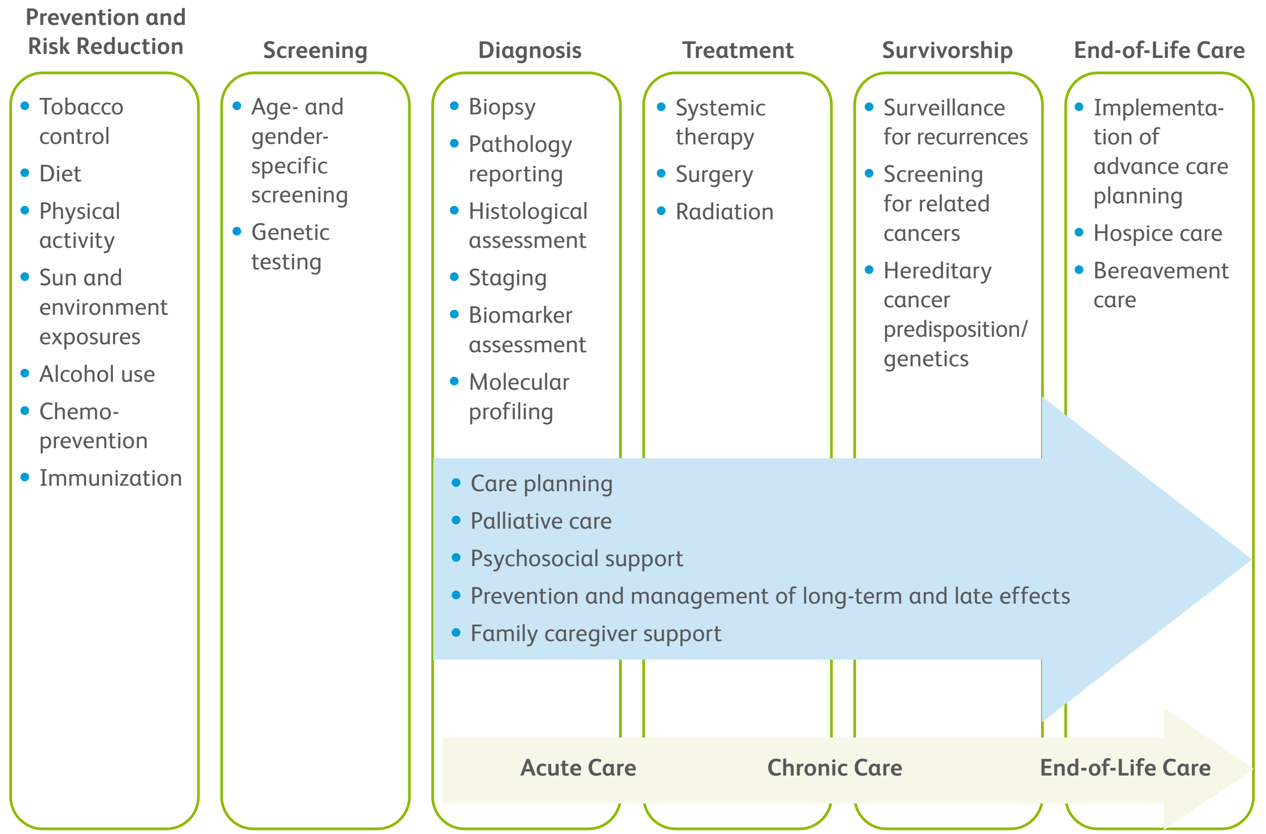
Depending on their work setting and role, navigators who work with underserved groups of patients throughout the cancer care continuum perform several key tasks to ensure that relevant care and services are understandable, available, accessible, affordable, appropriate, and accountable. These tasks typically require that navigators pass through several phases along the continuum, including community outreach and education on the merits of early detection; screening; proper diagnosis/staging; securing timely treatment; survivorship; and end-of-life (**Figure 2**).[4] Sometimes a navigator will perform similar overlapping tasks (eg, offering education) in several or all phases of the continuum.[5] Navigators may work in outreach/screening, an entry point into the care continuum, and oversee nonclinical staff to increase cancer screening rates.[6,7] They may also interact with patients at diagnosis, navigate them through the treatment phase, and then transition them into survivorship or end-of-life care.[8-11]

FIGURE 1. The Chronic Care Model



Source: Improving Chronic Illness Care. The chronic care model. www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2 Accessed January 28, 2018. Reprinted with permission.

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



The blue arrow identifies components of high-quality cancer care that should span the cancer care continuum from diagnosis through end-of-life care. The green arrow identifies 3 overlapping phases of cancer care, which are a way of conceptualizing the period of the cancer care continuum that is the focus of this report.

Source: Johnston D, Strusowski T, Bellomo C, Burhansstipanov L. Navigation across the continuum of care. In: Shockney LD (ed). *Team-Based Oncology Care: The Pivotal Role of Oncology Navigation*. Chapter 5. Cham, Switzerland: Springer International; 2018:85-110. Adapted from material originally developed by the National Cancer Institute. Reprinted with permission.

CCM elements are compatible with patient navigation during palliative care in oncology. The National Comprehensive Cancer Network (NCCN) states that the goal of palliative care is “to anticipate, prevent, and reduce suffering; promote adaptive coping; and support the best possible quality of life (QoL) for patients/families/caregivers, regardless of the stage of the disease or the need for other therapies…applying palliative care practices in a way that includes not only the patient but also families and caregivers.”[12] The navigator is key in educating the community on the difference between palliative care and hospice care. They promote palliative care for patients by seeking resources to address physical symptoms such as pain, shortness of breath or impaired mobility, psychosocial needs for adaptive coping, and mental health as well as any other barrier that does not protect the patients’ quality of life and autonomy. Palliative care is promoted in health organizations to facilitate care coordination and self-management support as patients/families and caregivers make the best educated decisions on care goals.

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 so they can make informed decisions; offer psychosocial support and access to resources; use their cultural awareness to advocate for patients’ unique needs when using 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.[13,14]

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XI. COMMUNITY OUTREACH AND PREVENTION

Community Outreach and Prevention

For many patient populations in various settings (eg, rural, community, academic), navigators are essential for community outreach and prevention, which are on the cancer care continuum (**Table 1**).[1]

The COVID-19 pandemic stalled many community outreach and prevention efforts,[2] but they are slowly returning.

Outreach is the process of contacting, engaging with, and helping people to learn about and use resources to improve their health and well-being. Outreach may be conducted with individuals, groups, organizations, and at the community level.[3] Outreach efforts can be conducted using media and printed materials that are appropriate for the patients based on their culture and education at booths during community 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 collaborate with community partners and educate community members on the importance of preventing or detecting cancer early to improve survival.[1,3]

Navigation programs involved in community outreach must be tailored to meet the needs of 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.[4]

Cancer prevention may target people who are healthy and at normal risk of developing cancer; extend to populations at intermediate risk resulting from environmental and lifestyle factors, genetic predisposition, or precancerous lesions; as well as include previous cancer patients at risk of developing secondary cancers.[4] Education on cancer prevention should address healthy behaviors such as diet, exercise, sun exposure, and smoking cessation, as well as follow cancer screening and vaccination guidelines to reduce cancer risk. 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.[4] Navigators can partner with community resources such as local hospitals and clinics, community health departments, local health fairs and screening clinics, or local church and cultural groups to assess and educate the population on the importance of healthy lifestyles, cancer prevention, screening, and early detection.

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.

Screening

Early detection of cancer is an important phase of the cancer care continuum. It greatly increases the chances of successful treatment and improves clinical outcomes.[5] Enabling care to be provided at the earliest stage possible is an important public health strategy in all settings.[5] Early diagnosis is especially significant for cancers of the breast, cervix, colon and rectum, skin, and lungs.

The 2 major components of early detection are early diagnosis (educating people to recognize possible warning signs of cancer) and screening.[5] Cancer screening programs may be offered in a variety of settings, such as community outreach health fairs, cancer awareness events, or other public events. Screening services may be provided at local health departments, local hospitals, primary care physician offices, or even in mobile vans that travel to rural communities.[4]

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 collaborate with community partners to ensure that screened participants with abnormal findings have a medical home.[4] Navigation has been shown to decrease the time to diagnosis and increase the number of individuals who complete diagnostic procedures.[4,6] The impact of navigators in facilitating timely care from abnormal findings to workup and diagnosis can be measured using the Academy of Oncology Nurse & Patient Navigators Standardized Evidence-Based Oncology Navigation Metrics (see **Appendix**).

NOTES FOR NAVIGATORS

Navigators should discuss current cancer screening guidelines with individuals and recommend the most appropriate test that increases awareness and promotes long-term health.

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 most appropriate test that increases awareness and promotes long-term health.[4] 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 them to genetic experts for testing that can lead to changes in medical management, such as increased screening or risk reduction.[1,4]

During the screening phase of the care continuum, navigators continue to assess, address, and remove barriers to cancer screening, such as transportation, medical coverage, availability, cultural reasons, lack of understanding/medical knowledge, and fear. Navigators should strive to find proactive solutions for each barrier. 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 work early morning or late hours, which would not interfere with an individual's work schedule. Navigators should educate misinformed individuals or those unaware of cancer screening tests. They can proactively address cultural barriers, anxiety, and fear by educating and communicating. Every effort should be made to educate, reduce the barriers to screening, and assist the patient to be seen by the right clinician.[4]

Diagnosis

Cancer is diagnosed through a combination of tests, procedures, and consultations with multiple healthcare providers. This can be very overwhelming to patients and their families. A 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 who ensures that every patient receives comprehensive, timely, and quality healthcare services. During the diagnostic phase, navigators can assess a patient's coping skills, provide emotional support, and refer them to psychosocial services if necessary. When a navigator assesses and addresses any distress and barriers after a cancer diagnosis, it allows patients to focus on making informed decisions and actively participating in their care.[4]

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 regarding their cancer care and life in general by asking[4]:

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

Navigators should have straightforward conversations with patients 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 conversations, it is also appropriate to provide patients with information about advance directives and listen to their questions and concerns. Patient life goals and advance directives should be documented in the patient's medical record to ensure that the oncology team is aware of them and they are incorporated into the treatment decision-making process.[4]

NOTES FOR NAVIGATORS

Armed with an understanding of a patient's goals, health literacy, and illness, the navigator can provide patient-centered education on the disease process, the staging workup, treatment options, and clinical trials.

Armed with an understanding of a patient's goals, health literacy, and illness, the navigator can provide patient-centered education on the disease process, the staging workup, treatment options, and clinical trials. As they educate, a key role of the navigator is to validate the patient's understanding regarding their diagnosis and treatment options, including surveillance, surgery, radiation therapy, chemotherapy, and precision medicine.[4] Precision medicine (also known as personalized medicine) uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat cancer.[7] Biomarkers, molecular testing, and targeted therapies deliver a personalized approach to cancer therapy.[8] To be an effective member of the care team, the navigator must have up-to-date knowledge on issues that affect patient education and care. Navigators must be able to understand and explain to patients why additional testing is important and why not all types or stages of cancers are the same molecularly.

As patient advocates who are members of the multidisciplinary team, navigators are important in coordinating multidisciplinary clinics and/or tumor board conferences.[9] As participating members of the tumor board, navigators play a role in expediting patient care based on their knowledge of the National Comprehensive Cancer Network (NCCN) guidelines and evidence-based practice. They also advocate for the patient based on their needs, beliefs, values, and preferences. After the tumor board conference, navigators educate patients on the recommended treatment options and communicate to the treatment staff the information reviewed.[9] 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, dieticians, social workers, and financial counselors. They are pivotal in facilitating communication and collaboration between the multidisciplinary healthcare team. They develop collegial and trusting relationships with various oncology team members, based on the shared goals of providing high-quality cancer care and exceptional patient experiences through coordinated care. The multidisciplinary team approach enhances safe, efficient, effective, timely, and quality patient-centered care.[9]

NOTES FOR NAVIGATORS

Navigators must know about the assessment and management of common treatment-related side effects to effectively coordinate care throughout the treatment phase.

Treatment

After a cancer diagnosis, phases in the continuum of care for patients include 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 needs changes. It includes treatment, survivorship care, palliative care, and hospice care.[10] Poorly coordinated care during transition can lead to a poor quality of life, increased emergency department use and hospital readmission rates, duplicated tests, and medication errors, which all lead to increased healthcare costs and suboptimal patient outcomes.[11] Navigators must know how to prepare patients for transition of care based on their preferences and goals of care.

As treatment begins, navigators should educate patients and their caregivers on the type and role of the treatment, number of treatments to be received, when they will be administered, and the dosing schedule. In addition, navigators should discuss with patients and their caregivers the potential side effects of treatment, how to recognize and report them to the healthcare team/clinic, and helpful strategies 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 body fluids, safe handling of oral chemotherapy/targeted therapy, and the importance of nutrition, hydration, and activity during treatment.[4]

Navigators must know about the assessment and management of common treatment-related side 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 these can have a profound impact on a patient's quality of life and well-being. Navigators can assist patients with cancer by identifying barriers; educating patients and families on coping skills, self-care skills, and symptom management; and coordinating referral to specialists in the multidisciplinary team, palliative care, and community resources that help patients have an improved functional status.[4]

Clinical trials investigating new therapeutics and treatment paradigms are critical in 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 patients' enrollment, educate and assess patients' understanding of the clinical trial process, and address any barriers to patient participation.[12] 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 be aware of the strategies for assisting patients to understand and participate in clinical trials. When patients are properly educated on clinical trials, which can offer additional therapeutic options, they can participate effectively in the decision-making process.[4] When determining treatment options, it is important to always consider the patient's quality of life. As patient advocates, navigators can refer patients to palliative care for symptom management and cancer rehabilitation, which supplements their care. Palliative care is specialized medical care for individuals with serious illnesses that is focused on providing relief from symptoms, pain, and the stress of illness. Its goal is to improve quality of life for patients and their families. Integrating palliative care into standard oncology care allows pain and symptom management to be prioritized, emphasizes communication with patients and families, and establishes coordination of care.[4,13]

NOTES FOR NAVIGATORS

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 be aware of the strategies for assisting patients to understand and participate in clinical trials.

Ideally, the navigator as early as at the time of diagnosis and across the care continuum can promote ways to maintain the patient's function and activity level, thus diminishing the impact 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 such as exercise therapy, pain management, physical and occupational therapy, and lymphedema and speech/swallowing therapy. Navigation through a complex oncology care continuum, including cancer rehabilitation, is of utmost importance for the best possible quantity and quality of life outcomes.[4] Navigator competencies during the diagnosis and treatment of patients along the continuum of cancer care and related care transitions are shown in **Table 2.**[14]

Survivorship

The American Cancer Society—in collaboration with the National Cancer Institute— estimated there were more than 18 million cancer survivors in the United States as of January 2022.[15] 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 their life.[4]

After active treatment, whether surgery, chemotherapy, or radiation therapy, is completed, patients may feel abandoned by the oncology team as they transition to survivorship. Cancer survivors have physical, social, psychological, and spiritual needs. They may experience a reduced health-related quality of life attributed to physical impairment and psychological issues. Many experience persistent physical symptoms and late or long-term effects of treatment, including fatigue, sleep-wake disturbance, pain, peripheral neuropathy, difficulties with memory and concentration, and decreased physical function.[4] They may also experience

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.

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. Also, psychological issues such as anxiety and fear of recurrence may occur.[4]

In the report by the Institute of Medicine (IOM), From Cancer Patient to Cancer Survivor: Lost in Transition, the importance of addressing the ongoing physical and psychological challenges of cancer survivors was emphasized to encourage a 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[4,16]:

1. Prevention of new and recurrent cancers and other effects
2. Surveillance for spread, recurrence, or second cancers, and assessment of 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 are essential in ensuring that quality survivorship care begins at diagnosis and continues throughout the patients’ lives. To address the needs of cancer survivors and provide patient-centered survivorship care, it is imperative for navigators to understand the issues that cancer survivors face. In the article Seasons of Survival: Reflections of a Physician with Cancer, Dr Fitzhugh Mullan described a model for cancer survivorship in which survivorship begins at diagnosis. It requires early identification and intervention to positively impact quality of life and patient outcomes.[17] He identified the seasons of survival as comprising of 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

NOTES FOR NAVIGATORS

Navigators, through their communication and open relationships with cancer patients and survivors, are instrumental in continually assessing quality of life.

palliative care), and a phase of permanent survivorship (long-term survival or presumed cured).[17]

In 2008, Miller and colleagues expanded on Mullan's paradigm.[18] 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 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. They 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 systems.[18]

Miller and colleagues also divided patients living within the extended survivorship season into 3 groups: (1) those in remission who are not receiving any ongoing maintenance therapy, (2) those who appear to be cancer-free due to ongoing treatment with targeted therapy, and (3) those who have been treated and are currently living with cancer as a metastatic or chronic disease.[18] In the season of permanent survival, 4 subgroups exist: (1) survivors who are "cancer-free but not free of cancer," (2) survivors whose cancer is in remission but continue to have significant "fall out" from cancer and its treatment, including psychosocial, medical, financial, or legal sequelae, (3) survivors who go on to develop additional cancers that may be unrelated to the first cancer or its treatment, or are more likely due to genetic or environmental factors, and (4) survivors who later develop cancers that are secondary to the initial treatment.[18]

Throughout the seasons of survival—whether treatment is delivered for cure or ¬control—it is imperative for healthcare providers and navigators to continually offer 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 managing its lasting physical and psychosocial effects; and coordination of cancer survivor care.[4]

Maintaining the quality of life of a cancer survivor is a key component of survivorship care. Physical well-being is 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 a patient's roles and relationships. Spiritual well-being helps them maintain hope and derive meaning from their experiences. Navigators, through their communication and open relationships with cancer patients and survivors, are instrumental in continually assessing quality of life. They educate, assess, and refer survivors to the right resources that will improve their function and quality of life.[4]

Two important components of survivorship care that navigators play a key role in are referral to rehabilitation (to address late and long-term side effects) and use of survivorship care plans (SCPs). It is key to prevent deconditioning and maintain function in activities of daily living as much as possible during acute cancer treatments so that less reconditioning is required after treatment. Navigation through a complex oncology care continuum, including cancer rehabilitation, is of utmost importance for the best possible quantity and quality of life outcomes.[4]

Planning for survivorship care using end-of-treatment summaries and SCPs has been recognized by the IOM as an important part of the continuum of cancer care.[16] The treatment summary and follow-up SCP provide guidance for primary care physicians, the oncology team, and other healthcare providers on how to coordinate continuity of care for the cancer survivor. The essential items in an SCP the IOM recommends include a follow-up care and management schedule, the providers responsible for follow-up, a list of symptoms of recurrence, and tests surveillance warrants. In congruence with the IOM's 4 goals of survivorship care (prevention, surveillance, intervention, and coordination), SCPs should provide[4,16]:

- 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 the 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 SCP is to help the survivor potentially live a higher quality and longer life. The care plan serves as a guide for the survivor and the primary care provider by highlighting essential screening tests and recommended lifestyle changes; identifying potential late and long-term effects of cancer and treatment; and assisting in identifying and accessing needed resources. With the growing shortage of oncology specialists in the United States, cancer survivors are no longer 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 through the transition process by educating patients on what survivorship care entails and helping to develop and implement the SCP.[4]

Online resources from the American Society of Clinical Oncology (ASCO) and Journey Forward can assist navigators and oncology programs to develop treatment summaries/SCPs.[19,20] 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.[19] A second form offered by ASCO, the Survivorship Care Plan, provides information about the treatment given, the need for follow-up care, the potential long-term/late effects of treatment, and tips for survivors to improve their health.[19] ASCO's Treatment and Survivorship Care Plan templates can be incorporated by navigators and oncology programs into their workflow and/or into their electronic health records system without seeking permission from ASCO.[19]

The Cancer Care Plan Builder (Survivorship Care Plan Builder, Journey Forward) is a free resource for navigators and oncology professionals to assist in developing personalized treatment plans, treatment summaries, and/or SCPs for patients.[20] Journey Forward's Cancer Care Plan Builder supports all IOM recommendations on survivorship care.[20]

The American College of Surgeons Commission on Cancer (CoC) 2022 update made developing and implementing a survivorship program (Standard 4.8) a requirement for accreditation. It requires a survivorship coordinator who will report to the cancer committee. The survivorship program team will document a minimum of 3 services that are offered each year to better support patients, with a focus on enhancing existing or developing new services. The CoC recommends that patients receive a SCP, but it is no longer required for accreditation.[21]

Competencies of the navigator in survivorship are shown in **Table 3.**[22]

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.

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. Care services are transitioned to hospice. Navigators are integral in helping patients who are transitioning to hospice care, a specialized 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 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 care between the patient and the treating oncologists.[4,22] 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 sooner in at-home hospice care actually live longer and have a better quality of life than those who continue treatment until they are too ill to tolerate it anymore.[4,22] Some insurance companies have "carve-outs," which allow patients in 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. As the patient's advocate, navigators can help support the patient and family by providing resources for planning legal, financial, and emotional end-of-life matters, and making sure that the patient's voice is heard and their quality of life and death goals are supported.[4] 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, which is comprised of the following elements[23]:

- 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 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 they will be spoken of fondly after they are 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 spiritual connection to a higher power (which for some, comes closer to the actual end of life).

Navigators provide vital 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, discourage enabling behaviors that result in patients continuing to receive active treatment when they do not want to, and promote closure for the family/caregiver. The navigator may be a source of consistency and support during this time.[23]

Competencies of the navigator at end-of-life are shown in **Table 4.**[22]

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.

Hypothetical 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.[24] 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.[24] Based on these data, the US Preventative Services Task Forces[25] and the American College of Radiology[26] 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 cancer screening guidelines, which recommend an annual screening with low-dose CT for current (>20 pack-year smoker) and former (<15 years since quitting) smokers aged 50-80 who are apparently healthy. Betty wished to pursue the low-dose CT screening. The nurse navigator assisted Betty to schedule and complete the low-dose helical CT screening.

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Betty met with Natalie to discuss next steps and address barriers to care. Natalie educated Betty on the recommended surgical procedure and postoperative care.

Betty's CT scan results indicated a 5-mm lung nodule. Based on the institution and the Lung-RADS™ guidelines for recommended follow-up,[25,26] Betty should continue low-dose CT screening every 12 months if there is no change in the nodule.[24,27] When lung nodules do not require immediate diagnostics, the surveillance program of the institution is implemented. The abnormality was communicated to Betty'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 non–small cell adenocarcinoma of the lung. 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. She 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 applications, etc). Natalie also referred Betty to national financial assistance resources (CancerCare® and Chronic Disease Fund®) and 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 mostly continued to use supplemental oxygen 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.[28] The sequential rather than concurrent treatment allowed Betty more time 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 and 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 chemotherapy, Natalie continued to assess and assist Betty with symptom management and barriers.

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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.

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 regarding treatment decisions and feeling "sadness," "fear," and "worry." In her discussion with the oncology social worker and the nurse navigator, Betty expressed her concern that the disease and treatment would affect her ability to care for herself and she would lose a "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.

After radiation therapy, Natalie met with Betty for her end-of-treatment 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 recommended 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 had trouble 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 leave a legacy for her daughter and granddaughters by writing cards and recording videos and audiotapes of her 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 the cancer staff and her updated on Betty's status, and report 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 8.1

As the need for and value of navigation programs for 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) require that a more formalized process be in place to support patients with cancer. The CoC standards aim to improve 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.

The CoC's newly revised Standard 8.1–Addressing Barriers to Care, which became effective in 2020, reads as follows "Each calendar year the cancer committee identifies at least one patient-, system-, or provider-based barrier to accessing health and/or psychosocial care that its patients with cancer are facing and develops and implements a plan to address the barrier."[1] Navigators have a unique opportunity to assist in meeting this standard. One strategy for healthcare systems that aim to meet this standard is to "design a patient navigation process that offers individualized assistance to patients, caregivers, and families to help them overcome a selected barrier."[2] "Patient navigation is designed to provide a patient-centered, sustainable service delivery intervention that removes barriers to cancer care throughout the care continuum, ensuring access to timely cancer detection, diagnosis, care, and integration into a healthcare system."[3]

Navigation can also promote health equity through addressing barriers to care especially in disparate populations. According to the Professional Oncology Navigation Task Force's Oncology Navigation Standards of Professional Practice Standard 4: Cultural and Linguistic Humility, all navigators must "demonstrate cultural humility, sensitivity, and responsiveness to diverse patient populations, including but not limited to those who are diverse in gender/gender identity, age, culture, race, ethnicity, religion, abilities, and sexual orientation."[4]

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 National Navigation Roundtable (Chapter IV), Association of Oncology Social Work, and Academy of Oncology Nurse & Patient Navigators (AONN+) domains of knowledge; responsibilities related to the CoC standards; and specific responsibilities related to the navigator's role within the multidisciplinary team as they traverse the continuum of care.

The Professional Oncology Navigation Task Force's Oncology Navigation Standards of Professional Practice should also be used as a guide and implemented in navigation programs. This document was created "to provide professional oncology clinical navigators and patient navigators with clear information regarding the standards of professional practice."[4]

Examples of job descriptions for navigation can be found at the University of Colorado Cancer Center's website (https://patientnavigatortraining.org/?s=patient+navigator+job+description) or the Association of Community Cancer Centers' website (www.accc-cancer.org/search-results?keywords=patient%20navigator%20job%20description).

For employees new to navigation or oncology programs, a strong orientation process is imperative for navigation programs to be implemented successfully and remain sustainable. 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.[5]

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.[5]

The Oncology Navigation Standards of Professional Practice Standard 7 states that all navigators should "assume personal responsibility for professional development to gain and maintain knowledge in the best interest of patients" and "engage in ongoing professional development to strive for improved competence within their scope of practice".[4]

As they develop and implement a navigator program, key stakeholders must agree on and ensure appropriate educational requirements, curricula for training, credentialing, and certification.[5]

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

NOTES FOR NAVIGATORS

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.

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. 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 their tasks, activities, and scope of work.[5] The following key stakeholders are essential to a successful program.[6]

- 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 tasks better allocated to either clinicians or administrators who are already in the care team. This leads clinical systems to develop in a way that navigators and clinicians are aware of and can coordinate their work. Although delineation of roles is necessary, it is also vital for the administration to be engaged with the team and to instill communication through meetings and huddles.[5] Multidisciplinary meetings (with navigators, social workers, nursing, outreach, and other team members), which educate on respective roles and referral processes and provide arenas for open communication and collaboration, help to build successful and sustainable navigation programs.[5]

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.

The strategy is congruent with Oncology Navigation Professional Practice Standard 5: Interdisciplinary and Interorganizational Collaboration, which states that all navigators should "ensure that the navigation role and responsibilities are clearly delineated and communicated to members of the healthcare team" and "communicate effectively with navigator colleagues, health professionals, and health related agencies to promote navigation services."[4]

Navigators should be able to communicate their role to the members of the health care 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 navigation—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 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**).[7]

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.[8] Additional patient entry points may include referrals from community agencies, survivors, or caregivers.

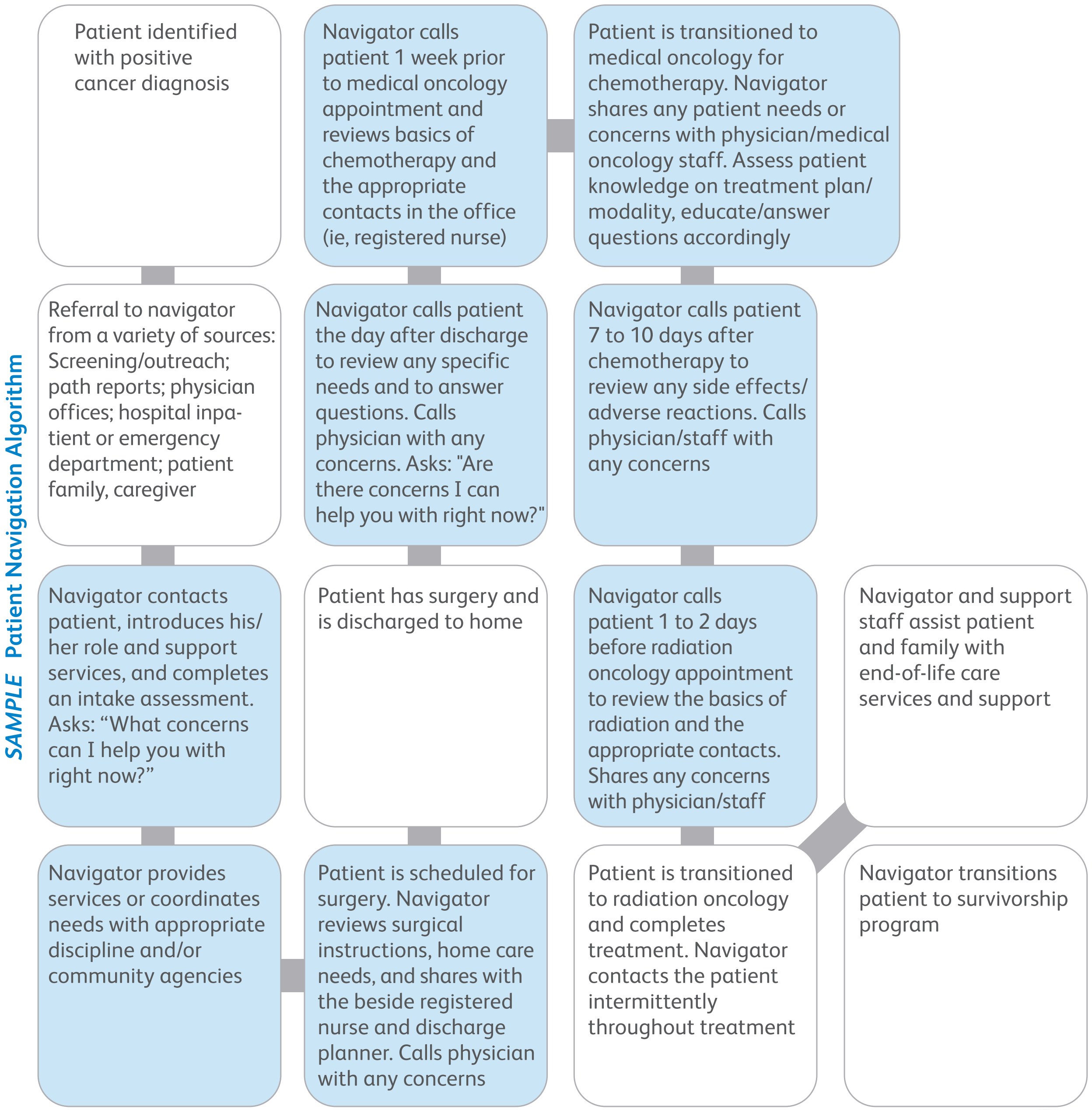
Navigation Processes: Intake Assessment

Upon referral of a patient to navigation services, it is essential for the navigator to assess whether the patient is ready for 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 assessment steps[9]:

- 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 them know you are listening, and to check your understanding of their shared information.
- 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 actively listening, navigators can assess the needs of the patient and family while developing a trusting relationship.
- Ask. 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 initiate the intake assessment process.

It is also important to "tailor the communication based on the educational, developmental, and health literacy level of the patient while also communicating "effectively with patients, families, and the public to build trusting relationships across a broad range of socioeconomic and cultural backgrounds."[4]

FIGURE 1. Example of Workflow Diagram



SAMPLE **Patient Navigation Algorithm**

Patient identified with positive cancer diagnosis

Referral to navigator from a variety of sources: Screening/outreach; path reports; physician offices; hospital inpatient or emergency department; patient family, caregiver

Navigator contacts patient, introduces his/her role and support services, and completes an intake assessment. Asks: “What concerns can I help you with right now?”

Navigator provides services or coordinates needs with appropriate discipline and/or community agencies

Patient is scheduled for surgery. Navigator reviews surgical instructions, home care needs, and shares with the beside registered nurse and discharge planner. Calls physician with any concerns

Patient has surgery and is discharged to home

Navigator calls patient the day after discharge to review any specific needs and to answer questions. Calls physician with any concerns. Asks: "Are there concerns I can help you with right now?"

Navigator calls patient 1 week prior to medical oncology appointment and reviews basics of chemotherapy and the appropriate contacts in the office (ie, registered nurse)

Patient is transitioned to medical oncology for chemotherapy. Navigator shares any patient needs or concerns with physician/medical oncology staff. Assess patient knowledge on treatment plan/modality, educate/answer questions accordingly

Navigator calls patient 7 to 10 days after chemotherapy to review any side effects/adverse reactions. Calls physician/staff with any concerns

Navigator calls patient 1 to 2 days before radiation oncology appointment to review the basics of radiation and the appropriate contacts. Shares any concerns with physician/staff

Patient is transitioned to radiation oncology and completes treatment. Navigator contacts the patient intermittently throughout treatment

Navigator and support staff assist patient and family with end-of-life care services and support

Navigator transitions patient to survivorship program

Source: Strusowski T. Value-Based Cancer Care: Creating Partnerships Between Oncology Nurse Navigators and Oncology/Hematology Physician Practices. Presented at: 24th Association of Cancer Executives Annual Meeting; January 28-30, 2018; Portland, OR.

CHARTIS oncology solutions

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 the patient up to successfully understand their cancer and treatment plan. Gathering essential information at the initial visit 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 cancers and aspects of the cancer care continuum, should include all the components outlined in **Table 1**.[9]

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 demonstrating cultural humility, sensitivity, and responsiveness to diverse patient populations"[4]
- 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.

An assessment tool is key to a consistent navigation foundation. It supports the primary navigator in educating the patient and family and it can be used as a reference for navigators who may be called on to cover for a colleague. 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.[9] (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 https://aonnonline.org/toolkits.

What is professional development and why is it important?

Like any profession, navigators of all disciplines should prioritize professional development to enhance and elevate their overall career growth.[10] Personal and professional growth is a continuous ever-evolving process and professional development in navigation, especially in oncology care, is no exception.

The Oncology Navigation Standards of Professional Practice Standard 7 on Professional Development states that all navigators should "assume personal responsibility for professional development to gain and maintain knowledge in the best interest of patients,... strive for improved competence within their scope of practice,...and incorporate the principles of professional development and lifelong learning to address [professional practice] gaps."[4]

Continuing Professional Development (CPD) is defined as "a self-directed, ongoing, systematic, and outcomes-focused approach to lifelong learning that is applied into practice. It involves the process of active participation in formal and informal learning activities that assist individuals in developing and maintaining continuing competence, enhancing their professional practice, and supporting achievement of their career goals."[11] "CPD can be defined as the system for maintaining, improving, and broadening knowledge and skill throughout one's professional life. CPD is focused squarely on promoting effective practice and is better positioned than other stages of learning to effect change because it occurs when professionals are most likely to be aware of their needs. It also integrates content and educational design for individual practitioners in the practice setting."[12]

Navigators have a unique role as they blend both care continuum knowledge with special communication skills and a business mindset that often propels them to a variety of settings in their professional life. The specialized skill set of navigators warrants an all-encompassing strategy that CPD offers. “Continuing professional development (CPD) involves not only educational activities to enhance medical competence in medical knowledge and skills, but also in management, team building, professionalism, interpersonal communication, technology, teaching, and accountability.”[13]

Benefits of Professional Development in the Navigation Profession

Some benefits of professional development include[10]:

- Expand knowledge base
- Boost confidence and credibility
- Increase earning potential and hireability
- Provide networking opportunities
- Keep professionals current on industry trends
- Open the door to future career changes

Developing the Future of Navigation (AONN+ Professional Development Opportunities)

As previously mentioned, a multitude of skill sets, knowledge, and education are required in navigation. Professional development can take place in many different capacities such as research, public speaking, publication, networking, continuing education, leadership roles, and enhancement of knowledge or a specific skill set among others. In addition to accessing these resources to grow, navigators should also prioritize self-care to thrive in their profession. AONN+, the largest specialty organization of oncology nurse and patient navigators, provides a multifaceted platform for navigation professionals to seek professional development and support in their careers, including:

AONN+ Navigation & Survivorship Conferences

“AONN+ Annual brings oncology’s most influential navigators, social workers, physicians, and administrators together to think boldly and enact change. Take action in your own institution after learning from and collaborating with like-minded professionals dedicated to accelerating the pace of change in navigation.” (https://aonnonline.org/conferences)

Podcasts/Blogs/Facebook Live

Podcasts — "Heart and Soul of Oncology Navigation provides a platform for navigators to discuss topics reflective of the Academy’s 8 Domains of Knowledge.” (https://aonnonline.org/podcasts)

Blogs — “Sharing the latest on all things AONN+ and oncology navigation. AONN+ invites all nurse and patient navigators, administrators, social workers, oncologists, and other members of the cancer care team to share their perspectives on the blog!” (https://aonnonline.org/blog)

Facebook Live — “Navigate Now: How Can We Help?” is a series dedicated to sharing resources and support with members of the cancer care community. (https://aonnonline.org/facebook-live)

Journal (Publishing Opportunities)

"The Journal of Oncology Navigation and Survivorship (JONS) promotes reliance on evidence-based practices in navigating patients with cancer and their caregivers through diagnosis, treatment, and survivorship. JONS also seeks to strengthen the role of nurse and patient navigators in cancer care by serving as a platform for these professionals to disseminate original research findings, exchange best practices, and find support for their growing community.” (www.jons-online.com/about-jons)

"CONQUER magazine features articles written by and for patients with cancer, survivors, nurse navigators, and other oncology team members.” (https://conquer-magazine.com/about)

Abstracts (Research)

"This is an opportunity to share your evidence-based navigation research studies, quality improvement projects, and best practices utilizing pre- and post-data elements to enhance your program with navigation and survivorship care colleagues." (https://aonnonline.org/abstracts)

National Committees

"Volunteering and participating on a committee as a member or co-chair offers a unique professional development opportunity to network, share best practices, collaborate with other colleagues, and work on meaningful projects that promote effective change." (https://aonnonline.org/committees/list)

Certification

See section XV and the criteria for patient or nurse navigation certification at the Academy of Oncology Nurse & Patient Navigators Foundation for Learning website (https://aonnffl.org).

Local Navigator Networks

"The Academy of Oncology Nurse & Patient Navigators (AONN+) is focused on developing a local and regional network of navigators in order to facilitate communication and education among peers and improve patient outcomes and survivorship. We invite you to either join an existing local navigator network (LNN) or start one in your area." (https://aonnonline.org/local-navigator-networks)

Mentorship

Mentorship is one way to exercise professional development for both the mentor and mentee. "Significant research has shown that mentorship not only improves job satisfaction but also improves productivity, facilitates personal growth, and can rekindle our passion while lessening the risk of compassion fatigue."[14]

"AONN+ has announced a new mentoring initiative, BOLD: Mentorship Academy "Building Oncology Leadership & Development" with the intent to elevate the profession of navigation by supporting and fostering a reciprocal and collaborative mentoring relationship between individuals who share mutual goals and shared accountability for the outcomes and success of the relationship." (https://aonnonline.org/bold)

Fostering an inclusive environment and mentoring relationship amongst navigation peers while also providing mentorship and professional development resources and tools will further grow and develop navigation as a profession. This program is aligned with the Professional Oncology Navigation Task Force Standard 9: Mentorship and Leadership, which states that all navigators should "participate in peer and colleague mentorship relationships to develop and support the navigation role" as well as "mentor and/or lead in the practice setting and in navigation professions."[4] Developing the future of navigation enhances the sustainability of the profession, which further reinforces the need for an intentional professional development strategy for all navigation professionals.

Professional Self-Care

The prevalence of compassion fatigue is a critical reality for oncology navigators. "Research has shown that oncology nurses have a high risk for burnout because of their intense emotional involvement with patients and families and their diminished sense of accomplishment when patients perish.[15] Compassion fatigue can have a negative influence on performance at work and negatively impact the personal lives of those suffering under its influence (**Table 2**).[16] Given that compassion fatigue can also be a significant factor in job turnover or dropping out of oncology altogether, health administrators cannot ignore it because it comes with a potential economic cost."[17]

AONN+ encourages navigators and oncology healthcare leaders to invest in professional self-care. AONN+ resources that enhance professional self-care include shared experiences from navigation colleagues in the form of blogs, inspirational podcasts, evidence-based practices, and educational events. Self-care resources can be found at AONN+.

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/september-2011/compassion-fatigue-when-caring-takes-its-toll. September 21, 2011. Accessed June 12, 2018.

Where to Find Professional Development Opportunities

Professional development opportunities are hiding in plain sight and available for the taking. Navigation professionals are encouraged to seek out opportunities to grow personally and professionally. Many organizations in the oncology care landscape provide these opportunities in many different forms and avenues such as committee involvement, conference attendance, research, public speaking, publication, and more. A navigator's direct manager and institution can provide another forum to grow and thrive within their current work setting.

Additional Professional Development Resources

Association of Community Cancer Centers (www.accc-cancer.org/home/learn)

Association of Oncology Social Work (https://aosw.org)

careeronestop (www.careeronestop.org/FindTraining/Types/professional-development.aspx)

Coursera (www.coursera.org)

edX (www.edx.org)

George Washington University Cancer Center (https://smhs.gwu.edu/gwci/survivorship/center-advancement-cancer-survivorship-navigation-and-policy-casnp/patient-navigator)

Institute for Healthcare Communication (https://healthcarecomm.org)

LinkedIn (www.linkedin.com/home)

Oncology Nursing Society (www.ons.org/develop-your-career/professional-development?ref=RO)

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XIII. NAVIGATION PROGRAM MONITORING AND OUTCOME MEASURES

Once established, a patient navigation program should be assessed annually to evaluate successes; identify unmet needs, 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 that need additional attention or require 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 provide a framework for setting goals and establishing benchmarks to evaluate and monitor programmatic growth and quality improvement.[1] The Commission on Cancer is currently updating their patient navigation standards, but the current 2020 version has specific standards for patient navigators to meet accreditation measures. For further information about the 2020 standards: https://web.archive.org/web/20201122160627/https://aonnonline.org/expert-commentary/aonn-blog/3229-an-update-on-the-commission-on-cancer-s-recent-accomplishments.

The overall evidence base for patient navigation is very strong and when implemented, navigation connects the medically underserved to need care and resources that help along the way. To guide common standards for implementing navigation, the Professional Oncology Navigation Task Force (PONT) recently released the Oncology Navigation Standards of Professional Practice that provide clinical oncology nurse navigators, social work navigators, and patient navigators with clear information regarding professional care best practices.[2]

NOTES FOR NAVIGATORS

Considering navigation and cost evaluation throughout the care continuum is needed to make the business case for patient navigation.

For established and new navigation programs, sustainability, which depends upon some contextual factors, must be considered. A variety of articles and publications examine the sustainability of oncology patient navigation programs by length of existence, funding, and payment models. Based on these publications, some critical guiding factors should be considered for sustainability. For example, a recent publication noted associations between both accreditation and work setting and measures of program sustainability. Accredited programs in larger, more resourced clinical institutions, particularly are likely to exhibit multiple measures of sustainability.[3] Another recent qualitative analysis noted that payer guidelines, accreditation requirements, community partnerships, and demonstrated need and demand for services drove sustainability. Inner factors such as alignment with organizational and leadership priorities, appropriate staff support and workload, and being able to show relative advantage were important to program success.[4] An overview of existing payment models that have been used to support patient navigation or similar services in the United States was released by the National Navigation Roundtable (NNRT) (https://navigationroundtable.org/) and can be considered while exploring sustainability strategies.[5] Economic evaluation is also a key consideration, particularly in the area of cancer screening patient navigation, where analyses demonstrate cost effectiveness.[6,7] Considering navigation and cost evaluation throughout the care continuum is needed to make the business case for patient navigation.

Different established sustainability models, which have many similar central tenets across frameworks, that public health intervention programs can consider exist. For guidance, the examples noted are from the University of Colorado Cancer Center and the NNRT who have adapted The Association of State and Territorial Health Officials (ASTHO) sustainability construct (**Table 1**).[8] Below are the primary recommendations from the ASTHO framework, incorporating patient navigation into the construct. To achieve these specific goals, a collective action approach with policy as a driving factor is imperative.

TABLE 1. The Association of State and Territorial Health Officials Sustainability Constructs

ASTHO Recommendation	Goal
Workforce development	Support standardized training and certification of patient navigators
Occupational associations	Create occupational networks to strengthen patient navigators' effectiveness in the workforce
Long-term financing	Support standard reimbursement for patient navigation services

To examine sustainability comprehensively, the NNRT also considered the elements necessary to sustain the role and function of patient navigation in a variety of settings; knowing that a variety of factors are needed for long-term sustainability. The NNRT examined existing constructs and toolkits that have been built to explore sustainability, including the Patient Navigation Sustainability Assessment Tool (PSAT),[9] Patient Navigation Sustainability Assessment Tool for Patient Navigation (PNSAT),10 and Paying for Colorectal Cancer Screening Navigation Toolkit.[11] Essential constructs from these sustainability models must be considered for patient navigation to be truly sustainable (**Table 2**).[9-11] Notably, funding is a key part of the sustainability constructs but not the only element needed to successfully sustain navigation.

TABLE 2. Eight Essential NNRT Sustainability Constructs and Domain Descriptions

Domain	Description
Funding stability	Making long-term plans based on a stable funding environment
Partnerships	**Connection between program and community**
Organizational capacity	Resources needed to effectively manage the program and its activities
Program evaluation	Monitoring and evaluation of process and outcome data associated with program activities
Program adaptation	Ability to adapt and improve to ensure effectiveness
Communications	Strategic dissemination of program outcomes and activities with stakeholders, decision-makers, and the public
Strategic planning	Process that defines the program direction, goals, and strategies
Environmental support	Internal and external political environment which influences program funding, initiatives, and acceptance.

To learn more about PNSAT sustainability constructs and applicability to programs and PN interventions, please visit: https://sites.google.com/view/ccsp-pn-sustainability. As mentioned previously, while funding/economic evaluation and making the business case for patient navigation is critical, sustainability is more than only paying for patient navigation. For example, a Colorado-based colorectal cancer screening navigation program within clinics and at the state level used the PNSAT in safety net primary clinics for its sustainability assessment and planning. Results showed that while funding was a priority for sustainability—workflow integration, communication, planning, and Implementation were prioritized above funding stability.[12]

Based on results from the NNRT survey conducted in 2021, we know that inconsistent collecting of data and reporting of oncology navigation programs remain a threat to sustainability. Aligning data collection with oncology accreditation, funding, and reimbursement is a viable path forward.[13] Using the outcomes and metrics noted within this Toolkit is essential to sustain a patient navigation program.

References: 1. Swanson JR, Strusowski P, Mack N, Degroot J. Growing a navigation program: using the NCCCP Navigation Assessment Tool. *Oncol Issues*. 2012;27:36-45. **2.** Franklin EF, Dean MS, Johnston DM, et al.. Solidifying roles, responsibilities, and the process of navigation across the continuum of cancer care: The Professional Oncology Navigation Task Force. *Cancer*. 2022. **3.** Garfield KM, Franklin EF, Battaglia TA, et al. Evaluating the sustainability of patient navigation programs in oncology by length of existence, funding, and payment model participation. *Cancer*. 2022;128 (suppl_13):2578-2589. **4.** Pratt-Chapman ML, Silber R, Tang J, Le PTD. Implementation factors for patient navigation program success: a qualitative study. *Implement Sci Commun*. 2021;2:141. **5.** Osundina F, Garfield K, Downer S. National Navigation Roundtable: patient navigation in cancer care. American Cancer Society. Published 2019. Accessed July 10, 2023. www.chlpi.org/wp-content/uploads/2013/12/Patient-Navigation-in-Cancer-Care-Review-of-Payment-Models_FINAL.pdf **6.** Gervès-Pinquié C, Girault A, Phillips S, et al. Economic evaluation of patient navigation programs in colorectal cancer care, a systematic review. *Health Econ Rev*. 2018;8:12. **7.** Wolf HJ, Dwyer A, Ahnen DJ, et al. Colon cancer screening for Colorado's underserved: a community clinic/academic partnership. *Am J Prev Med*. 2015;48:264-270. **8.** Ramsey M, Schneider J. Improving cancer prevention and control: how state health agencies can support patient navigators and community health workers. Accessed July 10, 2023. www.astho.org/programs/prevention/chronic-disease/cancer/materials/improving-cancer-prevention-and-control/ **9.** Luke DA, Calhoun A, Robichaux CB, et al. The Program Sustainability Assessment Tool: a new instrument for public health programs. *Prev Chronic Dis*. 2014;11:130184. **10.** Dwyer A, Weltzien E, and Harty N. Patient Navigation Sustainability Assessment Tool for preventive cancer screening. 2019. Colorado School of Public Health and University of Colorado Cancer Center: Aurora, CO. **11.** Dwyer A, National Colorectal Cancer Roundtable. Paying for colorectal cancer screening navigation toolkit: strategies for payment and sustainability. Updated June 2019. Accessed July 10, 2023. https://nccrt.org/resource/paying-colorectal-cancer-screening-patient-navigation-toolkit **12.** Dwyer AJ, Weltzien ES, Harty NM, LeGrice KE, Pray SLH, Risendal BC. What makes for successful patient navigation implementation in cancer prevention and screening programs using an evaluation and sustainability framework. *Cancer*. 2022;128(suppl_13):2636-2648. **13.** Battaglia TA, Fleisher L, Dwyer AJ, et al. Barriers and opportunities to measuring oncology patient navigation impact: results from the National Navigation Roundtable survey. *Cancer*. 2022;128(suppl_13):2568-2577.


TM

XIV. METRICS

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

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 and 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 improve the delivery of timely, effective, and equitable cancer services.[1]

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.[1,3] Each navigation program is expected to meet the needs of patients, the community, and the institution it was developed for. Indicators that measure its success must be tailored to 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 programmatic success are yet to be created and standardized. After a comprehensive literature search on navigation metrics, 3 main categories of metrics were identified: patient experience, clinical outcomes, and business performance/return on investment (ROI). To support the continuation or perhaps even expansion of patient navigation services, cancer programs will need to collect quality metrics in all 3 categories.[1,4]

Patient Experience Metrics

The "patient experience" is increasingly emerging as an 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 survey results also confirm the importance of ensuring that navigators and support staff know how to provide the appropriate level of education.

NOTES FOR NAVIGATORS

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.

Asking the 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 the implementation of a successful surveillance plan in the outpatient setting. Patient experience interventions are not difficult to create for a navigation program, but patient-centered care must always be applied to create appropriate metrics.[1,5]

Clinical Outcomes Metrics

Clinical outcomes metrics are much more familiar to healthcare providers because they use them to assess patients' clinical outcomes and quality care provision. Navigators can impact clinical outcomes by measuring their services and interventions. These navigation metrics include distress screening, pathway compliance, and timeliness of care. Clinical outcomes measurement in navigation programs should assess the psychosocial domain (quality of life and patient/family satisfaction).[1,4]

Business Performance Metrics

Unlike patient experience or clinical outcomes, business performance metrics are much less familiar in navigation programs. 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 report by the Institute of Medicine, 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] Now, administrators must measure the ROI for navigation programs and report metrics and outcomes to ensure the sustainability of the program.

Navigators focusing on business performance metrics may require additional training or education.[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, including[8]:

- 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 readmission penalties

Navigators can impact ROI through services and interventions that include[9]:

- Removing barriers
  - Allows for patients to undergo diagnostic/staging, workup, and treatment
- Promoting treatment adherence
  - Demonstrates cost-effectiveness, as navigators can impact treatment adherence through patient education and promoting shared decision-making
  - Increases continuity of care

- Enhancing revenue
    - Navigators can impact revenue by facilitating referral to downstream revenue generating services, monitoring "no shows," and decreasing outmigration
- Decreasing preventable emergency department (ED) visits
- Decreasing 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), which makes healthcare more cost-effective

AONN+ Standardized Metrics

With standardized metrics, navigation and cancer programs can demonstrate their success on a national level. By using the same metrics, navigators can truly partner and be on the same page on the 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 Commission on Cancer (CoC), National Accreditation Program for Breast Centers (NAPBC), Quality Oncology Practice Initiative (QOPI), and value-based care. National standards help drive continuous quality improvement and value, as well as identify best practice programs that elevate cancer care.[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 essential standardized metrics for measuring outcomes specific to their program. Perhaps they will have additional metrics to suit the needs of their own programs. The AONN+ 8 Domains of Knowledge were used to develop a set of standardized metrics for patient experience, clinical outcomes, and ROI (**Table**).[4] The domains of knowledge provide a comprehensive list of all navigation areas that can provide quality patient care and financial stability for organizations.[4]

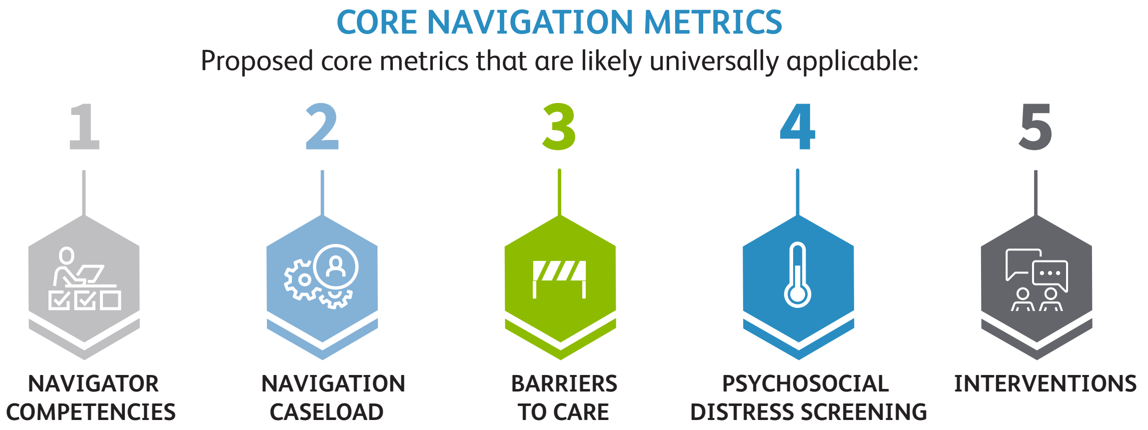
In 2019, a first of its kind IRB study measured 10 of the 35 national evidence-based AONN+ navigation metrics.[10] This study was conducted by AONN+, American Cancer Society, and Oncology Solutions. The participating study sites included all models of navigation in different settings. The 6-month study demonstrated significant positive outcomes in all 10 metrics. The metrics supported value-based cancer care, CoC, NAPBC, and QOPI. The study's outcomes can be reviewed via the infographic, "Highlights from the National Evidence-Based Oncology Navigation Metrics: Multisite Exploratory Study to Demonstrate Value and Sustainability of Navigation Programs."[11]

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.

FIGURE. The 5 Core Navigation Metrics



Source: Adapted from Academy of Oncology Nurse & Patient Navigators. Navigation metrics toolkit. Published August 2020. Accessed September 28, 2020. https://aonnonline.org/images/resources/navigation_tools/2020-AONN-Navigation-Metrics-Toolkit.pdf

Five metrics were identified as core to demonstrating the success of a navigator program. They include navigator competencies, navigation caseload, barriers to care, psychosocial distress screening, and interventions provided to the patient (**Figure**).[12]

In 2020, the Navigation Metrics Toolkit was released.[12] It reflects the current recommendations from AONN+ and the IRB metrics study, as well as best practices gleaned from navigators and navigation experts across the nation. The toolkit guides navigators in selecting, using, implementing, and reporting navigation metrics as they engage in quality/performance improvement and strategic decision-making.

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:

- Strusowski P, Sein E, Johnston D. 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;8:220-237[4]
- Strusowski T, Sein E. Standardized metrics source document. Academy of Oncology Nurse & Patient Navigators. www.aonnonline.org/metrics-source-document[5]

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

Becoming a member of a professional organization or using an organization's resources can be a great way to boost your professionalism.[1] AONN+ remains "the largest national specialty organization dedicated to improving patient care and quality of life by defining, enhancing, and promoting the role" of oncology clinical, social work, and patient navigators.[2] Why join? Because professional organizations offer an extensive menu of professional development opportunities, such as those available to AONN+ members.[3]

Other professional organizations are available to clinical, social work (**Table 1**), and patient navigators (**Table 2**) across the country. This allows you to tailor your development and membership to your specialization or individualized development plan (**Table 3**). Please note that these lists are in no way exhaustive, nor do they represent endorsement of these organizations over others that may be available locally or nationally.

TABLE 1. Organizations Providing Opportunities for Clinical and Social Work Navigators

Oncology Nursing Society (ONS)	"A professional association that represents 100,000 nurses and is the professional home to more than 35,000 members. ONS is 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 the quality of life and outcomes for patients with cancer and their families."[4]
Association of Pediatric Hematology/Oncology Nurses (APHON)	"The professional organization for pediatric hematology/oncology nurses and other pediatric hematology/oncology healthcare professionals. Its members are dedicated to promoting optimal nursing care for children, adolescents, and young adults with cancer and blood disorders, and their families."[5]
American Society for Radiation Oncology (ASTRO)	"ASTRO's mission is to advance the practice of radiation oncology by promoting excellence in patient care, providing opportunities for educational and professional development, promoting research and disseminating research results and representing radiation oncology in a rapidly evolving health care environment."[6]
American Society of Clinical Oncology (ASCO)	"The American Society of Clinical Oncology is the world's leading professional organization for physicians and oncology professionals caring for people with cancer."[7]
Association of Oncology Social Work (AOSW)	An international nonprofit 501(c)3 organization dedicated to the enhancement of psychosocial services to people with cancer, their families, and caregivers."[8]
Association of Pediatric Oncology Social Workers (APOSW)	"A group of passionate professionals focused on enhancing the lives of children with cancer and blood disorders and the families who care for them. We accomplish this by advancing pediatric psychosocial oncology care through clinical social work practice, research, advocacy, education, and program development."[9]
Association of Clinical Research Professionals (ACRP)	"Dedicated to representing, supporting, and advocating for clinical research professionals."[10]
American Society of Radiologic Technologists (ASRT)	"The mission of the American Society of Radiologic Technologists is to advance and elevate the medical imaging and radiation therapy profession and to enhance the quality and safety of patient care."[11]
National Hospice and Palliative Care Organization (NHPCO)	"As the leading organization representing hospice and palliative care providers, NHPCO works to expand access to a proven person-centered model for healthcare—one that provides patients and their loved ones with comfort, peace, and dignity during life's most intimate and vulnerable experiences."[12]

(continued)

TABLE 1. Organizations Providing Opportunities for Clinical and Social Work Navigators *(continued)*

Oncology Nutrition Dietetic Practice Group	"The practice of oncology nutrition covers research, prevention, treatment, recovery, palliative care, and hospice. The ON DPG provides dietetic professionals with resources and networking opportunities to deal with the complexities of oncology practice. Members work in clinical, public health, education, and research settings."[13]
Wound, Ostomy, and Continence Nurses Society (WOCN)	"Empowering your professional growth and improving outcomes for patients through relevant education, effective advocacy, cutting-edge science, a supportive network, and a patient-centric approach."[14]

TABLE 2. Organizations Providing Opportunities for Patient Navigators

The Patient Navigator Training Collaborative	"Provides national leadership for the development, education, standardization and sustainability of the growing patient navigation workforce."[15]
National Navigation Roundtable (NNRT)	"A national collaborative of organizations working together to advance patient navigation efforts."[16]
Patient-Centered Education and Research Institute	"Support evidence-based, patient-centered healthcare through education, research, certification, and communication throughout the United States."[17]
George Washington School of Medicine & Health Sciences	Oncology Patient Navigator Training: The Fundamentals "This comprehensive, competency-based training uses evidence-based information and case studies to prepare patient navigators to effectively address barriers to care for cancer patients and survivors."[18]

TABLE 3. Organizations Focused on Specialized and Disparate Populations

Racial and Cultural Minorities	African American Breast Cancer Alliance[19] Tigerlily Foundation[20] National Alliance for Hispanic Health[21] American Indian Cancer Foundation[22] Asian American Cancer Support Network[23] Intercultural Cancer Council[24] Native American Cancer Initiative[25]
LGBTQIA+	The National LGBT Cancer Network[26] National LGBT Cancer Project[27] National Resource Center on LGBTQ+ Aging[28]
Clinical Trials	National Cancer Institute[29] When We Tri(al)[30] American Association for Cancer Research[31]
Adolescent/Young Adult (AYA)	Ulman Foundation[32] Stupid Cancer[33] Teen Cancer America[34]
Financial and Employment Aspects of Cancer	Cancer Financial Assistance Coalition[35] Cancer and Careers[36]
Fertility	Alliance for Fertility Preservation[37] Livestrong Fertility[38]
Cancer Genetics	FORCE: Facing Hereditary Cancer Empowered[39]
Geographical Disparities	Rural Health Information Hub[40] Urban Indian Health Institute[41]

Certificate Programs and Certifications

It is important to understand the difference between certificate programs and certifications and recognize the benefits they offer to your professional growth and development.

Certificate programs "are designed around an educational event, whether that be a webinar, workshop, online course, or other program. A certificate program is one where you participate in the educational event and then complete a test or assessment afterwards to ensure you've learned the basic competencies outlined in the learning objectives. You receive a certificate showing competency in the knowledge/skill/attribute you learned, but you will rarely be required to renew the certificate or repeat the education."[42]

Certifications, however, "are designed to prove expertise in a specialized area of practice. These programs require intense work with professionals…to define and outline competencies to ensure the program represents current best practices…Because a certification is designed to exemplify expertise, candidates must complete an assessment…to show they meet the competencies outlined. With successful completion of certification, candidates receive credentials they may list in their professional signature."[42]

NOTES FOR NAVIGATORS

Accreditation is key to ensuring quality and rigor in the development of the program as well as the maintenance of quality program standards.

Regardless of whether you choose to complete a certificate program or sit for certification, it is important to first determine whether the institution providing the program is an accredited provider.[43] Accreditation is key to ensuring quality and rigor in the development of the program as well as the maintenance of quality program standards. For example, AONN+ Foundation for Learning is accredited through the American National Standards Institute National Accreditation Board (ANAB); therefore, all certifications available through the AONN+ Foundation for Learning are nationally accredited. Additionally, the current ONN-CG certification is recognized by the Commission on Cancer (CoC) and can be used for the Magnet Recognition Program.[44]

- Professional certifications offer many benefits, not only to the professional who earns the certification but also the certified individual's patients and their caregivers, employer, clients, and the multidisciplinary team (**Table 4**).[45] Certifications from the AONN+ Foundation for Learning are unique, as they are the only nationally-recognized, accredited general oncology navigation certifications available. Specifically, the current ONN-CG and OPN-CG certifications offer[44]:
    - Validation of advanced knowledge, skills, and practice in oncology navigation
    - Enhancement of professional credibility, marketability, and opportunities for career advancement
    - Recognition and respect from industry organizations, institutional leadership, peers, and patients as an integral member of the multidisciplinary oncology team

NOTES FOR NAVIGATORS

Professional certifications offer many benefits, not only to the professional who earns the certification but also the certified individual's patients and their caregivers, employer, clients, and the multidisciplinary team.

It's important to remember, however, that professional growth and development is a long-term commitment, not a one-time completion of certificate programs or

TABLE 4. 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.

certification exams. Instead, create goals to refine your scope of development as you further your career. A way to think about professional development is graphically, like this bullseye, with the rings becoming smaller and more specialized the further you grow in your career. A new oncology nurse may choose to first gain OCN certification to define her oncology expertise. After transitioning to an oncology nurse navigator role, they decide to obtain the ONN-CG certification to show expertise in the field of navigation. Finally, they may decide to specialize in breast cancer navigation and define their professional expertise even further by obtaining the Certified Breast Care Nurse certification. The bullseye is a common graphic used across education, marketing, and business to help define goals more clearly.[46] You can do the same with your professional development goals.

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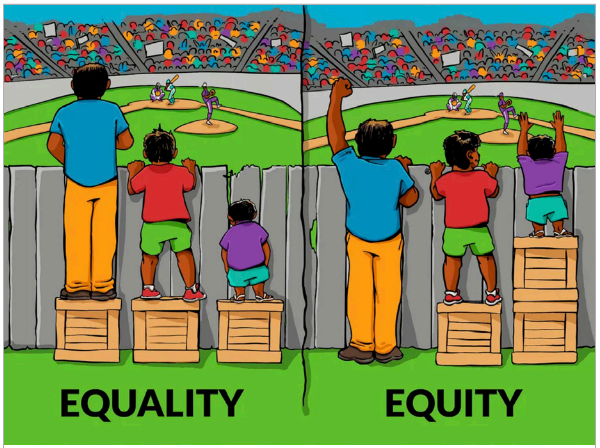
XVI. NAVIGATING TOWARD HEALTH EQUITY

Defining Health Equity

Health equity, also known as social justice in health, is the concept of reducing barriers such as social position or other social determinants so that anyone can reach their highest level of health. It is accomplished by focusing on those most at risk of unfavorable health due to socioeconomic circumstances (**Figure 1**).[1,2] No one should be denied the opportunity to be healthy because they are part of a group that has historically been economically or socially disadvantaged. The criteria employed to gauge progress in attaining health equity is health disparities.[2]

FIGURE 1. Equality vs Equity



Source: Rollston R. Health equity through the lenses of intersectionality and allostatic load. Medical Care Blog. Published February 20, 2019. Accessed July 10, 2023. www.themedicalcareblog.com/health_equity_intersectionality

Defining Health Disparities

Health disparities are unfavorable discrepancies in the burden of health that are experienced by racial and ethnic minorities and other medically underserved populations, such as people living in rural areas, people who identify as members of sexual and gender minorities, and people living in poverty.[3]

How do social determinants of health relate to disparities?

Social determinants of health (SDOH) refer to specific causes of poor health in individuals while disparities/inequalities refer to distribution patterns of health among individuals and social groups. SDOH is what causes health distribution patterns among social groups.[4]

Historically, social environment can contribute to disease and mortality.[4] Lower social conditions are strongly connected with unfavourable health and mortality in society. Research shows that healthcare spending and quality, individual actions, and genetic risk factors have a lower impact on health than socioeconomic factors. Therefore, societal structures need to change in order to reduce preventable diseases and early mortality in individuals as well as health inequalities among groups.[4] Studies show that the general health and well-being of a population declines with increasing socioeconomic disparity.[4] Enhancing the social foundations of dignity by fostering chances for wealth and income could enhance health accomplishments.[4]

SDOH explains the social gradient in health that exists in all societies. The concept of a good society or social justice needs to be re-examined against the backdrop of the movement from understanding the causes of disease as individual decisions and bad genetic luck and toward understanding the importance of social factors in diseases.[4]

Cultural Humility

Definition

Cultural humility is having a humble and courteous attitude toward individuals from other cultures and being ready to learn from them. It assists us to identify our own cultural prejudices and realize that we cannot fully understand every aspect of a culture.[5] Cultural humility is employed in public health, social work, education, and non-profit management.[5]

How Cultural Humility Ties Into Health Equity

Cultural humility is critical to health equity. It helps us better understand and recognize the distinctive cultural experiences of each patient. Patient-centered care guarantees that these values govern all healthcare decisions and is respectful of and responsive to each patient's preferences, requirements, and values. To do this, healthcare workers must be both culturally competent and culturally humble as they provide care for various communities and work toward health equity.[5]

Cultural Humility Skills to Improve Healthcare as a Whole

The Center for Health Equity Advancement (CHEA) defines cultural humility as the continuing process of learning a set of skills to interact with any individual from any culture at any time. Cultural humility emphasizes self-reflection, lifelong learning, eradicating power imbalances (such as between provider and patient) and displaying equal regard for different beliefs.[6]

"The practice of cultural humility involves viewing every encounter, be it with a patient or colleague, as a negotiation between two worldviews—yours and theirs," said Jaya Aysola, MD, MPH, Founder and Executive Director of CHEA and an Assistant Dean of Inclusion and Diversity at the Perelman School of Medicine at the University of Pennsylvania. "It's about approaching each person with the understanding that everyone has a culture and background, which may need to be unpacked to reach a common understanding."[6]

Cultural Humility and Cultural Competency

By maintaining an open mind, individuals can lower unconscious biases that impact daily interactions and contribute to health care disparities.[6] Cultural humility in healthcare can improve patient satisfaction and treatment outcomes by fostering closer relationships and mutual understanding between patients and healthcare professionals. For instance, including cultural humility into patient documentation can directly affect the outcomes of surgeries, pain management, readmissions, and general health. When a patient is labelled in their chart as "non-adherent" or "non-compliant," it usually affects all subsequent encounters.[6] It is important to have cultural humility and awareness. We all make assumptions about others based on their background and culture.[6] Open-ended questions and reflective listening exercises are crucial because every individual is an expert on their life. Demonstrate cultural humility in your interactions with patients as well as all other people you interact with daily.[6]

Cultural Humility: A Step Towards Health Equity

Self-questioning, absorption in a patient's perspective, active listening, and flexibility are all components of cultural humility that are used to address and challenge personal and cultural prejudices or presumptions. Healthcare workers might avoid having to acquire in-depth knowledge of a variety of cultural variations by exhibiting cultural humility.[7]

Role of Oncology Patient Navigators

Patient oncology navigation has been cited as a solution to health equity by the American Cancer Society, National Comprehensive Cancer Network, National Minority Quality Forum, and many published authors.[8]

From inception, a core competency of navigation has always been to demonstrate sensitivity and responsiveness to a diverse patient population.

Oncology Patient Navigators

The core of the Oncology Patient Navigators' (OPN) role is patient-centered, compassionate, appropriate, and effective care that promotes health and treats cancer. OPNs aid patients in accessing cancer care and navigating complex healthcare systems, while engaging patients and families to find solutions to financial, practical, and social barriers.[9] Interpersonal and communication skills are fundamental for OPNs to effectively communicate with patients, families, and the public and to build trusting relationships across a broad range of socioeconomic and cultural backgrounds.[9]

Professionalism is paramount in demonstrating sensitivity and responsiveness to people of diverse gender, age, culture, race, religion, abilities, and sexual orientation among others. To optimize health and wellness in these populations, interprofessional collaboration, an OPN knowledge and skill, is used when interacting with other health professionals to appropriately assess and address patient needs.[9]

Nurse Navigation Domains

Nurse Navigators are critical in coordinating patient care, including chronic cancer care, and identifying clinical and service barriers. Patient care involves offering a continuum of services including prevention, screening, risk assessment, diagnosis, clinical trials, treatment, survivorship, and end-of-life care while maintaining cultural competency.[10] Patient advocacy or patient empowerment, an important aspect of nurse navigation, includes building trust with patients, counseling, and educating patients and their families while remaining sensitive to cultural differences.[10]

Navigation as a Solution

The 2019 ACCURE (Accountability for Cancer Care through Undoing Racism and Equity) trial used a system-based approach to enhance treatment completion for both Black and White patients and lessen racial disparities in lung and breast cancer treatment.[11] A real-time alert system that employed automated data uploads from electronic health records was developed. Also, race-specific cancer treatment completion data was sent to clinical teams. The system was also made available to nurse navigators, who were crucial to the intervention's effectiveness.[11]

Figure 2 shows the racial disparity in treatment completion rates in the control populations and the elimination of this disparity resulting from the ACCURE intervention.[11]

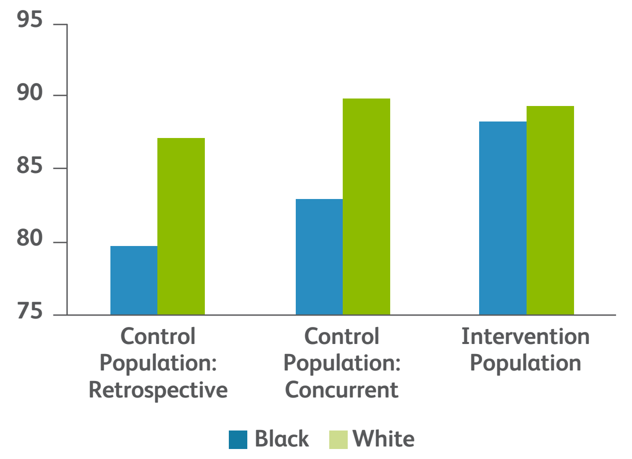
Moonshot Initiative

The Moonshot initiative pledges to reduce cancer deaths by 50% over the next 25 years, and enhance cancer prevention, early diagnosis, and treatment, as well as the care experience for cancer patients and their families. Although the United States has made great strides in lowering the cancer death rate, formidable obstacles still exist.[12]

Delaware is reducing cancer death racial gaps with the help of patient navigators

Patient navigators are essential to Delaware's progress in lowering cancer mortality rates and reducing or, in some cases, eliminating racial disparities in certain cancer types. Both are top priorities for the Biden administration, which recently reintroduced the Cancer Moonshot initiative.

FIGURE 2. Completion Rates (%) in the ACCURE Trial Control and Intervention Groups



Source: Cykert S. Reducing racial disparities in cancer care using the ACCURE trial as a model learning guide. Journal Oncol Navig Surviv. Updated January 18, 2022. Accessed July 10, 2023. https://jons-online.com/special-issues-and-supplements/2022/reducing-racial-disparities-in-cancer-care-using-the-accure-trial-as-a-model-learning-guide

The goal is to reduce cancer deaths by 50% among people of color in the next 25 years and address persistent disparities in screening and treatment. Across the United States, African Americans die from cancer at higher rates than all other demographics.[13]

In the United States, Delaware's way of treating cancer patients is unique. The state established universal cancer screening and treatment for its residents in 1998 using funding from the tobacco settlement. Delaware had one of the highest cancer death rates in the nation 2 decades ago. Even for undocumented residents, without insurance, or those who earn up to 6.5 times the federal poverty level, its Screening for Life program will pay for all cancer tests and, if cancer is diagnosed, will also cover treatment for up to 2 years.[13]

Patient Navigation and Population Health Navigation

Increased screening rates were found in 37 studies on patient navigation interventions for colorectal, breast, and cervical cancer screening in communities negatively impacted by health care inequities. This highlights the huge benefit of patient navigation.[14]

NOTES FOR NAVIGATORS

Patient navigation is patient-centered and aims to enhance patient experiences and cancer care provision.

To address the disparities that underprivileged communities frequently endure during their cancer treatment, the Wake Forest Baptist Comprehensive Cancer Center created a cutting-edge nonclinical navigation program for African American, Hispanic, and rural cancer patients. Population health navigators who are culturally and linguistically competent, help cancer patients, their families, and caregivers navigate the healthcare system and social barriers. This enables timely access to high-quality medical and supportive care during treatment.[15] The Population Health Navigation Program was expanded to include rural and African American populations after initial success with Hispanic patient navigators. The next step may be to identify distinctive characteristics of each demographic and places where navigation services could be further tailored by examining data for all demographics. Resources, workload, and clinical trial education are just a few areas that could be tailored. Ongoing analysis will show distinctions and potential intervention areas.[15]

Patient Navigation on the Path to Equity in Cancer Care:

Patient navigation is patient-centered and aims to enhance patient experiences and cancer care provision. It is described as "a community-based service delivery intervention designed to promote access to timely diagnosis and treatment of cancer and other chronic diseases by eliminating barriers to care."[16]

Patient navigators serve as a bridge between complex networks and procedures of cancer care systems and disenfranchised patients (**Figure 3**).[14,16] They are dependable middlemen and women who help patients make health decisions at every stage of care, from screening and diagnosis through treatment and cancer survivorship, as well as educate them on the diagnostic and therapeutic procedures. Patient navigators can help with transportation, interpretation, insurance applications, filling out medical forms, scheduling and coordinating appointments, emotional and psychosocial support (particularly during the uncertainty of diagnostic procedures and treatment), education about treatment and follow-up, and connection to local resources. These services address underlying differences in cancer care access and may impact cancer outcome disparities.[16]

Urgent Need to Address Disparities

Disparities across the cancer care continuum must be addressed immediately, especially considering the

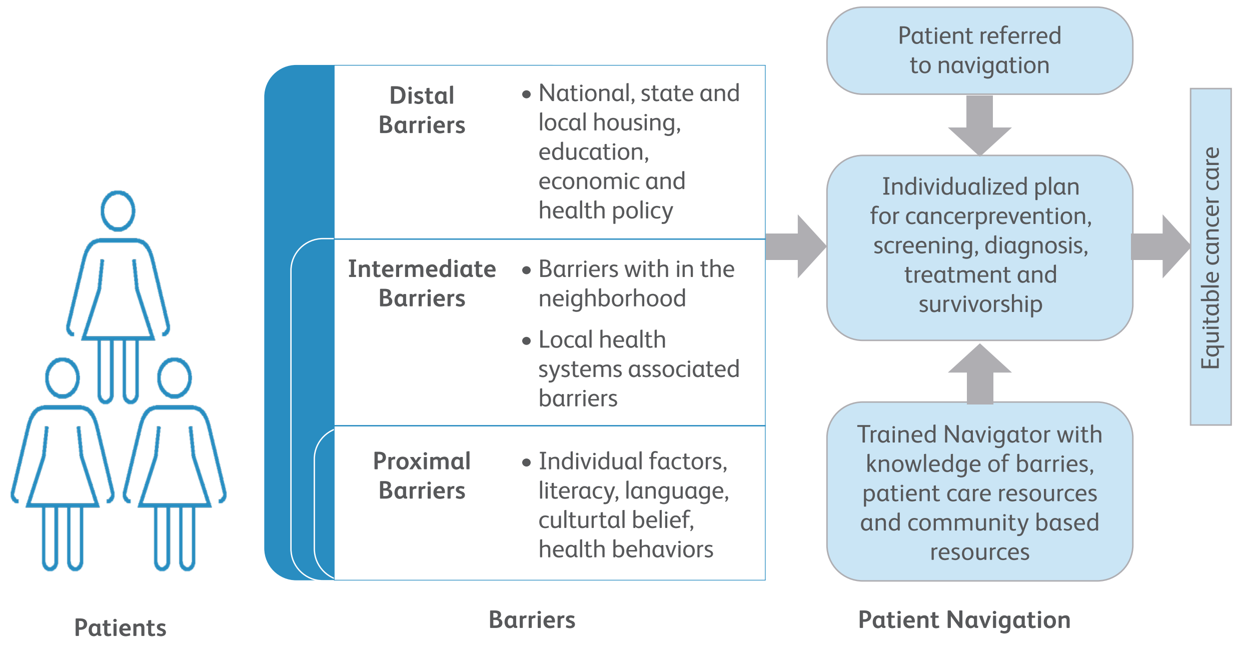


FIGURE 3. Role of Patient Navigation in Health Equity

Source: Dixit N, Rugo H, Burke NJ. Navigating a path to equity in cancer care: the role of patient navigation. *Am Soc Clin Oncol Educ Book*. 2021;41:1-8.

complexity of the healthcare system and the expansion of available treatment alternatives.[17] Everyone in the cancer care community is jointly accountable for ensuring access to high-quality care across the full continuum—not just within their own domain—due to the complex and interrelated structure of the cancer care continuum. If disparities are not addressed, health disparity will worsen, increasing the burdens on groups who are already underserved and vulnerable.[17]

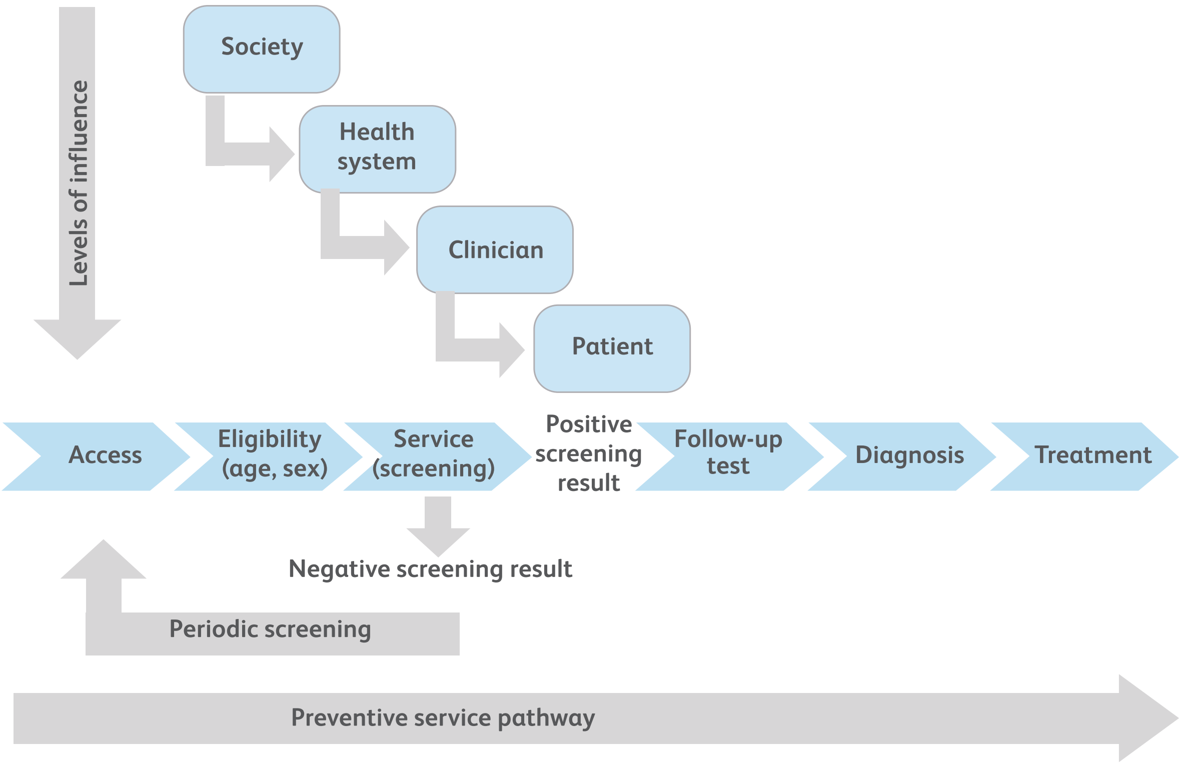
Beyond Health Disparities

Because of the health equity movement, many sectors are collaborating to address the difficult issue of health inequality.[18] Solutions are based on building up communities, involving non-health sectors, highlighting effective practices, pushing progressive policy alternatives, and identifying research gaps that might support the need to give health equality measures top priority. Progress has been made, but a pressing need for action remains.[18]

Patient Navigation as a Tool to Address Equity in Cancer Early Detection

To lower mortality rates and boost survival rates in the United States, it is crucial to identify breast and cervical cancer early. Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 to address this public health issue. As a result, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) of the U.S. Centers for Disease Control and Prevention was established. All 50 states, the District of Columbia, 6 US territories, and 13 American Indian/Alaska Native tribes or tribal organizations are funded by this federal program.[19] The NBCCEDP provides funding for screening through mammograms and Pap tests, diagnostic services like colposcopy, ultrasound, and biopsy, and patient navigation to assist patients in overcoming emotional and practical obstacles to receiving care.[19]

FIGURE 4. Preventative Service Pathway



Source: Nelson HD, Cantor A, Wagner J, et al. Achieving health equity in preventative services: a systematic review for a National Institutes of Health Pathways to Prevention Workshop. *Ann Intern Med*.2020;172:258-271.

Achieving Health Equity in Preventive Services

Achieving health equity is difficult in preventive services. Although preventive services are available to almost everyone, discrepancies can exist across several sociodemographic categories. Additionally, the efficiency of preventive services is dependent on complex clinical care paths with several opportunities for disadvantaged people to slip through the cracks (**Figure 4**).[20]

Inadequate data on effectively minimizing health disparities in clinical practice constrains efforts to achieve health equity in preventive services.[20] To address gaps and correct deficiencies of previous studies, more research is required. Additional research on understudied populations who experience healthcare disparities is needed. They include racial and ethnic minorities, socioeconomically disadvantaged and underserved rural populations, and sexual and gender minority populations.[20]

Patient Navigators Reduce Racial Disparities in Primary Care

According to a study published in the Journal of the American Board of Family Medicine, Hispanic patients who worked with patient navigators were 3 times more likely to have access to primary care than those who did not.[21] This suggests that patient navigators assist in avoiding issues related to social determinants of health.[21] Patient health literacy difficulties, such as not understanding where or how to receive care, and transportation issues were specifically addressed by the navigation services. However, the patient navigation services were unable to address some of the more systemic issues that patients frequently encounter, indicating the need for a thorough industry transformation.[21]

The Academy of Oncology Nurse & Patient Navigators (AONN+) was founded to enhance patient care and quality of life.[22] They are dedicated to assisting the professional workforce that has historically provided the most critical care to cancer patients, including patients of color who have long experienced racial, systemic, and institutional injustices. These injustices, which gave impetus to the development of the navigation profession, were well documented in our health and cancer care systems.[22]

NOTES FOR NAVIGATORS

Demonstrating sensitivity and responsiveness to patients of diverse race, ethnicity, gender, age, culture, religion, abilities, and sexual orientation is a core competency of patient navigation.

We are currently seeing a national tragedy that is rooted in racial injustice. This is made worse by the disproportionate effect of the COVID-19 pandemic on communities of color. By assisting patients in identifying their personal talents and using them to advance their preferences and priorities, navigators aim to improve the justice and equity of our healthcare system. They provide evidence of the significant difficulties that all cancer patients face. Demonstrating sensitivity and responsiveness to patients of diverse race, ethnicity, gender, age, culture, religion, abilities, and sexual orientation is a core competency of patient navigation. With this fundamental principle in mind, all navigators address patient needs and obstacles while exposing health disparities and identifying solutions to guarantee that everyone has the chance to live healthy, full lives. There has never been a greater need for this work.[22]

It has been demonstrated that navigation reduces cancer inequalities. Navigation is a fundamental, evidence-based method for alleviating health inequities in racial and ethnic minority communities. It is a vital tool in our toolbox for reducing cancer outcome inequities and increasing community trust in our health systems.[23]

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XVII. TELEHEALTH

Before uncovering the disparities around telehealth, one must first understand what it is. The U.S. Department of Health and Human Services describes telehealth as the “use of electronic information and telecommunication technologies to support and promote long distance healthcare, patient and professional health-related education, and public health and health administration.”[1] The rise of telehealth has illuminated a great deal of disparities not only for patients, but healthcare systems.

Telehealth plays a major role in the delivery of cancer care. However, much work is still needed to permanently increase access.[2] Often, we think of telehealth disparities on a singular patient level based on their age, income, race/ethnicity, health status, digital literacy, English proficiency, and geographic location. However, telehealth use has multilevel barriers at the patient, health system, telehealth platform, policy, and team levels.[3]

Telehealth disparities vary depending on patients’ geographic locations. Rural and suburban areas are less likely to use telehealth services compared with patients in urban areas.[3] Patients in rural settings may have fewer local telehealth service providers; however, those in urban settings may not have housing or a private space to participate in a virtual visit.

NOTES FOR NAVIGATORS

Telehealth use has multilevel barriers at the patient, health system, telehealth platform, policy, and team levels.

It is essential to account for telehealth technology. We often see patients who cannot share videos through a smartphone, tablet, and computer, or they may lack broadband internet access. Particularly in rural settings, many patients are unable to access internet, which forces them to drive into town where they can pick up Wi-Fi at a business. If the internet is spotty, it is difficult to access virtual healthcare services. Language barriers, not only spoken, but oral, written, and signed language can be barriers for patients using telehealth.[4]

Research found that African American patients were less likely to use telehealth services than non-Hispanic Whites. Telehealth use was lower among patients without insurance than those who had commercial insurance coverage or Medicare.[5]

Telehealth was once unheard of in the world of oncology. While primary care and other specialties were actively innovating in the technology space, oncology seemed to be way too complex and hands on to even begin to fathom the thought of conducting an appointment virtually. That quickly changed after the COVID-19 pandemic. A new modality, outside the typical multimodal care of surgical, radiation, and medical oncology, was introduced, welcomed, and implemented. Teleoncology was quickly coined as a new pillar in oncology care.[6]

The benefits of teleoncology began to emerge with its increased use and positive feedback. Navigators were then pulled into an essential telehealth role for the oncology care team. In 2021, the Association of Community Cancer Centers (ACCC) surveyed its members and published the findings. Regarding incorporation of telehealth in cancer care or plans to do so, nurses or nurse navigators tied with advanced practice providers in the second highest place behind physicians (**Figure 1**).[7] Thus, we witnessed the birth of telenavigation out of teleoncology.

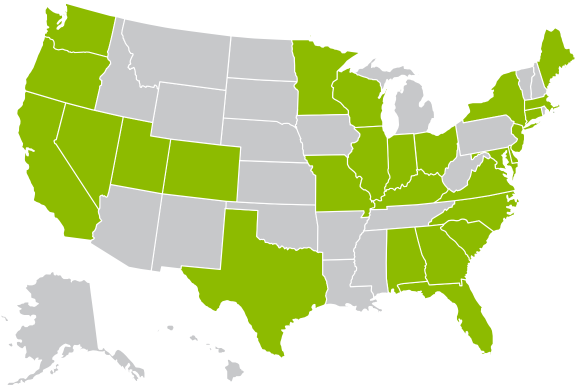
Telenavigation has brought about different barriers for navigators. The fundamental role of navigators to assess for barriers remains, but a new barrier needs to be assessed as teleoncology use increases. Telehealth use may increase disparities in healthcare access (**Figure 2**).[5] Navigators must be able to assess

FIGURE 1. Association of Community Cancer Centers (ACCC) Survey Regarding Multidisciplinary Roles in the Incorporation or Planned Incorporation of Telehealth in Cancer Care

The Association of Community Cancer Centers (ACCC) conducted a survey between February and March 2021 to gain an understanding of how cancer programs have incorporated or planned to incorporate telehealth services to care for patients during the COVID-19 public health emergency and beyond. This infographic summarizes findings from 71 ACCC members who voluntarily responded to the survey.

Respondent Demographics

Respondents from 27 cancer programs across the country represented a variety of roles and care delivery settings.



MULTIDISCIPLINARY ROLES IN CANCER CARE

Physician	15
Advanced practice provider (e.g., pharmacist, nurse practitioner, physician assistant)	13
Nurse or nurse navigator	13
Administrator or manager	8
Financial advocate	7
Social worker or mental health counselor	6
Genetic counselor	3
Other	5

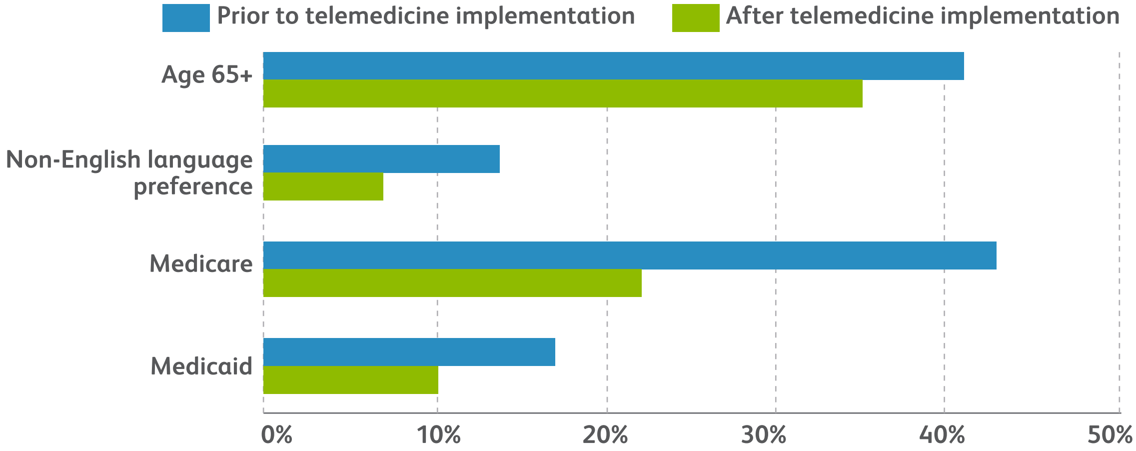
CARE DELIVERY SETTINGS

Community cancer program	40
Hospital or hospital system	28
Academic or NCI-designated cancer program	7
Private physician practice	6
Other	4

Source: Atembina L. Adoption and expansion of telehealth solutions overview. Association of Community Cancer Centers. Accessed July 10, 2023. https://www.accc-cancer.org/projects/telehealth-solutions/overview

FIGURE 2. Patient Visits by Age, Language, and Insurance Before and After Telemdicine Scale-Up

This chart shows the proportion of patient visits seen by age, language preference, and insurance type prior to (2/17–2/28/2020) and after (3/23–4/3/2020) scaled-up telemedicine implementation to address the Covid-19 pandemic at the UCSF General Internal Medicine Primary Care Practice (P=0.002 for age ≥65 and P<0.001 for other comparisons). A significantly smaller proportion of visits after scaled-up telemedicine implementation were with vulnerable patients.



Source: Nouri S, Khoong ME, Lyles CR, Karliner ML. Addressing equity in telemedicine for chronic disease management during the COVID-19 pandemic. *NEJM Catalyst*. Published May 4, 2020. Accessed July 10, 2023.

and identify patients who can use telehealth because they are often the first point of contact for the patient. However, with telehealth it is vital that the navigator also considers the plan of care for patients if a telehealth visit is scheduled. In today's virtual healthcare system, navigators have become a catalyst for assessing and addressing telehealth disparities for patients and health systems. We have seen them act in 4 key areas by: (1) proactively exploring potential disparities in telehealth access, (2) developing solutions to mitigate barriers to digital literacy and the resources needed for engagement in video visits, (3) removing health system-created barriers to accessing video visits, and (4) advocating for policies and infrastructure that facilitate equitable telehealth access. Without taking these actions now, healthcare systems risk creating telehealth programs that exclude vulnerable populations.[5]

NOTES FOR NAVIGATORS

In today's virtual healthcare system, navigators have become a catalyst for assessing and addressing telehealth disparities for patients and health systems.

Often, the navigator must advocate for the patient if they are not a good candidate for telehealth due to a disparity or barrier. An important role of the navigator is to help the patient and caregiver understand that the appointment, education, support group, or chemo suite tour is virtual, and what that entails. In the early years of the COVID-19 pandemic, many navigators became information technology (IT) support for patient portals, telehealth appointments, virtual chemotherapy education, and cancer conferences. Assessing this additional barrier is essential if teleoncology is to become more accessible.

We cannot assume that all navigators are nurses and confined to the walls of a healthcare system. Multiple models of navigation exist, and sometimes this can be a disparity. Navigators not connected to a healthcare system may not have an electronic platform or source to navigate virtually. Many have had to use common platforms such as Zoom, which without a paid subscription is limited to 1 hour. "Telemedicine can improve access to timely cancer care, but as this study points out, telemedicine must be available equitably, so that every patient can access the care they need and deserve," said Everett E. Vokes, MD, president of ASCO, in a statement.[3]

Where we're going, we don't need roads, but we do need broadband internet. This need for connectivity was highlighted as the adoption of telehealth services during the pandemic saved patients with cancer both time and travel costs, and thus reduced their care cost burden.[8] Telehealth is here to stay. However, to avoid inadvertently increasing disparities, navigators play an important role in assessing and addressing barriers for patients seeking telehealth services.

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XVIII. CONCLUSION

Navigating the cancer continuum requires a team of professionals who communicate seamlessly and effectively. Patient navigation is a value-based support strategy that assists in education, addresses barriers to care, enhances care coordination, and shared decision-making between patients and providers. From its inception, a core competency of navigation has been to demonstrate sensitivity and responsiveness to a diverse patient population. This focus will continue to foster a positive working atmosphere, and one of mutual respect, dignity, diversity, ethical integrity, and trust. Patient navigation aims to increase health equity among patients with cancer. It can be applied in a variety of inpatient and outpatient settings, based on the needs of the community and/or healthcare system. After many decades of evolution, oncology navigation is now supported with clear standards of professional practice. They include the knowledge and skills all professional navigators should possess to deliver high-quality, competent, and ethical care; standardized metrics for benchmarks of care in patient experience; clinical outcomes; certification with established baseline competencies for oncology navigators, centered on their roles, responsibilities, required knowledge and skills; and evidence-based best practices to help to ensure consistent delivery of optimized patient care across the care continuum. Operational management knowledge is key as navigators track patients along the continuum; record steps to reduce barriers and ensure cancer care meets selected standards; and document overall improvements in efficiency for the patient and healthcare system they are employed at. For sustainability, funding is critical, but equally critical is the operational knowledge domains as they demonstrate how navigation can impact a system and create a seamless care journey for patients.

XIX. 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
www.breastcare.org

Oncology Nursing Society
www.ons.org

The National Navigation Roundtable (NNRT)
https://navigationroundtable.org/about

Program Development and Training Programs

Association of Community Cancer Centers: Patient Navigation Resources and Tools for the Multidisciplinary Team
www.accc-cancer.org/projects/supportive-care-resource-hub/patient-navigation-resources

EduCare
https://educareinc.com

Association of Community Cancer Centers Financial Advocacy
www.accc-cancer.org/home/learn/financial-advocacy

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

(continued)

Joint Commission Cultural Competency Training
www.jointcommission.org/-/media/tjc/documents/standards/r3-reports/r3-report-issue-1-20111.pdf

Patient Navigator Training Collaborative
https://patientnavigatortraining.org

U.S. Department of Health & Human Services Health Literacy Training
https://health.gov/healthliteracyonline

Resources to Address Patient Barriers

Advocacy Connector
www.cancer.com

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

APPENDIX

-Academy of Oncology Nurse & Patient Navigators Standardized Evidence-Based Oncology Navigation Metrics

-Navigation Orientation Checklist, Navigation Annual Competency Checklist, and the AONN+ 8 Domains of Knowledge

-"Communicating Your Role: 30-Second Elevator Speech”

-Patient Navigation Intake Form and https://aonnonline.org/toolkits

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

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

Associations and Organizations:

Oncology Nursing Society (ONS)

Association of Pediatric Hematology/Oncology Nurses (APHON)

American Society for Radiation Oncology (ASTRO)

American Society of Clinical Oncology (ASCO)

Association of Oncology Social Work (AOSW)

Association of Pediatric Oncology Social Workers (APOSW)

Association of Clinical Research Professionals (ACRP)

American Society of Radiologic Technologists (ASRT)

National Hospice and Palliative Care Organization (NHPCO)

Oncology Nutrition Dietetic Practice Group

Wound, Ostomy, and Continence Nurses Society (WOCN)

The Patient Navigator Training Collaborative

National Navigation Roundtable (NNRT)

Patient-Centered Education and Research Institute

George Washington School of Medicine & Health Sciences Oncology Patient Navigator Training: The Fundamentals

African American Breast Cancer Alliance

Tigerlily Foundation

National Alliance for Hispanic Health

Native American Cancer Initiatives

American Indian Cancer Foundation

Asian American Cancer Support Network

Intercultural Cancer Council

The National LGBT Cancer Network

National LGBT Cancer Project

National Resource Center on LGBTQ+ Aging

National Cancer Institute

When We Tri(al)

American Association for Cancer Research

Ulman Foundation

Stupid Cancer

Teen Cancer America

Cancer Financial Assistance Coalition

Cancer and Careers

Alliance for Fertility Preservation

Livestrong Fertility

FORCE: Facing Hereditary Cancer Empowered

Rural Health Information Hub

Urban Indian Health Institute

AONN+ 2020 Navigation Metrics Toolkit - https://aonnonline.org/images/resources/navigation_tools/2020-AONN-Navigation-Metrics-Toolkit.pdf

Team-Based Oncology Care: The Pivotal Role of Oncology Navigation–Learn how effective navigation requires a team approach to oncology care and should never be considered an “add-on” resource or service. Written by experts and edited by Lillie D. Shockney, this book provides practical real-world insights on oncology navigation and cancer care. https://link.springer.com/book/10.1007/978-3-319-69038-4

Equipping the Novice Oncology Nurse Navigator: An ONS Collaboration with AONN+ - The Equipping the Oncology Nurse Navigator program was designed by expert nurse navigators, and is intended to supplement a navigator's orientation to the role. It provides an overview of critical elements to the navigator role including care coordination, reducing barriers to care, patient advocacy. www.ons.org/courses/equipping-novice-oncology-nurse-navigator-ons-collaboration-aonn#:~:text=The%20Equipping%20the%20Oncology%20Nurse,barriers%20to%20care%2C%20patient%20advocacy

Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum (Second Edition) - The second edition of Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum provides novice and experienced nurse navigators with an overview of the role of the nurse navigator in cancer care and outlines the development of a navigation program, the skills and training needed to work as a nurse navigator, methods to evaluate outcomes, and issues related to assisting patients with specific types of cancers. www.ons.org/books/oncology-nurse-navigation-delivering-patient-centered-care-across-continuum-second-edition

A Decade Later: The State of Patient Navigation in Cancer Volume 128, Issue S13 Pages: 2553-2677
July 1, 2022: https://acsjournals.onlinelibrary.wiley.com/toc/10970142/2022/128/S13
This special issue was intended to be a catalyst for action in achieving equity in cancer care through the

support of oncology patient navigation and the last decade of work among key oncology leaders in this area. The professional standard roles of oncology navigators, navigation models, program sustainability, workflow procession and the latest work of oncology navigation is highlighted in this publication.

Advisory Board Six opportunities to get the most out of your patient navigation program
www.advisory.com/topics/oncology/2019/10/patient-navigation#
This resource is a patient navigation assessment to enrich your patient navigation program as you envelope the role and incorporate it into your care team. It contains suggested metrics to enhance your program and tools to track performance.


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