Hematology Navigation 101

A Day in the Life of a Hematology Navigator
Evolution of Navigation

FIRST COMMUNITY OUTREACH MODEL OF PATIENT NAVIGATION
An intervention to address health disparities of the poor and eliminate barriers to care

1970s
Utilization review

1980s
Utilization management

19902
Beginning of patient navigation

1990s
Case management

2000–Present
Patient navigation

Definition of Navigation

Patient navigation is a patient-centric healthcare service delivery model that concentrates on the movement of patients along the continuum of medical care, beginning in the community and continuing on through testing, diagnosis, and survivorship to the end of life.

–Harold Freeman

Navigation is individualized assistance offered to patients, their families, and caregivers to help overcome barriers to care, whether through the healthcare system or the environment, and to facilitate timely access to quality medical and psychosocial care. Navigation encompasses prediagnosis through all phases of the cancer experience.

–Commission on Cancer

The process of helping 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.

–AONN+

CoC initially focused on establishing cancer clinics within hospitals to promote consistent diagnostic and cancer treatment services.

Approach for optimizing health system performance:
- Improving the patient experience of care
- Improving the health of populations
- Reducing the per capita cost of healthcare

CoC introduced the first set of navigation standards titled “Ensuring Patient-Based Care”
- Standards implemented in 2015

Today, there are several initiatives influencing the evolution of oncology navigation:

1. Commission on Cancer founded
2. Triple Aim
3. Commission on Cancer standards

Navigating the Cancer Continuum: Navigation Models

Cancer navigation models should be viewed as complementary and may be combined in the practice setting

5. Financial advocacy services seek to mitigate the patient cost burden of cancer care by maximizing health insurance benefits and reducing economic barriers to care via patient assistance programs, financial advocacy tools, and resources
6. Community-based navigators and resources
   - Foundation-based navigators
   - Church-based navigators
   - Community public health workers

**Nurse**
A professional registered nurse with oncology-specific clinical knowledge. The nurse navigator acts as a liaison between the patient and the healthcare team, providing education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum.

**Social Worker**
Social worker with oncology-specific clinical knowledge who offers individualized assistance and resources to patients, families, and caregivers to help overcome healthcare system barriers.

**Lay, Patient, Nonclinical**
With a basic understanding of cancer, healthcare systems, and how patients access care and services across the cancer continuum, they connect patients to information resources and support.
Example: American Cancer Society Patient Resource Navigation Program and National Cancer Information Center

**Financial**
Financial advocacy services seek to mitigate the patient cost burden of cancer care by maximizing health insurance benefits and reducing economic barriers to care via patient assistance programs, financial advocacy tools, and resources.

**Other**
Community-based navigators and resources
- Foundation-based navigators
- Church-based navigators
- Community public health workers
The Goals of Oncology Navigation

Coordinate Care
- Timely access to care and support services, appointment referrals, test procedures, and other consults
- Ensure that the patient care plan is being followed

Advocate
- Serve as the patient advocate to ensure their voice is heard

Educate
- Diagnosis
- Treatment
- Management of side effects
- Clinical trials
- Shared decision-making

Identify
- Identify and resolve barriers to care
- Clinical, financial, and other resources for patients and caregivers
- Patients' life goals and incorporate into treatment plan

Provide
- Psychosocial support to patient and family

The Evolution of Cancer Navigation: AONN+ 8 Domains of Knowledge for Navigators

Community Outreach/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/Healthcare Economics

Research, Quality, and Performance Improvement

AONN+ Competencies\textsuperscript{1,3}
- Finding community resources
- Community needs assessment
- Identifying and resolving barriers to care
- Interventions to remove barriers to care
- Community education on prevention and screening
- Population health
- Risk assessment
- Cultural awareness
- Lifestyle behavior modification
- Genetics

AONN+ Competencies\textsuperscript{2,3}
- Identifying and resolving barriers to care
- Patient education (diagnosis, staging workup, biomarkers, treatment modalities)
- Multidisciplinary approach to care
- Tumor Board
- Practice guidelines (advent of new therapies & latest recommendations)
- Genomic testing guidelines
- Clinical trials
- Palliative care & hospice
- Survivorship care

Patient Advocacy/Patient Empowerment

AONN+ Competencies¹,³
- Communication with patients
- Collaboration with multidisciplinary team
- Education
- Cultural awareness
- Informed consent
- Engagement in shared decision-making

Psychosocial Support Services/Assessment

AONN+ Competencies²,³
- Distress screening
- Strategies for coping: disease, treatment, distress/anxiety
- Referrals to psychosocial support and resources

AONN+ Competencies

1. Begin survivorship care at time of diagnosis
2. Establishing goal-setting, life goals, & integrating into plan of care
3. Providing survivorship education on late- and long-term effects & living with advanced cancer in a chronic state
4. Coordinating plans of care
5. Understanding CoC Standard 3.3 Survivorship
6. Understanding of Institute of Medicine report, “From Cancer Patient to Cancer Survivor: Lost in Transition”
7. Understanding palliative and hospice care

AONN+ Competencies

1. Critical thinking, problem solving, ethics
2. Team building, leadership
3. History/evolution of navigation
4. Definition of navigation and types of navigation
5. Tracking workload
6. Documentation
7. Orientation and competencies
8. Staying current on advances in treatment
9. Active in professional organizations

Operations Management/ Organizational Development/ Healthcare Economics

AONN+ Competencies1,3
- Healthcare reform
- Utilization of resources
- Workforce shortages
- Organizational structure, mission, and vision
- Organizational development
- Healthcare economics

Research, Quality, and Performance Improvement

AONN+ Competencies2,3
- Define Triple Aim and how initiative drives quality
- Define healthcare environment that is the driving focus on quality and outcomes
- Address Institute of Medicine reports concerning the need for quality in healthcare and how they shape practice and initiatives in oncology
- Define evidence-based practice, quality, and performance improvement terminology
- Identify regulatory agencies that mandate quality improvement
- Identify evidence-based practice models
- Identify key quality and performance improvement tools
- Describe the steps to develop a quality improvement project
- Discuss how data are used for continuous improvement

Navigating Across the Care Continuum\textsuperscript{1-4}

Phases of the Continuum

1. Prevention and Risk Assessment
   - Tobacco control
   - Diet
   - Physical activity
   - Sun and environmental exposures
   - Alcohol use
   - Immunization
   - Coordination with community resources

2. Screening
   - Age and gender-specific screening
   - Smoking status

3. Diagnosis
   - Biopsy
   - Pathology reporting
   - Histological assessment
   - Staging
   - Biomarker assessment
   - Molecular profiling
   - Distress screening
   - Tumor board/multidisciplinary clinic
   - Prehabilitation

4. Treatment
   - Surgery
   - Radiotherapy
   - Systemic therapy
   - Targeted therapy
   - Immunotherapy
   - Bone marrow transplant
   - Referral to clinical trials

5. Survivorship
   - Surveillance for recurrences
   - Screening for related cancers
   - Hereditary cancer predisposition/genetics
   - Immunization
   - Survivorship and/or support group enrollment
   - Readdress psychosocial care needs

6. End-of-Life Care
   - Implementation of advance care planning
   - Legal planning
   - Hospice care
   - Bereavement care

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Key Elements of Financial Navigation: Addressing Economic Barriers to Cancer Care

• Ensure that all demographic, insurance, and eligibility information is obtained and up to date
• Screen and monitor patients on a regular basis for risk of developing financial toxicity
• Conduct insurance verification and preauthorizations to minimize disruption to care
• Document precertification of therapies to ensure that all treatments are authorized accurately and in a timely manner
Key Elements of Financial Navigation: Addressing Economic Barriers to Cancer Care (cont’d)

• Maintain up-to-date knowledge of manufacturer, state, and local medication assistance programs, nonprofit foundations, Medicare prescription benefits, and state and federal assistance subsidies

• Evaluate patients for available assistance from federal and state subsidies or programs, disease-specific assistance programs, patient assistance programs, and local community resources

• Work collaboratively with the healthcare team to obtain clinical and financial information for assistance program enrollment

• Work with patients and their family/caregivers to apply to the programs for which they qualify
Navigating Hematologic Cancer Patients
Primary Types of Hematologic Cancer

Lymphoma\(^1\)
- Originates in the immune system, and occurs when lymphocytes change and undergo uncontrolled cell growth
- Impacts the body’s ability to fight infection and produce healthy cells
- Two primary subtypes are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL)

Leukemia\(^2\)
- Occurs when bone marrow produces abnormal white blood cells, which “crowd out” the healthy red blood cells (RBCs), negatively affecting normal RBC function
- The 4 main types of leukemia are acute myeloid (or myelogenous) leukemia (AML), chronic myeloid (or myelogenous) leukemia (CML), acute lymphocytic (or lymphoblastic) leukemia (ALL), and chronic lymphocytic leukemia (CLL)

Multiple myeloma\(^3\)
- Occurs when plasma cells release too much protein (called immunoglobulin) into the bones and blood
- As plasma cells build up in the body, they disrupt the immune system, causing organ damage and disruption of normal bone formation

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Nuances of Hematologic Cancers

- Originate in blood, lymph nodes, and bone marrow, rather than forming a solid tumor
- Surgery is typically not a treatment option
- Bone marrow transplant and CAR T-cell therapy may be treatment options
- Common symptoms include weakness and fatigue, infections, fever/chills, pain, and weight loss
- Recent new treatment advances have substantially extended life expectancy in many hematologic cancers
  - Deep, durable remissions approaching cure may be achieved in some hematologic cancers

Patient Perception

- Cancer is everywhere rather than localized and cannot be “removed”
- In most hematologic cancers, patients cycle through multiple therapies over time, and fear of relapse is a constant
- Extended duration of treatment may result in cumulative financial and psychosocial burden on patients, caregivers, and family members

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# Cancer Care Continuum: Role of the Hematology Navigator

## Diagnosis
- Role in expediting diagnosis and educating patients
  - Lab testing
  - Genetic testing
  - Staging workup
  - Histology and biomarker testing
- Facilitating shared decision-making
- Barrier and distress assessments
- Tumor board participation
- Referral for second opinion
- Clinical trials
- Prehabilitation
- Patient treatment goals and quality of life
- Patient life goals
- Family support
- Insurance optimization
- Coordinating financial assistance
- Initiate palliative care discussions

## Treatment
- Educating patients on treatment options/reinforcing physician teaching
- Educating patients on treatment side effects, management, and palliative care
- Provide psychosocial/emotional support to improve treatment adherence
- Addressing spiritual needs
- Internal and external coordination of patient care
- Re-education as treatments change over time
- End-of-life planning (if applicable)
Cancer Care Continuum: Role of the Hematology Navigator (cont’d)

**Survivorship**

- Providing patients with treatment summary/survivorship care plan, including:
  - Late and long-term side effects
  - Follow-up medical management
  - Follow up with primary care physician to manage comorbid chronic conditions
  - Healthy behaviors (diet, exercise, screenings)
- Referral to rehabilitation
- Integrating patients’ goals and preferences into plan of care
- Quality-of-life preservation/restoration
- Support group referrals

**End of Life**

- Setting expectations
- Facilitating and educating patients on transition to hospice
- Address remaining legal planning needs
- Support patient decision around ending treatment
- Provide information about advance directives

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“A Day in the Life of a Hematology Navigator”

- Identifying and Addressing Barriers
- Psychosocial and Financial Support
- Care Coordination
- Advocacy
- Patient and Caregiver Education
- Professional Development
Identifying and Addressing Barriers

• Preparatory pre-call to plan ahead for the first patient appointment
  – Ensure that appropriate treatment team members are available to speak with the patient in person

• Facilitate coordination of care for first appointment and communicate needs to multidisciplinary team

• Conduct barrier assessment using standardized tools – 360-degree view of the patient’s life circumstances, goals, and challenges
  – Identifying barriers to accessing care (including transportation)
  – Identifying financial barriers
  – Addressing cultural/language barriers
  – Determining patient life goals
  – Identifying supportive care needs

“It is a great opportunity if you can speak with patients ahead of time to identify any barriers before they come in for that first appointment.”*

Care Coordination

• Serving as the central point of contact
• Coordinating between members of the treatment team
  – Medical care (oncologists, nurses, NPs/PAs) – treatment goals, patient workup/lab results, side-effect management, clinical trial education, palliative care
  – Patient support professionals (social worker, financial navigator, mental health) – financial needs, psychosocial needs, transportation needs, fertility counseling
• Coordinating between different sites of care
  – Transitioning from inpatient- to outpatient-based care
  – Coordinating between the cancer center and transplant center, if applicable
  – Coordinating between outpatient treatment at the cancer center and local community-based primary and specialty care
• Coordinating with pharmacy staff
  – Cancer center inpatient pharmacy, if patient is hospitalized
  – Cancer center outpatient pharmacy
  – External specialty pharmacy (if mandated by payer or manufacturer)

“The physicians provide general overview information, but (navigators) really put those patients on our backs and navigate them through a lengthy amount of time. It’s not like you just leave them there. You’re constantly on the phone and coordinating appointments and helping with financial needs.”*

Patient and Caregiver Education

• Coordinating/participating in individual or group educational sessions
  – Tailoring educational content and delivery modalities (ie, web vs print, reading-level appropriate) to meet patient needs
  – Creating/gathering/organizing educational content into resource compendia
• Reinforcing teaching about the disease process
• Setting expectations about treatment – what to expect
• Reinforcing the importance of adherence to the treatment plan
• Raising awareness about community-based resources (ie, support groups, advocacy organizations, manufacturer programs, housing assistance)
• Telephone follow-up with patients and/or caregivers

“Many different people – oncologists, nurses, financial counselors – are providing a great deal of information at the outset. We follow up and answer their questions. It allows patients to better absorb all that information.”*

Psychosocial and Financial Support

- Addressing patient transportation, financial, and lodging issues by facilitating referrals to community-based resources
- Referral for cognitive assessment
- Referral to mental health counseling
- Helping patients cope with relapses and initiation of subsequent treatment
- Coordinating with caregivers and family members
- Helping patients address work issues
  - Family Medical Leave Act
  - COBRA
  - Americans with Disabilities Act
- Coordinating financial assistance options and insurance optimization

“When patients relapse, their emotional health often changes for the worse. The financial toxicity also adds up over the course of treatment. Those things start to become daunting for many patients.”

*Direct quote from proceedings of Best Practices in Hematology Navigation Roundtable, November 15, 2018, Dallas, TX.*
Advocacy

- Patient engagement – encouraging patients to advocate for themselves
- Directing motivated patients to reputable sources of information
- Referral/coordination with support groups and other sources of community support organizations (churches, civic organizations, etc)

“As a navigator, you see the whole picture and have a unique understanding of what your patients need, and advocating on their behalf.”*

Professional Development

- Attending navigation conferences
- Continuous education programs
- Keeping abreast of medical literature in hematology
- Mentoring new navigation staff

“It is important that we educate ourselves as navigators because hematology is complex. It’s not just one disease site. There’s 10 to 15 of them.”*

Hematology Navigation Case Reports
50-year-old male patient diagnosed with AML living in an isolated rural area

- Patient received chemotherapy and bone marrow transplant. Treatment was successful, and patient is in follow-up care.

- AML diagnosis created substantial emotional and psychosocial burden for patient and his family:
  - Distance to care created stress on patient and caregivers (tertiary medical center is 4½ hours away; no emergency services available in reasonably close proximity)
  - Financial burden due to inability to work and uncertainty about returning to work
  - Potential loss of health insurance benefits

- Patient was assigned a team of providers, including a hematologist/oncologist, direct care nurses, a dietitian, a social worker, and a nurse navigator who was instrumental in coordinating care between members of the multidisciplinary team. Collaboration with his primary care provider ensured that he underwent close surveillance between chemotherapy cycles. However, several barriers remained:
  - Timeliness in posting routine lab results caused delays in recognizing abnormal values
  - Distance to care required that appointments be clustered to help ease the burden of travel

- 6-hour trip to transplantation center required careful coordination between primary oncology care team and bone marrow transplant team

- Patient’s pharmacy needs were challenging and required considerable coordination due to geographic isolation:
  - Timely delivery, storage, and handling
  - 90-day fills for certain medications to minimize burden

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50-year-old male patient diagnosed with AML living in an isolated rural area (cont’d)

IMPLICATIONS FOR PATIENT CARE

• By individualizing care, ensure timely access to and coordination of care for all patients with cancer, particularly those with hematologic malignancies

• Consider patient limitations created by geographic isolation and/or availability of resources, and address these when coordinating care

• Improve care delivery and overall outcomes by assessing patients, identifying needs, and working to link patients with available resources

32-year-old male patient diagnosed with non-Hodgkin lymphoma

- Patient is married with 3 children. He and his wife both work full-time. Patient is the primary beneficiary of health insurance for the family (employer-sponsored coverage)

- Treatment plan
  - Surgery in September
  - Chemotherapy in October through December (every 21 days)
  - Radiation in December and January

- Patient will miss a considerable amount of work time due to scheduled treatment and perhaps more due to side effects
  - Caregiver (wife) will also miss time from work

- Financial navigator (FN) recognizes workplace challenges
  - Apply for intermittent Family Medical Leave Act coverage if patient is not feeling well post-treatment
  - Investigates whether premium assistance is available
  - Provides patient with information about Americans with Disabilities Act provisions

- Since treatment extends over 2 calendar years, patient faces 2 annual deductibles ($5000 each year) as well as treatment-related out-of-pocket costs
  - Review for copay assistance for chemotherapy (manufacturer programs) and radiation (Leukemia & Lymphoma Society)
  - Application for hospital financial assistance for remaining balances

- Patient’s wife loses job in October, and patient cannot work full-time due to persistent nausea associated with chemotherapy. Patient and family face substantial hardship
  - FN reviews new income, and helps patient apply for Medicaid, food assistance (SNAP), and copay assistance
  - FN helps patient identify resources to help pay mortgage and utilities
32-year-old male patient diagnosed with non-Hodgkin lymphoma (cont’d)

**IMPLICATIONS FOR PATIENT CARE**

- Patients’ employment circumstances may change during treatment, bringing about potential financial hardship. Without help, patients may feel that they cannot complete therapy. FNs can uncover sources of assistance, thereby keeping patients on treatment for the entire duration, and potentially resulting in a better outcome for the patient.

- When evaluating their circumstances, the savvy FN must consider the entire family dynamic with regard to finances and caregiver support.
72-year-old female patient diagnosed with refractory/relapsed multiple myeloma

- Patient received multiple treatments over the past 8 years. Last treatment was 2 years ago. Patient did not receive a stem-cell transplant
- Patient has many barriers to care:
  - Widowed and lives alone in a boarding house with little social support
  - Insurance concerns as she stopped her secondary insurance since she was not getting treatment and only has Medicare Parts A and B
  - Uses public transportation for treatments but will only travel during daylight hours
  - Need for education regarding targeted therapies and toxicities of treatment
- Treatment plan: Cyclophosphamide/bortezomib/dexamethasone since patient had tolerated this in the past with minimal toxicities and a good response
- Patient was assigned a team of providers, including a nurse navigator to help assess and mitigate barriers to care. Collaboration with her team ensured that she was able to receive treatment
  - Navigator referred patient to financial counselors regarding re-establishing secondary insurance and prescription plan and other copay resources
  - Patient was referred to social worker to address social concerns regarding housing, transportation, and additional supportive care resources such as food banks
  - Frequent follow-up needed regarding compliance with oral medications
72-year-old female patient diagnosed with refractory/relapsed multiple myeloma (cont’d)

IMPLICATIONS FOR PATIENT CARE

- Navigators collaborate with the team to help individualize care by improving access and mitigating barriers that impede patient’s compliance with the plan of care.

- Consider the overall picture of the treatment plan being proactive to identify barriers early on in the patient’s treatment course.

- Insurance issues must be identified early on, and the patient needs to be connected to the proper resources to decrease out-of-pocket costs for care.

- Management of multiple myeloma with targeted therapies present many challenges. Patients on targeted therapies need a strong collaborative team to manage the plan of care to promote best outcomes.

Resources

• Academy of Oncology Nurse & Patient Navigators (AONN+)
  – Resources & tools, learning guides for certification
    www.aonnonline.org
  – AONN+ Standardized Metrics Source Document
    https://aonnonline.org/metrics-source-document/

• American Cancer Society
  – www.cancer.org

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

• Association of Oncology Social Work
  – www.aosw.org

• CancerCare
  – www.cancercare.org

• Cancer Support Community
  – www.cancersupportcommunity.org

• International Myeloma Foundation
  – www.myeloma.org

• Leukemia & Lymphoma Society
  – www.lls.org

• Multiple Myeloma Research Foundation
  – www.themmrf.org

• National Comprehensive Cancer Network (NCCN) Patient Guidelines
  – www.nccn.org/patients/guidelines

• OncoLink
  – www.oncolink.org

• Oncology Nursing Society
  – www.ons.org

• Triage Cancer
  – www.triagecancer.org
Thank you for your participation!

Any Questions?