LESSON INTRODUCTION

Welcome to What is Patient Navigation and What does a Navigator Do?

This lesson is part of the Oncology Patient Navigator Training: The Fundamentals course. My name is Zarek Mena from Patient Navigation Advisors, and I will be your presenter for this lesson.

Before we begin, we would like to acknowledge the Centers for Disease Control and Prevention for supporting and funding this work.

Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

We would also like to thank:

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After completing this lesson, you will be able to:

- Describe political and social determinants of health and why these are relevant to patient navigation
- Describe why certain populations continue to experience cancer health disparities, and
- Define what patient navigation is and what a patient navigator does

The material in this lesson has been broken down into 3 videos. Please join me in the next video where we will begin this lesson by learning about what social determinants of health are, and how they impact people.

LESSON SECTION I

We will begin this section of the lesson by exploring what social determinants of health are and how they influence health outcomes.

To start, let's consider a story that illustrates how navigation can play a role in promoting health equity on a broader scale.

In the following video, Dr. Daniel Dawes discusses the concept of political determinants of health and their impact on communities.
[VIDEO]

Let's start with the most logical and straightforward reason why patient navigation is of value: As an evidence-based strategy to reduce historical health injustice, it is the right thing to do. This topic is also covered in another lesson titled the value of patient navigation.

As stated by Dr. Martin Luther King, Jr. in 1966: "Of all the forms of inequality, injustice in health is the most shocking and inhuman."

What is health literacy? The Centers for Disease Control and Prevention, provided an updated definition of health literacy in the August 2020 U.S. government's Healthy People 2030 initiative. The update provides the following definitions:

- Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

- Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

The new definitions emphasize people's ability to use health information rather than just understand it. They focus on the ability to make "well-informed" decisions. They also acknowledge that organizations have a responsibility to address health literacy directly to advance health equity.
Health equity is the attainment of the highest level of health for all people.

In a 2022 analysis, an estimated 88% of adults in the United States had challenges navigating healthcare due to limited health literacy. Low health literacy is frequently associated with other determinants like social and economic factors which reinforce health inequities. Improving health literacy throughout a population advances health equity and needs to be a priority of public health policy.

The consequences of low health literacy are linked to lower use of preventive care, less adherence to treatment, more hospital stays, and higher mortality. All of these consequences are costly to health care systems for a wide variety of reasons.

While low health literacy results in poorer health outcomes generally, the complexity of cancer care amplifies the challenges patients face in understanding and acting on information to optimize their health and wellbeing.

Cancer treatments are complex with multiple steps for screening, diagnosing, initiating treatment, surgery and managing cancer symptoms - especially with multimodal treatment regimens and the option of clinical trials.

Navigating the healthcare system for anyone, regardless of age or education level can be extremely challenging. As a person with cancer or an informal caregiver - especially for those facing multiple barriers to accessing health care - it can be an overwhelming experience.

Patient navigation can support patients through the cancer care continuum by offering tailored assistance and education at each stage of the journey. Let's explore the areas where patient navigation plays an important role:

1. Prevention: Promoting healthy behaviors within specific communities in a culturally-affirming way
2. Detection: Educating people about cancer screening guidelines, including age, intervals, and risk factors, helping people access insurance and screening programs
3. Diagnosis: Providing education on healthcare system protocols to help people understand the steps involved, facilitating coverage of diagnostic procedures, Checking patient understanding of next steps
4. Treatment: Assessing language and literacy to help patients comprehend their treatment plans, Helping prioritize questions, Educating on team roles and how each team member supports their care, Supporting adherence to treatment plans, Supporting self-advocacy and shared decision-making, Assisting with financial aid and resources

5. Survivorship: Educating about the importance of follow-up care, providing reading-level, culturally appropriate, evidence-based information on cancer survivorship, Serving as a liaison for patients and survivorship clinicians
6. End-of-Life Care: Educating on the difference between palliative care and hospice, Supporting the completion of advance care directives

Patient navigators have an important role in assisting patients to receive support and information they need at every stage of their cancer care journey.

You may often hear references to the social determinants of health.

According to the U.S. Department of Health and Human Services, 'Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.'

As highlighted in the video at the beginning of this lesson, the circumstances and environments surrounding us, the resources we can access, and the support systems available to us significantly shape our lives.

Both social and political determinants of health contribute to and sustain health disparities.

For patient navigators, understanding the impact of these determinants is important in recognizing the diverse challenges that people face beyond the clinical setting.

To better understand how these factors impact cancer care and health, let's explore five major social determinants of health. These are not all the ways that our contexts influence our health, but these are some of the primary influences on our health:

1. Degree of educational attainment is related to early childhood education and development, literacy, facility in the language that most teachers use in the classroom - in the U.S., this is primarily English. Degree of education includes high school graduation, attainment of a General Education Development (GED) diplomas, and enrollment in higher education, like college and university.
2. Access to quality health care, including access to a regular source of primary care, and health literacy strongly affect a person's health and health care.
3. Neighborhood and built environment is related to access to healthy foods, quality of housing, crime and violence and environmental conditions
4. Social and community context is affected by the degree of social cohesion a person experiences. Social cohesion means the strength of relationships in someone's life. Social and community context is also comprised of civic participation, perceptions and experiences of discrimination and privilege, and history of incarceration or institutionalization
5. Economic Stability is influenced by poverty and stability of employment as well as type of employment, benefits, and conditions of employment. Food security and housing stability rely on economic stability.

Proximity of services and transportation to services also affects accessibility. This is because being close enough to a service or social benefit or reliable transportation to that social benefit - such as ability to reach school, a job, a doctor, or emergency care - are fundamental to being able to benefit from that service. In other words, not only do educational services, opportunities for employment, and opportunities for social

engagement need to be available; people need to be able to physically get to those services to benefit from them. If someone is not within walking distance or is unable to walk and has no reliable transportation, they will also have challenges getting to a grocery store, a library, a pharmacy and any number of other services that directly affect their health and wellbeing.

By understanding a person's social and political circumstances, navigators can better address barriers to care that directly affect the health and wellbeing of that person.

Here's a brief video from the American Public Health Association to learn more about the social determinants of health and understand how those barriers may interfere in a person's health.

[VIDEO]

As mentioned in the video, our health is affected by many issues that can work together to be more challenging. It is important that these issues are taken into consideration by the health care team.

You might encounter the term underserved or medically underserved population. Medically underserved populations face significant barriers to accessing healthcare, which are influenced by social and political determinants of health previously discussed.

Medically underserved populations include people who are:

- underinsured or uninsured, including young adults and postsecondary graduating students who do not have coverage options through a parent's plan, a student plan, or an employer plan as well as Medicaid-eligible consumers who are not enrolled in coverage despite being eligible for Medicaid
- people with lower levels of education
- people with limited English proficiency (LEP)
- rural and inner-city populations
- people who are unemployed
- people with lower socioeconomic status
- new mothers and women with children
- people with disabilities
- racial and ethnic minorities in the U.S., including Black, African immigrant, American Indian and Alaska Native, and Hispanic/ Latino populations
- refugees, and
- lesbian, gay, bisexual, transgender, and queer populations also experience challenges in healthcare that others may not experience due to the impact of societal stigma.

Let’s take a moment to review this video from the American Association for Cancer Research on health disparities and what needs to happen to address disparities.

[VIDEO]

As noted in the video you just watched, factors that may contribute to cancer health disparities include financial constraints, psychological challenges, invisibility in the health care system, and logistical challenges.

Related challenges include:

1. Lack of Medical Coverage: Many people either lack health insurance altogether or have insurance that doesn't cover necessary treatments.
2. Barriers to Early Detection and Screening: High costs and low health literacy can prevent early diagnosis and timely intervention.
3. Unequal Access to Advanced Treatments: Not everyone has access to the latest and most effective treatments due to disparities in healthcare availability.
4. Socioeconomic Status: Factors such as income, education level, and occupation significantly impact a person's ability to access quality healthcare.
5. Healthcare Bias and Social Stigma: Discrimination and bias within the healthcare system, as well as societal stigmas, can further hinder equitable treatment and care.

These challenges collectively impede access to equitable healthcare for many individuals.

The opposite of health disparities is the achievement of health equity.

Health equity is defined by the World Health Organization as "the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically, or by other dimensions of inequality such as sex, gender, ethnicity, disability, or sexual orientation."

Patient navigators are essential in helping to achieve health equity.

In this section, we have covered the social determinants of health and cancer health disparities. Join me in the next video where we will dive into what patient navigation is, some key milestones and models of patient navigation.

LESSON SECTION II

In the prior section of this lesson, we've discussed social determinants of health which contribute to cancer health disparities. In order to reduce these disparities, let's turn our attention to this next topic to uncover what patient navigation is and how patient navigators contribute to health equity. Before we define patient navigation, let's learn about its formation.

Some of the earliest hospitals in the country were established in Philadelphia, New York, Boston, and Baltimore. Pictured here is the Pennsylvania Hospital established in 1751.

In the early 1800's, social assistance programs in London inspired the development of similar programs in the United States to meet the growing need for organized health care to treat infectious diseases. From 1898 to 1918, the American Hospital Association grew from eight to over 1,000 members. Then in the 10 year period between 1905 and 1915 social workers were hired in more than 100 hospitals throughout America.

Oncology social work evolved as a specialty within medical social work. Pioneers in medical social work developed professional roles similar to those of today's oncology social workers, working alongside physicians and nurses in hospitals and clinic settings. Long before the term patient navigation was coined, many of the functions of navigators were being performed by case managers, nurses and social workers. The emergence of patient navigation as its own field allows these health care professionals to focus on their skilled expertise while navigators focus on addressing logistical and practical barriers to care.

With this rich backdrop of care coordination in oncology practice, a new role was distinguished by Dr. Harold Freeman to specifically address nonclinical barriers to care for patients. The first patient navigation program was initiated in 1990 by Dr. Harold P. Freeman in Harlem, New York. Dr. Freeman, a surgeon, observed persistently worse outcomes for the African American women he treated for breast cancer. He noted that half of these people lacked insurance during their initial visit, and their 5-year survival rate was only 39%. Alarmingly, nearly half presented with stage 3 or 4 disease.

Dr. Freeman recognized that his patients fared much worse compared to national averages, often seeking care only after their cancer had significantly advanced. To address the health disparities among his patients, Dr. Freeman implemented two key initiatives. First, he offered free and low-cost exams and mammograms. Second, he hired patient navigators to help address barriers to timely care. He noticed a number of obstacles that delayed patient care: financial barriers such as lack of health insurance, communication and information barriers, complexities within the medical system, and emotional barriers like fear and distrust.

As a result of these efforts, the 5-year survival rate for his patients increased dramatically from 39% to 70%. Additionally, the percentage of patients presenting with late-stage disease decreased to about 20%.

These initiatives led to substantial improvements for patients who had previously faced significant health disparities.

Patient navigation, as defined by the Centers for Medicare & Medicaid Services, in the context of healthcare refers to providing individualized help to the patient (and

caregiver, if applicable) to identify appropriate practitioners and providers for care needs and support, and access necessary care timely, especially when the landscape is complex and delaying care can be deadly.

Patient navigation is an evidence-based strategy to address health disparities by providing personalized assistance to people with cancer, survivors, and their families and began as a way to address barriers to care among those having trouble attaining basic, standard of care. Barriers can include lack of reliable transportation, low health literacy, difficulty communicating with healthcare providers, and financial constraints. Patient navigators play an important role in addressing these challenges.

The Key Aspects of Patient Navigation are:

- Addressing Barriers: Patient navigators help people overcome obstacles that make accessing care difficult. For instance, they can arrange transportation to treatment appointments, explain medical information in understandable terms, facilitate communication between patients and healthcare teams, and find financial assistance programs.
- Individualized Assistance: A core function of patient navigators is to assess each person's unique needs and preferences. They develop personalized plans to help people overcome barriers, ensuring that the support provided is tailored to each individual's circumstances.
- Note that there are limits to what a navigator can do, so while navigators can address barriers to care, not all barriers can be removed for every person. We will learn about addressing barriers to care in another lesson.

There are different roles within and outside the healthcare system that perform navigating functions. Though they may fall under the umbrella term of "navigator," confusion exists about their unique roles and responsibilities. Community health workers (CHWs), patient navigators, and social workers, all may have overlapping yet distinct roles and responsibilities.

A Community Health Worker is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison, link, or intermediary between health, social services and the community to facilitate access to services and improve the quality and cultural appropriateness of service delivery. A community health worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.

A Professional Navigator is a trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of a navigator. Positions that fall under the professional navigator category include oncology patient navigators and clinical navigators. Clinical navigators are comprised of oncology nurse navigators and oncology social work navigators. The Oncology Navigator roles we focus on in this training fall under this category.

A Social Worker is a person with various professional activities or methods concretely concerned with providing social services and especially with the investigation, treatment, and material aid of the economically, physically, mentally, or socially disadvantaged.

To help clarify the different roles in oncology, in 2022 the Professional Oncology Navigation Task Force issued standards of oncology navigator professional practice, you may hear these referred to as PONT standards. The standards intend to provide benchmarks for healthcare employers and information for policy and decision makers. The standards provide guidance for application to professional practice.

Definitions of various navigation roles according to these standards fall under the umbrella of professional navigator. Again a Professional Navigator is 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.

According to the PONT standards, Oncology Navigation is defined as individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre diagnosis through all phases of the cancer experience.

An Oncology Patient Navigator is a a professional who provides individualized assistance to people with cancer 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.

A Clinical Navigator/Oncology Nurse Navigator is a professional registered nurse with oncology-specific clinical knowledge who offers individual assistance to people with cancer, 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.

A Clinical Navigator/Oncology Social Work Navigator is 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 people with cancer, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social worker 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.

Let's dive deeper into how their roles compare.

Specific scope of practice of navigating professionals should be based on their education, training, lived experience, and context. Here is an example of how an oncology patient navigator role differs from that of licensed professionals such as an oncology nurse navigator or oncology social work navigator who is performing navigating functions.

Of course, depending on whether there are patient navigators AND nurse navigators AND social workers on a particular team, Nurse Navigators and Social Work Navigators may take on patient navigator roles that don't require a clinical license.

The core function that all navigators have in common is addressing barriers to care to reduce health disparities. Barriers to care and/or health disparities refers to identifying and addressing barriers to care and reducing health disparities as defined by age, disability, education, ethnicity, gender, sexual identification, geographic location, income, or race and populations that often bear a greater burden of disease than the general population.

Community health workers might address barriers to access in the healthcare system and focus on reducing health disparities in general.

Patient navigators address structural, cultural, social, emotional, and administrative barriers to care. They focus on reducing health disparities for people who are medically underserved and help them get timely access to care across the continuum.

Nurse Navigators and Social Workers are uniquely positioned to address clinical and service delivery barriers to care.

All roles of a professional oncology navigator perform assessments for patients, most likely in the form of a distress screening.
Again, depending on whether there is a team in place for navigation or just one person,
nurse navigators and social workers may perform functions of patient navigators,

but oncology patient navigators that are not licensed as a nurse should never directly address a clinical need - that should be elevated to nurse triage.
Within assessing patients, oncology patient navigators who are not licensed as social workers should never provide counseling - that should be elevated to a mental health professional.

Survivorship and transition into end of life can share many similarities across these roles, with the biggest difference being in the support of psychosocial services to patients from navigators vs the provision of psychosocial services to patients which can only be done by appropriately licensed clinical oncology social work navigators.

While navigation is most often delivered by a navigator, an actual person, some also describe navigation as a process rather than a person. Different healthcare settings incorporate navigation in various ways. This is why patient navigation programs can vary widely across different organizations and can differ based on several factors such as the employing organization, the number of navigators, the point in the continuum of care they focus on, the type of cancer, and the type of patient served.
Types of Organizations: Many patient navigators work within cancer programs at hospitals or clinics, while others are part of community-based organizations. Some navigators work in hybrid roles, providing resources from their parent organization while operating within a cancer care setting.

Number of Navigators: The structure of navigation programs can also differ in terms of the number of navigators. Some programs may have a single navigator, while others may employ multiple navigators to handle different aspects care.

Continuum of Care: Patient navigation programs can focus on different points in the continuum of care. Some navigators follow patients across the entire continuum, from screening to treatment and beyond, ensuring consistent support. Others may specialize in specific stages, such as screening or treatment, and may either transition someone to another navigator or provide focused assistance at that particular stage.

Cancer Types and Patient Focus: Navigation programs may cater to people with specific types of cancer or any type of cancer. Additionally, some programs are designed to serve all people, while others focus on high-need or underserved groups of people, such as LGBTQ+ individuals, high-risk groups, and BIPOC (Black, Indigenous, and People of Color) communities.

Patient navigators are essential in bridging gaps in care and addressing the social determinants of health that contribute to cancer disparities. By providing individualized support, ensuring timely access to care, and advocating for necessary resources, patient navigators help move us towards a more equitable healthcare system. In the next section, we'll discuss the types of things navigators do.

LESSON SECTION III

Patient navigation can support people through the cancer care continuum by offering tailored assistance and education at each stage of the journey. Let's explore major areas where patient navigation plays an important role:

Prevention:

- Promoting healthy behaviors within specific communities in a culturally-affirming way.

Detection:

- Educating people about cancer screening guidelines, including age, intervals, and risk factors.
- Helping people access insurance and screening programs.

Diagnosis:

- Providing education on healthcare system protocols to help people understand the steps involved.
- Facilitating coverage of diagnostic procedures.
- Checking understanding of next steps.

Treatment:

- Assessing language and literacy to help people with cancer comprehend their treatment plans.
- Helping prioritize a person’s questions.
- Educating on team roles and how each team member supports their care.
- Supporting adherence to treatment plans.
- Supporting self-advocacy and shared decision-making.
- Assisting with financial aid and resources.

Survivorship:

- Educating about the importance of longitudinal follow-up care with survivorship clinicians or clinics.
- Providing reading-level, culturally appropriate, evidence-based information on cancer survivorship.
- Serving as a liaison for a person with cancer and survivorship clinicians.

End-of-Life Care:

- Educating on the difference between palliative care and hospice.
- Supporting the completion of advance care directives.

Patient navigators are essential in ensuring people with cancer receive the support and information they need at every stage of their cancer care journey.
In this section, we discussed the history of patient navigation and the key aspects of the patient navigation role. In the last section of this lesson, we will cover the tasks of the patient navigator and go through a few case studies that a navigator might encounter.

Another way of thinking about the duties of a navigator is to think about what actions can help people, or "tasks", and what ways to interact with others to eventually complete those, or how to "network". Navigator tasks can be categorized as navigating, facilitating, researching resources, maintaining systems, documenting activities, and receiving information. In another lesson we will review the different standards and levels of patient navigators.

Navigating tasks are those that specifically involve identifying and addressing barriers with someone with cancer. Such tasks may include explaining, like explaining health insurance. Asking questions, such as "what barriers make it difficult to attend appointments or adhere to the treatment plan?" Navigators engage in active listening.

This means to listen attentively to the person as they discuss their fears or goals. Finally, navigators coach them to be involved in their treatment and decision making. A form of coaching is to discuss questions with someone to help them prepare for appointments.

The next category of tasks, facilitating tasks, encompass activities completed for the patient. These include:

- Finding people who need navigation to follow up and ensure they are adhering to treatment.
- Coordinating team communication by updating members of the health care team on patient concerns
- Integrating information through documentation and sharing with team, and
- Collaborating by referring people to appropriate members of the health care team to address their needs and concerns.

As discussed in the previous lesson, the main role that all patient navigators have in common is addressing barriers to care. The patient navigator helps people identify and overcome potential challenges to getting the needed medical care. Sometimes the navigator directly removes barriers for people, but oftentimes the navigator helps the person remove barriers themselves.

Maintaining systems are tasks to complete that benefit all people. These include:

- Identifying potential people who can benefit from navigation services
- Building networks and referral routines, which includes helping clinicians understand the navigator role and criteria for referral and

- Reviewing cases

Documenting navigation activities and receiving information is the fourth navigating task. Depending on the institution, this may include:

- Charting to track navigation activities in the patient's record or navigation software or tools.

We will talk more about this in another lesson as well.

The "other" category includes tasks that may not be directly related to navigating someone, but may be important in supporting your organization. Examples could be

- administrative duties to support research, such as collecting informed consent forms, or
- collaborating with the healthcare team

These duties can vary based on your skill, background and the needs of your organization.

Networking duties of navigators may include:

- Communications with patients and their caregivers. These can be face-to-face or by phone call.
- You will also interact with healthcare team members. You will need to communicate patient concerns with the health care team and establish procedures for referrals.
- Your activities will extend to non-clinical staff as well, such as receptionists or administrators. You may work with these professionals to facilitate financial paperwork or to schedule appointments.

- To further address someone's barriers, you may need to connect with formal support services such as social workers, certified medical interpreters or transportation staff, or with informal support sources like family or friends.
- Finally, although documenting navigation activities has been covered as a navigator task, it is important to know that you also interact with paper or electronic medical records. You may need to consult these documents before determining the best course of action.

This concludes our lesson on "What is Patient Navigation and What Does a Navigator Do?" Throughout this lesson, you've gained an understanding of the social determinants of health and their critical role in patient navigation. We've also explored why certain populations continue to face cancer health disparities and discussed the role patient navigators play in addressing these challenges. By understanding these concepts, you are better equipped to support diverse populations and contribute to more equitable healthcare outcomes.

Thank you for your active participation in this lesson. Your commitment to learning and improving patient navigation practices is invaluable as we work together to provide the highest quality care to all people.