LESSON INTRODUCTION

Welcome to 'Addressing Barriers to Care with Strengths-based Community and Individual Assessments', part of the Oncology Patient Navigator Training: The Fundamentals course. My name is Jess Quiring, Owner and Managing Partner at Patient Navigator Advisors, and I will be your presenter for this lesson of the course.

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After this lesson you will be able to:

- Describe potential barriers to care that patients may encounter
- Describe the purpose and navigator role in community needs assessments

- Identify strategies to conduct a community needs assessment
- Create a resource directory
- Evaluate resources for appropriateness
- Describe a framework to assess patient's strengths and assist patients
- Identify strategies to remain neutral and non-judgmental
- Determine and prioritize challenges to accessing care with a patient
- Describe and apply strategies for helping patients cope with a cancer diagnosis
- Identify situations in which clinical referral is required

This lesson is divided into 7 sections where we will cover a few of these objectives at a time. Join me in the next video to get started.

LESSON SECTION I

Patient navigation is an evidence-based intervention to address the barriers to care faced by people affected by cancer through individualized assistance. Barriers to care are those obstacles that prevent a person with cancer from accessing treatment, services, resources, and/or support.

How do oncology patient navigators identify and determine barriers to care for a person with cancer? Most programs use tools which may have a variety of titles by may be called assessments, surveys, or distress screenings. We will revisit these tools later in the training. For now we are going to focus on the different barriers patients may encounter.

The Supportive Care Framework for Cancer Care categorizes patients' needs into 7 domains. The framework was designed as a tool for cancer care professionals and program managers to conceptualize what type of help a person with cancer might require and how planning for service delivery might be approached. While enhancements and revisions have been made to this framework to reflect more holistic care for the entire patient, this original framework helps us to understand barriers. These domains are:

- Physical
- Informational
- Emotional
- Psychological
- Social
- Spiritual
- Practical

When addressing barriers for individuals diagnosed with cancer, it is important to consider their current physical condition at the time of diagnosis and throughout the treatment process. There are several key physical barriers to keep in mind before, during, and after treatment:

- Pain and Pain Management: Consider the level of pain the patient is currently experiencing and how pain will be managed throughout treatment.
- Physical Comfort and Mobility: Assess the patient's need for physical comfort and mobility assistance. Does the patient have full mobility or rely on assistive devices like a wheelchair or walker? Will treatment affect their mobility? When visiting the clinic, will they require special assistance or equipment to ensure their comfort and facilitate their care? These factors will influence the type of resources needed. It is important to consider these patient needs when scheduling appointments, especially when specialized equipment or transportation is required.
- Comorbidities: It is important to account for any pre-existing chronic conditions the patient may have. By addressing the specific effects of these comorbidities on cancer treatment, more tailored interventions can be provided.
- Treatment Side Effects: Side effects such as nausea, pain, fatigue, cognitive changes, and others may present additional barriers for patients. While some side effects may not interfere with treatment, others can hinder the patient's ability to continue their treatment plan. In such cases, a patient navigator can provide resources and strategies in consultation with the clinical team.

Patients require clear, comprehensive information to understand their diagnosis, treatment, and available services. The challenge is creating a comfortable environment that encourages open dialogue and provides opportunities for patients to ask questions. Information needs include details about cancer, care processes, symptoms, treatments, procedures, coping strategies, and available support services.

Several barriers can arise originating from the health care team that may hinder communication, including:

- Biases in medical recommendations, such as offering clinical trials more frequently to white patients than to patients from other socially constructed racial groups
- Difficulty communicating with patients who have low literacy levels
- Communication in only English with patients who have limited English proficiency
- Cultural dissonance, where differences between cultural expectations and institutional practices cause discomfort and harm to patients. An Example of this would be if traditional healers are not included in treatment discussions for patients who rely on them.
- Missed opportunities for care, where certain tests or procedures that could inform and improve care are not recommended

In addition, barriers may emerge from inefficiencies within the healthcare setting itself, including:

- Lack of access to interpreters
- Long wait times
- Shortages of critical health care professionals
- Inconvenient appointment times that do not work for people that do not have paid time off during business hours

All patients need emotional support to help them navigate the challenges of their cancer journey. The key is finding the right type of support, whether that involves connecting them with a support group or referring them to a mental health professional. Emotional barriers relate to a person's need for comfort, belonging, understanding, and reassurance during stressful times. Because these needs can shift as life changes and unexpected events arise, it can be difficult to determine the best way to assist or intervene to help someone cope.

Common emotional barriers include:

- Mistrust of the healthcare system or professionals - and to be clear, this mistrust is often deserved based on past historical abuse of Black, indigenous, and queer populations
- Emotional distress
- Grief and loss
- Feelings of powerlessness
- Fear or anxiety
- Abandonment
- Shame or self-blame
- Lack of knowledge about health and the healthcare process
- Low priority placed on personal health, and
- Belief in health myths, which can lead to delayed care. - For instance, in some communities, hospitals are seen as places where people die. This myth can prevent individuals from seeking timely medical attention. As a result, when they eventually seek care for advanced cancer, their chances of survival may be reduced, which reinforces the misconception that hospitals are places where death is inevitable.

Psychological barriers can also play a significant role in a patient's experience. Some individuals may face challenges such as:

- A crisis of self-worth, struggling to find meaning or value in their life after diagnosis
- Heightened concerns about body image or changes in sexual health
- Difficulty coping with the emotional and physical aspects of their diagnosis and treatment
- Stigma, fear, or feelings of social isolation, and
- Mental health challenges such as anxiety, depression, or other psychological conditions

Social barriers can also impact a patient's well-being. Some individuals may face:

- Shifts in roles within their household, relationships, or social status - consider, for example, if the primary caregiver of the family is diagnosed with cancer and now has to accept help from other family members - this requires role changes, patience and flexibility across the family
- Challenges related to family dynamics and support systems
- Difficulty navigating the reactions of family members, children, or their community
- Struggles in maintaining social relationships at school or work
- Interpersonal communication difficulties, whether due to treatment side effects or emotional coping
- Feelings of stigma or shame in sharing their diagnosis with others

Spiritual and personal barriers can also emerge throughout someone's cancer journey, often stemming from deeply held emotions, values, beliefs, or cultural traditions. These barriers may manifest in several ways, including:

- Emotional distress during the search for meaning or purpose in life.
- Shifts or changes in spiritual or religious beliefs as a result of the diagnosis.
- Discomfort or distress when contemplating death, dying, or the afterlife.
- Conflicts between personal beliefs and recommended cancer treatments.
- Reevaluation of personal values and priorities, possibly leading to feelings of uncertainty or confusion.
- A deep sense of hopelessness or despair about the future.
- Specific ritual or dietary needs that must be considered during treatment.
- Changes or struggles in one's relationship with the sacred or divine.

Practical barriers often relate to a patient's daily life and environment, and they can significantly affect access to care. These obstacles might include:

- Financial challenges, such as high treatment costs, copays, coinsurance, or deductibles that may be difficult to afford.
- Lack of reliable transportation, whether due to not having a vehicle, insufficient funds for public transportation, or difficulty accessing transportation services.
- Language barriers, which can make it hard for patients to fully understand their diagnosis, treatment options, or medical instructions.
- Work-related difficulties, such as trouble getting time off for appointments or the risk of losing a job due to time spent away for medical care.
- Limited access to food, which may affect nutrition and overall health.
- Insurance issues, where patients may lack coverage, face claims denials, or struggle with limited coverage for the treatments they need. Navigators can play

a key role in resolving denied claims and guiding patients through the insurance process.

- Unstable housing, which can impact a patient's ability to maintain consistent care.
- Immigration status, which might prevent individuals from seeking preventive screenings or accessing necessary medical services.

Navigators regularly encounter a range of barriers in their work. A 2017 systematic review published in the Journal of Oncology Navigation and Survivorship identified common barriers in oncology patient navigation. These included financial and insurance challenges, care coordination issues, transportation difficulties, lack of information, and social/psychological barriers such as fear, distrust, lack of child care, and family healthcare education. Marginalized populations also often face language or cultural barriers.

The variety and severity of these barriers can be influenced by the location of the cancer center and the demographics of the patient population. While research has highlighted these common barriers over time, navigators work most efficiently and effectively when they have a deep understanding of their specific community and its unique needs.

This leads to the next important topic: community needs assessments.

A patient navigator with a solid understanding of the general community, the health system, and the strengths and weaknesses of both will be better prepared to address barriers for patients efficiently. In the following section, various assessments will be reviewed to help identify the barriers and strengths present within the community.

The Public Health Accreditation Board defines a Community Health Assessment (CHA) as a comprehensive analysis of a community's current health status, the factors contributing to higher health risks or poorer outcomes, and the available resources to improve health. CHAs compile data from multiple sources to describe demographics, health status, morbidity and mortality rates, socioeconomic characteristics, quality of life, community resources, behavioral factors, the built environment, and other social and structural determinants of health. These assessments are typically conducted by local public health departments, often at the county level, every five years.

Similarly, Community Health Needs Assessments (CHNAs) are the responsibility of hospitals and focus on identifying the health needs within the hospital's service area. Depending on the scope of the hospital or health system, a CHNA may cover a local area or a broader regional or statewide population.

Both CHAs and CHNAs aim to collaborate and prioritize a community’s most pressing health needs, implementing strategies to address them. Hospitals and public health departments can work together to effectively meet these community health needs.

Community assessments offer several key benefits. The results can guide navigators in identifying barriers that may frequently impact their patients and help pinpoint resources to improve service delivery. The process of conducting an assessment also brings its own advantages. Through the coordination and exchange of information required, it provides an opportunity to build connections with public health professionals and organizations in the community.

An excellent resource for assessing and addressing barriers to care within your community is the GW Cancer Center's Roadmap for Addressing Barriers to Care. This road map was developed to guide cancer care professionals and administrators in identifying both health and psychosocial barriers that patients may encounter when accessing care.

The road map is a helpful, actionable tool for understanding patient needs and can be downloaded from the resource section of this training.

The GW Cancer Center's Roadmap for Addressing Barriers to Care outlines four key steps that are particularly valuable when conducting a community needs assessment or evaluating barriers in your cancer program:

Step 1: Conduct an analysis of cancer care barriers by reviewing and analyzing the strengths and barriers within your program. There are several resources you can use in this step, such as Cancer Quality Improvement Program (CQIP) reports, patient satisfaction surveys, and local or state data on cancer care.

Step 2: Identify the barriers that are most relevant to your program. Barriers can exist at various levels, including patient, healthcare team, or system-level. For example, you may discover specific challenges related to patient access to care, implicit biases that are perpetuating health outcome disparities, or policies that that do not provide affirming care environments

Step 3: Implement strategies to address identified barriers. Leverage community resources, collaborate with local organizations, or develop partnerships to close gaps in care. For instance, you might collaborate with local health centers to host screening events or find teams that offer specialized cancer exercise programs.

Step 4: Modify or enhance the process based on the short-term outcomes. This step involves evaluating the entire process, identifying areas for improvement, and finding ways to streamline care processes for better patient outcomes.

LESSON SECTION II

Now that we have discussed common barriers and the importance of analyzing both the community and health system, we will transition to identifying and cataloging resources that are responsive to patient needs.

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Resources and assets are available at various levels. We will provide a brief overview here and delve deeper into each category later. Begin by engaging with patients to help them identify their own strengths and personal network resources. This includes connections with family and friends. Next, explore local community resources, followed by state, regional, and national assets that can support patient needs.

To find out about state, regional, and national resources, you can search online and call organizations. You can learn about governmental and nonprofit assistance this way. For example, www.benefits.gov is the U.S. government's portal to searching for and finding out about public benefits. The website lets you type in the patient's information and desired services and makes a list of benefits that your patient might be eligible for. Examples include childcare, housing, income and food support.

Other websites can help you identify additional resources available through the non-profit sector. Sometimes finding resources can be hard because each non-profit organization has a different menu of services, have their own eligibility criteria and documentation requirements, have different language capacity, and may only service specific geographic locations or patients with specific types of cancers. The Cancer Financial Assistance Coalition's website www.cancerfac.org can be useful in helping you find a good match for your patient by allowing you to search for organizations by diagnosis, assistance type and zip code. Large well-established cancer organizations may be good starting points for identifying resources because they often offer a wide variety of services ranging from support groups, to print materials and workshops, to financial assistance. Even if these organizations do not have the services that your patient needs, organization staff may be very well-connected and may sometimes be able to refer you to other organizations that they know about who can help. For example, CancerCare has a published directory of organizations that provide financial and other material support.

Here are some more examples of government and non-profit organizations that many navigators find useful:

The National Cancer Institute is an authoritative source on cancer-related information and has cancer-specific patient and provider information.
If you want to find an affordable medical home for a low-income patient, you can search the Health Resources and Services Administration’s national network of safety net community health centers.

The government can also offer your patient tangible assistance through programs such as disability benefits through the Social Security Administration, food stamps, and Home Energy Assistance Program. There may be special programs and resources offered through your state or city government as well. For example, in New York City, Access-A-Ride provides low cost door-to-door shared rides to eligible residents who can’t access public transportation due to disabilities.

There are many national non-profit organizations that support people with cancer in a wide variety of ways. For example:

The American Cancer Society and CancerCare offer patient education print materials in multiple languages. In addition the American Cancer Society may be able to assist patients with transportation and lodging.

The Cancer Support Community delivers free navigation resources to people with cancer and their caregivers. They also administer a toll-free helpline, and produce educational and digital resources on cancer support.

Colorectal Cancer Alliance provides free resources like a navigator help line, and The Blue Hope Financial Assistance Fund and screening support is here to help low-income individuals receive screening support and help meet financial needs during cancer treatment.

Facing Hereditary Cancer Empowered, known as FORCE, is dedicated to providing up-to-date, expert-reviewed information and resources that help people make informed medical decisions. facing hereditary breast, ovarian, pancreatic, prostate, colorectal and endometrial cancers. FORCE assists those with an inherited gene mutation and those diagnosed with Lynch syndrome through education, support, advocacy and research efforts.

The Leukemia & Lymphoma society provides information, education and support services for people affected by blood cancers and has chapters across the country.

The Patient Advocacy Foundation provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

Support for People with Oral and Head and Neck Cancer (SPHONC) is a non-profit supporting people with oral and head and neck cancer Susan G. Komen focuses on breast cancer and has affiliates across the country, including a navigation network. Triage Cancer Provides free education on the legal and practical issues that arise after a cancer diagnosis.

These are some examples of large national organizations, but there may be some more local ones as well that offer assistance to people at the regional, state, or city-wide level. In some cases, non-profit organizations can offer low-income patients important assistance such as free housing during treatment, free wigs, financial help with bills and other expenses, or transportation support.

The National Cancer Center Network also has a web page that links to patient resources.

Asset mapping is a valuable tool for identifying resources that can support patients. These assets may include individuals within the patient's personal network, such as family, friends, or other supporters. Community organizations and local institutions, like the YMCA or places of worship, also serve as important assets.

On a broader scale, national organizations such as the Leukemia & Lymphoma Society or the Cancer Support Community can offer additional support. Other useful resources may include services like transportation programs, senior services, or co-pay assistance programs.

Conducting community asset mapping helps to uncover the strengths and available resources that can benefit both patients and their caregivers.

Patients often have existing resources and support networks that form what is commonly referred to as their support system. As a patient navigator, it can be helpful to ask questions like, "Who are the key people in your life?" or "Who do you rely on for support?" You might also explore by asking, "How have your friends or family supported you during challenging times in the past?" These questions can help patients identify their personal support network and build on those relationships during their care journey.

Collaborating with community partners and staying informed about local resources is one of the most important roles of a patient navigator. A community consists of individuals with diverse characteristics, linked by social connections, shared concerns, or common perspectives, who often work together in a specific geographic area. It's important to recognize that individuals may identify with multiple communities.
At the local level, it can be valuable to connect with key community "gatekeepers" — individuals who are community leaders or have strong knowledge of community activities. Other patient navigators, social workers, or educators in your cancer center or hospital may also have insight into available resources. Additionally, scanning websites, community directories (such as those available through 211), and other online platforms can provide further information on local services.

Reaching out to schools, libraries, religious organizations, and other community groups may help identify resources that meet your patients' needs. For instance, churches may host cancer support groups, libraries may offer educational workshops, or minority-serving community organizations might hold screening events in non-English languages.

You can collect resources and make an inventory of local informal organizations by searching for local services in online community directories; contacting local institutions such as schools, churches and parks and recreation; and contacting opinion leaders and individuals in the community who seem to know what is going on in their community. It might be helpful to start with your community's 211 directory, which includes a wide variety of organizations that you might not have otherwise considered. You can look up 211 services at 211.org, and this link is in the resources section of the learning management system.

However you choose to maintain a list of resources, advancements in software and websites are making this process more efficient. Platforms like Find Help, UniteUs, Wellsky, and Modivcare, among others, specialize in cataloging community resources and centralizing them in one place, making it easier to meet the tangible needs of individuals. Some platforms may have fees associated for their use, but sites like findhelp.org is free. While GW does not endorse any specific platform, exploring these emerging technologies may offer significant benefits in supporting your role. Take a moment to explore some of these platforms and consider how they might enhance your resource management.
[VIDEO]

There is a wide range of resources available to help patient navigators and their patients organize and access needed support. For example, the National Comprehensive Cancer Network (NCCN) provides a free, pocket-sized resource card that can be downloaded, printed, and distributed. This card includes information on free resources for individuals affected by cancer and serves as a practical tool for waiting rooms, patient engagement sessions, events, and more. It's an excellent resource to keep on hand for your patients and their caregivers.

While technology platforms are useful, there may still be a need to document and organize some resources manually. Creating a resource directory can help you systematically capture essential information about each resource. For example, it is often helpful to document an organization's name, contact details, type of services provided, target population, and eligibility requirements. Here's an example of a template you can use to develop a directory or track services for your patients. Depending on your setting, there may already be systems in place, or you may need to collaborate with your program's leadership or other navigators to create a directory tailored to your needs. If your state has a comprehensive 211 directory, you may not need to duplicate efforts, but it's still useful to have a structured way to note your impressions of the quality, availability, and reliability of various resources.

Here is a template we provide for you in the resources section of this training. This can help you create your Resource Directory.

To create your resource directory:

- Identify personal, network, and community assets.
- Interview representatives from various organizations.

- Search for resources at the local, state, and national levels.
- Include disease-specific resources in your list.
- Complete a resource directory form for each organization.
- Compile the information in a notebook, database, or utilize existing resource directories.
- Regularly update program eligibility requirements and ensure that patients are referred only to programs for which they qualify to avoid unnecessary delays or distress.

As you develop and maintain your list of resources, follow up with patients you have referred to learn about their experiences, both positive and negative. This feedback will help you refine your resource list and guide you in choosing the most reliable and appropriate resources for future patients.

One of the most valuable resources for patient navigators is connecting with other navigators. These colleagues are not only within your own healthcare system but also across your region, state, and the nation. Many areas have established navigation networks to support collaboration.

The Academy of Oncology Nurse & Patient Navigators (AONN+) develops local and regional networks of navigators, and some states already have well-established navigation networks. If one doesn't exist in your area, consider working with other local navigators to start your own. Susan G. Komen hosts a network of breast cancer specific navigators.

Additionally, the Association of Community Cancer Centers (ACCC) offers an exchange forum where oncology professionals can post questions and connect nationwide. Exploring these networks and memberships can provide valuable support and knowledge in your role. Beyond professional development, connecting with other navigators within your community and state can streamline patient handoffs and ensure continuity of care for your patients.

LESSON SECTION III

Now that we've explored how to find various resources to support individuals with cancer, it's essential to evaluate their credibility, usefulness to patients, literacy level, accessibility, and reliability. In the next section, we will guide you through the process of assessing these resources effectively.

There are several key factors to consider when evaluating the credibility of a resource, especially a website. Let’s go through them step by step.

The first step in assessing a website’s credibility is to identify its sponsor. Ask yourself: Who is sponsoring this site? Is the sponsor clearly identifiable? What is the mission of the sponsoring organization, and could they have any biases influencing the information provided? Understanding their purpose for hosting the website is important.

Government-sponsored websites, such as the National Cancer Institute (www.cancer.gov), are generally credible. Educational institutions with ".edu" domain names, like universities, are also trusted sources. Non-profit organizations often use ".org" domains, such as the American Cancer Society. However, keep in mind that anyone can purchase a ".org" domain, so it's not a foolproof indicator. Commercial sites typically end in ".com," and while they can be useful, they may prioritize profit over public benefit.

Consider when the site was last updated. A credible resource will provide the most current information, so regular updates are essential. The date of the latest revision should be clearly displayed, and the site should be consistently maintained and accessible.

Information presented should be factual, not based on personal opinions. It should be verifiable through primary sources such as professional literature or trusted websites. If opinion-based content is included, it should be clearly identified as such, with the source being a qualified professional or reputable organization. Always keep in mind that the information should complement, not replace, the relationship between the patient and their doctor.

Consider who the website is targeting. Most websites include an "About" section that outlines their mission and vision. It should clearly indicate whether the information is intended for consumers or health professionals. Many health information websites feature separate areas for each audience, and the site’s design should make it easy for users to navigate to the appropriate section.

Confirm that the websites referenced respect privacy and confidentiality, particularly regarding any personal data submitted. They should also be transparent about their financial governance, including annual reports and financial statements, which can help reveal the site's motivations and potential biases.

In addition to ensuring that resources are safe and reputable, it is important to determine whether they are truly a good fit for your patient.

Is the resource aligned with your patient’s needs and preferences? While you may think a certain resource would be beneficial, it is important to ask the patient rather than make assumptions. For example, some patients facing financial hardship might refuse financial assistance due to personal convictions. In such cases, although you can inform the patient about available help and try to make them comfortable with accepting it, it's essential to respect their decision and not push unwanted resources.

Eligibility criteria are another key factor when assessing fit. A patient may need and want the support offered by a resource, but they might not qualify based on factors like income or citizenship status. For instance, if a financial aid program requires applicants to be below a certain income level or limits assistance to U.S. citizens, a patient with a higher income or a non-citizen status would not be able to access it.

You must also consider whether the resource is appropriate for your patient's unique situation. Factors such as reading level, health literacy, culture, language, and how much information the patient desires should guide this assessment. For example, while the National Cancer Institute provides valuable information on cancer, some content is tailored for health professionals and may include medical jargon that is too complex for the average patient. On the other hand, a patient with a strong desire for in-depth information might benefit from such resources. Similarly, some patients prefer attending workshops over reading pamphlets, so it's important to offer resources that align with their learning preferences.

Language and cultural relevance are particularly important for immigrant patients. Referring a non-English-speaking patient to a resource where only English is spoken may create frustration for the patient. For instance, if a Spanish-speaking patient is referred to a food pantry that only operates in English, they may struggle with documentation requirements and leave without assistance. Likewise, a dietitian might provide meal plans that don’t resonate with a patient’s cultural background. It's important to ensure that the organizations you refer patients to have the capacity to serve them in their language and understand their cultural needs. Are there bilingual services? Does the organization have experience serving patients like yours? Identifying culturally and linguistically appropriate resources can make a big difference in the patient’s experience.

Finally, assess whether the patient can realistically access the resource. If your patient is fatigued or has limited transportation options, it might not be helpful to refer them to an in-person support group far from home. Similarly, a patient undergoing daily radiation therapy might not be able to use a meal delivery service that requires them to be home all day. Ensuring the resource fits within the patient’s practical constraints is essential to its usefulness.

LESSON SECTION IV

In the next section, we will cover some practical tips for acquiring new resources. Once potential sources of assistance have been identified, the next step is accessing those resources for the patient. It is important to be well-prepared to ensure professionalism and to avoid unnecessary follow-up calls.

Start by considering the patient's perspective. What specific assistance is required, and within what timeframe? In some cases, the assistance may be time-sensitive, such as needing to secure a service before a treatment start date. Gathering relevant information, such as application processes, timelines, locations, and any patient actions required, will help set clear expectations and ensure the patient has the necessary information.

It is also essential to approach the situation from the organization’s perspective. Has the organization been previously contacted by someone from the healthcare system? Professionals like social workers or health educators may have existing relationships with the organization and can provide useful contacts or advice on how best to proceed. Many organizations have websites outlining their services, eligibility criteria, and access procedures. If making a preliminary inquiry, having a brief, clear statement summarizing the patient’s situation and specific needs is helpful. It is important to have the patient’s information readily available to answer any questions, such as preferred appointment times or an application number for follow-ups.

Additionally, it is important to confirm whether the patient needs to be present during the conversation or if a signed release of information is required for the patient navigator to act on their behalf.

Persistence is often necessary when connecting patients with services. Service providers may be managing high volumes of requests, so multiple follow-up calls may be required. Likewise, patients may need reminders to complete necessary paperwork to access resources. Patient navigators should maintain professionalism, persistence, and diligence to ensure patients receive the assistance they need.

When contacting an organization, it is important to maintain professionalism by introducing oneself with name, position, and the affiliated organization. This ensures that the representative understands who is calling and the relationship to the patient, avoiding any confusion where one might be mistaken for a patient or family member. Start by clearly stating the main request in the most concise manner possible. This allows the person answering the phone to immediately determine how to direct the call if they are not the appropriate person to handle the inquiry. By doing this, time is saved, and the need to retell the patient's story multiple times is avoided.

Once connected with the correct representative, they will typically ask the necessary questions about the patient in order to provide assistance. However, it may be helpful to inquire about eligibility criteria if certain details remain unclear. For example, financial assistance might only be available for individuals undergoing active treatment. In this case, it would be good to ask how the organization defines "active treatment." If a patient has recently had surgery, but the assistance is only for those undergoing chemotherapy or radiation, this key information can prevent the submission of an application for which the patient is ineligible. If there are urgent timelines or special circumstances regarding the patient, it is essential to ensure this information is communicated.

Before ending the conversation, it is important to have a thorough understanding of the assistance being offered, including any restrictions or specific conditions. The process for applying, required documentation, and timelines for receiving the resource should be clearly understood. If follow-up may be needed, be sure to ask for the representative’s name and direct contact information, if available. If the resource does not fully meet the patient's needs, it can be beneficial to inquire if the representative knows of other organizations that may offer the necessary services.

When interacting with other organizations, it is important to remember that you represent your organization, and these interactions may be part of a larger, ongoing relationship. It is essential to maintain positive relations with external organizations, as this can impact future opportunities for collaboration and services for patients. Building rapport through each interaction is key to fostering long-term connections that benefit both organizations and patients.

Be mindful of the time and resources of the staff at other organizations. While they may be willing to assist, they are often managing heavy workloads. It is important to avoid overburdening them or misusing their goodwill. Understanding their eligibility criteria and the specific information they require can streamline processes. Ensure that applications submitted on behalf of patients are accurate and complete to prevent unnecessary follow-ups or corrections, making the process as efficient as possible for all involved.

Maintaining respect and courtesy during these interactions is important. A positive attitude can enhance your reputation and build trust. This, in turn, makes it easier to resolve any issues that may arise and can encourage mutual referrals in the future.

Expressing gratitude for the assistance provided by other organizations is another way to strengthen relationships. A simple thank you, whether verbal, through an email, or even a card, can demonstrate appreciation for their hard work and the difference they are making for patients.

Professionalism must always be maintained. Only share patient information that is required for the services being requested, safeguarding patient privacy and adhering to professional boundaries. In cases of conflict or disagreement, it is important to remain calm and composed, using professional language and demeanor to resolve the issue.

Going above and beyond by finding ways to support or give back to the organizations can also be beneficial. If appropriate, leading a fundraising team for their events or promoting their services to patients are ways to foster goodwill.

Finally, consider formalizing relationships with organizations that frequently provide essential services to your patients. This could involve establishing a letter of agreement (LOA), a business associate agreement, or a formal contract for services.

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Patient navigators play an important role in being good stewards of limited resources, ensuring that those most in need receive the appropriate support. Prioritizing resources is essential when the demand exceeds availability. For instance, if your organization manages a patient assistance fund of $500 but serves 50 patients, it becomes necessary to allocate the funds effectively to maximize their impact.

Being a good steward also involves using community resources wisely. For example, over-reliance on a single organization that provides transportation assistance could strain that resource unnecessarily, especially when similar alternatives are available. This is why it is important to engage with organizations and understand their capacity and eligibility requirements.

Effective stewardship also means matching patients with the resources most relevant to their specific needs. With so many potential resources available, the navigator's responsibility is to help identify and prioritize those that best address each patient's unique situation.

Lastly, resources are constantly evolving, so it is important to regularly update the list of available resources to ensure patients have access to the most current and applicable support.

When navigating a patient's care, it is important to first assess the specific information they need. This includes understanding the type of information they require, the amount that will be helpful without being overwhelming, and the format that will best suit their needs, whether that be written, verbal, or visual content.

Next, it is important to be aware of credible resources that are available. Knowing which resources are reliable and trustworthy ensures that patients receive accurate, helpful information.

Finally, match the patient's needs with the appropriate resources. It is important to provide them with relevant information while being mindful not to overload them with too much at once. Striking the right balance helps the patient process the information effectively and feel supported in their care journey.

LESSON SECTION V

Now that we have discussed barriers, conducted assessments, and reviewed strategies for organizing resources, it's time to focus on how to work with patients to effectively apply these resources. Using the 5A's framework, we'll explore how to remove barriers to care and ensure patients have the support they need.

Let's begin by discussing the first two A's, which work closely together: asking and assessing.

Asking and assessing are the first steps in providing personalized support to patients. Navigators should avoid using a one-size-fits-all approach because each patient comes with unique strengths, knowledge levels, and personal barriers. To offer tailored and effective assistance, begin by assessing the patient's knowledge, attitudes, beliefs, and readiness to proceed.

The aim is to understand what the patient already knows, their perspectives, and how prepared they are to move forward. For example, ask the patient what they understood from the medical visit: Was a diagnosis made? Were any new tests ordered? Was a treatment plan discussed?

Ensure the patient has clarity on their diagnosis, treatment options, or the next steps. While assessing, remember that patients may come from diverse linguistic, educational, social, and cultural backgrounds, which can influence their understanding, attitudes, and readiness.

Here are some strategies for effectively asking and assessing:

Pay attention to patient cues. What concerns or difficulties are they expressing? For example, a patient might say, 'I'm not sure how I'm going to pay for my treatment,' signaling financial worries or stress.

Notice changes in the patient's tone or body language. These can reveal underlying emotions like doubt, anger, or uncertainty. For instance, a patient might say, 'The doctor says I need to come back for another test,' but their posture or tone suggests hesitation or reluctance.

Clarify by reflecting back what the patient may be feeling or thinking. For example, ask, 'It sounds like you're worried about managing daily treatments,' or 'It seems like you're uncertain about changing your diet. What do you feel might work for you?'
Ask about potential barriers the patient may foresee when accessing care. For example, 'What challenges do you think could come up when trying to attend your appointment?' or 'How can I assist you with this issue related to your insurance?'
The process may not always follow a clear path. You might start with asking questions, or you may first notice something in the patient's demeanor before they speak.

There are several tools available to help assess the needs of individuals with cancer. One such tool is the National Comprehensive Cancer Network (NCCN) Distress Management Screening tool, which can be used to guide conversations about how patients are coping throughout their cancer treatment. This tool is designed to facilitate meaningful discussions and better understand the patient's emotional and practical needs. You can find this resource in the training's resource library.

It is good to note here that the Commission on Cancer requires distress screening for its accredited facilities. This doesn't mean the navigator is always the role who completes the distress screening with the patient. Depending on the established roles and responsibilities of the care team, another position, like a social worker or nurse navigator on the care team administers the screening. Be familiar with your facilities distress screening procedures and requirements.

Social workers may use other additional tools to screen for mental health like the BSI or The Brief Symptom Inventory (BSI). It's a 53-item-self-report screening tool. The BSI was designed to assess psychological symptoms during the last 7 days in patients.

A strengths-based approach to patient support originated in the discipline of social work and emphasizes the individual's capacity to grow, make the best choices for themselves, and tap into their own strengths. This approach recognizes personal attributes like faith, humor, and flexibility; interpersonal assets such as supportive friends or family; and external resources like community services. The care team collaborates with the patient to identify and utilize these strengths to support recovery and well-being.

To effectively implement a strengths-based approach, it is essential to identify the patient's strengths. While this can be difficult in the context of brief clinical visits, using a formal strengths evaluation tool can help guide the conversation and encourage patients to identify strengths they can leverage during their care.

A strengths-based approach is valuable in helping patients resolve barriers by focusing on their individual strengths. Does the patient have a resilient personality, a high level of health literacy, or reliable transportation? Identifying these strengths is important, as patients will not always have access to support for every personal or medical challenge. Encouraging patients to recognize and use their own strengths helps them become more self-reliant and better equipped to manage difficulties independently when guidance is not readily available.

Strengths can be:

- Innate or acquired
- Personal, such as an ability to cope with stress
- Within the family or social network, like having a relative with strong health literacy
- Within the community, such as a support group at the patient's place of worship

Here are some examples of the types of strengths patients may have.

To help assess a patient's strengths, here are some helpful questions you could ask:

- How have you managed difficult situations in the past?
- How has your support system (family, friends, etc.) helped during past difficulties?
- How do you typically cope with adversity?
- Who do you rely on for support?
- What strategies worked for you, and which ones didn't in that situation?
- What do you do to make your symptom or situation better?
- What do you do to enjoy yourself?
- Who is important in your life?
- What is currently going well for you?
- What can you do to improve the current situation?

Your personal philosophies, attitudes, personality, behaviors, language, and lifestyle can influence your ability to stay neutral and non-judgmental. It's important to reflect on your own beliefs and commitment to addressing patient barriers, as this self-awareness will guide you in these situations.

Staying neutral can be challenging, but it means refraining from taking sides and using active listening skills to fully understand the patient's needs.

To remain non-judgmental, avoid placing value judgments on what the patient shares. For example, if a patient expresses a decision not to pursue treatment, as a navigator, you could:

- Focus on understanding the patient's perspective
- Reassure the patient that you're not there to persuade them one way or another
- Reflect back what the patient says, without labeling it as good or bad
- Assist the patient in considering the pros and cons of their decision, without pushing for a specific outcome

The elicit-provide-elicit strategy is a useful approach for guiding communication with patients. This three-step process begins by asking open-ended, neutral questions to understand what the patient already knows. For example, you might ask the patient to share what the doctor explained during their visit. Next, with the patient's permission, offer any additional or new information that may be helpful. Finally, ask for the patient's thoughts or reactions to what has been discussed, ensuring they feel heard and supported.

Let's observe the interaction between Etta-Cheri and her patient.

[VIDEO]

What are some of the ways she remains neutral and non-judgmental? She:

- Maintains her body language and tone
- Asks questions focused on getting information from the patient
- Supports the patient's belief that his nephew will get a new place
- Does not comment on whether the nephew should pay rent
- Asks a neutral question about how the boys are taking the diagnosis. A neutral question is one that has no judgment attached to it.
- Offers help for the patient's boys but says that it is an option and ok for them not to attend the group

When advising patients, the goal is to collaborate with them to develop a plan that addresses their specific needs.

The patient should always determine the priority of their needs, not the navigator. However, the navigator can assist by guiding the patient in identifying which barriers may have the greatest impact on their care and well-being.

Once the patient has set their priorities, the navigator can support the patient in developing a plan to address those needs.

While working on the plan, the focus should remain on connecting the patient with available resources to meet their needs. It is important to note that navigators do not provide clinical advice; any clinical concerns should be referred to the appropriate health care professional, with the navigator helping to prepare the patient for that discussion.

You can guide patients in developing their own problem-solving skills by following these steps. It's important to remember that not everyone may have strong problem-solving abilities, especially during moments of crisis. Your role is not to solve their problems for them but to collaborate with the patient in finding solutions.
This step-by-step process is also available in the resources section of the learning management system.

Now, let's explore each step using a case example.

You and the patient need to agree on what the problem is. Figure out what, if anything, can be done to solve the problem and decide whether the problem is so large it needs to be broken down into smaller pieces. These questions can help you better understand the problem.

- What is the problem?
- Does the problem need to be broken down into smaller issues?
- How urgent or important is the problem? If the problem is important, provide feedback to make sure you understand the patient's issue. For example: "It sounds like you are worried about taking time off for the biopsy, is that right?"
- Does the problem affect the patient's ability to continue with a test or treatment? Can the patient move ahead with tests or treatment without solving the problem?
- What will happen if the problem is not solved? Will the patient be unable to stay in treatment? Will the problem go away when a family member leaves?

- And, can the patient navigator help?

The goal is to make sure you understand the patient's issue.

For example, when working with a patient who is upset because their insurance company is refusing to cover treatment, it is important to ask clarifying questions. For example, you might ask whether this is for treatment that has already been received or treatment that is scheduled to happen. The patient explains that it is for an upcoming treatment, and the doctor is concerned about delaying it. You can also ask what steps the patient has already taken. In this case, the patient might mention that they called the insurance company but hung up after being on hold for 20 minutes.

Through this conversation, you determine that the problem is that the insurance company won't cover the treatment, and this is a time-sensitive issue. If the problem isn't resolved, the patient won't be able to afford the necessary treatment. As a patient navigator, you can assist in finding a solution to ensure that the patient can move forward with their care.

When addressing obstacles to solving a problem, it is important to consider a variety of potential factors, including thoughts, feelings, motivations, and barriers. Each of these can play a significant role in why a patient might hesitate to move forward.
For example, if a patient is reluctant to take time off for a biopsy, there could be several reasons for this, such as:

- Financial concerns: The patient may not get paid for missed work.
- Fear: They could be afraid of the pain associated with the biopsy.

- Work-related issues: They might be worried about job security and fear losing their position if they miss work.
- Emotional factors: The patient may not want their supervisor to know about their medical condition.
- Insurance barriers: They may have a high co-pay for the biopsy and lack the funds to cover it.

It is essential to have a conversation with the patient to avoid making incorrect assumptions about their hesitancy. By discussing the issue directly, you can better ensure that the solution addresses the true underlying concern.

As you work through the situation, focus on identifying the facts. Facts are verifiable pieces of information that can help guide the process. It is easy for emotions to cloud understanding, but by staying grounded in the facts, you can provide clearer support. For example, in a case where a patient is upset and overwhelmed because they believe their insurance won’t cover treatment, it’s important to verify the details. If a patient expresses concern that their treatment won’t be covered, reaching out to someone in the billing department for clarification is a logical next step. You might call but need to leave a message, knowing that further clarification is needed before the issue can be fully understood.

Many barriers require assistance from others, such as family members, case workers, social workers, or other agencies. It is essential to identify who the key players are and understand what they can and cannot do to help address the problem. Ensuring clarity on the patient's situation is important by providing feedback to confirm your understanding.

For example, if a patient is elderly and unfamiliar with using the internet, you might ask if a spouse or children could assist with accessing online resources. Alternatively, you could inquire if a nearby library has a librarian who could provide help.

When there is a payment concern, multiple parties might need to be involved, including the billing department, the insurance company, the patient, and possibly the patient's employer. Each of these individuals or organizations plays a role in resolving the problem.

Determine if a brainstorming session is necessary, and identify who should participate. Often, it may just involve the patient and the navigator, but in some cases, the family or caregiver might need to be included. Sometimes, the patient may need to brainstorm with a doctor. Typically, the navigator helps coordinate all the pieces in such situations.

Keep the brainstorming process positive. At this stage, there are no right or wrong ideas. The goal is to generate as many suggestions as possible without judgment, no matter how unrealistic they might initially seem. Once all ideas are presented, you and the patient can later assess which are feasible and more realistic.

Use open-ended questions to encourage brainstorming. Here are some examples:

- "What usually happens at your work when someone is sick?"
- "How have you requested time off for special events or appointments in the past?"
- "What do you think your coworkers would do in a situation like this?"

For instance, when working with a patient who is struggling with insurance coverage for treatment, you might brainstorm solutions like finding an organization that offers financial assistance, consulting with the facility's financial counselor, or contacting a case manager within the insurance company for further support.

Here’s another example of brainstorming possible solutions. Imagine working with a patient who is having difficulty understanding the doctor during appointments. Together, you and the patient discuss various options. Some ideas may come from the patient, while others may come from you. Here are potential solutions the two of you might identify:

Someone could accompany the patient to appointments to take notes and ask questions. Consider if someone from the strengths assessment, such as a family member or friend, could assist.

If no one is available, and the navigator is unable to attend, other possibilities might include:

- Asking the clinician for permission to record the visit, ensuring it’s okay beforehand.
- Requesting the clinician write down key information or draw diagrams for better understanding.
- Asking for handouts summarizing the important points from the visit.
- Taking personal notes immediately after the appointment to ensure key details are captured.
- Writing down key dates for future appointments, tests, and treatments.
- Clarifying the best method to follow up with additional questions—whether through another appointment, email, phone, or text.

After brainstorming, the next step of the problem-solving cycle is to walk the patient through weighing the pros and cons of each option. For example, if the patient is considering getting a second opinion, the pros might be that it helps to have someone else review their case. The cons might be that it costs too much money, the patient feels like they might offend the doctor and that the second opinion might have a different take on treatment options than the patient's current doctor.

Based on the pros and cons, the patient should make the decision that feels right for them. The patient navigator's role is to offer support and guidance during this process but not to make decisions or offer specific recommendations.

In this case, the patient decides that starting with the billing department and the insurance company is the best approach.

It's important to recognize that, at times, patients or time constraints may prevent a full action plan from being developed. In these instances, summarizing the discussion with written bullet points, providing a recording of the conversation, or offering printed materials can be beneficial for the patient.

The final step is creating a personalized action plan to address the patient's needs. This plan should outline who will handle each task and when those tasks will be completed. The plan should include specific, behavior-focused goals, identify potential barriers, and propose strategies for overcoming them. It should also include a follow-up plan. Depending on the nature of the barrier, the plan might involve not only the patient and the navigator but also family members, friends, or other support systems.

An essential part of the plan is setting realistic expectations, including when and how follow-up will occur, as patients may sometimes anticipate quicker results than are possible. Once the plan is in place, ensure that the patient fully understands and agrees with it. With permission, share the plan with the healthcare team and relevant support persons.

It is also important to avoid assumptions about relationships with family or friends. Not all patients may have strong family support, or they may choose not to involve family in their care. Always ask for permission before including or sharing the plan with family members or others.

In this scenario, permission will be granted to speak with the insurance company on the patient’s behalf. There will also be follow-up with the billing department, either by waiting for a return call or visiting the office in person if no response is received.

Once a plan has been developed to address the patient's barriers and needs, the next step is to begin assisting in its implementation.

These are examples of situations where a patient navigator may provide assistance:

- Helping to identify and remove barriers, either directly or by guiding patients
- Preparing patients for medical visits
- Providing support during medical visits (if allowed)
- Assessing patient understanding of information and recommendations provided during visits
- Assisting with adherence to the treatment plan and ensuring completion of tests and exams
- Connecting patients with clinical staff for detailed information regarding diagnosis, treatment, and managing symptoms or side effects

- Securing additional support and information needed for informed decision-making

LESSON SECTION VI

In the previous section, we discussed various barriers patients may face. While the aim is to empower patients to address issues themselves, there are times when a patient navigator may be the best person to directly address barriers. Other times, the navigator's role is to provide patients with the necessary resources.

Let's explore some common barriers and ways to address them:

Treatment Costs:

Identify financial assistance programs and help the patient complete necessary paperwork.

Refer the patient to a financial navigator.

Transportation Issues:

Discuss possible solutions, such as asking a friend for assistance.

Provide information about transportation options like parking vouchers.

Connect the patient to local transportation resources such as Road to Recovery, RSVP, or volunteer transport services.

Language Barriers:

Schedule a medical interpreter for the next appointment.

Provide educational materials in the patient's preferred language.

Insurance Issues:

Identify sources of insurance if the patient is uninsured or underinsured.

Prepare the patient to contact their insurance company.

Call the insurance company on the patient's behalf, with permission.

Anxiety or Emotional Concerns:

Refer the patient to a social worker for professional support.

Support Needs:

Refer the patient to a support group or counseling services. Avoid offering direct counseling unless formally trained.

Understanding Treatment Options:

Help the patient develop a list of questions for their medical team.

Provide or recommend credible resources, such as those from the American Cancer Society or the National Cancer Institute.

Attend appointments to offer support.

Let's observe Fernando talk with a patient after a visit with the doctor.

[VIDEO]

What did you notice Fernando did to assist the patient? He

- Assesses the patient's understanding of treatment plan and options, realizing that the patient is unclear and has questions
- Assists the patient with making a list of questions that he can use when talking to the doctor and
- Offers to help connect the patient with a clinician so he can have his questions answered immediately

Also note what Fernando did NOT do. He did not

- Assume the patient understood
- Answer the patient’s questions or
- Provide any clinical information

The final step in the 5A’s process is arrange. During this phase, follow-up is arranged to assess the patient’s progress, review their needs, and determine if any changes to the plan are necessary.

To support the patient in implementing their plan, it is important to document the tasks, assign responsibilities, and set clear deadlines. Writing out the plan ensures both you and the patient have a mutual understanding of the next steps.
Maintain communication with the patient by phone to offer reminders and provide updates on progress. Address any concerns or adjustments needed for the plan.
During the next meeting, review whether the deadlines were met and assess if any new barriers have arisen that need to be addressed.

Let’s review a sample action plan. A patient navigator is working with a patient actively in treatment. On May 12, they meet to discuss how things are progressing. The patient expresses concerns about feeling weak due to treatments, having difficulty preparing healthy meals, and a lack of appetite. Additionally, they are struggling to cover the copays for chemotherapy drugs. The navigator schedules a same-day meeting with the dietitian to help create a manageable food plan. They also plan to reach out to the financial counselor by the end of the week to explore prescription drug assistance programs the patient may qualify for.

During the follow-up, the navigator provides information about the financial assistance programs and arranges to complete the paperwork at the next appointment. The navigator also checks in on how the diet plan is working and discusses whether a follow-up with the dietitian is needed to explore additional options.

Let’s put the 5As together:
Screening barrier: At a community health event, you encounter a participant who understands the importance of breast health but expresses difficulty finding time to get a mammogram due to work obligations.

How would you apply the 5As?
Ask: Start by exploring the specific barrier. For example, ask, “What about your schedule makes it challenging to get a mammogram?” After the conversation, document that the individual wants to get a mammogram but cannot take time off work due to financial obligations and the need to support their family.

Assess: Assess whether an alternative solution would interest the participant. For example, ask, “Would you be interested in a mobile mammography service that operates after working hours?” You note that the participant is interested in learning more about this option.

Advise: Offer advice by informing the participant about a mobile mammography service that provides screenings near their workplace and offers appointments after work hours.

Assist: Help the participant schedule an appointment. After receiving consent, you schedule the mammogram during the next available visit of the mobile service, aligning it with their after-work availability.

Arrange: Arrange follow-up by contacting the participant the day before the scheduled mammogram to remind them and following up the day after to ask about their experience. You note that the participant was pleased with the service and relieved to have completed the screening.

This showcases how the 5As framework helps address barriers and provide personalized support.

Diagnostic barrier: A 54-year-old individual recently had a breast ultrasound following suspicious tissue identified during a mammogram. The radiologist recommended a biopsy to remove tissue for cancer screening, but the patient missed the scheduled appointment. You call to follow up.
How would you apply the 5As?

Ask: Begin by inquiring about the missed appointment. For example, ask, “What led to missing your biopsy appointment?” After the conversation, document that the patient wants to get the biopsy per the doctor’s recommendation but was unable to afford the co-payment required by the insurance, which led to missing the appointment.
Assess: To assess if the patient is open to applying for financial assistance, ask, “Would you be interested in applying for the hospital’s patient assistance program?” You note that the patient expresses interest in learning more about this option.

Advise: Offer advice by discussing the patient's current financial situation and the available options through the hospital's patient assistance program.

Assist: Help the patient apply for the assistance program. After obtaining consent, you work together to complete and submit the application. A few days later, you follow up on the application's progress and encourage the patient to reschedule the biopsy.
Arrange: Arrange follow-up with the patient. A week later, inform the patient that the application has been approved and that $50 from the assistance fund will cover the biopsy co-payment. The patient then schedules the necessary appointment.
This illustrates how the 5As can address diagnostic barriers while ensuring patient-centered support.

Treatment barrier: A 64-year-old patient with prostate cancer has been referred to outpatient radiation therapy, requiring five days a week for 8 weeks. You meet with the patient to discuss the treatment plan.

How would you use the 5As?
Ask: Start by asking about the patient's ability to get to and from treatment. For example, ask, "Will you be able to attend treatment for the 8 weeks prescribed by your doctor?" After the conversation, document that the patient does not have a car and cannot afford public transportation. The patient has relied on family and friends for previous appointments but is uncertain if they will be available for the full 8 weeks of treatment.

Assess: Evaluate the resources that might be available. For instance, ask, "Would you be interested in learning about transportation services provided through Medicaid?

Could you ask your family and friends to assist with rides a few days a week?" Explore additional options, such as programs like Road to Recovery or transportation grants to supplement other support. Note that the patient is interested in learning more and reaching out for support.

Advise: Provide advice by brainstorming various transportation options. After verifying eligibility for different services, inform the patient of local ride programs and Medicaid transportation options. Suggest a plan where Medicaid provides transportation for two days a week, while family and friends cover the remaining three days.

Assist: Help the patient set up transportation. After obtaining consent, you review the patient's Medicaid plan together. Provide clear, written, and verbal instructions on how to arrange transportation. You and the patient then call Medicaid to schedule the first week of rides. Additionally, you work with the patient to confirm transportation with family and friends for the rest of the week.

Arrange: Arrange for follow-up. At the end of the first week of treatment, check in with the patient to see how the transportation plan worked. Even though there was some confusion on the first day, you note that the patient made it safely to treatment and feels confident about continuing with the plan for the remaining weeks.

Survivorship barrier: A 27-year-old cancer survivor was diagnosed with non-Hodgkin lymphoma at age 11. During a recent survivorship clinic visit, the doctor recommended increasing weekly physical activity. You meet with the patient to discuss an exercise plan.

How would you use the 5As?

Ask: Start by asking about the patient's weekly schedule and potential challenges. For instance, ask, "What does your weekly schedule look like?" or "Are there any factors preventing you from exercising regularly?" After the conversation, document that the patient works two jobs and only has Sunday off. The patient is concerned about being too tired after work and lacks the motivation to exercise. Additionally, they do not have the financial means for a gym membership.

Assess: Evaluate available options for the patient. Ask, "Would you be interested in participating in an affordable exercise program offered by your local community center?" Consider whether there are online or remote programs to allow for at-home exercise. The patient expresses interest in learning more about the community center's exercise offerings, with your assistance.

Advise: Provide guidance by exploring options together. You and the patient contact the community center to inquire about its programs. The center offers affordable exercise classes before the patient's work hours and on Sundays. You suggest meeting with the staff to create a program that fits the patient's schedule.

Assist: Help the patient connect with the exercise program staff. After obtaining consent, arrange a meeting for the patient to develop a weekly exercise plan with the community center staff that accommodates their schedule.

Arrange: Arrange for follow-up. A few weeks later, check in with the patient to see how the exercise plan is going. The patient is now exercising at least four times a week and has found an accountability partner to help stay motivated. The patient is pleased with the progress and is already noticing positive results.

End-of-life barrier: A 38-year-old woman has been diagnosed with stage 4 lung cancer. Due to her age, the cancer was not detected until it had reached an aggressive, fast-growing stage. Her doctor has informed her that chemotherapy and radiation treatments have not stopped the cancer from spreading.

How would you use the 5As?
Ask: Start by asking how the patient is feeling and what concerns they may have. You might ask, "How do you feel about what was discussed with your doctor?" or "What are your concerns?" After the conversation, document that the patient and their partner have two children, aged 13 and 11. The patient expresses feelings of depression and concern for their children. They mention being an active member of a church before the diagnosis and emphasize that their religious beliefs are very important. While the patient is not interested in counseling for themselves, they are open to discussing support for their children.

Assess: Evaluate the patient's interest in available support services. You might ask, "Would you and your family be interested in connecting with a social worker or participating in support groups, such as the Children's Treehouse Foundation CLIMB program, which offers support for children whose parents have cancer?" The patient expresses a desire to learn more about the support services offered by the hospital.

Advise: Provide information on relevant services. You discuss options that may benefit the patient and their family during this difficult time. You inform the patient about the availability of hospital social workers and support groups for both the patient and their family. The patient also mentions wanting more involvement from their church and asks if you can reach out to the Pastor.

Assist: Help the patient connect with the support system. After obtaining consent, reach out to the patient's church and Pastor to coordinate ways the church can assist the family. The church offers to set up a meal delivery schedule, with members volunteering to cook for the family and provide carpool assistance so the children can continue their after-school activities. You also refer the patient to the hospital social worker, who invites the family to attend support groups available at the hospital.

Arrange: Arrange for follow-up. Two weeks later, check in with the patient to see how things are progressing. The patient reports being happy to have reconnected with their church and is meeting regularly with their Pastor for counseling. The patient's partner and children have started attending a weekly counseling group, and the patient believes they are benefiting from the additional support. The patient also mentions that their partner feels less overwhelmed now that they are receiving help with meals and other responsibilities.

The Patient Navigation Barriers and Outcomes Tool or PN-BOT(TM), is freely available and includes worksheets and barriers list to track specific types of barriers – logistical, insurance-related, financial or employment. More specific logistical categories include transportation, housing, utilities, dependent care, food and nutrition, clothing and immigration status. Specific insurance barriers include being uninsured, underinsured or having high deductibles or co-pays. Specific financial barriers might be a need for financial planning, low financial literacy or other non-medical financial needs. Employment barriers include being unemployed, needing job accommodations, not being able to work through treatment or having family members with employment difficulties.

This tool provides fields to track when you identified this was a barrier for the patient, the date it was resolved, the action you took to address or resolve the barriers and the time it took you to resolve the barrier. This could be minutes or hours.

Sometimes, even after an extensive search and consulting with colleagues, it may not be possible to find a resource to meet a patient’s need. In these situations, it's important to be transparent with the patient. Explain that, despite your efforts, no suitable options were found. Provide the patient with the details of the organizations you’ve contacted and the leads you’ve explored, so they have the information if they wish to follow up independently. Encourage shared responsibility by asking if the patient has any other ideas or suggestions to explore further.

It’s important to recognize that not every patient problem or barrier can be resolved by a patient navigator alone. When you’re unable to address an issue, the patient may require additional coaching or counseling. Let the patient know that you would like to involve a colleague who can provide further support. With the patient’s consent, bring in a counselor or social worker to assist. In more severe cases where it is necessary to inform the broader healthcare team, be sure to follow the appropriate protocols as outlined in the Ethics and Patient Rights guidelines.

LESSON SECTION VII

In this final section of the lesson, we will explore the patient navigator's role in supporting patients as they cope throughout their cancer journey. Additionally, we'll cover when it's appropriate to refer patients for mental health services. Please take a moment to view this brief video from Cancer.net on 'Finding Mental Health Support During Cancer.'

[VIDEO]

It is essential to recognize the signs and symptoms of mental health challenges, but you should not diagnose or provide counseling. If you notice signs of generalized anxiety disorder or depression in a patient, it is important to refer them to their clinical oncology team or connect them with a mental health specialist, such as a licensed counselor, psychologist, or psychiatrist. A list of relevant organizations and programs can be found in the resources section.

Generalized anxiety disorder involves excessive and uncontrollable worry that affects daily functioning and persists for more than six months. Symptoms include difficulty relaxing, heightened startle response, poor concentration, irritability, muscle tension or aches, fatigue, frequent headaches, difficulty sleeping, sweating, trembling or twitching, nausea, shortness of breath, and other physical signs like sweaty palms or frequent trips to the bathroom.

Depression, on the other hand, involves severe symptoms that interfere with daily activities such as work, sleep, and enjoyment of life. Symptoms can include persistent sadness or anxiety, feelings of hopelessness or guilt, irritability, loss of interest in hobbies or activities (including sex), fatigue, difficulty concentrating, changes in appetite or sleep patterns, thoughts of suicide, and physical complaints like headaches or digestive issues. The intensity and combination of symptoms vary among individuals.

For someone who is going through a cancer diagnosis, recognizing depression can be particularly challenging because symptoms like sleep disturbances, appetite changes, and mood shifts can also result from treatment. If there is uncertainty, always seek assistance from a licensed mental health professional.

Again, this information simply helps you to be knowledgeable about symptoms, but patient navigators must maintain proper professional roles and work within their professional scope. Navigators must refer the patient to the properly licensed clinical provider for additional assistance.

People with cancer and survivors face significant uncertainty through their experience as well. This uncertainty can be related to:

- Having to put plans on hold
- Fear about treatment and side effects
- Worry that treatment won't work
- Worry that treatment will stop working
- Worry the cancer will come back or
- Fear of dying or losing a loved one

This is a level of uncertainty and fear that comes with a cancer diagnosis. Patients may have a lot of questions about their future. Your role is to

- help assess how much information a patient wishes to know about his or her illness,
- be aware of the signs and symptoms of mental health support needs in your patients,
- know when to refer a patient to a mental health specialist,
- build the patient's awareness of coping strategies and match stressors with specific strategies and
- assess patient's support system and help enhance it.

The emotional challenges of cancer can be significant, and the patient should work with clinicians who have been trained to address these impacts. As a patient navigator, your role is NOT to provide any clinical information, such as diagnosis or prognosis to patients or family members, to diagnose mental illness or counsel patients or to be the sole source of a patient's social support. If you feel you are getting close to crossing any of these boundaries or starting to feel like you might be burning out, please reach out to a colleague or member of the clinical team for support and advice on how to proceed.

People cope with difficult situations, including cancer and its treatment, in different ways. Beyond the physical effects, cancer often triggers emotional, social, psychological, economic, and spiritual changes. Navigating these changes can present a wide range of challenges for individuals with the disease and their families. Some say that life is forever changed once they hear the word "cancer." While some individuals confront their diagnosis successfully using familiar coping strategies, others may find their usual approaches inadequate. Some manage the challenges they face effectively, while others struggle with ongoing difficulties and distress. Reactions to cancer vary greatly, even within the same family, as no two individuals will experience the same response to the diagnosis.

At one end of the spectrum, some patients may have a very limited ability to cope and might avoid discussing their diagnosis, prognosis, or emotions altogether. High distress may manifest as avoidance coping strategies, such as denial, distraction, or venting. These individuals may cope best by focusing on immediate treatment options and could benefit from a referral to a social worker or mental health specialist for counseling. On the other end, a few patients may cope exceptionally well, discussing their prognosis openly and balancing the reality of their situation with a healthy sense of hope. While some individuals may struggle with the psychological impact of cancer, others may report enhanced psychological well-being, finding meaning in their experience, feeling more resilient, and prioritizing life more fully in the present.
Most patients will fall somewhere in between these two extremes. Some may intellectually grasp the medical situation but feel emotionally detached from the complications of the diagnosis. Others might be emotionally aware but unable to express their feelings, and still others may be both emotionally and intellectually connected but unable to engage in extended discussions about their situation. It is also common for patients to fluctuate along this coping spectrum over time, even within a single interaction. Recognizing where a patient falls on this spectrum can help guide them toward appropriate coping strategies.

[CHECKPOINT]

Coping strategies should help reduce both the intensity and duration of a stressor, as well as minimize the risk that stress will lead to further health complications. Effective coping is generally defined as any approach that lowers the stressor's impact while reducing negative outcomes. There are two main categories of coping: problem-focused and emotion-focused. Most people use a combination of both, and the choice of strategy depends on factors such as the nature of the problem, the individual's personality, age, and other personal characteristics. Neither type of coping is inherently better than the other.

Problem-focused coping is designed to remove or reduce a stressor or to strengthen a person's resources to handle it. Emotion-focused coping, on the other hand, aims to regulate emotional responses to stress. While some emotion-focused strategies are healthier than others, both types of coping have their place. Problem-focused coping is useful for addressing aspects of a situation that can be changed, while emotion-focused coping helps manage reactions to things beyond control.

Research indicates that problem-solving and acceptance-based coping tend to be the most effective at reducing stress and distress in the long term. Further strategies and their applications will be discussed later, but for now, it's important to note that there are many reputable sources available to guide patients on how to cope with cancer. Please consult the learning management system's resources section for updated and specific supportive materials.

Patients cope with stressors in various ways, often depending on whether the stressor is controllable or uncontrollable. Controllable stressors are those a person can influence through their actions. For example, while a cancer diagnosis itself is uncontrollable, a patient has control over the treatment path they choose. Similarly, while genetic predisposition to cancer cannot be changed, a person can manage diet and physical activity to help lower their cancer risk. Controllable stressors typically call for problem-focused coping strategies. Coping strategies can be either active or passive: active strategies involve taking direct action, while passive strategies involve not directly addressing the stressor.

Active problem-focused strategies include seeking information, setting goals, making decisions, resolving conflicts, or requesting help. In contrast, passive problem-focused strategies might involve behavioral avoidance (such as not taking any action) or cognitive avoidance (such as denying or ignoring the problem). For example, if someone notices blood in their stool but avoids visiting a doctor, they are engaging in behavioral avoidance. If they convince themselves that the issue isn't serious, they are using cognitive avoidance.

Uncontrollable stressors, on the other hand, often require healthy emotion-focused coping strategies. When a patient acknowledges that they cannot control a situation, they can work toward accepting it and seeking emotional support. Active emotion-focused strategies might include reframing thoughts, managing emotions, engaging in stress-reducing activities like exercise or meditation, accepting negative emotions, or talking with supportive individuals. Passive emotion-focused strategies, however, can be unhealthy—such as smoking, overeating or undereating, heavy drinking, substance abuse, neglecting self-care (missing medications or appointments), or bottling up emotions.

While some coping strategies promote well-being, others do not. The healthiest strategies are typically the active ones, whether they are problem- or emotion-focused. Passive strategies, like denial, are common but may lead to negative health outcomes if used for too long. In such cases, patients should be encouraged to adopt more active, constructive coping approaches.

Each patient will express emotions, cope, and communicate in unique ways. Knowing when to refer a patient to a mental health specialist can be challenging, but here are some general guidelines. As a rule of thumb, it's better to over-refer than under-refer. A referral to a mental health specialist should be made if a patient exhibits or reports symptoms consistent with anxiety, depression, or other mental health issues. Other signs include significant distress, difficulty making medical decisions or taking action regarding their illness or other life areas, or challenges in significant relationships (family, partner, etc.). Additionally, sudden changes in behavior, aggressive actions, impulsivity, risky or self-destructive behaviors (such as drug or alcohol abuse, compulsive sexual behavior, or illegal activities), or any expression of a desire to harm themselves or others, should also trigger a referral. It's essential to make the oncology doctor or health care team aware of these symptoms and request assistance in facilitating a referral if a social worker is not available on site.

Caregivers play an important role in supporting patients throughout their care journey. Encourage patients to involve a caregiver in their appointments for emotional support and assistance in taking notes or asking questions. If the caregiver cannot attend in person, suggest using technology like WhatsApp, FaceTime, or Messenger to include them remotely during the appointment. These options are especially helpful when patients need assistance understanding treatment but cannot have a caregiver physically present.

It's also important to remember that caregivers need support themselves. Help caregivers find ways to rejuvenate and take care of their own well-being. CancerCare offers free support services and is an excellent resource to refer caregivers for additional assistance. Navigators can also refer caregivers to other members of the healthcare team like the social worker to provide supportive services.

Let's review situations where it’s necessary to refer a patient to their clinical team, like a social worker.

[VIDEO]

Certain patient needs will fall outside of a patient navigator’s scope of practice. It is important to recognize these professional boundaries and collaborate with other members of the patient’s medical team, such as the doctor, social worker, nurse navigator, or other clinicians, to address these needs.

In emergency situations, immediate action is required. If a patient confides in you that they are at risk of harming themselves or someone else, this information must be shared with the medical team without delay. If the patient begins experiencing symptoms such as chest pain, shortness of breath, or any other signs of a potential life-threatening emergency, medical assistance should be sought immediately.
Patients may sometimes ask for advice about their medical treatment, ask whether certain experiences are normal, or inquire about their prognosis. These questions are outside the scope of a navigator’s role. Use these moments as an opportunity to help the patient document their concerns and questions for their next clinician visit. Additionally, if a patient mentions experiencing side effects or taking supplements,

confirm whether their clinician is aware, and if not, ensure the information is reported to the clinical team.

Building strong rapport with patients during their cancer journey can lead them to seek emotional support from you. While active empathetic listening and compassion are important parts of your role, it's essential to recognize that providing counseling is beyond your expertise. For patients in need of counseling, refer them to licensed mental health professionals who are trained to provide those services.

This concludes the 'Addressing Barriers to Care with Strengths-based Community and Individual Assessments' lesson, part of the Oncology Patient Navigator Training: The Fundamentals course. In this lesson, we learned to:

- Describe potential barriers to care that patients may encounter
- Describe the purpose and navigator role in community needs assessments
- Identify strategies to conduct a community needs assessment
- Create a resource directory
- Evaluate resources for appropriateness
- Describe a framework to assess patient's strengths and assist patients
- Identify strategies to remain neutral and non-judgmental
- Determine and prioritize challenges to accessing care with a patient
- Describe and apply strategies for helping patients cope with a cancer diagnosis
- Identify situations in which clinical referral is required

We encourage you to explore the additional resources available in the space below this video, and in our resource section. Thank you for your participation.