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WASHINGTON, DC

Patient-Centered Navigation and Care for Bladder Cancer

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GW Cancer Center **GW Cancer Institute**
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GW Cancer Center
Institute for Patient-Centered Initiatives & Health Equity




THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

- Founded in 2003
- Vision: To set the standard for patient-centered care and achieve health equity.
- Mission: To ensure access to quality, patient-centered care across the cancer continuum through community engagement, patient and family empowerment, health care professional education, policy advocacy, and collaborative multi-disciplinary research.

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Why is Patient Navigation Needed for Bladder Cancer Patients?

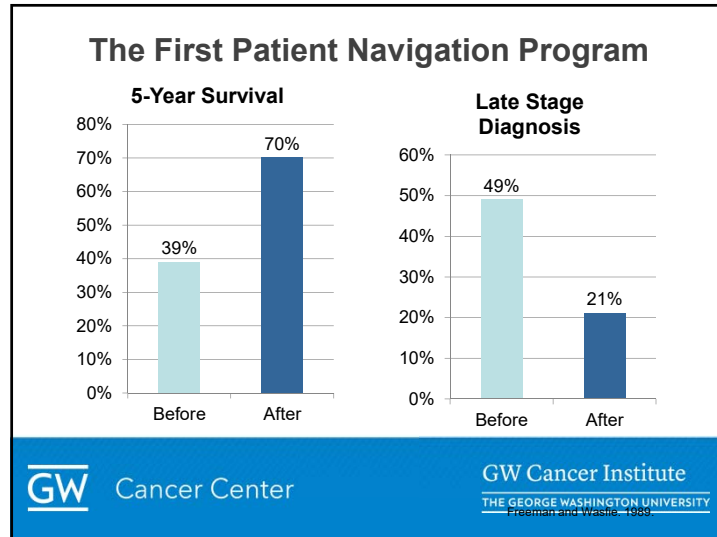
- 5th most common cancer in the U.S.
- 77,000 Americans will be diagnosed this year.
- 16,000 will die from the disease this year.



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“ Patient Navigation is an intervention that addresses barriers to quality standard care by providing individualized assistance to patients, survivors, and families. ”

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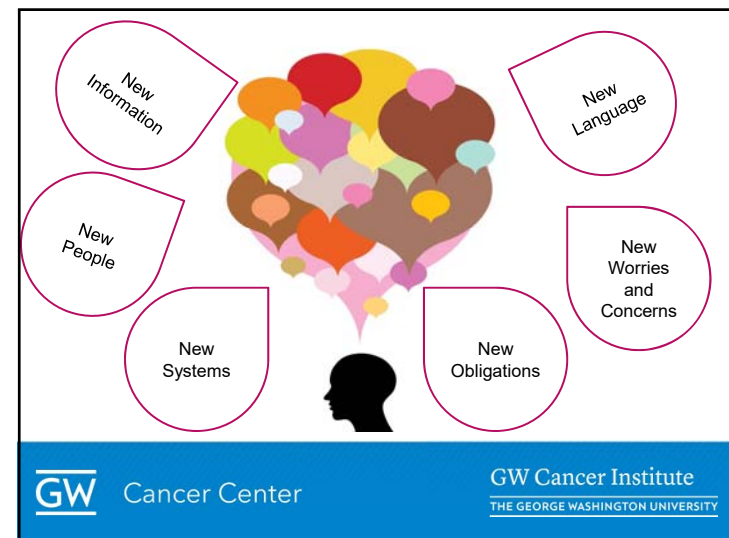
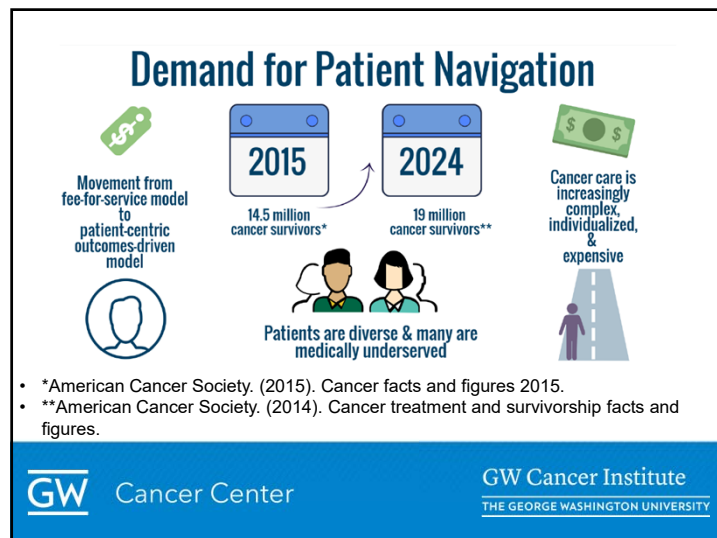
CANCER PROGRAM STANDARDS: Ensuring Patient-Centered Care

Chapter 3: Continuum of Care Services

STANDARD 3.1 Patient Navigation Process

A patient navigation process, driven by a triennial Community Needs Assessment, is established to address health care disparities and barriers to cancer care. Resources to address identified barriers may be provided either on-site or by referral.

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Why is Patient Navigation Needed?



After 30 years of no new medicine, finally hope for bladder cancer patients

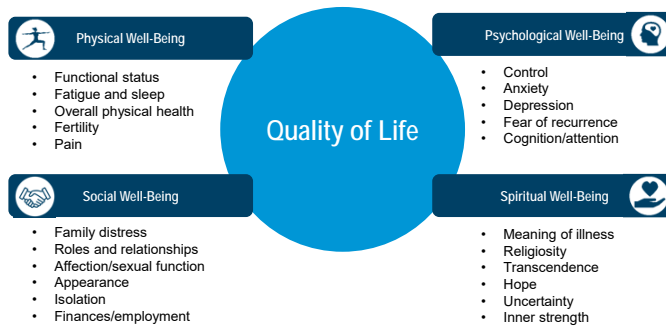
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Why is Patient Navigation Needed?




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Quality of Life





Physical Well-Being


- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain


Psychological Well-Being

- Control
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention


Social Well-Being

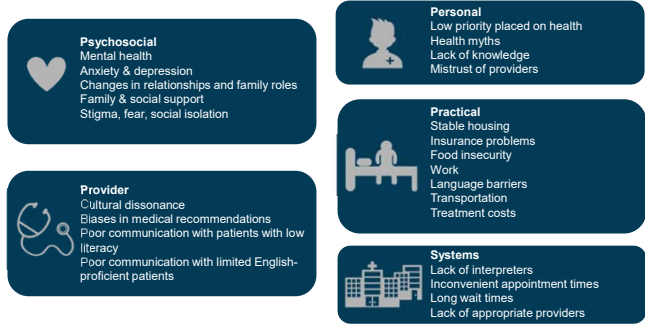
- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment



Spiritual Well-Being

- Meaning of illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner strength


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Barriers to care...





Psychosocial


- Mental health
- Anxiety & depression
- Changes in relationships and family roles
- Family & social support
- Stigma, fear, social isolation


Personal

- Low priority placed on health
- Health myths
- Lack of knowledge
- Mistrust of providers


Practical

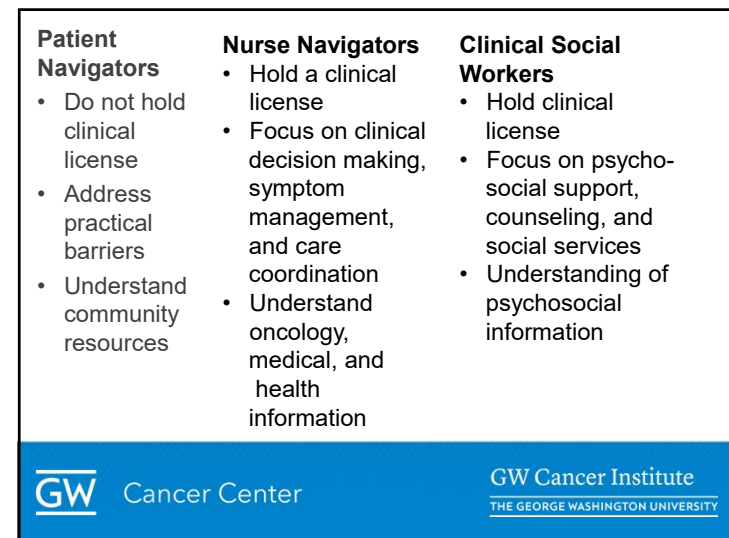
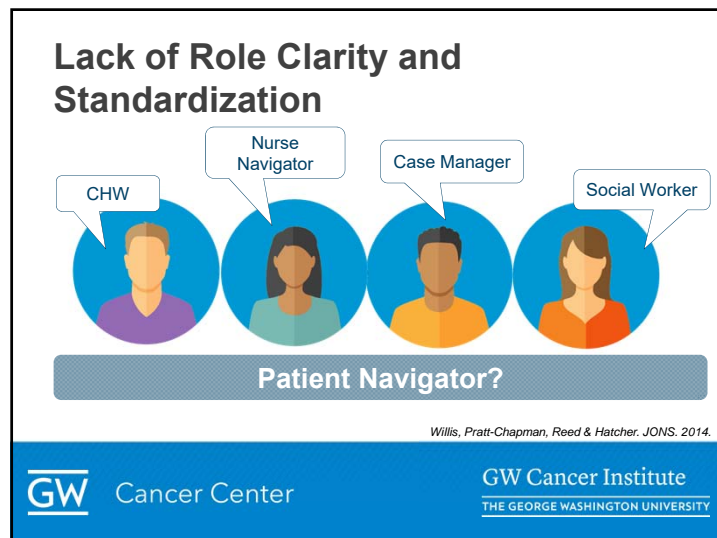
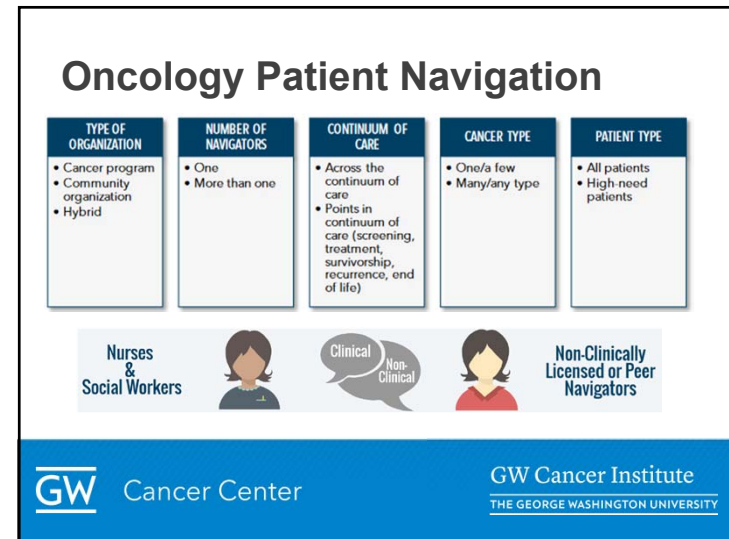
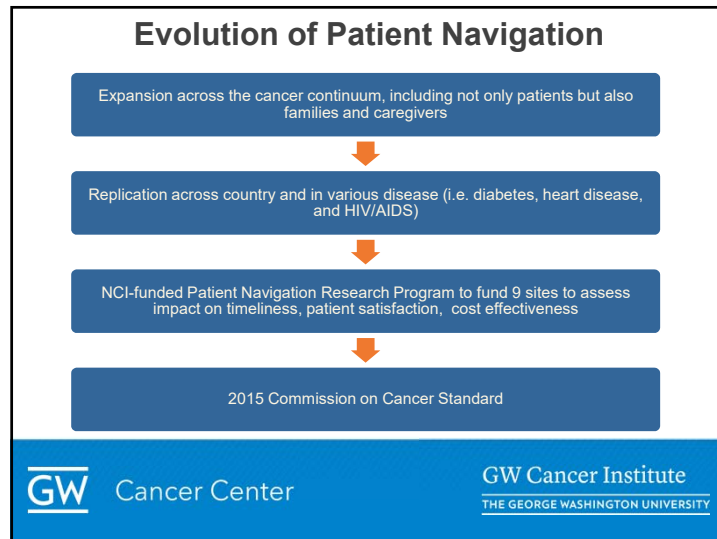
- Stable housing
- Insurance problems
- Food insecurity
- Work
- Language barriers
- Transportation
- Treatment costs


Systems

- Lack of interpreters
- Inconvenient appointment times
- Long wait times
- Lack of appropriate providers

Source: PNTC

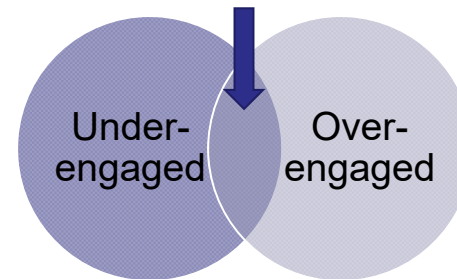
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Professional Navigation Examples

- Accompany patients to appointments
- Address health literacy challenges
- Assist in appointment scheduling
- Assess family/caregiver needs
- Coordinate care (internal)
- Coordinate care with referring physicians
- Help to recruit patients for clinical trials
- Conduct informational classes[†]
- Coordinate clinic or multidisciplinary conference
- Conduct distress screenings[†]
- Assist with employment needs and referrals
- Assist with external/community resource referrals
- Assist with financial assessment and referrals
- Assist with genetic counseling referrals
- Improve timeliness of care
- Assist with insurance coverage issues
- Coordinate language assistance
- Address logistical barriers (e.g., housing utilities, dependent care)
- Assist with nutrition referrals
- Provide patient education[†]
- Provide or refer for psychosocial support[†]
- Coordinate transportation assistance
- Coordinate treatment planning[†]
- Coordinate vocational/career counseling

The Zone of Helpfulness



Navigating Patients



Self-Determination

Patients have a right to identify and clarify their own goals. They have freedom over their course of care (unless they pose a risk to themselves or others).

Your words and actions have power and can leave a legacy.

Understand your communication style.

Understand the communication styles of patients and/or loved ones.



Do not assume you know what will be helpful to a particular patient or family.

What might be comforting to you may not be helpful to another person.



Addressing Patient Goals

Help patients to consider...

What they hope for

What their worries are for the future

Things they wish they could talk about

Things their family needs help with

How you can best help them

Culturally Appropriate Communication

- Seek to genuinely understand
- Do not make assumptions
- Let the patient take the lead and set priorities
- Do not judge
- Understand that there may be different health beliefs and behaviors
- Do not contribute to stigma
- Recognize the impact of your own culture as well as your own limitations

Harmful Words

- Are cold or cynical
- Disregard feelings or concerns
- Suggest lack of control over the situation
- Take the form of platitudes
- Indicate support was conditional
- Compare patients to statistics
- Destroy hope



Helpful Words

- Are proactive and empowering
- Normalize the experience
- Reframe problems positively
- Validate feelings and concerns
- Acknowledge individual differences
- Assure continuing support
- Show genuineness and compassion
- Convey hope



It is hope, above all else, that gives us strength to live and to continually try new things, even in conditions that seem as hopeless as ours do, here and now. In the face of this absurdity, life is too precious a thing to permit its devaluation by living pointlessly, emptily, without love, and finally, without hope.

-Vaclav Havel

- A psychological asset
- A guard against despair
- A way of coping
- A quality of life enhancer
- An essential experience of the human condition



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Hope is NOT

- Optimism
- Wishing
- Denial
- False



Hope is Complex

- People learn to hope differently
- People define hope differently
- People use hope differently



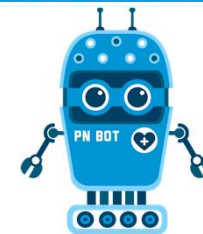
Changing Mosaic of Hope



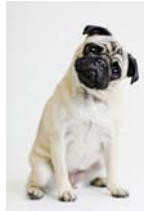
Cure
Feeling Healthy
Long-Term Survival
Living to See Milestones
Mending Relationships
Remaining at Home
Peaceful or Pain-Free
Death

Oncology Patient Navigator Training: *The Fundamentals*

Advancing the Field of Cancer Patient Navigation:
A Toolkit for Comprehensive Cancer Control Professionals



Questions?



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