

Nurse Navigation: Promoting Well-Being Throughout the Survivorship Continuum

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The Role of the Nurse Navigator in Developing and Implementing a Sustainable Survivorship Program

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Objectives

- Describe oncology nurse navigators' roles throughout the survivorship continuum
- Identify best practice strategies to improve the quality of life of people with cancer who are preparing for, undergoing, or who are post treatment

“Being cancer free does not mean being free of cancer.”

Julia Rowland, PhD

Formerly, Director, Office of Cancer Survivorship

<http://dccps.nci.nih.gov/ocs/>

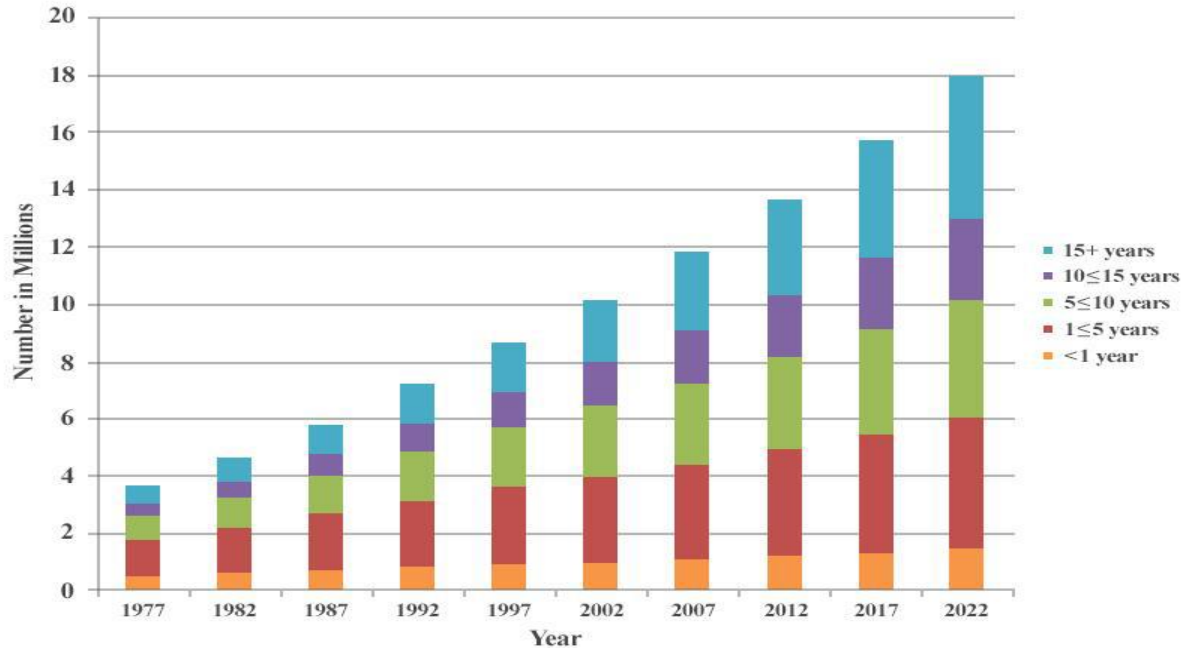
Who Is a Survivor?

- “From diagnosis through the balance of life...”
 - Expanded to include family, friends, and caregivers
- Some individuals don’t like the term or don’t consider themselves a “survivor”

The Changing Demographics of Cancer Survivors

- The majority of survivors diagnosed today can expect to survive ≥ 5 years (67%)
- Treatments are increasingly complex and multi-modal
- Patients receive most of their care in community-based outpatient settings
- For many, cancer is a chronic illness

Estimated/Projected Number of Cancer Survivors in the US



American Cancer Society (2016).

What Survivors Tell Us...

- They want to know how to reduce the morbidity and mortality associated with their diagnosis
- They are also worried about the health as well as the impact on their family members
- They want to work with their healthcare providers to address these issues, but are frustrated that these individuals often have little to offer them in this regard
- The diagnosis of cancer may present a 'teachable' moment

Navigator Tasks

■ Program

- Define survivor
- Community Needs Assessment
- Determine Metrics
- Budget/Staffing
- Relationship building/collaborations

■ Survivor

- Assess survivor/family needs
- Serve as liaison between oncology/survivor/PCP
- Ongoing Surveillance/Risk Reduction
- Survivorship Care Plan

Survivorship Models & Programs

Survivorship Models & Programs

- Consultative Model
 - One time comprehensive visit at end of treatment
 - Treatment summary and care plan provided
- Integrated Model
 - Survivors remain under care of primary oncology team, but care is provided by an Advanced Practice Provider
 - Can be disease specific
- Multidisciplinary Model
 - Multiple providers are available (costly/resource intensive)
 - Pediatric/AYA & disease specific in academic settings
- Shared Care
 - Collaboration with primary care
- Embedded Model
 - Nurse Navigator initially meets with the patient during treatment and as patients are completing active treatment
 - Provides education, resources, support at scheduled appointment

What's the Role of the Nurse Navigator in Survivorship Care?

- Dependent upon your institution
 - Work in a specific survivorship program/center
 - Identified as the survivorship navigator
 - Disease specific or the only navigator
- Responsibilities may include:
 - Triage survivors for early support utilizing distress screening tool
 - Education regarding long-term/late effects including psychosocial issues utilizing evidence-based strategies
 - Screening at periodic intervals to assess for ongoing concerns
 - Refer patients to resources within or outside of your institution for support
 - Complete and individually review treatment summary and care plan

Commission on Cancer Accreditation Standards

- Implemented in 2015:
 - Standard 3.3 Survivorship Care Plan (SCP)
 - *Analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy.*
 - *Reduced to 50% in 2018*
 - *2019 forward: Provide SCPs to ≥ 75 % of eligible patients who have completed treatment.*

What Do Survivorship, Rehabilitation, and Palliative Care Have in Common?



Rehabilitation

Supportive and Palliative Care

Surveillance and Health Promotion

- Medical history and physical exam every 3 to 6 months for 3 years, then every 6 months for 2 years, then annually
- Specific imaging tests/lab work recommendations are disease specific
- As appropriate, refer to genetic counselors
- Implement healthy lifestyle changes
- Encourage survivors to report any new or persistent symptom
- Continue with regular medical and dental screenings

Rock, C. et al. (2012).

What to know: ASCO's guideline to follow-up care. Retrieved March 28, 2018 from https://www.cancer.net/sites/cancer.net/files/what_to_know_follow-up_care_for_breast_cancer_2.pdf.

Summary

- Survivorship care plans ≠ survivorship care!
- Cancer is becoming a chronic disease
- Treatment related side effects may linger on or appear years later
- Survivorship is not a linear process
- Survivor education must be ongoing & include signs and symptoms to report to their health care team

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Thank You!

Navigators' Contributions to Quality Cancer Care with Extended & Permanent Survivorship in Mind

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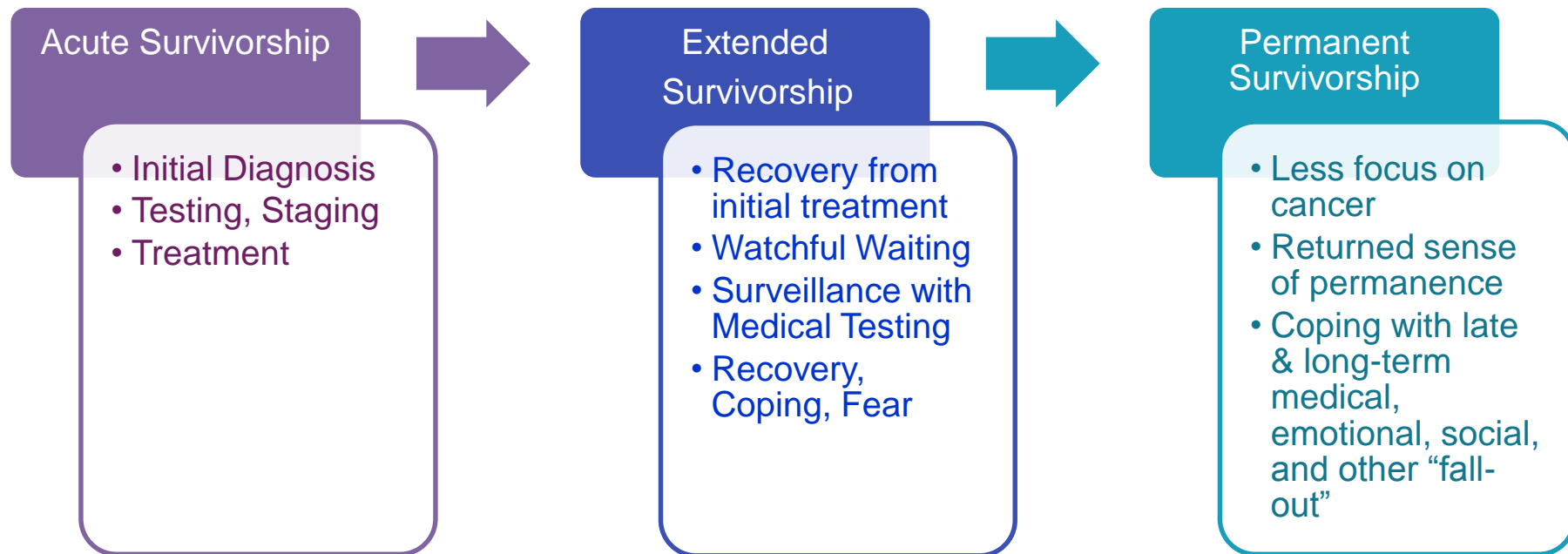
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There are no benign therapies. All treatment is potentially toxic and some therapy may itself be carcinogenic. People are living long enough to manifest the health consequences of efforts to cure or control their cancers. Who amongst our clinicians is responsible for helping us watch out for those consequences for the balance of our lives?

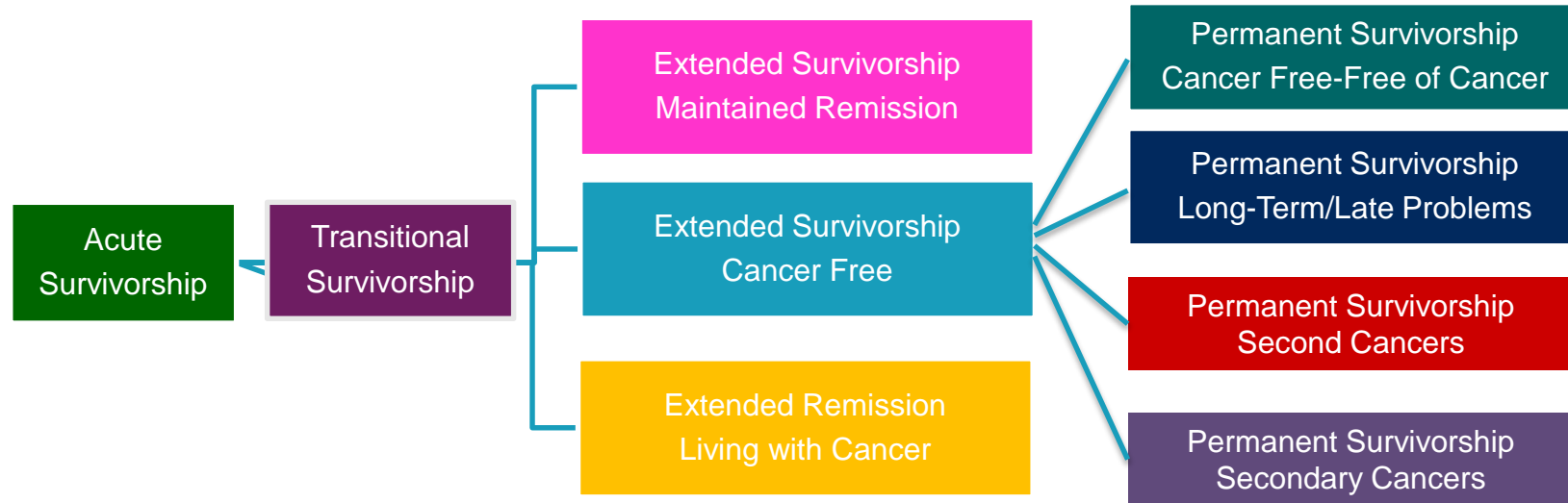
(Jessie Gruman, 2011)

Seasons of Survivorship (Mullan, 1986)



Proposed Model for “Seasons of Survivorship”

(Miller, Merry, Miller, 2008)



Navigation for People in “Acute Survivorship”

Treatment Planning with Survivorship in Mind

Traditional Risk Management Principles

(particularly useful in treatment planning and survivor risk reduction strategies)

Quality risk management involves:

- Anticipation
- Management
- Mitigation
- Avoidance



of the risk

What Does the Survivor Population Look Like?

- 64% diagnosed > 5 years ago
- 15% diagnosed 20 or more years ago
- 5% younger than 40 y/o
- 46% \geq 70 y/o
- 62% of prostate cancer survivors are \geq 70
- 32% of melanoma survivors are \geq 70

Enter: Oncology Nurse Navigator

Survivors with complex medical histories...

- Multi-morbidities
- Age-related changes
- Information needs
- Anxiety, fear, depression
- Residual and lingering symptoms
- Threats to fertility
- Actual and potential long-term and late effects
- Potential and actual barriers to reaching the best outcomes

Establish a Practice Environment and Communication Strategies Conducive to Shared Decision Making

- Consider the context in which decision-making occurs
- Recognize facilitators:
 - ✓ patients' emotional readiness
 - ✓ levels of health literacy and numeracy
 - ✓ support, information, and trust in the physician
 - ✓ physician's beliefs and values around patients' roles in decision-making and communication skills
 - ✓ physician's perception of patients' life expectancy
 - ✓ providers' understanding of patients' beliefs, values, and wishes

What Does THIS Survivor Look Like?

- Age
- Gender
- Ethnic & Cultural Background
- Co- or Multi-morbidities
- Evidence of frailty
- Ability to fully participate in Shared Decision Making
- Cancer site and stage
- Possible treatment regimens & duration
- Potential & known risk factors associated with Rx
- Distress
- Family participation in care
- Family support & resources
- Financial status
- Employment status
- PCP level of involvement
- Other barriers
- “Have you ever served?”

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Have you or has someone close to you ever served in the military?

- When did you serve?
- Which branch?
- What did you do while you were in the military?
- Were you assigned to a hostile or combative area?
- Did you experience enemy fire, see combat, or witness casualties?
- Were you wounded, injured, or hospitalized?
- Did you participate in any experimental projects or tests?
- Were you exposed to noise, chemicals, gases, demolition of munitions, pesticides, or other hazardous substances?

Have you ever used the VA for health care?

- When was your last visit to the VA?
- Do you have a service-connected disability or condition?
- Do you have a VA primary care provider?

 American Academy of Nursing

“Have you ever served?”

A simple question with far-reaching impact.

Risk Assessment at Diagnosis & Treatment Planning

Goal is for patients to receive *the most effective treatment* for their cancer and *prevent major toxicities*

- ✓ Underlying heart disease
- ✓ Age (> 65 y/o)
- ✓ High blood pressure
- ✓ Obesity, Diabetes & other Co-morbidities
- ✓ Smoking (or other unhealthy behaviors)

- ✓ Physical frailty
- ✓ Functional impairment
- ✓ Vision impairment
- ✓ Hearing
- ✓ Literacy
- ✓ Self-care abilities
- ✓ Living arrangements
- ✓ Transportation
- ✓ Other?

ID and Discuss Potential Treatment-Related Long-term and Late Effects

- Provide patient & caregiver information crucial to informed & shared decision-making
- Provide information and education to facilitate adherence to the treatment regimen
- Provide information and education to facilitate adherence to follow-up

Follow Standards of Care for Molecular Testing

Molecular profiles obtained from tumor DNA and RNA may guide the clinical management. They may...

- Offer diagnostic or prognostic information
- Identify potential treatment regimen or targeted therapy
- Determine eligibility for the other Food and Drug Administration (FDA) defined protocols (Li et al, 2017)

Assess for Issues of Sexuality and Sexual Function

- Sexual dysfunction is a common and enduring sequela of cancer treatment
- Estimates indicate half of women survivors of breast and gynecologic cancers have severe and long-lasting sexual problems
- Adolescent and Young Adult (AYA) survivors, both male and female, report low satisfaction with sexual function, particularly when combined with depression
- Consider psychological rehabilitation support during and after cancer treatment
- Recommend critical elements of AYA-specific, developmentally appropriate psychosocial care be made available to this population:
 - ✓ Fertility and sexuality counseling
 - ✓ Programs to maximize academic and vocational functioning
 - ✓ Financial support

Fertility Preservation

- Loss of fertility is one of many possible late effects of cancer treatment for men and women
- A potential source of emotional distress (now and later)
- Options for fertility preservation must be discussed and implemented prior to initiation of treatment

Rehabilitation

Health care services that help a person keep, get back or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt, or disabled.

<https://www.asha.org/practice/Health-Care-Reform/Essential-Health-Benefits/>

Prehabilitation

A process on the cancer continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment... includes physical and psychological assessments that establish a baseline functional level, identify impairments, and provide interventions that promote physical and psychological health to reduce the incidence and/or severity of future impairments.

Silver, Balma, Mayer. (2013). CA Cancer J Clin. 63:295-317.

Value of Prehabilitation in Oncology Care

- Improved physical function is linked to improved psychological health and QoL outcomes
- Survivor's improved ability to function decreases financial burden r/t occupational.
- Patient-centered care encourages newly diagnosed persons to participate in preparing themselves for rigors of treatment.
- Survivors' active participation in strategies aimed at improving health outcomes is empowering and may have lasting positive effects throughout life
- Safely navigating the oldest and sickest patients through the cancer care continuum [is imperative] to improving health status may reduce complications and increase the likelihood that the patient will recover w/o hospital readmission

Examples of Multimodal Prehabilitation Interventions

- **Lung Cancer**

- Breathing exercises
- Balance exercises
- Total body strengthening
- Cardiovascular exercises
- Smoking cessation

- **Head and Neck Cancer**

- Swallowing exercises
- Balance exercises
- Cervical ROM
- Stress reduction strategies
- Smoking cessation

- **Prostate Cancer**

- Pelvic floor exercises
- Balance exercises
- Nutrition
- Smoking cessation
- Psychosocial support & stress reduction

- **Breast Cancer**

- Shoulder & cervical ROM
- Upper body strengthening exercises
- Total body strengthening
- Nutrition
- Smoking cessation
- Psychosocial support & stress reduction

Nutritional Assessment and Interventions:

The prevalence of malnutrition among people with cancer is noted as 39%, and is a predictor of toxicities and outcomes in people with cancer (Gyan, Raynard, Durand, Guily, et al, 2017)

- Pre-operative low albumin level is correlated with worse outcomes – particularly post-operative wound healing
- BMI > 30Kg/m² increases post-operative risks of venous thromboembolism

Distress & Mental Health

- The incidence of cognitive distress and suicide is higher among patients with some cancers (bladder cancer with cystectomy in particular) than that of distress in the general population, and is increasingly recognized as a public health challenge
- It is recommended that patients with high risk of suicide be identified as early as possible, with appropriate action plans initiated proactively
- Older men with localized (low risk) prostate cancer have a high burden of mental health illness, and in particular, men with anxiety linked to “watchful waiting” (Ravi, et al, 2014)

Wound Ostomy & Continence Nurse Referral for Pre-operative Stoma Marking and Self-care Guidance

- 30% of the 79,000 individuals diagnosed with bladder cancer in the U.S. are staged with bladder muscle wall invasion
- Stoma outcomes negatively affect quality of life of the person with the stoma and their caregivers
- Stoma-related quality of life issues & patient-identified priorities: pouch leak problems, stoma appliance problems, and risk of hernia
- Marking optimal stoma location preop enhances likelihood of patients' independence in stoma care, predictable pouching system wear times, resumption of normal activities, and improved HRQoL

Palliative Care Assessment

According to its standard definition, palliative care involves providing relief of distressing symptoms. Palliative care has an important place throughout the cancer continuum.

- Presenting symptoms
- Anxiety, distress, uncertainty
- Diagnostic & staging processes
- Painful &/or distressing co-morbidities
- Treatment-related toxicities
- Fatigue

Cardio-Oncology... For Example

- Many women are vulnerable to developing heart disease in conjunction with cancer
- Identify women at risk of developing heart disease
- Offer cardiology tests to ensure patients can receive cardiotoxic therapies if recommended for use

A Breast Cancer Patient May Have Underlying Cardiomyopathy AND the Most Effective Treatment for Her is Doxorubicin & Trastuzumab: What's the plan?

- Change the regimen or dose to protect the heart
- Offer cardiac testing (e.g., ECHO with strain imaging & analysis, cardiac MRI)
- Lifestyle changes to decrease risk of CHF
- Medications (ACE inhibitors or beta blockers)
- Cardiac monitoring during treatment
- Ongoing cardiac monitoring throughout survivorship

In Summary

Cancer invades not only your body but every other area of your life. After treatment, although you may survive, you may be left with damage. The heart and other organs. The immune system. Emotions. Finances. Intimacy. Stress. Fatigue. There's almost no place the tentacles of cancer don't reach.

Darryle Pollack, 2012
Writer, Mosaic Artist, Cancer Activist.

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