Patient-Care Team Communication: How Can the Survivor Prepare to Manage a Lifetime of Care

Wednesday, April 29, 2015
3:00pm-4:30pm EDT
NCCS Mission

Advocate for quality cancer care for all people touched by cancer
NCCS Public Policy Priorities

...ensure that every cancer patient has access to cancer care planning and coordination services
Cancer Policy Advocate Training

- Late and long-term effects – recent research findings
- Survivorship care plans
- Cancer care workforce challenges
- New value-based cancer care payment systems – do they foster better survivorship care
- Disparities in survivorship care

knepote@canceradvocacy.org

June 25-26, 2015
Washington, DC
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Patient-Care Team Communication: How Can the Survivor Prepare to Manage a Lifetime of Care?

*NCCS Cancer Policy Advocate Training*

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Objectives

At the completion of this program, the learner will be able to:

• Describe who is a cancer survivor
• Discuss who are the health care team members for survivorship care
• Distinguish key transitions along the cancer continuum
• Consider the role of communication to facilitate survivorship care
• Identify resources about survivorship care
Survivor

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

– Adapted from the National Coalition for Cancer Survivorship
Survivorship Defined

• Living cancer free
  – For remainder of life
  – Experiences $\geq 1$ treatment complication
  – But dying after a late recurrence
  – But develops another cancer

• Living with cancer
  – Intermittent periods of active disease on/off treatment
  – Continuously without disease free period
Survivorship Definition and Attributes

• Defined as those who have lived through a potentially deadly or life altering event.
• It is a dynamic process
• It involves uncertainty
• It is a life changing experience
• It has duality of positive and negative aspects
• It is an individual experience with universality

LIVING WITH CANCER TAKES GUTS
Who is on your health care team?

• You
• Your family and friends
• Your primary care provider
• Your cancer doctors and nurses
• Any other providers that you may need
Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering

How do you ask questions when you don’t know what to ask?
Cancer Care Continuum

**Prevention and Risk Reduction**
- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

**Screening**
- Age and gender specific screening
- Genetic testing

**Diagnosis**
- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

**Treatment**
- Systemic therapy
- Surgery
- Radiation

**Survivorship**
- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition/genetics

**End-of-Life Care**
- Implementation of advance care planning
- Hospice care
- Bereavement care

**Acute Care**
**Chronic Care**
**End-of-Life Care**
UNCHARTED
From Cancer Patient to Cancer Survivor: Lost in Transition

The IOM 2005 recommendations:

– Raising awareness of medical and psychosocial needs of survivors
– Providing survivorship care plans for all patients completing primary treatment
– Developing evidence-based clinical practice guidelines for survivorship care
– Refining quality care measures for cancer survivorship
IOM Essential Components of Survivorship Care

• Surveillance for recurrence
• Screening for new cancers
• Identification and interventions for consequences of cancer and its treatment
• Health promotion strategies
• ‘Shared Care’ coordination between oncology specialists and primary care providers
IOM Essential Components of Survivorship Care

• **Surveillance for cancer coming back (recurrence)**
  – What tests should I have?
  – How often should I have them?
  – Who will order them?
  – When and how will I get the results?
IOM Essential Components of Survivorship Care

• **Screening for new cancers**
  – What screening should I have?
  – How often should I have them?
  – Who will order them?
  – When and how will I get the results?
IOM Essential Components of Survivorship Care

• **Identification and interventions for consequences of cancer and its treatment**
  – What will my recovery be like?
  – Will all my side effects go away?
  – If they don’t go away, will they get better?
  – What might happen later because I had this cancer and this treatment?
  – Is there anything I can do to prevent them from happening?
  – Who should I talk to if I develop any of these problems?
IOM Essential Components of Survivorship Care

• Health promotion strategies
  – What can I do to become or stay healthy?
  – Are there things I should avoid?
  – Are there any programs available to help me with this?

• Lifestyle changes
  – Stop smoking.
  – Achieve or maintain healthy weight.
  – Maintain regular exercise.
  – Moderate alcohol intake.
  – Control sun exposure.
  – Receive appropriate vaccinations.
IOM Essential Components of Survivorship Care

• ‘Shared Care’ coordination between oncology specialists and primary care providers
  – How will you keep my [primary care provider or cancer doctors] in the loop about how I am doing and about any of my tests?
  – Will I ever stop seeing my cancer doctors? If so, when?
  – How will I know if I need to see my cancer doctors or go to my primary care provider?
Survivorship Care Plans

- Enhance communication
- Coordinate care
- Increase surveillance
- Identify and manage long term/late effects
- Encourage health monitoring and promotion

Hewitt et al., 2006; Ganz & Hahn, 2009; Earle, 2006; Jacobs et al., 2009; Salz et al, 2012.
Cancer Survivors Unmet Needs

SEARCHING: THE ANSWER IS OUT THERE
Unmet Needs of Survivors

• N =1668 from VT Tumor Registry 77% >5 years after diagnosis; 62% had >1 treatment

• **Most unmet needs were informational and emotional**

• Greatest unmet needs:
  – Help to address sex life problems (40.7%)
  – Help dealing with impact on partner (35.5%)
  – Help reducing stress (34.4%)
  – Help reducing worrying (29.5%)
  – **More information about side effects after treatment** (22.9%)
  – Help with recurrence concerns (21.7%)

  » Geller (2014) *J Fam Prac*
Unmet Needs of Cancer Survivors (ACS Cohort)

• N=1514, 2, 5 and 10 year survivors

• Not associated with time since diagnosis but there were gender and age differences

• Unmet needs included:
  – Physical (38.2%)
  – Financial (20.3%)
  – Information (19.5%)

Survivors’ Information Needs

1040 Survivors 2-5 years after diagnosis:

- Tests & treatment 70.8%
- Health promotion 67.8%
- Side effects & symptoms 63.3%
- Interpersonal & emotional 54.4%
- Insurance 42.1%
- Sexual function and fertility 30.9%

Greater information needs were associated with worse perceived mental and physical health.

## Survivors Needs >50%

<table>
<thead>
<tr>
<th>Need</th>
<th>% reporting need</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access to Care</strong></td>
<td></td>
</tr>
<tr>
<td>To fell like you were managing your health together with your team</td>
<td>68.6%</td>
</tr>
<tr>
<td>To screening for recurrence or other cancers</td>
<td>63.8%</td>
</tr>
<tr>
<td>Assurance that your doctors talked to each other to coordinate your care</td>
<td>62%</td>
</tr>
<tr>
<td><strong>Information</strong></td>
<td></td>
</tr>
<tr>
<td>Provide in understandable way</td>
<td>62.5%</td>
</tr>
<tr>
<td>Possible effects <em>after</em> treatment</td>
<td>63.2%</td>
</tr>
<tr>
<td>Possible side effects of treatment</td>
<td>61.8%</td>
</tr>
<tr>
<td>More about diagnosis</td>
<td>60.7%</td>
</tr>
<tr>
<td><strong>Emotional, Social, and Spiritual Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Help managing concerns about cancer returning</td>
<td>54.1%</td>
</tr>
<tr>
<td>To talk with others who have had cancer</td>
<td>52%</td>
</tr>
<tr>
<td>A group or person with whom you feel safe expressing how you feel?</td>
<td>50.1%</td>
</tr>
<tr>
<td><strong>Physical Issues</strong></td>
<td>none</td>
</tr>
</tbody>
</table>
Management of Long Term and Late Sequelae
Long Term and Late Effects

**Late effects:** unrecognized toxicities that are absent or subclinical at the end of treatment and manifest months or years later

**Long term effects:** any side effect or complication for which the survivor must compensate
Long Term Issues

- Fatigue
- Weight changes
- Pain
- Sleep
- Depression
- Cognitive changes
- Osteoporosis
- Sexuality changes
- Lymphedema

https://www.ons.org/practice-resources/pep
Comorbidities in Cancer Survivors

- Obesity
- Diabetes
- Dyslipidemia
- Hypertension
- Osteoporosis/osteopenia
- Hypothyroidism
- Depression
- Cognitive changes
- Age related changes
Long-term and Late Effects

Source: From Cancer Patient to Cancer Survivor: Lost in Transition; page 24, Box 2-2.
Barriers to Survivorship Care

• Fragmented Delivery System
  – Hampers coordinated care
  – Lack of HCP education/training
  – Lack of standards of care/guidelines
  – Care documentation/sharing/tracking
  – Capacity

• Communication
  – HCP to HCP
  – HCP and Survivor

• Research
  – Lack of data on long term and late effects
  – Few longitudinal studies of adults
BEFORE...DURING...AFTER (2008)
What is a Cancer Care Plan?

One way to help make sure you and your health care team understand each other is by using cancer care plans. If you were going on a trip, you would likely have a plan of how to get to your destination and what to do when you arrive. In the same way, cancer care plans are roadmaps that make sure you know where you are going and how you will get there. This roadmap should be discussed with your health care team and can be shared with other health professionals you see, such as your primary care doctor, radiologist, and surgeon. Cancer care plans are useful whether you are newly diagnosed, making the transition off of active treatment, or changing your treatment course.

Post-Treatment Care Planning

There are currently more than 12 million Americans who are considered cancer survivors, and their ranks are growing rapidly as more than a million new cases of cancer are diagnosed each year. Unfortunately, the current U.S. health care system is failing to deliver the comprehensive and coordinated follow-up care cancer survivors deserve. Too many survivors are lost in transition once they finish treatment.

Every cancer survivor should have a comprehensive care summary and follow-up plan once they complete their primary cancer care that reflects their treatment and addresses a myriad of post-treatment needs to improve their health and quality of life.
Survivorship

Today, there are more than 14 million Americans alive with a history of cancer. Cancer.Net’s survivorship section provides helpful information for cancer survivors and their friends and family.

- **About Cancer Survivorship**
  An introduction to survivorship. Learn about adjusting to various changes in your life following cancer treatment and find information about the Institute of Medicine report on survivorship.

- **Follow-up Care After Cancer Treatment**
  This section outlines the importance of follow-up care after cancer treatment along with tips for healthier living.

- **Long-Term Side Effects of Cancer Treatment**
  Learn about the side effects that can occur months or years after cancer treatment is finished.

- **Dealing With Cancer Recurrence**
  Learn more about diagnosing and treating a cancer recurrence.

- **Life After Cancer**
  This section outlines a wide variety of resources to help with the transition to survivorship once active treatment is completed.

- **Making a Difference**
  Learn about volunteer opportunities to help people cope with cancer.

- **Survivor Artwork**
  View artwork submitted for the American Society of Clinical Oncology (ASCO) annual wall calendar.

- **Survivorship Resources**
  Find additional resources about survivorship.
Survivorship

There are millions of people in the United States who are cancer survivors. Many say that they felt they had lots of support during their treatment, but once it ended, it was hard to make a transition to a new way of life. It was like entering a whole new world where they had to adjust to new feelings, new problems and different ways of looking at the world.

A New Normal
Adjusting to physical and emotional changes after cancer treatment and tips on coping with fear of recurrence.

Follow-Up Medical Care
Information about follow-up medical care for patients who have completed cancer treatment. Discusses your follow-up care plan, getting a wellness plan, and guidelines for a healthy lifestyle.

Physical Changes
Information about the physical changes you may experience after you complete cancer treatment.

Family Issues
Discusses common family problems and issues that often occur after treatment and ways to cope.

As hard as treatment is, many cancer survivors say that the experience led them to make important changes in their lives. It helped them learn the value of being grateful for each day and for the people in their lives.

Related Resources
Facing Forward: Life After Cancer Treatment
Facing Forward: Making a Difference in Cancer
Moving Beyond Breast Cancer Videos
Office of Cancer Survivorship

Posted: December 2, 2014
Survivorship: During and After Treatment

In this section you'll find information and tips on staying active and healthy during and after cancer treatment. You can also get information on dealing with the possibility of cancer recurrence, and find inspiration and hope in stories about other people whose lives have been touched by cancer.

Nutrition for People With Cancer

Nutrition is an important part of cancer treatment. Eating the right kinds of foods during and after treatment can help you feel better and stay stronger. Learn more about the importance of good nutrition during and after cancer treatment here.

Staying Active

Find out more about staying active during and after cancer treatment. Learn about the importance of exercise, as well as what you need to know if you are planning on working during treatment or returning to work afterwards.

Survivorship Videos from the American Cancer Society

More people than ever are surviving cancer and thriving after treatment. Watch this video series to learn how to cope with the physical and emotional challenges that come during cancer treatment and beyond, and find inspiration in the experiences of other survivors.

National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaborative effort to shape the future of cancer survivorship care and improve the quality of life of cancer survivors as they transition from treatment to recovery. Learn more about The Survivorship Center and view resources for survivors, health care professionals, and the policy and advocacy community.
National Resources

• Cancer Care-helps with financial, emotional and supportive needs of cancer patients
  www.cancercare.org

• MD Anderson’s Life After Cancer Care
  www.mdanderson.org/departments/lacc

• George Washington Collection of Resources for Patient Navigators Assisting Cancer Survivors After Treatment (2013)
National Resources

- Cancer Survivorship in Primary Care
  www.cancersurvivorshipprimarycare.org
- Cancer Survivorship E-Learning Series
  https://cancersurvivorshipcentereducation.org/
- Lance Armstrong Foundation (LIVESTRONG)
  www.livestrong.org
When life is sewn back together, it has changed
Do I have cancer?
Will I die?
How long do I have?
What treatment is there?
How much will this cost?
Does my insurance cover it?
What do all these tests mean?
Will I be in pain?
Will I lose my hair?
Can I keep working?
What will this mean for my family?
What are the side effects?
What don’t I know?

Any questions?
Q&A

• Type your question in the chat box area located on the lower left corner of your screen

• If you are dialed in, select *1 on your telephone keypad
Thank You

WHILE WE HOPE FOR THE CURE...
WE MUST FOCUS ON THE CARE