

# Lillie D. Shockney

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DR. LILLIE D. SHOCKNEY HAS INDICATED SHE HAD NO RELEVANT FINANCIAL RELATIONSHIPS WITHIN THE PAST 12 MONTHS.

# Dialogue for Action



## *Engaging Patients in Their Health Care: Patient Navigation and Breast Cancer Screening*

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# Disclosure Statement

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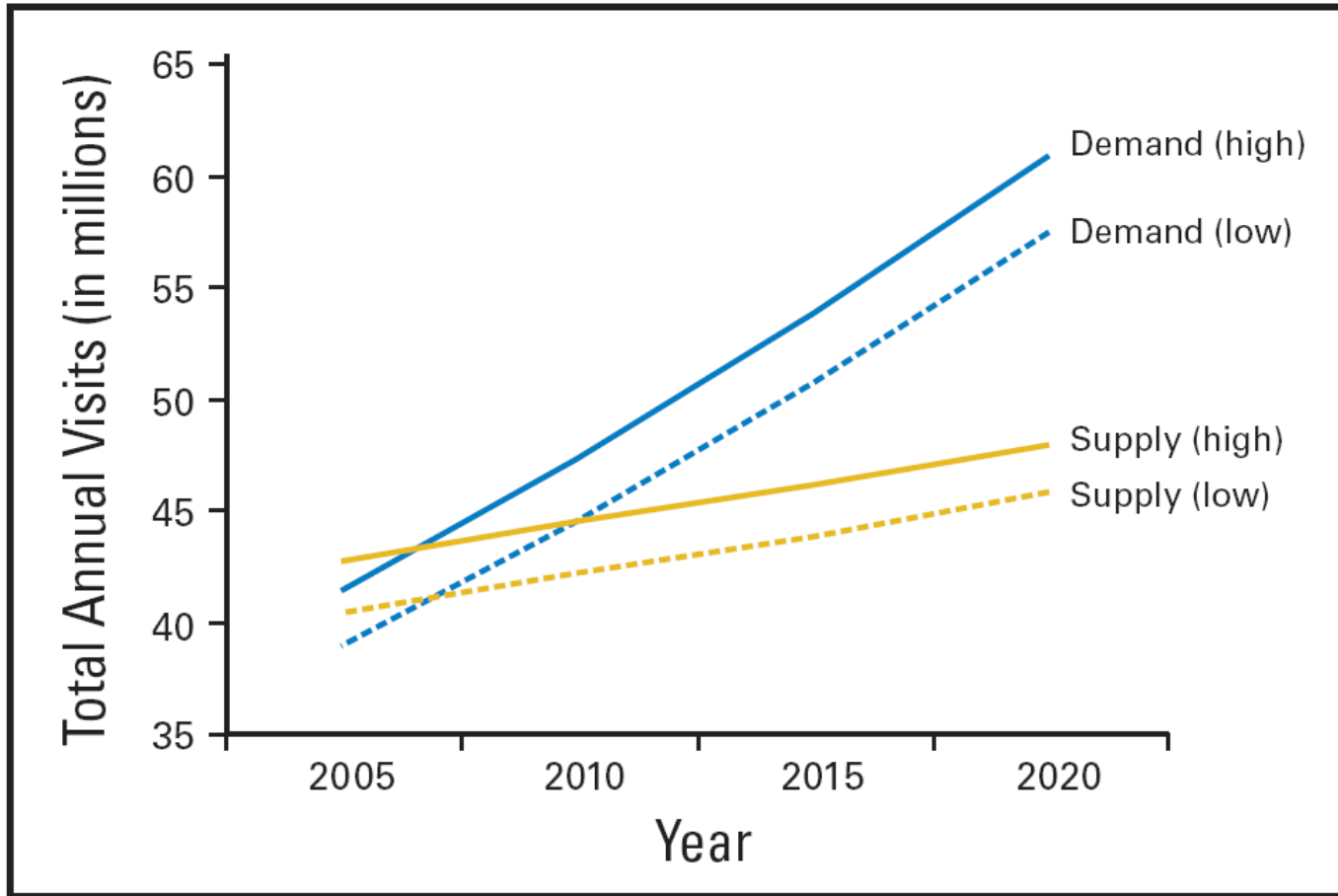


- Nothing to disclose

# At the Conclusion of this presentation the participants should be able to:

- Explain the cause of the oncology specialists' shortage predicted to worsen in the coming years.
- Describe the role navigators have in community outreach, diagnosis and treatment and breast cancer survivorship care
- Describe the pivotal role navigators have in engaging patients in breast cancer screening and prevention
- List at least 3 medical issues of concern for patients regarding their cancer survivorship monitoring
- Learn from examples the concept of a breast cancer survivorship shared care model among oncology specialists/NPs/PAs and PCPs as well as gynecologists.
- Learn about a successful method of educating consumers about breast health and breast cancer

# Baseline Projected Supply and Demand for Oncologist Visits



*Erikson et al. J Oncol Practice 3:79, 2007*

# Cancer Statistics



- 12 million cancer survivors – Dec 2011
- 13.7 million cancer survivors- June 2012
- 22 million cancers by 2020
  - 24% are breast cancer survivors

**Deficit of oncologists projected to be  
between 41- 48% by 2020**

**Onc work force will only grow 14%**

# Essential Components of Survivorship Care

- Prevention of recurrent & new cancers, and of other late effects
  - Surveillance
    - Cancer spread, recurrence, or second cancers
    - Assessment of medical and psychosocial late effects
  - Intervention for consequences of cancer and its treatment
    - Medical problems (e.g., lymphedema, sexual dysfunction); symptoms (e.g., pain, fatigue); psychological distress (survivors, caregivers); employment, insurance, and disability
  - Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met
- Cancer Patient to Cancer Survivor: Lost in Transition (IOM 2005)*

# Essential Components of Survivorship Care

Table 1: Essential Components of Survivorship Care

Care Component	Goal	Example
Rehabilitation	Optimize survivor's health potential	Physical therapy program for urinary continence rehabilitation following prostate cancer surgery
Surveillance for cancer recurrence	Early detection of cancer recurrence	Regularly scheduled colonoscopies for colorectal cancer survivors
Detection of and intervention for late consequences of cancer and its treatment	Early intervention for therapy-related complications when they are most amenable to treatment	Regular mammograms and breast MRIs in young women treated with chest radiation for Hodgkin's lymphoma to allow for early detection of radiation-related breast cancer
Health promotion	Reduction of risk for development of subsequent malignancies and comorbid conditions	Smoking cessation program for bladder cancer survivors to reduce risk of developing pulmonary dysfunction and future tobacco-related cancers
Psychosocial support	Optimize psychosocial functioning following cancer treatment	Local psychosocial support group for breast cancer survivors
Evaluation of and intervention for socioeconomic consequences of cancer and its treatment	Normalize access to work, school, and insurance for cancer survivors	Referral for advocacy services for survivors experiencing employment discrimination



# Shared-Care Model

- Cancer care domain
  - Short/mid-term surveillance
  - Acute/short term complications
  - Screening for 2<sup>nd</sup> cancers
- Primary care domain
  - Preventive services (diabetes, heart disease, osteoporosis, vaccinations, ...)
  - Screening for 2<sup>nd</sup> cancers
  - Long-term surveillance (if necessary)
  - Long-term complications (if applicable)

# Percentage of patients not receiving care for their concerns

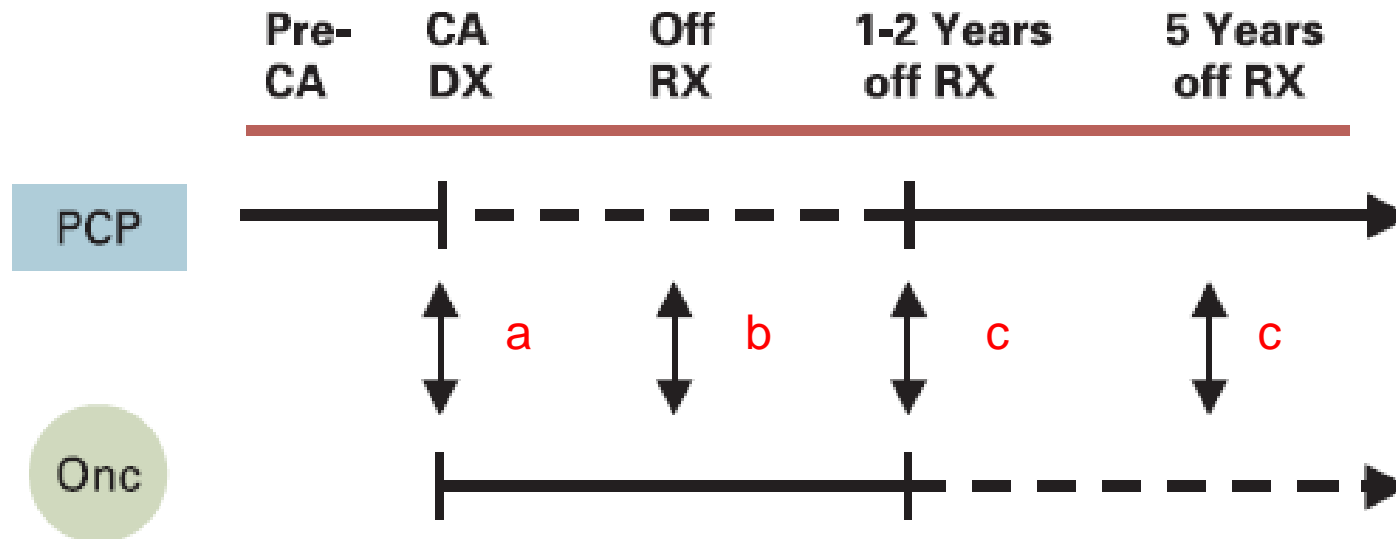


According to a survey from the living strong organization, out of 2,307 participants:

- 1,356 cancer survivors had concerns about Energy - 56% of these did not receive care
- 1,261 about Concentration - 83% did not receive care
- 1,058 about sexual function – 71% did not receive care
- 963 about Neuropathy - 60% did not receive care
- 780 about pain - 37% did not receive care
- 527 about Lymph edema – 33% did not receive care
- 503 about Incontinence – 69% did not receive care
- 367 About Lungs – 47% did not receive care
- 184 About Heart – 32% did not receive care

Ruth Rechis, P. L. (2010, June). *HOW CANCER HAS AFFECTED POST-TREATMENT SURVIVORS: A LIVESTRONG REPORT*. Retrieved July 15, 2011, from Live Strong. org: <http://www.livestrong.org/pdfs/3-0/LSSurvivorSurveyReport>

# Shared Care Model



## Roles and Responsibilities

### Oncology specialist

- Cancer therapy
- Keep PCP informed
- Guidance in long term survivorship care
- Transition of pt to PCP
- Availability for questions, consults, referrals

### Primary Care Provider

- Ensure physical & emotional health needs of survivor are addressed
- Assume responsibility for chronic disease as relevant for primary care
- Refer for problems and/or periodic evaluations
- Consult in areas of uncertainty

### Communication Points

- a.** Cancer diagnosis, stage and/or TNM classification, planned therapeutic approach, brief overview of chemotherapy, radiation therapy, and/or surgery
- b.** *Survivorship Care Plan*: summary of cancer and cancer therapy, a list of potential late effects, up to date recommendations for monitoring for recurrences and late effects, contact information
- c.** Continued update with changes in surveillance recommendations and new information regarding potential late effects

# Shared Care Model

- Has demonstrated to improve patient outcomes and enhance patient management of patients with various chronic diseases including diabetes, chronic renal disease and those receiving anticoagulant therapy.
- With monitoring, some late effects will be diagnosed at an earlier more treatable stage.
- With interventions the risk of some late effects can be reduced.

Jones, C; Roderick, P; Harris, S, et al. An evaluation of a shared primary and secondary care service for managing patients with advanced CKD. Am Kidney Dis.47:103-114. 2006.

Renders, CM; Valk, GD. Et al. Quality of care for patients with type II diabetes: a long term comparison of two quality improvement programmes in the Netherlands. Diabetic Med 20:846-852.2003

# Common Symptoms After Breast Cancer Diagnosis/Rx

Problems/Symptoms (based on Hayes, NEJM 2007)	<i>Who should be involved?</i>		
	Cancer specialist	PCP	GYN
Bone health	x	x	x
Cardiovascular	x	x	
Cognitive dysfunction	x	x	
CHF	x	x	
Depression	x	x	x
Fatigue	x	x	x
Hot flashes	x	x	x
Lymphedema	x		
Musculoskeletal	x	x	
Sexual dysfunction			x
Weight gain	x	x	

# Be specific regarding which provider is to do what

- Reduce risk of over utilization and under utilization of healthcare resources
- Reduce confusion for providers and patients
- Create a process that provides a means of tracking/quality control to ensure no patient drops through the cracks

# Recommendations can and do change over time

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- So communication among providers is essential
- Frequency of communication may depend on the risks and comorbid conditions of the survivors.
- If patient develops a recurrence then care is transferred back to the oncologist.

# Shared Care Model using a risk stratified approach (Wallace model)



- Survivors at low risk for future health problems are transitioned to the PCP soon after completion of acute treatment
- Survivors at moderate risk are evaluated on alternating years by the oncology team or PCP.
- Survivors at high risk for late effects are followed by the oncology team annually

Wallace WH, Blacklay A, Eiser C, et al. Developing strategies for long term follow up of survivors of childhood cancers. BMJ 323:271-274, 2001



# Who is responsible for what? example---



- **PCP** to follow patient for general health needs and wellness— vaccines, management of chronic illness, acute respiratory illnesses, etc.
- **Gyn---** pelvic health, breast health
- **Oncology specialist (primarily an NP)** for cancer recurrence screening; side effects management

# The role for a nurse navigator



There is an evolving role for a navigator to serve across the continuum of care...

1. Conduct community outreach to promote screening and early diagnosis
2. Identify barriers to diagnosis and treatment—transportation, myths, cultural issues, financial issues, education, psychosocial issues— and obtain resources to eliminate the barriers
3. Serve as the patient advocate and educator across the continuum of care including ensuring efficiency in delivery of care and completion of treatment in keeping with NCCN Rx guidelines
3. Serve as a conduit/bridge for the PCP, survivor, and oncologist.

# Breastivals™

A successful Method to  
Engage Consumers in  
Community Outreach  
Events

# Specific Goals--

- Create an interactive event that students and will willingly attend with enthusiasm and demonstrate an interest in learning about how to improve and maintain good breast health.
- Educate students about at least 8 facts regarding breast health/breast cancer
- Train students how to perform breast self examinations
- Educate students about breast reconstruction options for a young woman facing a diagnosis of breast cancer today

- Create an event that can be replicated at other college campuses
- Educate students as to proactive steps they can take to reduce their risk of developing breast cancer themselves
- Create an event that provides a means of measuring success
- Educate students about the various breast cancer organizations offering resources for: support for patients and families; education of consumers; promoting research for a cure; fostering outreach to communities

- Provide a mechanism for staying in touch with students to update them on new educational information about breast health and breast cancer.
- Help to reduce fear of discussing breast cancer, its diagnosis and treatment.
- Reach a large number of students at once.

# How it works...

- \* Created 80 flash cards (multiple choice and true/false) related to breast health and breast cancer.**
- \* Recruited local and national Breast Cancer Organizations to staff booths for the event— ACS; Komen; MSDBC; MABC; LBBC; YSC; Y-ME, Hopkins Breast Center**

# Room Layout and Instructions-

- Breastival™ passport card and instruction
- Hard Rock Café— a reward for visiting every booth
- Desserts and other food/drinks
- Cosmetics/hair care products
- “Booby” prizes (as rewards and door prizes)
- Jazzercise (to demonstrate exercise for risk reduction)
- Presentations by faculty
- Games and breast cancer facts posters



# Making Posters and Slogans



- Don't be a boob and miss our Breastival!
- It's 11 o'clock; do you know where your breasts care? Our Breastival starts at 11AM!
- You've only got 2— learn to take care of them at our Breastival!
- October 11<sup>th</sup> is DD cup Day!
- Guess how many jelly beans are in the largest bra on campus!!

# What we measured---

- # of students attending the event
- # of students visiting every breast cancer education booth and answering a flash card question correctly
- # of participants for Jazzercise class
- # of students learning the correct technique for BSE on a breast model
- # of students who signed the banner saying “I got the message about the importance of my breast health”

- # of students requesting additional information after the event ended
- Survey results of satisfaction as a participant of event and educational method used
- Survey planning committee to determine ease of replicating this event for future years at Hopkins and on other college campuses

# How did we do?

- Over 600 students attended out of campus of 1100.
- 347 students completed their Breastival™ passport cards, having visited every booth and answered a flash card question correctly as well as demonstrated on a breast model BSE correctly

# How did we do?

- Over 600 students attended out of campus of 1100.
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- 22 students participated in jazzercise class (lots more watched!)
- 252 women signed the banner recording that they “got the message.”
- 326 students provided their email addresses giving us an easy way to reach them for surveys, educational updates, and notifying them of future health education events. A subset of these students are now receiving notification reminders to do their monthly BSEs
- 100% of students responding to our post-event survey said that they would attend a Breastival™ again.

- Breastival™ is now trademarked by Johns Hopkins Medicine
- Breastival™ Resource and Planning Kit available from JH Breast Center
- Over 300 colleges, Breast Cancer Organizations, Breast Centers and International Organizations have purchased kit to hold their own Breastival™ program.



















- This type of community outreach works well in “mini breastival” form at shopping malls, churches, PTO meetings, and businesses.
- This is an ideal role for a navigator to coordinate and conduct in local community settings!

# Selected References

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