People who develop a serious illness have no psychosocial map to help navigate the experience. This is not the case with hereditary disease.

The presence of a history with the illness – the idea that the illness existed before the individual, that the individual is born onto the illness experience rather than being born entirely healthy and unaware of future medical trouble – distinguishes this from other categories of disease.

Rolland and Werner-Lin, 2006
Unique Challenges and Needs – For Young Women and those with Hereditary Risk

- More Treatment, Greater Side Effects/Late Effects
  - Complex Decision Making, More to Gain and Lose

- Impact on Developmental Life Trajectory
  - Multiple Roles – Work, Home, Identity
  - Can shape developmental life goals

- Higher Rates of Depression, Anxiety, Isolation
- Multigenerational legacies with cancer
The Journey Through Cancer is Defined by Movement

- Not fixed state, but fluid and evolving experience
- Processed differently at different stages – of trajectory and life span
- Marked by periods of stability/mastery and vulnerability/uncertainty
Stress in the Cancer Context
Stress is a Normal Human Response

- Comes from perceived sense of life threat
- Physiological, Cognitive, Emotional Response
- Meant to be Short –Lived

- Modern Life: unremitting stress, not life threatening
- Stress in context of cancer risk/survivorship: stress that feels life threatening BUT
- Unclear what you can do about it.....
The Challenge with Cancer Journey

- How do you manage your sense of
  - Threat
  - Danger
  - Anxiety

When the Threat is
- Not immediate, not imminent, does not pass
RE -BALANCING
Rebalance your equilibrium

Know what it is and when it is happening

Accept that it cannot be eliminated, but can be managed

Exercise the choices that help YOU
Triggers for Stress

- Disruptions in Equilibrium brought on by Expected and Unexpected Events
Domains for Stress and Challenge to Young Women

- Dating/Intimacy
- Fertility/Parenting
- Social Isolation
- Health Surveillance
- Financial Toxicity
- Work/Career
- Media
Challenges and Strategies

- Individuals with less social support express greater anxiety and worry – Liu et al Cancer 2011

- Talk through your evolving feelings and needs
- Prepare for good and bad stressful events
- Focus on relationships, not roles
- Have someone who understands
Challenges and Strategies

- Higher levels of distress expressed by those who engage in high rates of health surveillance without accessing healthcare - Thewes et al Support Cancer Care 2012

- Find your healthcare “team”
- Define your parameters of care
- Check your own fears/biases
Challenges and Strategies

- Fear during cancer is reduced with higher levels of confidence in ability to engage in healthy behaviors – McGinty et al Psycho Oncology 2-12

- Avoid all or nothing thinking
- Set and commit to realistic, achievable goals
- Allow for sadness/grief
- Practice self compassion and share the experience
- Know your own Story and move back into your LIFE
- Locate YOUR sources of Meaning, Joy, Comfort and Strength
Uncertainty in the Context of Hereditary Cancers

can’t be eliminated
- is connected to deep knowledge of vulnerability
- and a challenge to manage but also....

- Opportunity to clarify and prioritize what is most precious in YOUR LIFE now
Support and Resources

- Dating/Intimacy
- Fertility/Parenting
- Social Isolation
- Health Surveillance

- Financial Toxicity
- Work/Career
- Media
Grace: a documentary

Rachel Pikelny
Director and Producer
Isolation and Sense of Community

Aimee Sax, MSW
Sharsheret California
Program Coordinator
Isolation and Sense of Community

- Sharsheret founded for this reason
- Cancer diagnoses can be isolating for anyone, but can be more so at younger ages
- Speaking to someone who has walked in your shoes can be uplifting and reassuring
Isolation and Sense of Community

A recent study at Ohio State University found,

"dealing with stress is important because research... has found that high levels of stress can lead to not just depression, lower quality of life and negative health behaviors, but also lower immunity and faster disease progression." *

One of the factors studied was “seeking social support.”

Isolation and Sense of Community

- Sharsheret can help
  - Specific Peer Support matching
    - Examples: dating, age of children, type of treatment/surgery/reconstruction, job
  - Social Workers
  - Resource referral to support groups (in your neighborhood)
  - Survivorship kit answers questions you didn’t know to ask
  - Best Face Forward kit for the cosmetic side effects of treatment
  - Busy Box for children of women in treatment
  - Family Focus program educates and supports caregivers
  - We can help educate YOUR community!
Isolation and Sense of Community

- Sharsheret events to educate your community
- Workout Studios
- Schools
- Offices/Organizations
- Houses of Worship
- Women’s groups
- Private homes

Always remember: YOU call the shots
- Community can be a double-edged sword
- Overwhelming at times
- You define your community; you get to decide
Isolation and Sense of Community

Get in touch with Sharsheret!

www.Sharsheret.org

Email our Clinical team: clinical@sharsheret.org

Email Aimee: asax@sharsheret.org

Visit Booth #17
Resources for financial toxicity

Donna Williams, DrPH
Gulf States Young Breast Cancer Survivor Network
Costs of Treatment - Employment Challenges

- Missed worked days while undergoing treatment
- Unable to work while undergoing treatment
- Caregiver missed work
- Unable to return to work
- Struggle to rejoin the workforce after treatment
Medication Challenges

- High co-pays for one drug
- Multiple drugs with co-pays
- Specialty drugs not available
- Multiple trips to multiple pharmacies
Medications and Lower-income Cancer Patients

- Skip doses
- Delay refills
- Taking less than prescribed
- Don’t take at all
Financial Hardship and Cancer

- 28% of cancer survivors between the ages of 18 and 64 report financial hardship associated with treatment
  - Borrow money/go into debt
  - Declare bankruptcy
  - Forego recommended care
- Increases to >40% for the uninsured or those with public insurance
- Female and nonwhite more likely to report financial hardship
Financial Toxicity and Cancer

Bankruptcy after a cancer diagnosis is a risk factor for mortality\(^3\)

Risk greater in younger, women, nonwhite
The Cost of Cancer

Loss of Income

+ Costs of Care

POOR OUTCOMES
Overcoming Financial Toxicity

- Identify those at high risk for financial toxicity
- As few visits as possible
- Keep close to home
  - Telemedicine
  - Home Health
- Utilize support organizations, local and national
- Navigation
Financial Assistance & Free Services

Dealing with cancer can get very expensive and complicated. But there are resources out there to help you with medical bills, prescription expenses, legal assistance, insurance coverage, careers, household costs and more. You can even find free services such as cleaning and transportation! Be sure to look at these resources to see what might be available to you.

Local Resources

Cancer Association of Greater New Orleans (CAGNO)

This New Orleans non-profit provides financial assistance for medication, gas for transportation, breast forms, wigs, and a variety of other supplies. Their new partnership with Breastoration offers financial assistance to women who cannot afford their breast reconstruction surgeries.
References


3. Yabroff KR; Dowling EC; Guy GP Jr; Banegas MP; Davidoff A; Han X; Virgo KS; McNeel TS; Chawlà N; Blanch-Hartigan D; Kent EE; Li C; Rodriguez JL; de Moor JS; Zheng Z; Jemal A; Ekwueme DU. Financial Hardship Associated With Cancer in the United States: Findings From a Population-Based Sample of Adult Cancer Survivors. *Journal of Clinical Oncology*, 34(3):259-67.

Resources for understanding research in the media

Kelly Owens, PhD
Director of Research and Education
FORCE
Examining the Relevance of Articles for Young Survivors (XRAYS)

Supported by a cooperative agreement with the Centers for Disease Control (CDC).

Contents are the responsibility of the authors and do not necessarily represent the views of the CDC.
Media coverage of cancer news can be misleading.

XRAYS was developed to help young women understand breast cancer research in the news.
XRAYs rates the clinical relevance of research studies

Media

'Angelina Jolie gene' may be linked to Alzheimer's, researchers say
Scientists at the University of California, San Francisco found low levels of BRCA1, the DNA repair gene, in the brains of patients who had died from Alzheimer's.
WWW.DAILYMAIL.CO.UK

Research report

DNA repair factor BRCA1 depletion occurs in Alzheimer brains and impairs cognitive function in mice

XRAYS Rating

Our overall rating approach
How this study was rated
XRAYS summarizes research in plain language

**Research Report**

**Adjuvant Chemotherapy Guided by a 21-Gene Expression Assay in Breast Cancer**


July 12, 2018


DOI: 10.1056/NEJMoa1804710

**XRAYS Report**

**STUDY: Can some women with early-stage breast cancer forego chemotherapy?**

A research study named the "Trial Assigning Individualized Options for Treatment" (TAILORx) asked whether chemotherapy is beneficial for women who have mid-range Oncotype DX tumor recurrence scores. This trial — the largest breast cancer treatment trial ever conducted— showed that endocrine therapy alone was as effective as endocrine therapy plus chemotherapy in women with certain types of early-stage breast cancer. The results of this trial are expected to be immediately practice changing (7/20/18)

More Info
XRAYS rates different media coverage of same research

STUDY: Evaluation of some direct-to-consumer genetic testing reveals inaccuracies and misinterpretations

A clinical genetic testing laboratory examined results from direct-to-consumer genetic testing ordered directly by patients. They found many instances of false positives—reported mutations that were not actually present—and in some cases, reports of variants that “increased risk,” but were actually benign. This study emphasized the importance of involving genetics experts in the interpretation of genetic test results. (6/28/18)

Who Covered This Study?

<table>
<thead>
<tr>
<th>Source</th>
<th>Rating</th>
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<tbody>
<tr>
<td>ScienceNews</td>
<td>★★★★★</td>
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<tr>
<td>Forbes</td>
<td>★★★★★</td>
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<tr>
<td>CNN</td>
<td>★★★★</td>
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<tr>
<td>Geek.com</td>
<td>★★★★</td>
</tr>
<tr>
<td>Newsweek</td>
<td>★★★★</td>
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</tbody>
</table>

Our overall rating approach
How these media articles were rated
XRAYS rates the accuracy of media articles

**XRAYS Rating**

**ARTICLE: Headlines claim drug combination destroys tumor in 11 days—is this too good to be true?**

A recent IFLScience headline proclaimed "Remarkable Breast Cancer Trial Destroys Tumors in Just 11 Days." This sounds amazing but it leaves out key facts. First, the finding applies only to HER2-positive breast cancer, not all breast cancers. More importantly, the results are from a conference presentation and have not yet appeared in a peer-reviewed scientific journal. What does that mean for breast cancer patients? (12/6/16)

More Info
Hereditary Research Matching Tool

Featured Research

Tips for Searching Studies
- Basic search tips
- Searching treatment studies
- Searching prevention, detection and risk studies
- Searching quality of life and wellbeing studies
- Learning if you are eligible

Other Resources
- Participating in research FAQs
- Glossary of terms
- Use our Peer Navigation Program
- Clinical trial safety
- Making the decision

Search for Studies

Search Now
Peer Navigation Program

Matches people with peer volunteers and information based on:

- personal situation
- age
- mutation
- diagnosis
- geographic location
Connect with us

Website:
FacingOurRisk.org

XRAYS:
FacingOurRisk.org/XRAYS

Helpline:
866-288-RISK (7475)

Email:
info@FacingOurRisk.Org

Get Social:
FacingOurRisk
Resources for dating and sexuality

Amanda Nixon
Young Survival Coalition
Young Survival Coalition

Dating and Sexuality
Amanda Nixon
Regional Outreach Manager

I have no actual or potential conflict of interest in relation to this program/presentation.
Dating and Sexuality

- Telling your partner
  - When
  - How
  - What
- Sex
In Person Resources

- Summit
- Regional Symposium
- Face 2 Face Meet Up Groups
Print Resources

- Navigators
- ResourceLink Guidebook
- Books
Audio/ Visual Resources

- All of You: Sex, Intimacy, Body Image
  - Audio files

- Family, Dating, Relationships
  - Audio files

- Single Ladies & Breast Cancer
  - YouTube video

- Sexy After Cancer videos
  - Courtesy of Barbara Musser
Online Resources

- Website (https://www.youngsurvival.org/learn/sex-and-intimacy)
- Blog (https://blog.youngsurvival.org/)
- Lacuna Loft partnership
Thank you

Now in its 20th year, Young Survival Coalition (YSC) is the premier organization dedicated to the critical issues unique to young women who are diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.
To connect people with trusted breast cancer information and a community of support.
Young Women’s Initiative

• LBBC offering programs and services for young women since founding in 1991

• Through 3-year cooperative agreement with Centers for Disease Control and Prevention, YWI was launched in Nov 2011

• Expands and strengthens LBBC’s existing programs for young women while developing new programs and resources for this community

• Over 100,000 young women and their families per year have been reached through YWI since 2011
Online
LBBC.ORG
Webinars
Twitter Chats
BC 360
Social Media

In print
Publications
*Insight*
Newsletter

By phone
Helpline

In person
Conferences
BC 360
Young Advocate
Volunteers

To learn more visit: LBBC.ORG
Resources for Parents
Background

• Young women who are diagnosed with breast cancer face a number of challenges that affect their parenting and the parent-child relationship.

• Newly diagnosed parents struggle with how to tell their children about their diagnosis.

• Aspects of their mother’s treatment, such as hair loss and results of surgery can be stressful for children.
LBBC’s Approach

• To identify resources that would be most useful for parents, LBBC posed questions on our closed Young Women’s Initiative Facebook Group and conducted key informant interviews with mothers. 21 individuals provided suggestions and insight.

• Themes among the responses included the need for children books that help parents talk to their children about cancer; desire to hear advice from other parents, and a need for centralized resources for parents with a breast cancer diagnosis and their children.
LBBC’s Resources

• Expanded Section on LBBC.ORG
  • Caring for Your Mental Health
  • Caring for Your Children’s Mental Health
  • Talking to Your Children
  • Parenting Resources

LBBC.ORG/parenting

Other Programs
• May 2017 Twitter Chat on Parenting
• Workshops for parents at LBBC’s two conferences
Reading for Reassurance Program

• Books are a great tool for answering many questions that children often have about a parent or grandparent facing an illness.

• Reading for Reassurance provides two free children’s books about cancer to parents and other LBBC resources in a gift package.

• All of the books included in the program have been reviewed by a childhood educator who has been affected by breast cancer.
Reading for Reassurance

• Fulfilled over 145 orders since January 2018

• Evaluation Findings: 78% reported that the books were of excellent quality, and 80% said they were extremely relevant.

To order your books: LBBC.ORG/reading
Young Women’s Initiative Program Staff:
Arin Ahlum Hanson, MPH
Becky Mastin, MPH

Come visit us at the LBBC Exhibit table or contact us at
ywi@lbbc.org
484-708-1546
Transforming the Patient’s Journey

Using Survivorship as a Catalyst

Maimah Karmo
Tigerlily Foundation Mission

- Tigerlily Foundation’s mission is to educate, advocate for, empower and support young women – before, during and after breast cancer.
Survivorship Facts

- Treatment options have improved and expanded, which extends survival rates.
- Currently there are about 15M cancer survivors living in the U.S. Of that number, 3.6M (23%) are breast cancer survivors. (NCI)
Survivorship Facts

Good news and bad news...
Survivorship Facts

▪ Good News
  ▪ The population of survivors is expected to continue growing. The bad news is that many survivors face ongoing challenges even after their cancer has been “cured.” This is where survivorship programs can make a big difference in the length and quality of survivors’ lives.

▪ Bad News
  ▪ Survivors are living longer, have many challenges that can negatively impact their quality of life.
What is Survivorship?

- Begins from the day of diagnosis and throughout the patient’s life.
Who Survivorship Affects & How?

- It affects every aspect of the patient’s life... and it brings “invisible problems”.
  - Survival outcome
  - Physical changes
  - Sexuality
  - Dating
  - Fertility
  - Finances
  - Side effects
  - **Mental health**

- It affects caregivers and family members...
  - Fear of recurrence
  - Fatigue
  - Worry
  - **Mental health**
How Tigerlily Foundation Addresses This Need

- Helps Patient Adjust to New Normal
- Provides Support to Enhance Quality of Life
- Integrates Spirituality
- Shines the light on Mental Health
- Provides Connection
- End isolation
- Helps patient get back to living life
- Transforms patient by inspiring them to use cancer as a catalyst
How Tigerlily Foundation Addresses This Need

Educational Programs
- Pink Power Alerts
  - Have the Chat *

Empowerment Programs
- New Normal Journal
- MY LIFE Toolkit

Advocacy Programs
- YWBHD
- ANGEL Advocacy Program

Support Program
- MY LIFE Program *
- Send Me On Vacation Program
- BREATHE Program *
- SPIRIT Program *
- SPIRIT Retreat *
- 24/7 Prayer Line *
Contact us

- Visit www.tigerlilyfoundation.org
- Follow us on Instagram @tigerlily_foundation
- Follow us on Twitter @tigerlilycares
- Email us at info@tigerlilyfoundation.org
THANK YOU!