Survivorship @ PMH: Empowerment, Integration and Coordination

Pamela Catton MD MHPE FRCPC
Director Education and Butterfield Drew Chair
Medical Director PMH Cancer Survivorship Program
Professor and Vice Chair Department of Radiation Oncology
University of Toronto
Outline

1. Background and rationale
2. Empowerment – grappling with the issues
3. The Program in 2011
Welcome to the Weekend to End Breast Cancer Survivorship Centre

Sponsored by the Princess Margaret Hospital Foundation
**Background and rationale**

**Survivorship: A Growing Reality**

**Prevalence (10 year)* for the most common cancers, Ontario, by sex, 2004**

- **Male**
  - Lung
  - Colon and rectum
  - Prostate
  - All other cancers**

- **Female**
  - Lung
  - Colon and rectum
  - Breast
  - All other cancers**

*Prevalence (10 year) is the number of Ontarians diagnosed during the previous 10 years who are still alive on December 31, 2004

**Excludes basal cell and squamous cell skin cancers, which are not registered in Ontario

Source: Cancer Care Ontario (Ontario Cancer Registry, 2007)

**Funding models slow to respond to consumer advocacy in this area**
1. Raise awareness of the needs of survivors
2. Survivorship Care Plan
3. Evidence-based clinical practice guidelines
4. Quality of survivorship care measures
5. Support for demonstration programs to test models of coordinated, interdisciplinary survivorship care
6. Comprehensive cancer control plans must include consideration of survivorship
7. Educational opportunities to health care providers
8. Minimize adverse effects of cancer on employment
9. Access to adequate and affordable health insurance
10. Increase support of survivorship research

IOM/ASCO RECOMMENDATIONS
Components of Survivorship Care

**Post Treatment Surveillance**
- Recurrence and 2nd primaries
- Persistent and late effects

**Post Treatment Prevention**
- 2nd primaries
- Persistent and late effects

**Interventions**
- Minimize / reverse side effects
- Promote healthy behavior change

**Survivors taking responsibility**
- For their care guided by an organized plan (Care Plan)
## Components of Survivorship Care

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Components of Survivorship Care

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
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<tbody>
<tr>
<td>Informed decision-making</td>
<td>Health services and outcomes research</td>
<td>Coping Health promotion for survivors</td>
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</table>

**Post Treatment Surveillance**
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Survivor-centred Perspective

Quality of Life Model for Cancer Survivors

Survivor: An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. It includes patients, families and friends.
Barriers to Optimal Survivorship Care

- Fragmented delivery system
- Poor coordination of services
- Absence of a locus of responsibility
- Lack of survivorship standards of care
- Difficulties in communication
- The capacity for delivering survivorship care
- Lack of guidance on how survivors can maximize their own health outcomes
Program Approaches

Medical Models
- Multidisciplinary
  - Specialized multidisciplinary clinics
  - Integrated multidisciplinary survivorship services
- Shared medical models (Specialist/primary care)
- Nurse led models

Chronic Care Management Models
- Empower and prepare patients to manage health and health care with self-management support
- Mobilize community resources to meet needs
The Chronic Care Model

Wagner et al, 1999

http://www.improvingchroniccare.org/change/model/components.html
Inspiration: Cancer Survivors Identify Wishes and Needs

We need:
- Education
- Clinical Care
- Support
- Research

Walkers and fund-raisers for the Weekend to End Breast Cancer insisted:

“We want a Survivorship Program”
PMH Survivorship Program Goals

- Empower and prepare survivors to manage their health with appropriate self management support
- Recruit and train survivors as a human resource
- Reallocate health care resources through changing scopes of practice
- Apply ehealth technologies to engage survivors by providing information and support at point of need
- Organize patient and population data to facilitate education survivorship research and efficient and effective survivorship care
PMH Survivorship Program Themes

- Empowerment
- Educate for Self Management
- Enhance Clinical Care
- Enable Community Connections
- Coordination
- Research

Integration
Welcome to the Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research (ELLICSR)

Funded by the CFI, ORF and the PMHF
Empowerment: Grappling With the Issues

World Bank Definition:
“The process of increasing capacity of individuals or groups to make choices and transform those choices into desired actions and outcomes”

WHO Definition 1998
“Process by which people gain greater control over the decisions and actions affecting their health”
Operationalizing Empowerment

Self-management

• the individual living with a chronic disease has the knowledge, skills, judgement, ability and confidence to be an advocate and an expert in the management of their own symptoms, health and wellness.

  Bodenheimer et al. 2002

Self-care

• the personal and medical care performed by the patient, usually in collaboration with and after instruction by a healthcare professional

  The American Heritage® Medical Dictionary
Self-Management Central Concept

Self-Efficacy - Psychosocial perspective
• belief in one’s competence to carry out behaviour required to deal with difficult and challenging tasks.
• to **cope** with adversity to reach a desired goal

Bandura 1997

Self-Efficacy - Education perspective
• **confidence** to carry out a behaviour necessary to reach a desired goal.
• enhanced when patients succeed in solving patient identified problems.”

Bodenheimer 2009
Measuring Empowerment

Stanford Self-Efficacy Scale
Cancer Behavioural Index
• confidence scales about managing issues

PMH Cancer Empowerment Scale (25 items)
• 4 subscales
  • involvement in decision making
  • knowing enough about myself
  • having a supportive healthcare context
  • problem solving
How to Adapt Pt Education Programs

Stanford Self-Management Education Approach

• Group interaction
• Personal goal setting and action planning over at least six weeks
• Active problem solving
• Peer support
• Encouragement of partnerships between patient and health care provider

What Do Patients Need to Know?

To manage chronic conditions patients need to:

• Make informed decisions
• Understand health information about their condition and treatment options
• Understand the concept of risk
• Follow complex medical regimens
• Plan and make lifestyle changes
• Know when and how to access care
What is health literacy and why should it be important to physicians? Health literacy has profound implications for how people interact with their physicians and other health-care professionals, how they interact with the health-care system, and how they manage their illnesses. For physicians and other health-care professionals, assessing the patient’s level of literacy is critical throughout the assessment, diagnosis, and treatment stages.
How Do We Take A Systems Approach to Empowerment?

Ambulatory Care Redesign-Empowerment Work Stream

• Empower the institution by enabling empowering care
• Partner with patients in all aspects of treatment and care
• Provide patients with the infrastructure to be involved in, plan for and self-manage their care
• Support patients to acquire with the knowledge, skills and confidence to navigate the health care system
• Use new and innovative technologies to reach and empower patients
• Improve transitions to primary care by enabling community engagement.
Integration of a Disease Self-Management Approach in the Cancer System to Optimize Health and Living With Cancer: A Road Map For Implementation

Principal Investigator: Doris Howell

**Objective**: To develop and approach to optimize the implementation of a disease self management approach in the cancer system

**Aim 1**: Characterize the quality of self management support currently delivered in the cancer system

**Aim 2**: Assess health care professionals current practice abilities and perceptions of self management support and determine barriers to the integration in routine cancer care

**Aim 3**: Identify an approach for integration
Survivorship @ PMH : 2011

Interdisciplinary Team

Audrey Friedman
David Wiljer
Janet Papadakos
Sara Urowitz
Michelle Snow
David Willson
Nazek Abdellmutti
Myann Marks
Alaina Cyr
Madelyn Fler

Jennifer Jones
Doris Howell
Alex Jadad
Christine Maheu
Joyce Nyhof-Young
Tara Walton

Pamela Catton
Sara Ferguson
Robert Buckman
Scott Secord
Alex Chafranskaia
Aronela Benea
Lori Bernstein
Sylvia Crowhurst
Norma D’Agostino
Linda Durkee
Pam Hammond
Stephanie Phan

Mary Hooey
Jim Redding

Supported by the PMHF
PMH Survivorship Program in 2011

- **Case management**
  - 3-5%

- **Specialist management**
  - 15-20%

- **Supported self management**
  - 70-80%

Kaiser Permanente
Population Health Risk Pyramid

Level one

Level two
PMH Survivorship Program

Level one

Level two

complexity

Diagnosis  Treatment  “Survivorship”

time
378 Survivorship Consults

Self Management Program
Information, Education classes
Tools and Support
1678 attendees in formal classes

1846 clinic visits

Self Care Program

Level one

Level two

POPC

TRI/WCH
Survivorship Program

1 Survivorship Consultation with the CSCP
- Understanding of Diagnosis and Treatment
- How to Work With Your Team
- Learn What to Expect Find Resources Set Goals

2 Survivorship Self-Management Classes
- Managing your Cancer Journey
- Surgery, Radiation, Chemo
- Getting Back on Track Management

3 Survivorship Self-care Treatment
- Assess and Provide Self-care Treatment
- Referral to Healthcare Experts
- Referral to Healthy Lifestyle Programs
## DOCH 2 Undergraduate Medical Education Annual Outcomes Summary

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*Courtesy Joyce Nyhof-Young*
Survivorship Consultation: A Patient-centered Reflective Interview

Standardized and captured in eCancer collaboratively with patient

Engagement at the start of care with survivors through the consult fundamental to collaborative care concept
Problem Solving, Goal Setting!

Survivorship goals

Short-term survivorship goals:
- To find a support system that meets my needs
- To learn how others have coped by speaking with other breast cancer survivors
- To learn how to allow others to help me
- To learn how to lower my stress and have a greater sense of control in my life
- To learn how to manage and organize my activities of daily living with treatment demands
- To learn what I can do to help manage my cancer treatment and side effects
- To learn what to expect from my cancer treatment
- To spend time with family and friends
- Other

Long-term survivorship goals:
- To achieve personal milestones that are important to me
- To adjust to my "New Normal" after treatment has finished
- To be present for meaningful milestones with family and friends
- To explore spiritual issues more fully
- To learn new ways of living, relationships, sexuality and general functioning
- To make changes as a result of my financial situation
- To make decisions regarding changes in occupation, work, or career
- To make travel plans
- To reflect on life and think about making meaningful changes in my life
- To resume and get back to what life was like before cancer
- Other

Survivorship plan:

CancerCare

Smith, Jane
MRN: 00000001
Note in progress

Survivorship perspective

Jane identified a number of challenges she is currently facing while living with breast cancer, which fall into four domains:

Physical well-being: she currently identifies fatigue, and functional activities issues.
Psychosocial well-being: she currently identifies anxiety, and depression issues.

Presently, Jane rates her overall level of distress over the past week to be 0 (none) on a scale of 1 to 10.

Survivorship goals

In the short-term, Jane's goals are: to find a support system that meets my needs, and to learn how others have coped by speaking with other breast cancer survivors.

In the long-term, Jane's goals are: to be present for meaningful milestones with family and friends, and to adjust to my "new normal" after treatment has finished.

Recommendations

Jane was provided information about side effects and late effects from treatment and oriented to the followup and aftercare clinics offered by the Breast Cancer Survivorship program. This consult has provided Jane with information on symptom management and long term surveillance including: managing their cancer journey, general wellness, lymphedema, mobility and function, fatigue, cognition, weight management, and bone health issues.
Demographics

Phase at Time of Consultation N(583)

- Phase 1 - Diagnosis
- Phase 2 - Treatment
- Phase 3 - Post Treatment
- Phase 4 - Recurrence Local/Regional/Metastatic

Stage of Cancer at Time of Consultation

<table>
<thead>
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<th>Stage</th>
<th>1</th>
<th>2</th>
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<th>4</th>
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<td>133</td>
<td>173</td>
<td>121</td>
<td>206</td>
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</table>
Distress Scores

Overall Level of Distress in the Past Week Scale of (1 to 10)

- 0 to 3
- 4 to 7
- 8 to 10

Moderate to high levels of distress at time of consultation
## Challenges Identified During Consultations n(639)

### 73% Physical (465/639)

<table>
<thead>
<tr>
<th>Category</th>
<th>Fatigue</th>
<th>Pain</th>
<th>Fertility</th>
<th>Functional Activity</th>
<th>Overall Health</th>
<th>Strength</th>
<th>Sleep and Rest</th>
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<tr>
<td>Percentage</td>
<td>56.90%</td>
<td>53%</td>
<td>3.40%</td>
<td>55.20%</td>
<td>16.50%</td>
<td>37.90%</td>
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<tr>
<td>Overall Percentage</td>
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### 71% Psychosocial (456/639)

<table>
<thead>
<tr>
<th>Category</th>
<th>Anxiety</th>
<th>Attention</th>
<th>Cognition</th>
<th>Memory</th>
<th>Depression</th>
<th>Distress w Dx</th>
<th>Enjoyment of Life</th>
<th>Fear of Recurrence</th>
<th>Control</th>
<th>Overwhelmed</th>
</tr>
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<tr>
<td>Percentage</td>
<td>59.90%</td>
<td>23.20%</td>
<td>13.20%</td>
<td>36.20%</td>
<td>26.50%</td>
<td>35.50%</td>
<td>5.50%</td>
<td>45.80%</td>
<td>5.00%</td>
<td>10.70%</td>
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<tr>
<td>Overall Percentage</td>
<td>71.3%</td>
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</table>

### 37% Social (289/639)

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<tr>
<th>Category</th>
<th>Affection/ Sexual Func</th>
<th>Appearance</th>
<th>Family Distress</th>
<th>Finance</th>
<th>Isolation</th>
<th>Roles and Relationships</th>
<th>Work</th>
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<tr>
<td>Percentage</td>
<td>45.20%</td>
<td>13.80%</td>
<td>23.90%</td>
<td>31.50%</td>
<td>36.70%</td>
<td>21.50%</td>
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### 19% Spiritual (121/639)

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<tr>
<th>Category</th>
<th>Hope</th>
<th>Inner Strength</th>
<th>Meaning of Illness</th>
<th>Religion</th>
<th>Spirituality</th>
<th>Uncertainty</th>
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<tr>
<td>Percentage</td>
<td>18.90%</td>
<td>18.90%</td>
<td>11.60%</td>
<td>18.20%</td>
<td>14.90%</td>
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<tr>
<td>Overall Percentage</td>
<td>18.90%</td>
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</table>
Median delta = 2.0 (p = 0.03; means SD = 7.2)  Median delta = 0.2 (p = 0.06; mean SD = 0.9)
Most Appropriate Time to Provide Survivorship Consult

"When do you feel is the best time to provide this interview?"
(n=40)

- Time when I was diagnosed: 14 participants
- During the time that I was undergoing treatment: 12 participants
- Post treatment (up to 6 months following last treatment): 4 participants
- Long term survivorship (more than 6 months following last treatment): 6 participants
- Other: 2 participants

Survivorship Program

1. Survivorship Consultation with the CSCP
   - Understanding of Diagnosis and Treatment
   - How to Work with your Team
   - Learn What to Expect
   - Learn What to Expect
   - Find Resources

2. Survivorship Self-Management Classes
   - Managing your Cancer Journey
   - Surgery, Radiation, Chemo
   - Getting Back on Track Management

3. Survivorship Self-care Programs
   - Assess and Provide Self-care Teaching
   - Referral to Healthcare Experts
   - Referral to Healthy Lifestyle Programs
Introduction

At Princess Margaret Hospital (PMH), an interdisciplinary team of social workers and education specialists developed a series of classes collectively called, “Managing Your Cancer Journey”. These classes were developed for breast cancer patients with the goal to empower patients to manage their cancer through education and support.

Using data collected from a qualitative evaluation of the course with breast cancer patients, the curriculum and course materials have been revised to be applicable to all cancer patients at PMH.

Now, a two-part education course, Managing Your Cancer Journey (MYCJ), places cancer survivors at the centre of their care, connects them to self-management education and focuses on teaching coping strategies and skills for navigating the health care system. Since the diagnosis of cancer is known to be accompanied by fear, anxiety, and depression, the MYCJ course is designed to increase a person’s control over their situation and help to reduce these emotional challenges.

MYCJ consists of 2 two-hour classes, using didactic and interactive teaching strategies, and is facilitated by a social worker and medical oncologist. A pilot evaluation of the course with both qualitative and quantitative components was conducted to determine whether MYCJ decreases anxiety and increases self-efficacy in CS.

Objective

The objectives were to determine:
- the efficacy of MYCJ in improving patient anxiety and self-efficacy as measured by two validated scales.
- the most important elements of the program as reported by the participants through qualitative analysis.

Methods

Using a pre-post design, anxiety and self-efficacy were measured before and after attending a MYCJ session, and three weeks later, as reported by the State-Trait Anxiety Inventory (STAI) and Cancer Behaviour Inventory (CBI), respectively. Additionally, qualitative data were collected through a satisfaction survey to determine the most important elements of the program.

Results

Attendance at MYCJ is associated with a decrease in anxiety and an increase in self-efficacy, indicating that this programmatic goal was successfully met.

Anxiety (Figure 1): The STAI was used to measure the level of participant anxiety immediately before and immediately after the MYCJ session.
- Mean pre-class STAI = 44 (high-anxiety on STAI).
- Mean post-class STAI = 37 (anxiety level of working adults)
- Mean difference: p=0.002

Self Efficacy (Figure 2): The CBI was used to evaluate the immediate effect of the MYCJ session on self-efficacy.
- Mean pre-class CBI: 89
- Mean post-class CBI = 99
- Mean difference: p=0.002

Conclusions

- Low levels of self-efficacy in patients with cancer have been shown to increase the incidence of anxiety, depression, pain, and fatigue.
- The MYCJ curriculum was capable of increasing self-efficacy and decreasing anxiety in a small sample of patients.
- The results from this pilot, when taken together with the existing literature, indicate that MYCJ is capable of impacting two psychosocial factors – anxiety and self-efficacy – that play a critical role in the well being and quality of life of cancer survivors.
- Further research is needed to determine if MYCJ can accomplish its aims with a larger sample size.

References
Getting Back on Track: A Single-Session Psychoeducational Group Intervention for Women with Breast Cancer Completing Adjuvant Treatment

Jennifer M. Jones PhD
Terry Cheng MSW
Maureen Jackman MSW
Susan Haines RD
Gary Rodin MD
Pamela Catton MD

Jones et al, Journal of Psychosocial Oncology, 28:269-290, 2010
Getting Back on Track: Life After Treatment: Information Booklet

- Developed with a 2002 educational grant from CBCF
- Provided to all patients at end of adjuvant treatment
- 2002/03 evaluation of GBOT-B
  - Patient’s very satisfied with the booklet
  - GBOT booklet alone did not address the info needs of many of the women completing adjuvant treatment for BrCa
- Response: Developed a single-session group educational class
  - based on the content of the GBOT-Booklet
  - 2 hours in duration
Study Design: RCT

Standard Print Material + Psychoeducation (Intervention) Pre-Test (T1) → GBOT → Post-Test 3 months (T2) 6 months (T3)

Standard print Material (Control) Pre-Test (T1) → Post-Test 3 months (T2) 6 months (T3)

Funded by the WEBC Innovation Fund
Summary of Findings

- Acceptable intervention that women enjoyed and appreciated
- Significant difference (INT vs CTL) in mean change in scores from baseline for overall knowledge and perceived preparedness for re-entry
- Group effect was maintained over time
- No differences (INT vs CTL) in the mean change in self-efficacy, mood, and stress scores from baseline
  - low distress scores at baseline may account for little change
Survivorship Self-Care Programs

- Lymphedema Clinic
- Fatigue Clinic
- Neurocognitive Clinic
- Function and Mobility Clinic
- Healthy Bones Program

Healthy Lifestyle Programs@ ELLICSR

- Healthy Steps
- Healthy Eating
- Taking Charge
## Self Care Survivorship Clinics - Level One Care

### Standardized Elements for Level One Care

1. Interdisciplinary assessment
2. Individualized care plan
3. Education - Single or group
4. Opportunity to practice
5. Reinforcement of behaviour change
6. Follow up

### Self-Care Outcomes Assessment

1. Acquisition of knowledge and/or competency
2. Improvement on Stanford Self Efficacy scale
3. Improvement in quality of life/reduced anxiety – (State Trait Anxiety Inventory)
4. Documentation of adoption of new behavior
Survivorship Self-Care Programs

- Lymphedema Clinic
- Fatigue Clinic
- Neurocognitive Clinic
- Function and Mobility Clinic
- Healthy Bones Program

Healthy Lifestyle Programs@ ELLICSR

Healthy Steps

Healthy Eating

Taking Charge
Building Recipes and Understanding Nutrition for Cancer-Survivor Health (BRUNCH)

PRINCIPAL INVESTIGATOR:
Robert Luke, Sara Urowitz, PMH

Objectives: To develop, evaluate and test healthy recipe prototypes for people with colorectal cancer to encourage mindful eating post active treatment.

Results will help guide development of educational materials to support cancer survivors on their journey to mindful eating post colorectal cancer treatment
eEmpowerment

- Tailored education available anywhere, anytime
- Support diverse education needs before, during and after treatment
- Reinforce self management education.

Information Education Tools and Support
Wiljer D, Friedman A, Catton P. Supportive Care Quarterly Spring 2007
<table>
<thead>
<tr>
<th>Patient Portal Group</th>
<th># Users/Group</th>
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<tr>
<td>CKD</td>
<td>108</td>
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<tr>
<td>Diabetes - Type 2</td>
<td>115</td>
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<td>Total Number of Users</td>
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**Mean Anxiety Score amongst Total Patient Population**

- Mean change in anxiety from pre to post was -1.6; p-value = 0.031
CaringVoices.ca Communities

- Over 3000 registered users
- Bone 36
- Breast 535
- Digestive/Gastrointestinal 70
- Endocrine 27
- Eye 6
- Genitourinary 20
- Germ Cell 51
- Gynecologic 139
- Head and Neck 57
- Hematologic/Blood 146
- Musculoskeletal 14
- Brain/Neurologic 35
- Respiratory/Thoracic 23
- Skin 29
Synchronous Moderated Events

- Between 15 – 20 synchronous events/month
- Number of Event Types Held
  - *Talking Sticks*
    - Breast 80
    - General 17
  - *Clinical*
    - Breast 64
    - General 103
    - Gyne 29
    - Hem 8
  - *Living Well*
    - Breast 66
    - General 92
    - Gyne 11
    - Hem 10
Moderators of Synchronous Chats

- Active moderators = 94
  - 20 Allied health including social workers, dieticians, PT, psychologist
  - 24 Other professionals
  - 13 RNs
  - 10 MRT (Medical Radiation Therapists)
  - 9 Physicians
  - 8 Peer-leaders
  - 4 Community-leaders
Benefits of Participating in Online Health Communities

- In breast cancer:
  - Associated with lower levels of depression (Winzelberg et al, 2003)
  - Improved mood and decreased psychological distress (Rodgers, S., and Chen, Q. 2005).
  - Improved quality of life (Lieberman et al, 2005)
  - Increased self-efficacy (Rodgers, S., and Chen, Q. 2005)
ELLICSR research programs will:
• Make new discoveries in survivorship, innovations in clinical processes, and new models of care delivery
• Positively impact the quality and quantity of survivorship research conducted and survivorship care delivered
• Make major contributions to improving the health and quality of life of cancer survivors