Assessing patient experiences with Survivorship Care Plans:
Findings from an online registry of breast cancer survivors

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CANCER SURVIVOR REGISTRY
THE BREAST CANCER M.A.P. PROJECT

CANCER SUPPORT COMMUNITY

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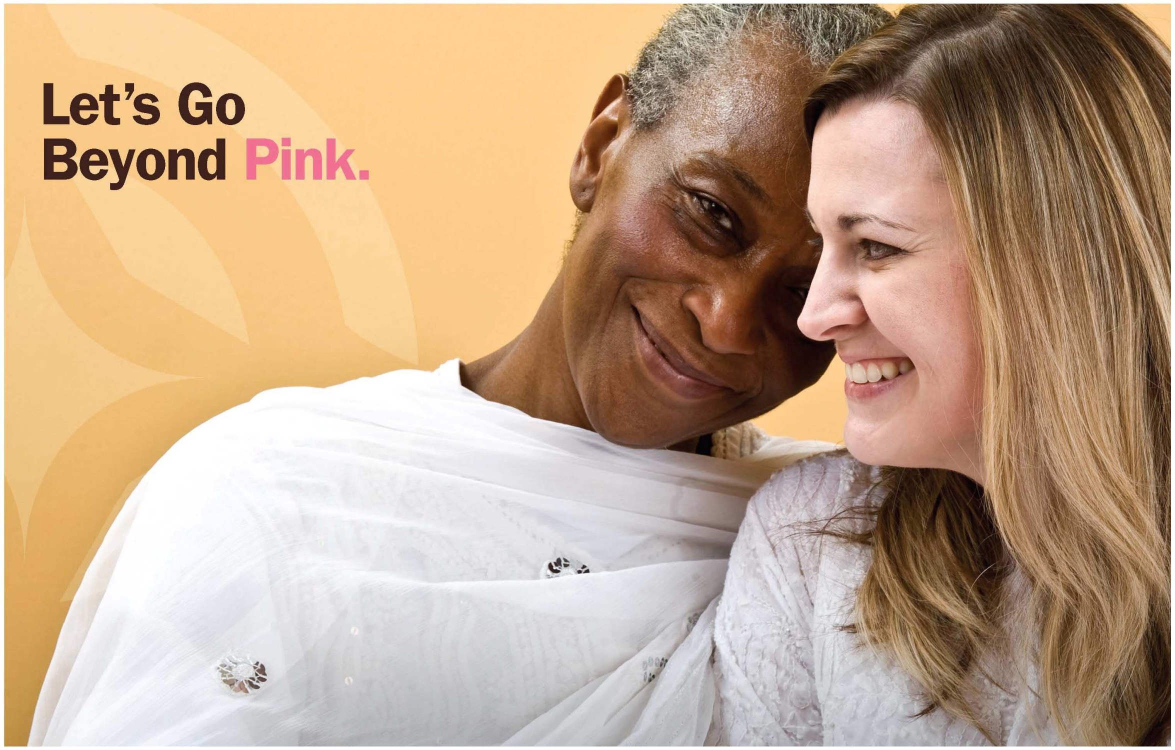
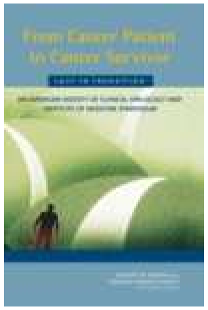


Complete Cancer Care

Must include social and emotional needs

- The good news: more than 2.5 million breast cancer survivors living in the United States
- Institute of Medicine highlighted psychosocial needs
  - *From Cancer Patient to Cancer Survivor: Lost in Transition (2005)*
  - *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (2007)*



- When people with cancer struggle with distress, emotional and social problems, the <u>result is sub-optimal health outcomes and increased cost of care</u>

The Cancer Survivor Registry

Harnessing the power of survivor insights

- The Vision of the Cancer Survivor Registry
  - Give cancer survivors a unified voice to advance the understanding of their social and emotional needs
  - The *Breast Cancer M.A.P. (Mind Affects the Physical) Project* inaugural Index from Registry
- Three key areas of focus

  1) Communication during the treatment decision making process

  2) The role of survivorship care plans (SCP)

  3) Screening for social and emotional distress
- Key findings that should capture the attention of the healthcare community

Survivorship Care Plans (SCPs)?

SCPs are meant to summarize information critical to the individual's long-term care, such as:

- Treatment summary, including the cancer diagnosis, diagnostic tests, tumor characteristics, type(s) and details of treatment, dates of treatment initiation and completion, and potential consequences
- Timing and content of follow-up visits
- Tips on maintaining a healthy lifestyle and preventing recurrent or new cancers
- Legal rights affecting employment and insurance
- Referrals for psychological and support services

SCPs are intended to integrate primary and follow-up cancer care, recognizing patients are mobile across healthcare systems.

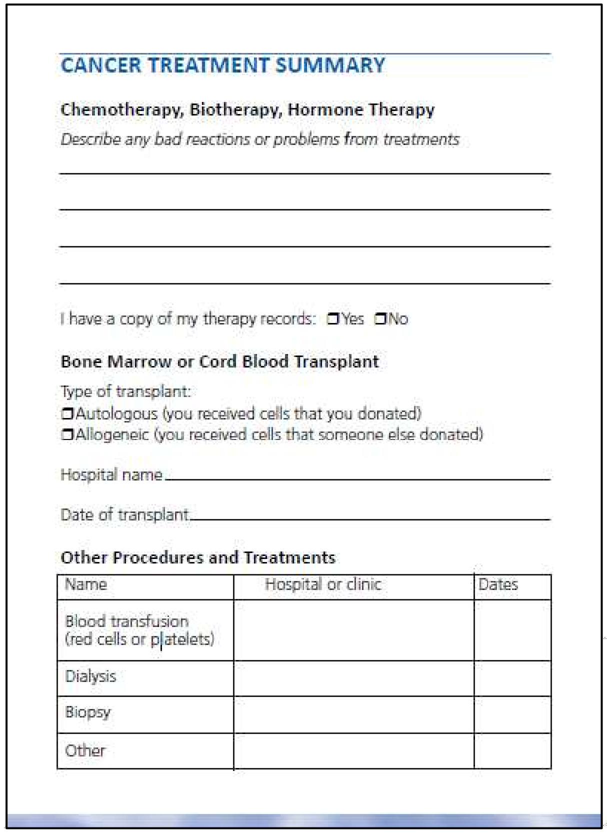
Survivorship Care Plans

Goal

A core recommendation of the IOM is for each cancer patient to receive an SCP

Better integrate primary and follow-up cancer care, which is particularly important for cancer survivors

Little is known about their use and value to cancer patients



CANCER TREATMENT SUMMARY

Chemotherapy, Biotherapy, Hormone Therapy

Describe any bad reactions or problems from treatments

I have a copy of my therapy records: ☐Yes ☐No

Bone Marrow or Cord Blood Transplant

Type of transplant:
☐Autologous (you received cells that you donated)
☐Allogeneic (you received cells that someone else donated)

Hospital name

Date of transplant

Other Procedures and Treatments

Name	Hospital or clinic	Dates
Blood transfusion (red cells or platelets)		
Dialysis		
Biopsy		
Other		

Minnesota Cancer Alliance: Life After Cancer Treatment

SCP needs to be more than a medical and treatment summary, but rather a passport to health for addressing the ongoing social and emotional needs of cancer survivors

About the Registry & Methodology

Design

- ✓ Captures demographic and clinical disease information
- ✓ Captures social and emotional experiences
- ✓ Ability to interact and generate new data in real time
- ✓ Follows patient population over a period of time to identify trends/changes

Recruitment

CANCER SUPPORT COMMUNITY

- 50 affiliates
- 100 satellite locations
- CSC online community

LIVING BEYOND BREAST CANCER

- Living Beyond Breast Cancer
- Sisters Network, Inc.
- Susan G. Komen for the Cure

- Television
- Print
- Online
- Radio

- Facebook
- Twitter
- Blogs

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MAP SCP Question Methodology

In October 2010, registrants were emailed and asked to log into their *M.A.P. Project* account and answer study specific questions about:

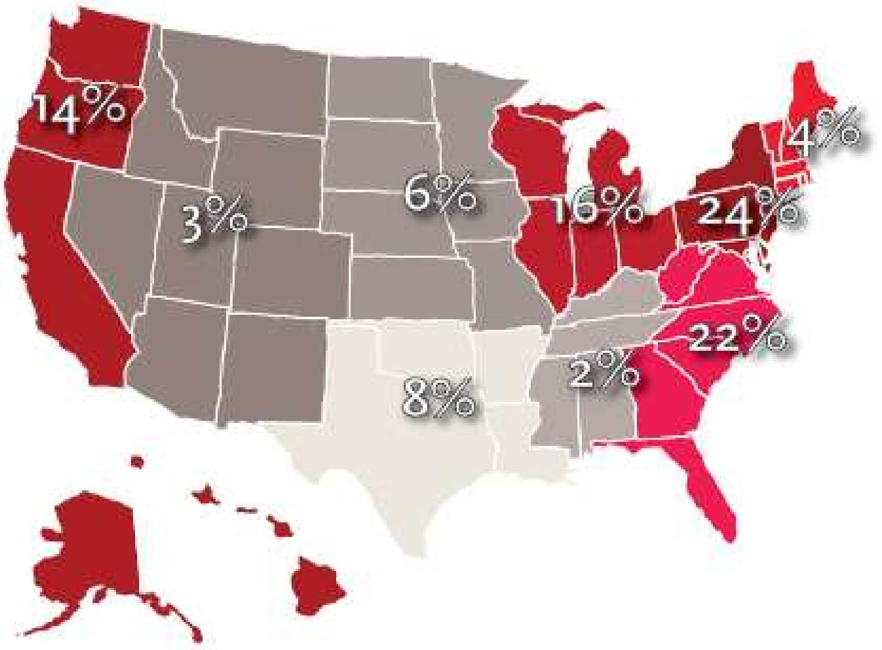
- Whether they received a SCP or TS
- If received, satisfaction with SCPs
- Queries about information desired but not provided

Demographics (N=844)

99% - Female
88% - Caucasian
55 - Average age
5.6 - Average number of years since diagnosis

Medical Data

- 56 percent reported at least one co-morbidity
- More than half of all tumors were diagnosed at Stage II or above
- Nearly 20 percent were diagnosed at Stage III or above



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Results: Prevalence of SCPs

Cancer survivors (n=844) answered questions about Survivorship Care Plans

- 90% did NOT receive a SCP
- 88% had NOT received a Treatment Summary (TS)
- There was no relationship between time since diagnosis and receipt of a TS or SCP

Results: Among survivors who received SCP (n=86)

Approximately 70% of their SCPs covered information related to medical content

- A treatment summary (dates of treatment, test results, etc.)
- Information about side effects and treatment next steps
- Contact information for their medical team

Far fewer SCPs included content related to the social and emotional needs of survivors (16%-40% depending on the specific domain of socio-emotional referral)

- Emotional, physical (i.e. pain, sexual dysfunction, swelling), and nutritional needs
- Financial support

71% found their SCP to be useful or very useful.

Results: Among survivors who did not receive SCP

Of those who did not receive a SCP (n=758):

•96% would have liked one

•They would have wanted theirs to include:

- A document with TS information (i.e. test results, treatment summaries, dates of treatment, etc.)
- Information and referrals for emotional, physical, and nutritional needs
- Referral for financial concerns or/and personal relationship difficulties

Survivorship Care Plans- Summary of Results

- ✓ 90 percent of registrants did not receive a survivorship care plan
- ✓ 96 percent would have liked to have received one
- ✓ 71 percent of the survivors who did receive one found the plan to be useful or very useful

Survivorship Care Plans- Comparing Evidence

Emerging Data:

Stricker et al., (2011). Survivorship care planning after the Institute of Medicine recommendations: how are we faring?

- Key Findings:
  - 7 NCI designated comprehensive cancer centers and 6 community hospitals
  - 54% of IOM content recommendations were not met for treatment summaries; 41% of IOM content recommendations were not met for SCP's
  - No sites achieved 75% overall concordance with IOM recommendations
  - At over 60% of sites, less than 10% of breast cancer survivors received a SCP

- Conclusion: Gaps in SCP delivery exist even in dedicated survivorship centers!

Future Directions for Delivery of SCPs

- The effective delivery of meaningful SCPs requires time and resources from the medical practice.
- Attention is needed on how to partner with providers to enhance survivorship care planning and coordination of care.
- Focus on underserved populations

Future Research Directions

- Understand the barriers to delivery of survivorship care plans
- Examine who (e.g., oncologist, nurse, patient navigator) and how SCPs are delivered to patients
- Understand the value and utility of survivorship care plans from patients and providers
- Inform and develop innovative **patient-centered** models of implementing SCPs

Opportunity for a Paradigm Shift

SCPs should be a living document that has clear applications for addressing the *ongoing* social and emotional needs of cancer survivors

With the goal for improving communications with health care providers around:

- treatment decisions
- long-term health and maintenance of healthy lifestyle behaviors
- palliative care

Toward a New Way of Thinking

cancer support source

A PROGRAM *of the* CANCER SUPPORT COMMUNITY

cancer transitions

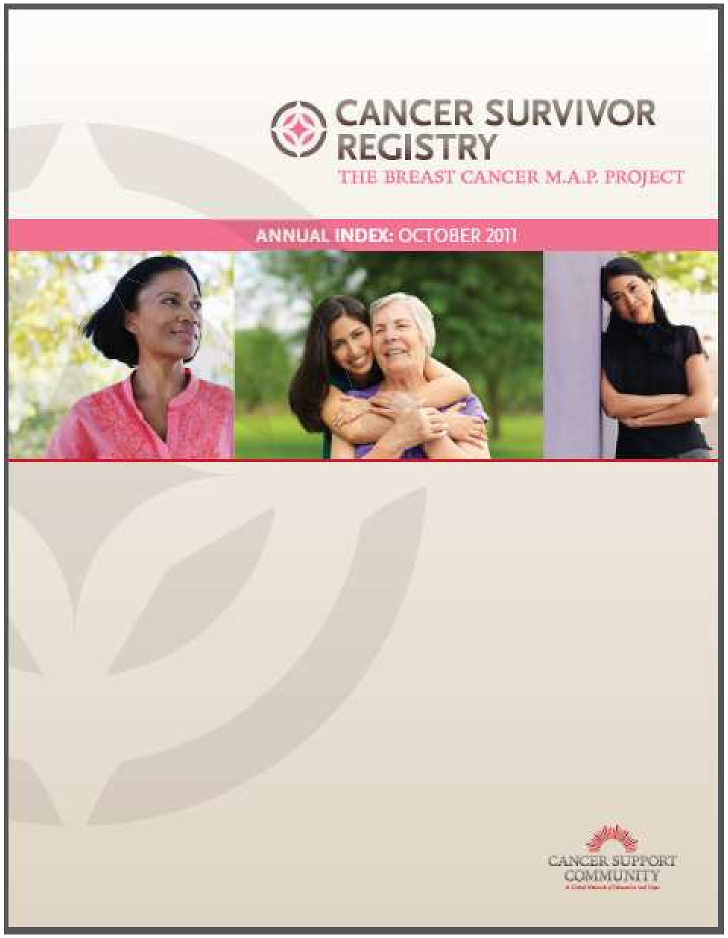
Moving Beyond Treatment™

A Program of
Cancer Support Community
and LIVESTRONG™

- CancerSupportSource™ (CSS) is the first validated 25-item web-based distress screening program developed for community-based hospitals, physician practices and advocacy organizations
- CSS fully integrates screening, referral and follow up care, all through a single, streamlined, web-based program.
- CSS is HIPAA compliant and can be linked to the EHR using HL7 and web services interface.

- Cancer Transitions was developed by the Cancer Support Community and LIVESTRONG to support and empower survivors as they transition from active treatment to post-treatment.
- Our research shows that both men and women who participate can experience:
  - Less worry about the negative impacts of cancer
  - Better physical and social functioning
  - More commitment to physical activity

Download the Full Report



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To download the Index, please visit:

www.cancersupportcommunity.org/BreastCancerMAP

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