

Patient experience with survivorship care plans: Findings from an online registry of breast cancer survivors

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Cancer Support Community

Introduction

- In 2005, the Institute of Medicine recognized that survivorship care plans (SCP) and treatment summaries (TS) are critical to the delivery of comprehensive survivorship care.
- SCPs are meant to summarize information critical to the individual's long-term care, such as:
 - TS 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
- The plans are intended to integrate primary and follow-up cancer care, recognizing patients are mobile across healthcare systems.
- These recommendations present a significant challenge to oncology practices; yet, little is known about their use and value to patients.

Purpose

- Presently, there is no consensus in the medical community on the breadth and depth of content that should be included in a SCP.
- Little is known regarding patients' knowledge of SCPs, their utility or their value.
- As such, the Cancer Support Community (CSC), the largest provider of psychosocial support to cancer patients in the US, surveyed breast cancer survivors about their experience with SCPs to identify areas of unmet needs.

Methods

- Nearly 3,000 breast cancer survivors have joined the *Breast Cancer M.A.P. Project*, an online registry designed to examine the psychosocial impact of breast cancer.
- 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

Sample Characteristics (N=844)

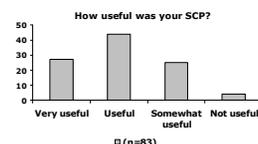
Female: 99%	Annual Household Income
	18% < \$40K
Mean Age	15% \$40K-\$59,999
55 (SD=9.36)	15% \$60K-\$79,999
	15% \$80K-\$99,999
	38% \$100K+
Ethnicity	Insured: 98%
88% Caucasian	
6% Afr-Am/Black	Mean Age at Diagnosis
3% Latino	49.5 (SD=9.00)
1% Asian	Mean Years Since Diagnosis
Education	5.7 (SD=5.43)
8% HS or less	Stage
18% Some College	10% Stage 0
38% College Degree	33% Stage I
34% Graduate Degree+	40% Stage II
Employment:	15% Stage III
47% Full-time	2% Stage IV
14% Part-time	Recurrence: 13%
24% Retired	
14% Unemployed	

Results

- 12% reported that they had received a TS
- 10% reported having received a SCP
- Almost half (45%) of those who received a TS, also received a SCP.
- There was no relationship between time since diagnosis and receipt of a TS or SCP.
 - For example, a recently-diagnosed breast cancer patient was as likely to receive a TS/SCP as patients diagnosed years ago

Received a SCP

- Of those who received a SCP (n=86), 71% found their SCP to be useful or very useful.



Results, cont.

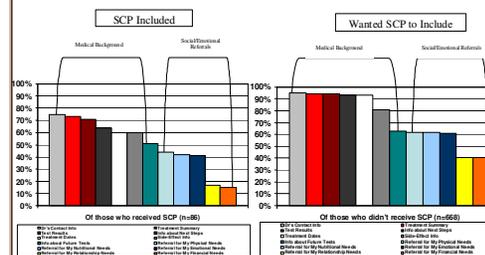
- Registrants who received a SCP (n=86) were asked what their SCPs included.
 - Most registrants who received a SCP reported inclusion of medically related information
 - A treatment summary including dates of treatment, test results, etc.
 - Information about side effects and treatment next steps
 - Contact information for their medical team
- SCPs were less likely to include information or referrals for common survivorship needs, including the following:
 - Emotional, physical (i.e. pain, sexual dysfunction, swelling), and nutritional needs
 - Financial support

Did not receive a SCP

- Of those who did not receive a SCP (n=758), 90% would have liked one.
- Those who did not receive a SCP (n=758) were asked what they wanted a SCP to include if had they been given one.
 - Majority wanted a document to include TS information (i.e. test results, treatment summaries, dates of treatment, etc.)
 - More than 60% wanted it to include information and referrals for emotional, physical, and nutritional needs
 - Over 40% would have liked a referral for financial concerns or/and personal relationship difficulties

A comparison

- The charts below show the information included in a SCP of those who received a SCP, compared what those who did not receive a SCP would want in a SCP.



Conclusion

- These data indicate that the majority of breast cancer survivors did not receive a survivorship care plan. There continue to be gaps in the adoption, delivery and utility of cancer survivorship care plans.
- Of the minority of breast cancer survivors who received a SCP, approximately 70% of their plans covered information related to medical content (e.g., diagnosis, staging, treatment summary), all of which are important to patients and coordination of follow-up care.
- In contrast, 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). This 'other content' is essential to treating the "Whole Cancer Patient" as specified by the IOM (2007).
- SCPs do not typically include content about survivors' social and emotional needs, which contrasts directly with the patients' desire for information about how to manage their whole cancer survivorship experience.
- More attention is needed to improve the delivery and the substance of the survivorship care plan, so that the ongoing needs of breast cancer survivors can be met.

Future Directions

- The effective delivery of meaningful SCPs requires time and resources from the medical practice. Future research is needed to understand the barriers to delivery of survivorship care plans. Also, research needs to examine who (e.g., oncologist, nurse, patient navigator) and how SCPs are delivered to patients.
- Greater research is needed with respect to understanding the value and utility of survivorship care plans from the perspectives of the cancer survivor and the provider including associated costs.
- Findings from future research can be used to inform and develop innovative models of implementation of SCPs that are patient-centered. Attention is needed on how to partner with providers to enhance survivorship care planning and coordination of care.

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Background:

The IOM (2005) recognized that survivorship care plans (SCP) and treatment summaries (TS) are critical to the delivery of comprehensive survivorship care. The plans are intended to integrate primary and follow-up cancer care, recognizing patients are mobile across healthcare systems. These recommendations present a significant challenge to oncology practices; yet, little is known about their use and value to patients. The Cancer Support Community, the largest provider of psychosocial support to cancer patients in the US, surveyed breast cancer survivors about their experience with SCPs to identify areas of unmet need.

Methods:

To date nearly 3,000 breast cancer survivors have joined the *Breast Cancer M.A.P. (Mind Affects the Physical) Project*, an online registry designed to examine the psychosocial impact of breast cancer. In November 2010, 844 consecutive registrants were provided study-specific questions: 1) receipt of a SCP or TS, 2) if received, satisfaction with SCPs, and 3) queries about information desired but not provided. This sample was 99% female, 88% Caucasian, and the mean age was 55. 72% had at least a college degree. The majority (58%) was initially diagnosed with at least Stage II disease; 14% reported having had a recurrence.

Results:

Of the respondents, only 12% of breast cancer survivors had received a treatment summary (n=101) and 10.5% had received a survivorship care plan (n=90). Of those who received a SCP, 53% found it to be useful or very useful. Among registrants who received a SCP, 25% reported that information about test results, dates of treatment, and information about future tests were missing from their SCP. Registrants would have also liked their SCP to include information about: 1) general survivorship resources, 2) complementary and alternative treatments, 3) recurrence, 4) late effects, and a summary of the diagnosis and prognosis.

Conclusions:

The data from the *MAP Project* indicate that the majority of breast cancer survivors did not receive a survivorship care plan and of those who did receive a plan, a substantial proportion did not find it useful. There continues to be gaps in the adoption, delivery, and utility of cancer survivorship plans.