NCCS:
A Look Back and a Look Ahead

2020

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Our Purpose

Impacting Policy ♦ Empowering Survivors ♦ Transforming Care

NCCS advocates to transform the health care system for the nearly 17 million cancer survivors and their families
CPAT Activities

- Monthly e-newsletter, “CPAT Chronicles”
- Regular webinars on policy issues and advocacy skills
- Private Facebook group
- Share information and match advocates to engagement opportunities
  - Research grant review, conference scholarships, training programs, quality measurement committees
  - Speaking engagements and media opportunities
- Examples:
  - Department of Defense (DoD) Congressionally Directed Medical Research Program (CDMRP) Peer Review
  - NBCC Project LEAD
  - AACR Scientist <-> Survivor Program
  - National Quality Forum committees
  - National Consumer Scholars Program
  - San Antonio Breast Cancer Symposium
Study Objectives

To explore experiences and needs surrounding cancer survivorship across a range of cancer patients.

- Profile respondents on various dimensions (type of cancer, stage, treatment/s, side effects, demographics, etc.), to understand differences by key audiences
- Identify the most frequent and severe side effects, and where patients need help
- Understand what assistance patients need in post-treatment information and care
- Learn more about information sources, and where gaps exist today
Survey Methodology

Online Survey of 1,380 cancer patients
- Completed Treatment: n=688 patients
- In-Treatment for Initial Diagnosis: n=388 patients
- In-Treatment for Recurrence: n=258 patients
- Metastatic Cancer: n=166 patients
- Immunotherapy: n=262 patients*

Distributed by NCCS and 9 partner cancer advocacy/care organizations
- 56% from NCCS e-mail and social media
- 10% Cancer Care
- 9% Fight Colorectal Cancer
- 4% Melanoma Research Alliance; Ovarian Cancer Alliance
- 3% Livestrong; Melanoma Research Foundation
- 2% Supporting Our Sisters Inc.
- 1%: Cancer Support Community; LUNGevity

Survey Note:
- The survey instrument was peer reviewed by NCCS staff and other experts in the field.
- As with all online surveys, this survey uses a convenience sample of respondents drawn from multiple channels. As such, findings are not generalizable to the cancer population as a whole.

*Note: N=101 patients with either breast, brain, prostate, liver, pancreatic or myeloma cancer indicated they had received immunotherapy. These respondents were removed from this audience for analysis, as there were no immunotherapy products with FDA-approved indications for these cancers at the time the survey was conducted.

Blue (higher) / Red (lower) indicates statistical significance across 3 or more key audiences
Executive Summary

Treatment Experiences

- Patients report many physical and emotional side effects. Fatigue and anxiety top the list of both the most common and long term effects. These are also among the most severe side effects reported by patients.

- However, patients report that while healthcare providers are helpful at addressing their physical side effects such as nausea and vomiting, HCPs are far less helpful at addressing fatigue, anxiety, depression and cognitive effects.

Post-Treatment Information and Care

- Few feel very prepared for the transition to post-treatment, nor informed about how to manage their health post-treatment.

- While most patients have spoken to a healthcare provider about post-treatment care, over half say they asked their doctor/HCP, and far fewer say their provider initiated these conversations.

- Satisfaction with post-treatment care is varied, with few describing it as excellent. As a result, more rely on online sources for information rather than their HCPs.
Executive Summary

Survivorship Needs

- When asked to identify their level of concern about a range of issues, financial issues tops the list (getting/keeping health insurance, having financial support), followed by managing ongoing side effects, uncertainty about the future, and having the energy to make it through the day.

- There is clearly a disconnect between patient concerns and support from HCPs. Less than a third rate their HCP as “very helpful” on their top issues.

- Many are interested in survivorship resources, especially programs for managing long-term symptoms, but few say these are available from the HCPs today.
Patients report many physical and emotional side effects

- Feeling overly tired and anxiety are most common and long lasting.

**Symptoms during/following treatment and today**

- Feeling overly tired: 41% (During/after treatment), 67% (Still experiencing)
- Anxiety: 40% (During/after treatment), 58% (Still experiencing)
- Nausea/vomiting or diarrhea: 18% (Still experiencing)
- Muscle/joint pain: 25% (During/after treatment)
- Depression: 28% (Still experiencing)
- Memory loss, cognitive issues: 31% (Still experiencing)
- Neuropathy: 26% (Still experiencing)
- Dermatological problems: 13% (Still experiencing)
- Uncertainty around status of your cancer: 13% (Still experiencing)
- Fever/chills: 9% (Still experiencing)
- Bone, joint, and soft tissue issues: 15% (Still experiencing)
- High or low blood pressure: 11% (During/after treatment)
- Uncertainty around when to stop or how long to continue therapy: 18% (Still experiencing)
- Lymphedema: 12% (Still experiencing)
- Endocrine issues: 11% (Still experiencing)
- Respiratory issues: 7% (Still experiencing)
- Cardiac issues: 5% (Still experiencing)

**Anxiety & Depression Higher Among:**
- Income <$50k: 70%, 62%
- Medicaid: 63%, 55%

5.65 side effects reported on average
I wish I had known....

- Patients say they wish they had known more about the severity of side effects and long term management; mental health side effects; and fertility/sexual health side effects.

More information about immunotherapy and the possible side effects.
- Immunotherapy patient, In Tx Recurrence

How living with the fear of recurrence or metastasis can be exhausting, but CAN be managed, through diet, exercise and support groups.
- In Treatment for Initial Diagnosis

I wish I had known about fertility preservation.
- Metastatic Cancer patient

I wish the oncologist would have told me it was ‘normal’ to experience pain, fatigue, and depression with cancer.
- Completed Tx

Long term survivorship issues such as loss of libido and its effect on marriage, how to handle lasting aches and pains, value of exercise to mental health.
- Completed Treatment

The mental side of things would be worse after treatment is finished.
- Immunotherapy patient, Completed Tx
Meet Elevate Ambassador, Kim Richardson

“I felt like I was wandering around aimlessly in my advocacy work until I became an Elevate Ambassador. The program gave me the support I needed to get my ideas off the ground and implemented.”
Measuring Functional Status

• Patient-centered measure development project to define cancer outcome measure(s) in this critical area, using the Principles of Patient-Centered Measurement

• Original Title: *Return to Functional Status (RFS): Patient-Led Cancer Outcome Measurement*

• American Institute of Research (AIR) funded, with support from the Robert Wood Johnson Foundation (RWJF): Pilot projects to implement Principles of Patient-Centered Measurement
High Level Project Steps

• Convened diverse committee of 10 cancer survivors, as well as Technical Expert Panel (TEP) of oncologists and quality measurement methodologists

• Developed conceptual definition of “return to functional status” (RFS) by cancer patients and survivors using RAND Delphi methodology

• Evaluated existing validated surveys for best alignment with the conceptual definition

• Developed patient-centered specifications for RFS outcome measures (PRO-PMs)
What Patients Want

• Holistic care that recognizes the patient as an person, rather than a diagnosis, and helps the person LIVE WELL with cancer, during and after treatment.

• Understanding of and help with the serious non-physical effects of cancer, especially psychosocial and financial

• Team-based care that includes coordination among providers
Prioritized Outcomes

• Overall Quality of Life
  • Physical and mental health
• Physical Function
• Pain Interference
• Fatigue Interference
• Cognitive Function
• Psychosocial Impact
Redefining Functional Status Measure Set

Who is accountable/being measured?
Medical oncology teams

Denominator/people for whom quality of care is being assessed?
1) Those who have completed chemotherapy
2) Those who are receiving extended chemotherapy

Process: Survey-based assessment of priority outcomes
Process: Action taken when indicated by survey responses
Outcomes: experience of care (communication re: side/late effects and financial impact)
Outcomes: prioritized patient reported outcomes
RFS Committee Members

• Rebecca Esparza
• Betsy Glosik
• Matt Goldman
• Candace Henley
• Allen Hirsch

• Kirby Lewis
• Allison Rosen
• Susan Strong
• Desiree Walker
• Dan Weber
2019 CPAT Symposium

Save the Date!
June 22-24, 2020
The CCPC Act will help cancer patients by supplying them a written plan or roadmap.

The CCPC Act will promote shared decision-making between patients and their cancer care teams.

The CCPC Act will empower patients with information necessary to help manage and coordinate their care.
Wenora Johnson on participating on the Advisory Panel on Clinical Trials: “While this position is new for me and I have much to learn, I am grateful for the chance to make a difference in research. This was day one and just the beginning of many more productive meetings that will make a large impact on research.”
What’s in Store in 2020?

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