Welcome!
2019 Cancer Policy & Advocacy Team (CPAT) Symposium
#CPAT19
NCCS Cancer Policy & Advocacy Team

- 2014: Inaugural training
- 2015: Added Hill Day; expanded from annual training to year-round program of engagement
- 2016: Included medical students from the Cancer in the Under-Privileged, Indigent, or Disadvantaged (CUPID) program
- 2017: Advocated to protect Affordable Care Act (ACA) during repeal efforts
- 2018: Advocates participated in press conference on pre-existing conditions
Who Has Attended All Six Years?

Valerie Fraser
Agenda Overview – Day 1

• We have a packed agenda!
• There are a few breaks – take additional breaks if you need them.
• Advocate Panel
• Health Policy Outlook for 2019
• Keynote - Disparities in Cancer Care and Outcomes
Agenda Overview – Day 1

• Communications Breakouts
  • Your Story in a Nutshell (for first-time attendees) – Madison Room
  • Media Training – Telling Your Story

• Congressional Cancer Survivors Caucus
  • Congressmen Mark DeSaulnier (D-CA) & Buddy Carter (R-GA)

• Staging Your Impact – Meeting with Policymakers

• Grief and the Cancer Care Journey

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Agenda Overview – Day 1

• Break/Reception – Ballroom I
• Dinner
• Improving Doctor/Patient Communication
Agenda Overview – Day 2

• Breakfast
• Hill Prep & Rally
  • Congressman Jamie Raskin (D-MD)
  • Congresswoman Debbie Wasserman Schultz (D-FL)
• Hill Meetings
Updates on NCCS Projects
Elevating Survivorship

A patient- and advocate-led initiative to improve survivorship care in the United States

- Surveyed nearly 1,400 cancer survivors
- Association of Community Cancer Centers (ACCC) conducted provider survey
- Published article in ACCC’s Oncology Issues magazine
- Presented results presented to Congressional Cancer Survivors Caucus
Elevating Survivorship

A patient- and advocate-led initiative to improve survivorship care in the United States

• Launched Speakers Bureau & Survivorship 101 presentation template
• Recruited 10 Elevate Ambassadors from across the US to engage in projects to improve survivorship care at the local level
• Trained Elevate Ambassadors in April 2019 in Arlington, VA
Survey Results – 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.
Survey Results – Post-Treatment Experiences

• 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.
Survey Results – 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.
Providers are more helpful with nausea and vomiting, but less helpful with key side effects like fatigue, anxiety, and depression.
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

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

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 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
Half initiate conversations with their healthcare team about post-treatment

- Who is responsible for post-treatment care is the topic most discussed. Few discuss financial services/support, survivorship plans, or emotional support.

84% have spoken with doctor/HCP about post-treatment

- Yes, doctor/HCP brought it up, 30%
- Yes, I asked doctor/HCP, 54%
- No, 16%

More likely provider-initiated:
- Immunotherapy: 44%
- In Tx (Recur): 42%
- Stage 2: 42%

Which of the following did you discuss/receive from your doctor/HCP about transition to post-treatment? (select all)

- What HCP should manage post-tx: 42%
- Long-term side effects: 39%
- Exercise and nutrition: 38%
- Emotional/psychological services/support: 31%
- Survivorship care plan or next step summary: 30%
- Financial services/support: 13%
- None of the above: 11%

More likely discussed:
- Immunotherapy: 21%
- In Tx (Recur): 22%
- Medicaid: 23%
Patients are mixed on the quality of their post-treatment care

- Just a quarter describe it as “excellent,” and in open-ended questions, many voice concerns about getting enough attention and preparation from their providers.

In their own words...

**I think there are "survivorship" issues that should really be discussed as part of treatment, not just when treatment ends.**
- Completed Tx

**Once I was out of active treatment, I was no longer be considered a priority to my oncology team.**
- Immunotherapy patient, Completed Tx

**Survivorship was harder than treatments.**
- Immunotherapy patient, Completed Tx

**I wish that my healthcare team would address survivorship issues and long term effects of my cancer diagnosis. At this point I am just told to call if there are any changes in the way that I feel, this leaves me feeling uneasy and uncertain about the future of my health.**
- Immunotherapy patient, In tx reoccurrence

Satisfaction levels were consistent across audiences
Wrap-up: Key Areas of Need

- There are many ways that NCCS and its partners can impact the survivorship needs of diverse groups of cancer patients.

1. Mental health side effects (depression and anxiety) are common and last well beyond treatment, yet are not well addressed by healthcare providers. Patients say emotional support is a big area of need post-treatment—from mental health counseling to support groups.

2. While many are discussing post-treatment with their healthcare providers, these conversations are mostly logistical (i.e., who will manage post-treatment care). As a result, many rely on online sources for information and support, and indicate they need more resources.

3. Insurance coverage, financial support, and long term symptom management are top patient concerns. There is also high interest in access to resources/programs for these issues through HCPs. However, few HCPs are currently providing them and many patients wonder where they can go to get these supports.

4. Younger patients (18-39) and more vulnerable populations (low income, Medicaid, in poor health) have higher levels of concern across a range of issues. More vulnerable populations are also less likely to say their HCPs have been helpful with these issues.

5. Immunotherapy patients are more satisfied with their post treatment experiences. They are significantly more likely to report feeling prepared and informed, and while they share many concerns around financial and emotional issues, they also report higher levels of help from HCPs in dealing with these challenges.
Survivorship Checklist

OBJECTIVE:
Empower cancer survivors to take charge of their care with a simple checklist to navigate the complexities of cancer survivorship.
Quality Measurement
Redefining Functional Status (RFS) Project

• Convened committee of 10 cancer survivors, representing different cancers and stages of disease, as well as Technical Expert Panel (TEP) of oncologists and quality measurement methodologists

• Conducted RAND Delphi survey process to reach consensus regarding priority areas for quality measurement related to functional status

• Convened patient committee for two-day meeting to discuss survey results and priorities for measurement, as well as additional recommendations

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Quality Measurement
Redefining Functional Status (RFS) Project

- Prioritized outcomes for measurement of RFS
  - Physical function, pain, fatigue
  - Cognitive functional, mental health, emotional health, depression
  - Independence, control, resilience, grief
  - Overall quality of life

- Currently evaluating validated surveys for best alignment with the conceptual definition

- Next step will be to develop patient-centered specifications for RFS outcome measures
Engaging CPAT Members

- Nominations
- Media opportunities
- Webinars/Facebook Live
- Facebook Group
- CPAT Chronicles

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