

INFORMING AND EMPOWERING CANCER PATIENTS ABOUT IMMUNOTHERAPY: A PSYCHOEDUCATIONAL WORKSHOP ADDRESSING NEEDS IN AN EMERGING FIELD



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Rationale

Immunotherapy has become an area rich with new discoveries and treatments with potential for success for many cancer types, yet patients potentially eligible for immunotherapy are often not aware of options. The past several years in particular have been a period of significant gains in knowledge and available treatment options in this area.

According to a 2014 Cancer Support Community (CSC) online survey, only 34.8% of cancer survivors knew the term “immuno-oncology” and 64.9% had heard of “immunotherapy.” In spite of their limited knowledge, 84% of respondents wanted to know more about these topics.

Recognizing the need, the CSC developed and ran psychoeducational workshops on this topic, *Frankly Speaking About Cancer: Your Immune System & Cancer Treatment* in 2014-15. The current analyses investigate workshop outcomes and correlates.

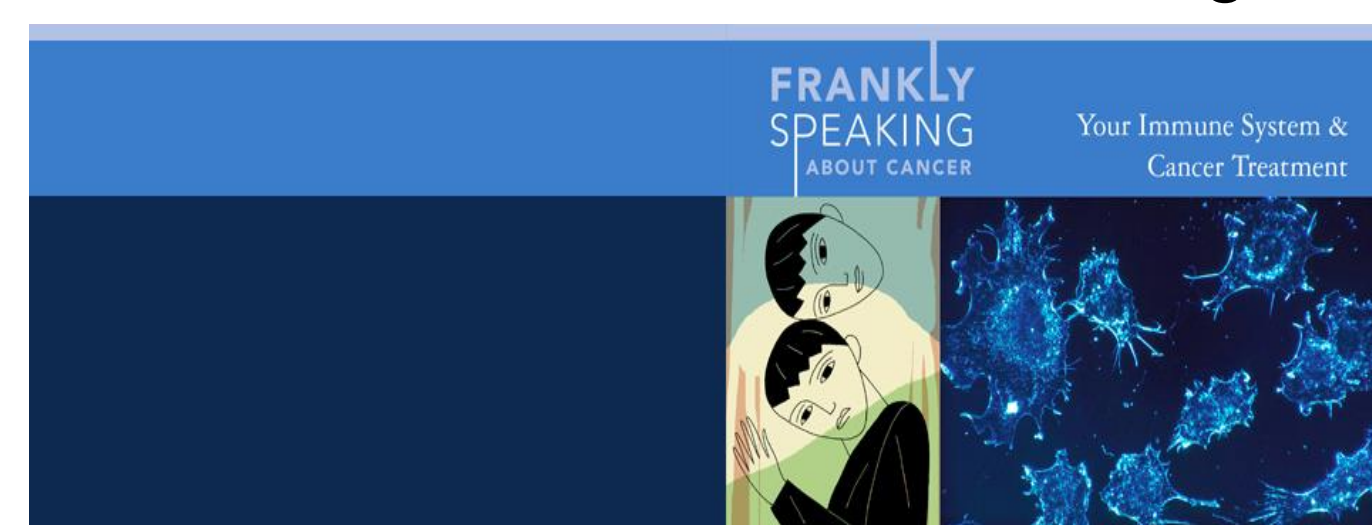
Objective

- To assess the educational and empowerment outcomes of a psychoeducational workshop focused on immunotherapy for those affected by cancer
- To better understand decision-making behaviors, patient-provider communication patterns, and information-seeking correlates in those attending an immunotherapy program

Frankly Speaking About Cancer Program Background

The *Frankly Speaking About Cancer* (FSAC) series provides in-depth coverage of topics relevant to those affected by cancer that are often not otherwise available in a comprehensive format.

Topics covered include: metastatic breast cancer, lung cancer, cancer treatments and side effects and coping with the cost of care. *Frankly Speaking About Cancer* is delivered through in-person workshops, print publications, online content and through a radio show.



Frankly Speaking About Cancer: Your Immune System & Cancer Treatment is the newest program in the FSAC Series.

Premise: Understanding how the immune system works opens the doors to new treatments that are changing the way we think about and treat cancer

Program goals: To educate and to empower patients and caregivers on the topic of immunotherapy

Methods

Design

In 2014-15, 367 program attendees of the CSC’s *Frankly Speaking About Cancer: Your Immune System & Cancer Treatment* workshop run nationally completed a post-program self-report evaluation assessing multiple program outcomes. Descriptive analyses and pre- and post-workshop comparisons were conducted to assess workshop outcomes.

Respondents:

Individuals with cancer comprised 72.5% participants in the workshop

Workshop Outcome Measures:

Asked for both pre- and post-workshop (5-point scale):

- Immunotherapy knowledge
 - Information-seeking about immunotherapy
 - Speaking with Dr. about immuno. treatment options
 - Asking Dr. about potential side effects of immuno.
 - Making treatment decisions in partnership with Dr.
 - Discussing clinical trials with Dr.
 - Asking about treatment options for my cancer
- Post-workshop outcomes:
- Overall workshop satisfaction
 - Most valuable aspect of attending the workshop

Respondent Characteristics

Background Characteristics:

- Average Age = 62.4 years (s.d.=13.8 years)
- Sex: 77.7% female
- Racial Identification:
 - 82.9% Caucasian
 - 6.9% African-American
 - 5.4% Asian
 - 2.6% Hispanic
- Workshop attendees (n=367):
 - diagnosed with cancer/ survivor = 72.5%
 - partner/family caregiver = 20.5%
 - healthcare professional = 5.8%

Cancer History:

- 42.6% had breast cancer
- 54.9% metastatic disease
- 53.9% in active treatment

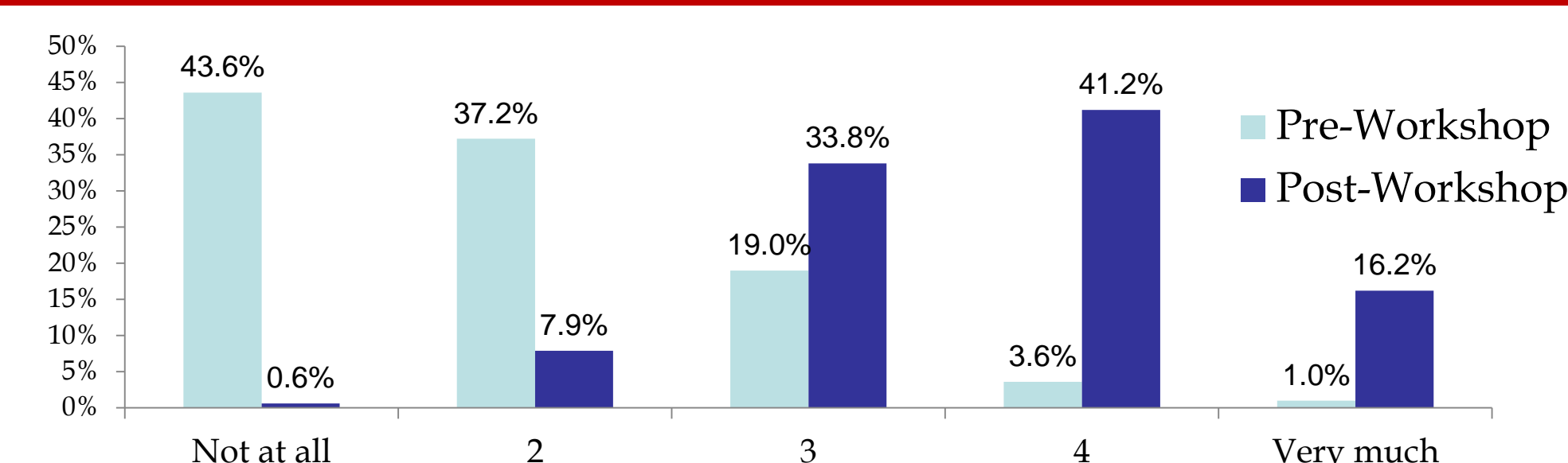
Time since diagnosis:

- 22.1% <1 year
- 31.7% 5+years

Other Characteristics:

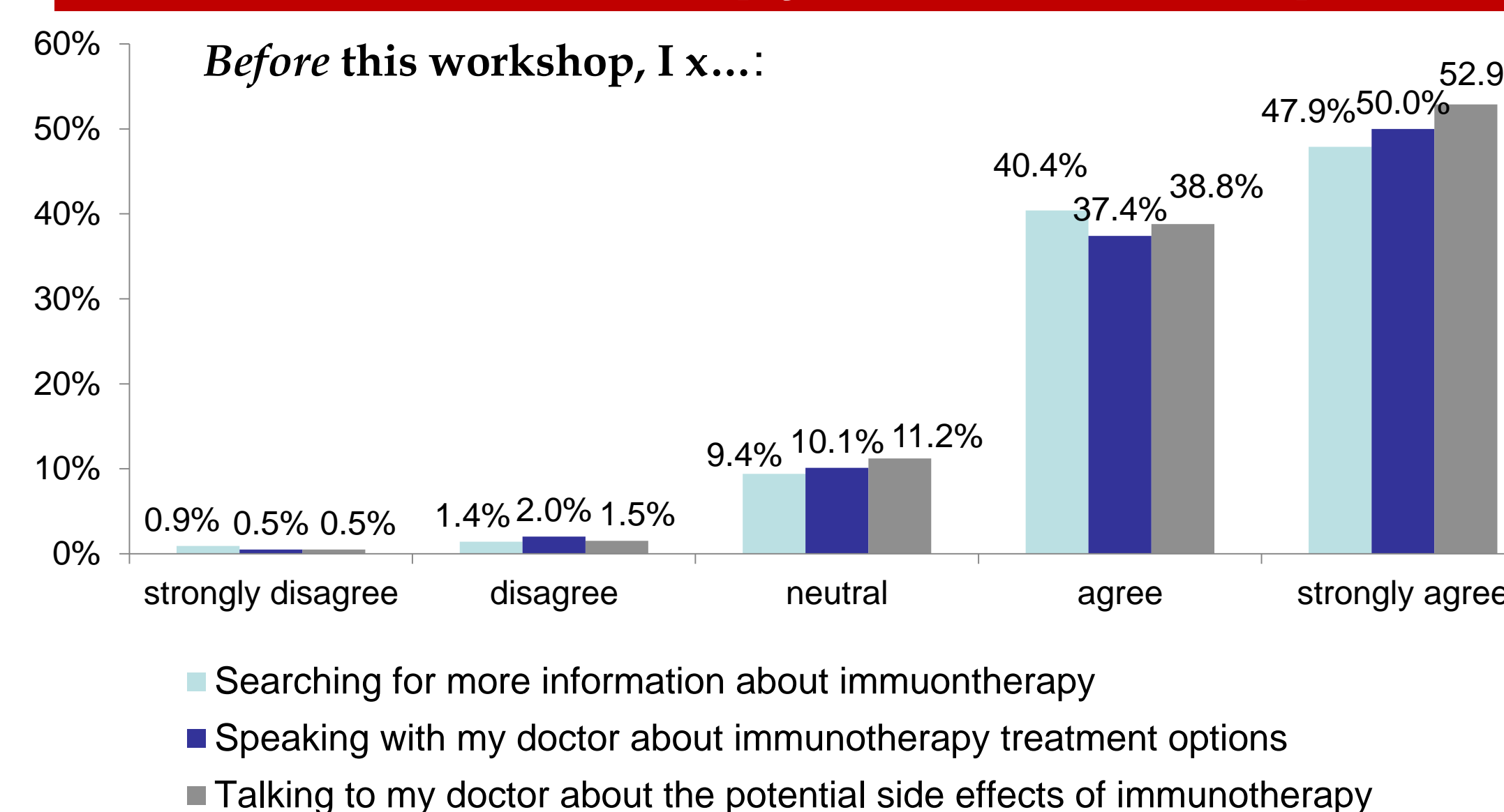
- 25.3% Currently in support group
- 62.3% First psychoeducational workshop

Immunotherapy Knowledge



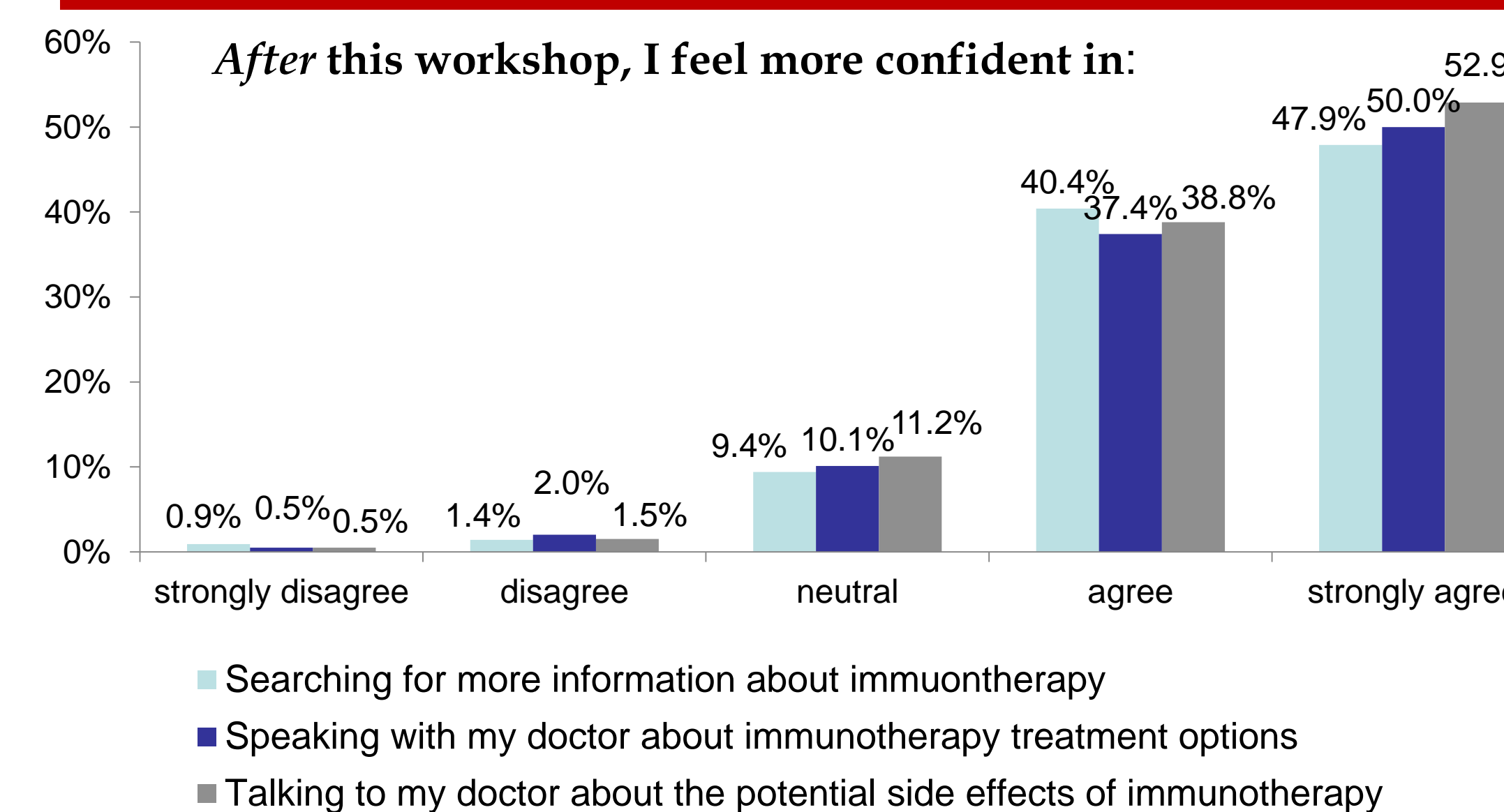
- The majority reported a ‘high’ or ‘very high’ level of knowledge about immunotherapy after participating
- Post-workshop levels were significantly higher than their pre-participation knowledge levels (p <.05)

Immunotherapy Pre-workshop



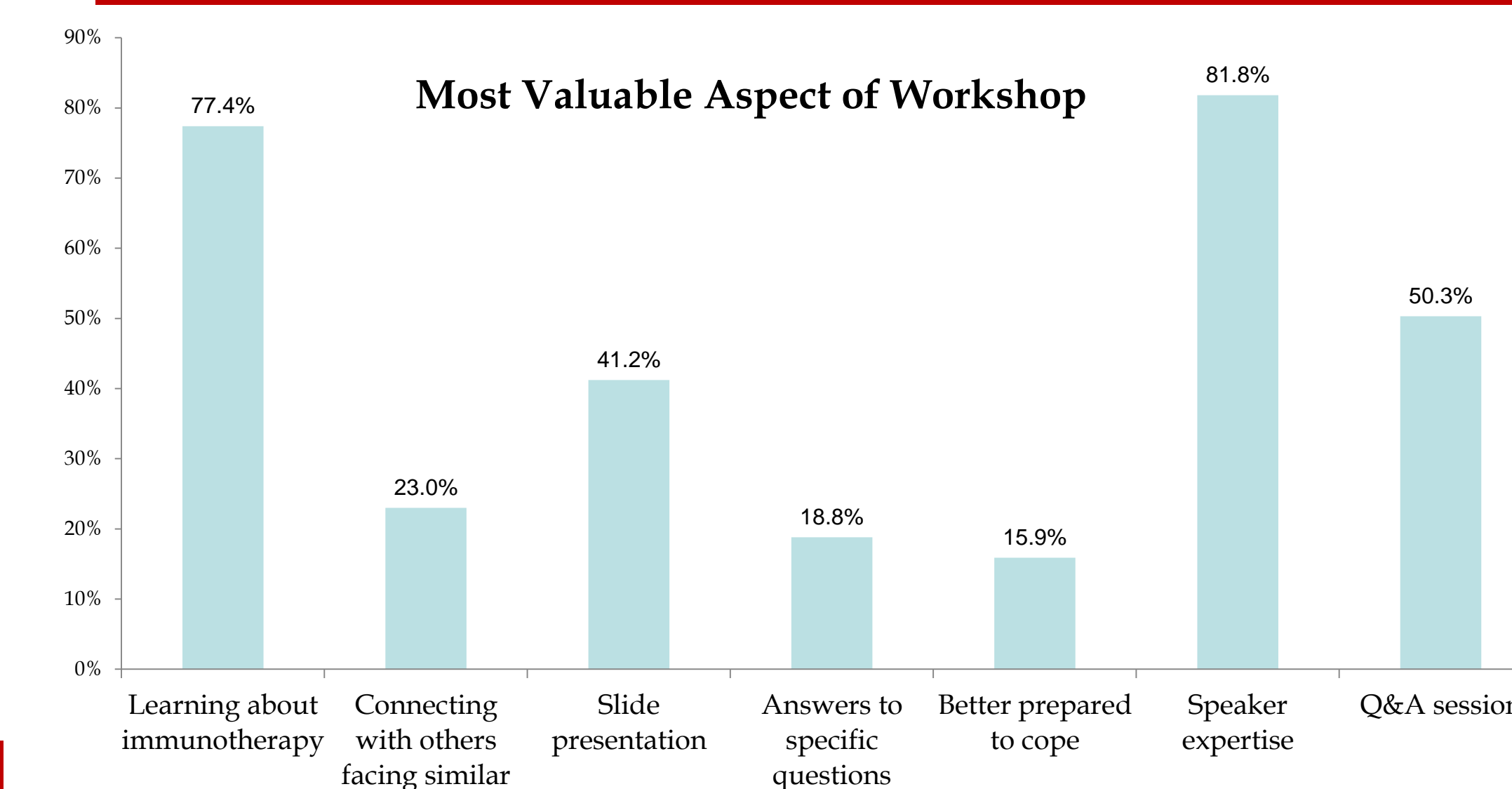
- Before the workshop, 33.2% of attendees with cancer had spoken with their doctor about immunotherapy and 24.7% asked about potential side effects
- 40.2% had searched for information about immunotherapy on their own
- Half (51.1%) reported being very involved in their overall treatment decision-making, yet 48.6% were unsure whether immunotherapy was a treatment option for them

Immunotherapy Post Workshop



- After the workshop, 87.4% felt confident speaking about immunotherapy with their doctors
- A majority felt better equipped to discuss potential side effects (86.8%), ask about treatment options generally (91.5%), and make treatment decisions with their doctors (87.9%)

Workshop Feedback



- Nearly all (92.8%) recommend the workshop

Summary & Discussion

- After attending the workshop, attendees reported increased knowledge, feeling more aware of options and how to become a partner in discussing potential treatment options
- Though many workshop attendees reported already being “partners” with their healthcare team when making decisions, many had no idea whether or not immunotherapy was an option for them
- Results from the attendee evaluations demonstrate a significant level of workshop content-specific informational and empowerment gains can be obtained from attending a two-hour psychoeducational workshop
- Results support the notion that providing clear, relevant, and comprehensive information about immunotherapy to individuals affected by cancer meets the current need and demand

Implications

Research Implications:

Results support the program goals of successfully improving access to comprehensive information about immunotherapy and promoting communication between the patient and the healthcare team about treatment options and decision-making.

Clinical Implications:

Results reaffirm the need to continue to provide clear and relevant information about immunotherapy and to support individuals affected by cancer by offering a comprehensive psychoeducational program focused on emerging treatment options in immunotherapy.

Acknowledgement of Funding

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