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CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Perceptions about cancer clinical trials among metastatic breast cancer patients: Findings from a patient powered registry

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Introduction

- The Cancer Support Community (CSC) represents a global network of nonprofit, community-based organizations that provide professionally led support and education to cancer patients and their families.
- An estimated 155,000 people are living with metastatic breast cancer (MBC) in the United States.
- With new developments in treatment, people are living longer with MBC.
- Advances in treatment are handicapped by patients' limited participation (3-5%) in cancer clinical trials (CCTs).
- While much effort has been placed on better training physicians and health care providers in talking to their patients about the appropriateness of such participation, barriers remain.
- This study was designed to better understand the perceptions and potential barriers to participating in a CCT.

Methods

- The CSC's Cancer Experience Registry is an online initiative designed to collect patient reported data and raise awareness about the psychosocial impact of cancer.
- Currently, over 7,400 cancer patients and survivors have enrolled in the Cancer Experience Registry.
- Since March 2013, 968 people living with MBC registered with the Cancer Experience Registry and 599 of these MBC registrants answered questions about their beliefs, attitudes and experiences with CCTs.
- The present analysis includes 577 US based registrants with completed data.

CANCER EXPERIENCE REGISTRY
METASTATIC BREAST CANCER

- CSC established the Cancer Experience Registry to track the immediate, ongoing and changing social and emotional experiences of cancer survivors.
- The Registry reaches cancer patients and survivors across the country and engages them to share their voices about issues that matter to them.
- Through the Cancer Experience Registry we are able to:
  - Collect, analyze and disseminate insights and knowledge toward the goal of improving the lives of those experiencing cancer.
  - Help the nation's health care systems to be more responsive to the needs of cancer survivors.
  - Accelerate and enhance the productivity of research to improve quality outcomes.
- Currently, there are over 7,400 cancer patients and survivors in the Cancer Experience Registry from over 35 countries and representing more than 40 cancer diagnoses.

Anyone who has ever been diagnosed with cancer of any type can join the Cancer Experience Registry at:

www.CancerExperienceRegistry.org

Results

Table 1. Participant responses to statements about clinical trials

Statement	% Agree or Strongly Agree	% Agree or Strongly Agree if did NOT take part in CCT (n=419)	% Agree or Strongly Agree if DID take part in CCT (n=126)	p
I am uncomfortable with being randomly assigned to a treatment.	67	68	60	< 0.001
I don't trust the medical establishment and fear I will be used as a "guinea pig" for research.	18	20	8	0.01
I fear receiving a placebo in a clinical trial.	63	66	52	< 0.001
I don't understand what clinical trials are.	6	7	2	< 0.001
I fear side effects that might come with treatment on a clinical trial.	54	58	43	< 0.001
I would be unable to fulfill trial requirements due to logistical barriers such as transportation.	22	24	13	< 0.001
There are no clinical trials available in my community.	22	25	12	< 0.001
My health insurance would not cover it.	27	30	18	< 0.001

Summary of Results

- Only half of the registrants reported that a member of their health care team spoke to them about participating in CCTs.
- Nearly one-quarter (23%) report that they took part in a CCT.
- Over half of the registrants noted concerns about:
  - Random-assignment to treatment (67%),
  - The potential receipt of a placebo (63%), and
  - Possible side effects with a CCT treatment (54%).
- Significant differences in beliefs and perceived barriers were evident between those who participated in a CCT and those who had not (see Table 1).
  - Compared to those who had not participated in a CCT, registrants who had participated in a CCT were less likely to report barriers related to health insurance coverage, availability of CCTs within one's community, or logistical concerns (e.g., transportation).
  - Perceptions of fear and mistrust were also lower among registrants who had taken part in a CCT compared to those who had not.

Sample Characteristics *(n=599)*

Characteristic	Proportion
Female	99%
Caucasian	91%
Education ≥ College Degree	69%
	Median
Age	56
Time Since MBC Diagnosis	3 years

Conclusions and Future Directions

- This research supports previous reports of low participation in CCTs.
- CCT concerns , including fear of receiving a placebo or treatment randomization, were evident among the MBC registrants. Thus, efforts to educate MBC patients about participation in CCTs should address fears , misconceptions and concerns about trust.
- Perceived barriers related to CCT access and availability were also evident, and, importantly, were greater among those who did not participate in CCT compared to those who did. Efforts to improve participation in CCTs for this population might need to center on improving access to and coverage for CCTs.
- Finally, given that only half of the registrants reported that a member of their health care team spoke with them about CCTs, there is a continued need to educate and train health care providers to communicate with their patients about CCTs.

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