

Breast cancer clinical trials: Patient experiences, preferences, and insights into increasing participation



Claire Saxton, MBA, Marni Amsellem, PhD, and Joanne Buzaglio, PhD
Cancer Support Community, Washington D.C.
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Research rationale

Clinical trials offer breast cancer patients access to the most innovative treatments, high levels of care and hope for a better future. Yet, fewer than 5% of individuals with breast cancer participate in clinical trials nationally. Education is commonly identified as a target for intervention to increase rates of participation.

In late 2015, the Cancer Support Community (CSC) conducted an online survey assessing cancer clinical trials to inform development of an educational program aimed to increase clinical trial awareness and participation. Results from this survey highlighting the experiences, beliefs, and preferences of breast cancer patients are reported here.

Research objectives

- To better understand the perceptions and awareness of clinical trials among individuals diagnosed with breast cancer
- To better understand how their experiences receiving information about clinical trials matched their preferences
- To inform the development of an educational program to increase clinical trial awareness and participation

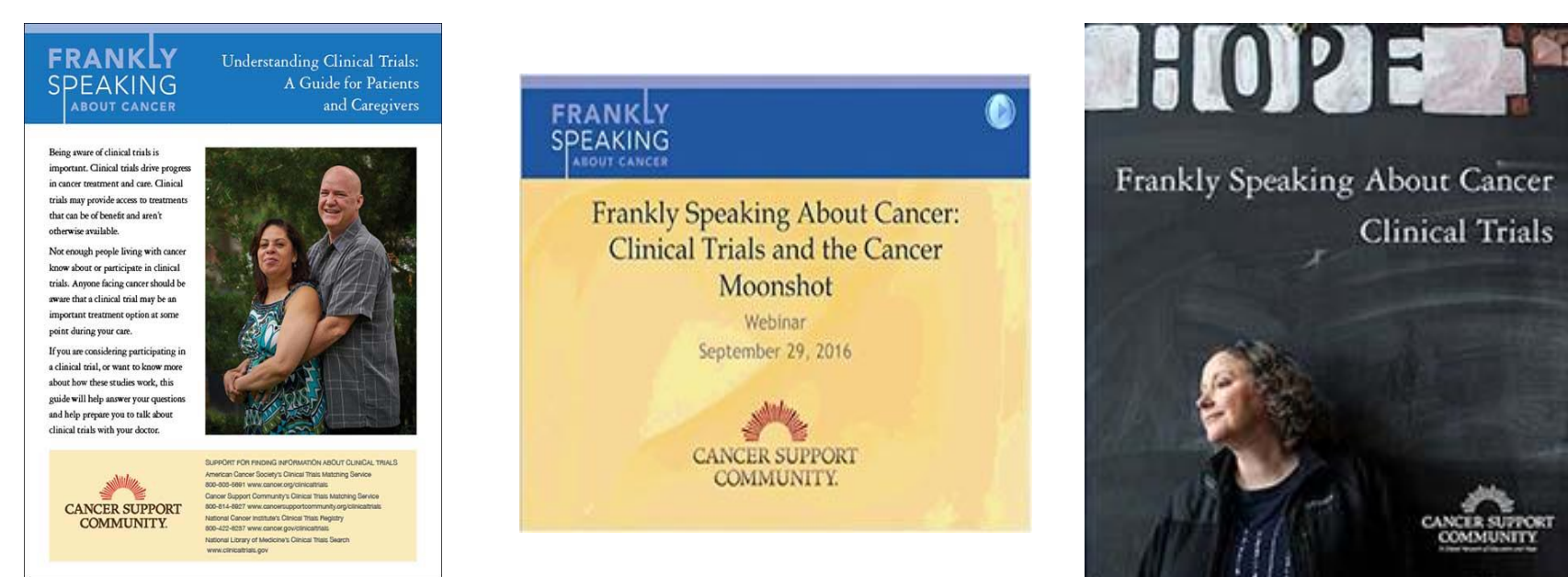
Frankly Speaking About Cancer program background

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, skin cancer, colorectal cancer, cancer treatments and side effects, new discoveries, and coping with the cost of care. *Frankly Speaking About Cancer* is delivered through multiple modalities, including in-person workshops, webinars, print publications, online content, and a weekly radio show.

The newest addition to this series is *Frankly Speaking About Cancer Clinical Trials*, which is an initiative aimed at increasing patient and caregiver awareness and knowledge of cancer clinical trials to boost participation rates.

For more information about this program or its products, please visit our website at: www.CancerSupportCommunity.org/ClinicalTrials



Methods

Respondents:

- In 2015-2016, 506 cancer patients and 81 caregivers participated in a national online survey assessing experiences with clinical trials conducted by CSC
- Survey recruitment via CSC's Cancer Experience Registry, CSC social media, and our partners
- 239 individuals with breast cancer (47.2% of respondents with cancer) participated

Survey Measures:

- Background/demographic characteristics
- Cancer history (breast cancer diagnosis)
- Treatment setting(s)
- Current treatment status
- Knowledge and beliefs about clinical trials
- Communication about cancer clinical trials
- Participation in clinical trials
- Informational preferences regarding clinical trials
- Resources provided/ found about clinical trials

Respondent characteristics (n=239)

Background Characteristics:

- Age: $M = 59.6$ years ($SD = 9.7$ years)
- Sex: 99.6% female
- Racial/ Ethnic Identification:
 - 84.9% Caucasian
 - 10.0% African-American
 - 1.7% American Indian
 - 1.3% Asian
 - 6.6% Hispanic
- Highest Level of Education
 - 5.5% High school, trade school, or GED
 - 25.7% Some college
 - 32.9% Bachelor degree
 - 35.9% Graduate degree or higher

Breast Cancer History:

- 21.4% diagnosed with metastatic breast cancer
- 22.4% had experienced a recurrence
- 45% were currently receiving treatment
- 75.2% were considered to be in remission

Year of Initial Diagnosis:

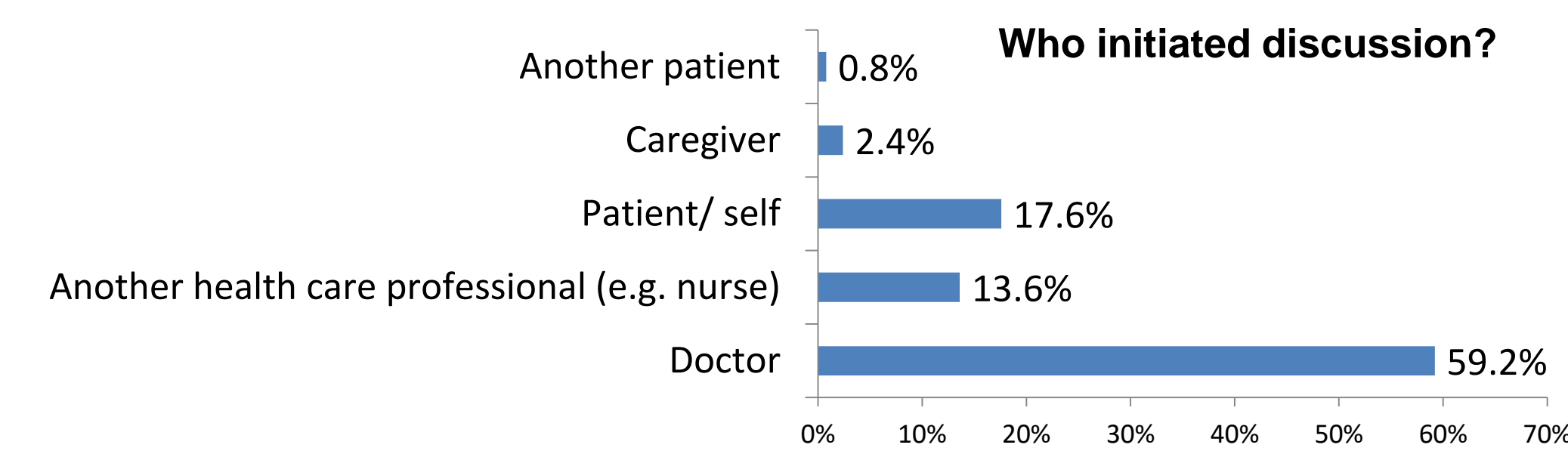
- 44.5% were diagnosed 2011 or after
- 16.4% were diagnosed 2014 or after

Treatment setting (initial):

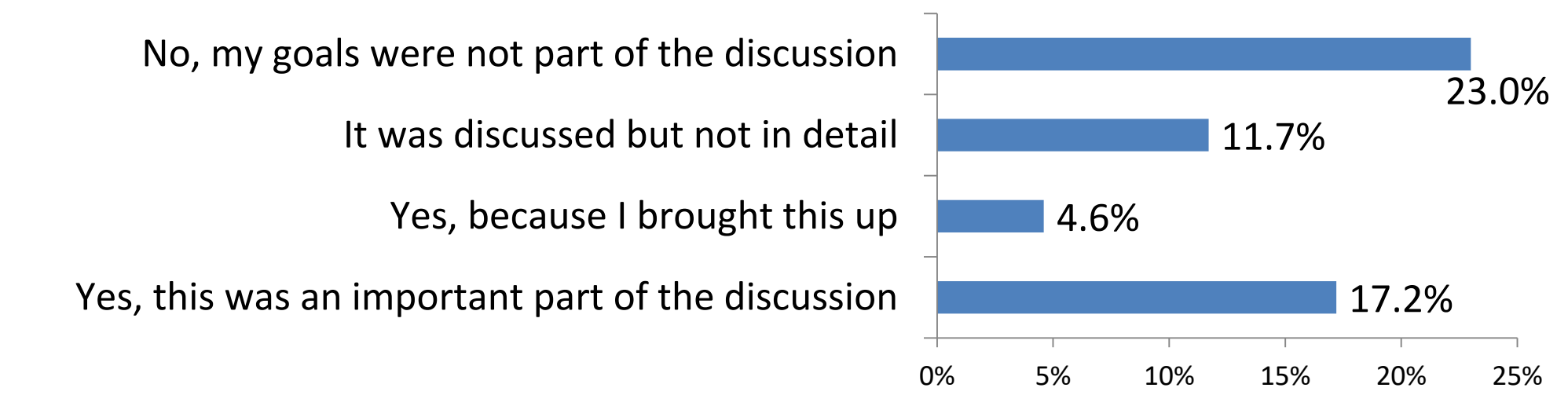
- 28.0% Academic or comprehensive cancer center
- 38.9% Community hospital/cancer center
- 25.9% Private oncology practice
- 0.4% Veterans Affairs (VA) hospital/medical center
- 2.5% Family practice/primary care physician
- 32.5% have changed treatment setting
 - For those who had changed, 55.2% are now at an academic or comprehensive cancer center

Discussion of clinical trials

- Most (87.5%) had heard of clinical trials pre-cancer
- For over half (53.6%), clinical trials were discussed with the patient. For these patients:
 - 28.3% of the time, trials were discussed at diagnosis
 - 73% of the time, trials were introduced by healthcare team; 17.6% of the time it was initiated by the patient

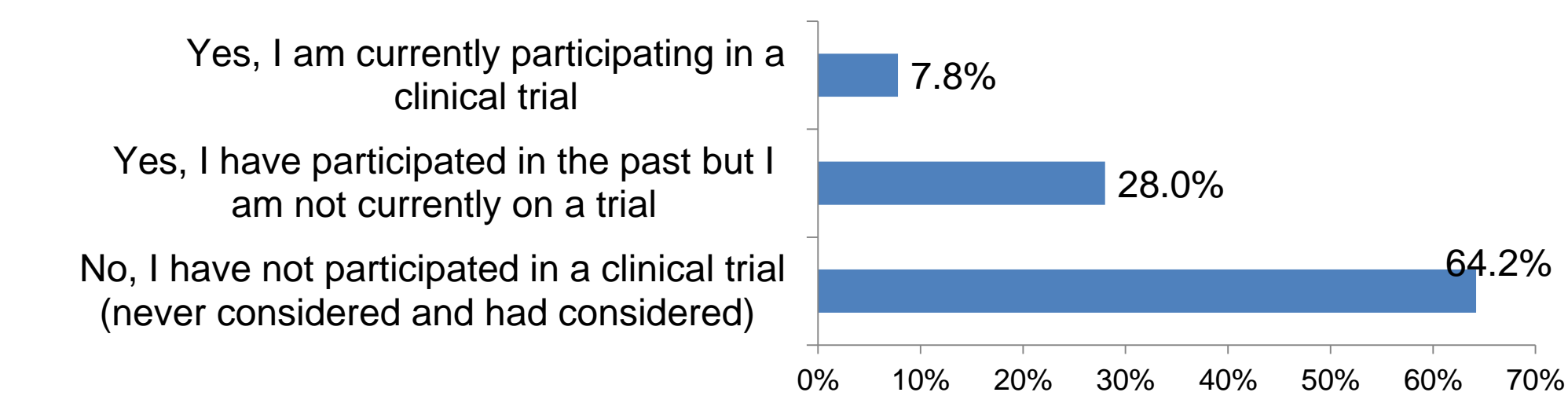


- When clinical trials were discussed, less than half felt their goals and concerns re: participation were meaningfully addressed (regardless of who initiated discussion)



Notably one quarter reported not discussing clinical trials at all

Participation in clinical trials



- 35.8% have participated in breast cancer clinical trials
- 57.9% had never considered participating in a clinical trial

Clinical trials resources offered/used

Resources	Offered to me by my health care team	I found on my own	Offered by my healthcare team and I also found	Wasn't offered/ couldn't find
A website that explained clinical trials	18.3%	31.0%	8.7%	42.1%
Time with my doctor to discuss the trial	53.1%	7.8%	10.2%	28.9%
Time with a nurse/research coordinator to discuss the trial	52.8%	3.9%	10.2%	33.1%
A conversation with another patient who has participated in a trial	5.6%	7.2%	3.2%	84.0%
Printed, easy to understand materials to take home and read	48.0%	7.1%	7.1%	37.0%
Videos from health care providers and patients explaining clinical trials	6.5%	4.9%	1.6%	87.0%
Images (photos, illustrations and/or animation) explaining clinical trials	10.6%	10.6%	0.8%	78.0%

- 97.4% reported that a website which included clinical trial information would be "somewhat" or "very helpful" in identifying clinical trials or aiding decision-making, yet such a resource was shared with only 27.0%
- 80.0% reported that speaking directly with another patient who had participated in a clinical trial would be helpful; yet this was only offered to 8.8% of patients

Useful decisional tools for clinical trials

Decisional Tools	Not at all helpful	Somewhat helpful	Very helpful
A website that explained clinical trials	6.9%	43.1%	50.0%
More time with my doctor to discuss the trial	8.4%	39.5%	52.1%
More time with a nurse or research coordinator to discuss the trial	6.0%	35.0%	59.0%
A conversation with another patient who has participated in a trial	20.4%	45.4%	34.5%
Printed, easy to understand materials to take home	7.7%	30.8%	61.5%
Videos from health care providers and patients explaining clinical trials	22.7%	44.5%	32.7%
Images (photos, illustrations, animation) to explain clinical trials	22.5%	47.7%	29.7%
An internet forum with Q&A about clinical trials and could interact and learn from other patients who have been on clinical trials	15.3%	30.6%	54.1%
A website/tool that helps me locate clinical trial options in my area	9.0%	25.2%	65.8%

Of decision-making tools and resources that would be/were "somewhat"/"very" helpful for them in this process:

- most reported wanting more time with a member of healthcare team to discuss clinical trials
- Nearly all reported a website which included clinical trial information

Summary

- Results from this survey describe the experiences and preferences of individuals with breast cancer as it relates to clinical trials:
 - Over half of patients with breast cancer have had discussions about clinical trials. During these conversations, most report that their concerns about or goals for participating in trials were not meaningfully addressed
 - Over one third have participated in breast cancer clinical trials, suggesting that this sample is likely more aware of and/or interested in clinical trials than the general population of cancer patients
 - There is a meaningful discrepancy between what patients find valuable in decision-making and information-gathering and what resources are available to them

Discussion and implications

- The survey data yields insight into the contents of a successful education and support program around clinical trials and highlights the necessity to provide a comprehensive program that addresses patient preferences for more time to discuss clinical trials with the oncology team and with other patients who had elected to participate in a clinical trial
- Based in part on these findings CSC, along with partner organizations are developing a series of products and programs to educate individuals who may be eligible for clinical trials

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