



Improving patient-provider communication and shared decision making in metastatic breast cancer.

Background: People with metastatic breast cancer (MBC) are often overwhelmed for multiple reasons, including managing medical appointments, fear about the future, and the need to reassess or make new treatment decisions. Even if treatments are currently working, patients will most likely find themselves contemplating their treatment options. Allied health professionals play a critical role in educating MBC patients, eliciting concerns and helping them weigh treatment options- all of which can greatly improve care. More than ever, there is a need to improve the standard of care for MBC patients, and provide patients and providers with the tools to ensure quality care.

Purpose/Objectives Based on this background, in 2012, the Cancer Support Community (CSC) built on its existing *Frankly Speaking About Cancer: Advanced Breast Cancer* and *Open to Options* programs. The purpose of the development of this new program was to: a) create a patient tool to help women with advanced breast cancer prioritize their concerns and be better prepared for oncology and related medical appointments; and b) host an educational webinar for allied health professionals (oncology nurses and oncology social workers) to improve patient-provider communication and shared decision making.

Methods/Approach To inform program development, CSC conducted an online survey designed for people with metastatic breast cancer assessing respondents' support systems, exploring their physical and psychosocial issues of concern, understanding how respondents communicate with their health care team about these concerns and identifying priority concerns that influence treatment decisions. 146 people with metastatic breast cancer participated in the survey. Participants were recruited through CSC's affiliate network and partners. At the conclusion of the health professionals webinar participants completed a brief post-program evaluation online.

Results Survey results indicated that the top two patient considerations impacting treatment decisions are: effect on survival (80%) and impact on quality of life (71%). 80% noted they were satisfied with healthcare team communication, yet 55% indicated they wanted access to more resources to help them make treatment decisions. Survey findings guided the development of the patient decision making tool and health professional's webinar. More than 100 health professionals participated in the webinar which aimed to improve communication about psychosocial issues unique to this population, promote shared decision making and educate about the *Open to Options* treatment counseling program.

Conclusions Metastatic breast cancer has become a disease that can be managed for a longer period of time through various treatments. The assessment of patients' cancer experience and considerations in treatment decision making gave valuable direction to the tool for patients and educational webinar for allied health care professionals. Yet, it is clear from the online patient survey that there is still a need to continue to improve the resources and support available for metastatic breast cancer patients, particularly around treatment decision making.



Improving Patient-Provider Communication and Shared Decision Making in Metastatic Breast Cancer

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Cancer Support Community Mission

To ensure that everyone impacted by cancer is:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community



Background

- People with metastatic breast cancer (MBC) are often overwhelmed
- Even when treatments are currently working, patients often find themselves contemplating their treatment options
- Need to improve care for MBC patients, and create tools for patients and providers to ensure quality care



Purpose/Objectives

- CSC sought to integrate two existing programs:
 - *Frankly Speaking About Cancer: Metastatic Breast Cancer*
 - *Open to Options*
- Goal of integration:
 - Create a patient tool to help prepare individuals for oncology-related medical appointments
 - Educate allied health professionals via webinar to improve patient-provider communication and shared decision making

Methods/ Approach

- CSC conducted an online survey for people with MBC
- Survey assessed:
 - respondents' support systems
 - physical and psychosocial concerns
 - how respondents communicated with their health care team
 - priorities/concerns that influence treatment decisions
- Recruitment through CSC's affiliate network and partners

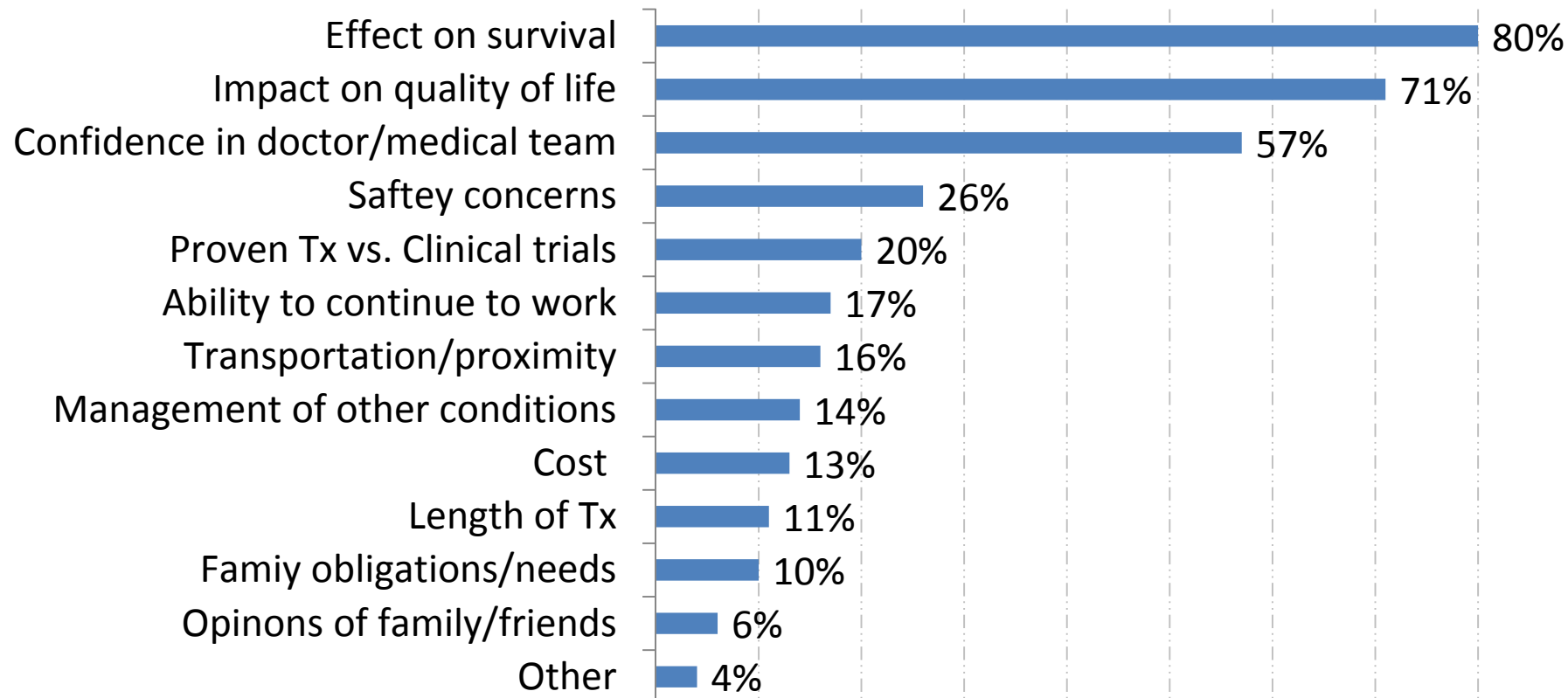
Respondent Characteristics

- N= 146 (Female: n=145)
 - For 60% this was their first breast cancer diagnosis.
 - 68.4% of respondents were more than one year post-diagnosis (ranging from 1 to over 4 years), the remainder were less than 1 year post-diagnosis
 - Average age was 54.2 years

Social Support

- 97% of respondents described their level of support as very or somewhat supportive
- 80% of those with a first-time diagnosis reported a high level of support vs. 67% for those with a recurrent diagnosis
- Top 3 sources of support:
 - Family and friends (94%)
 - In-person support group (26%)
 - Online support group/chat room (26%)

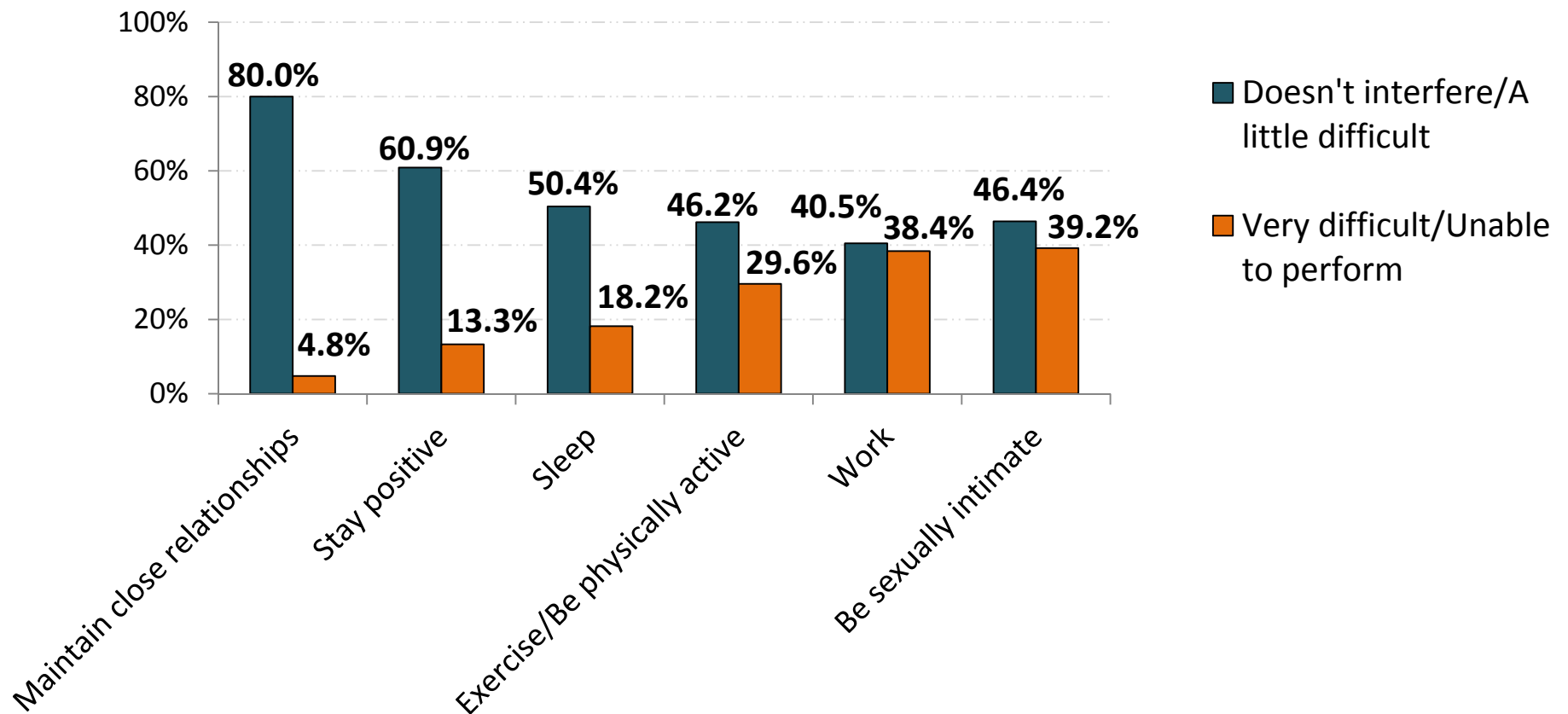
Factors Influential in Treatment Decision Making



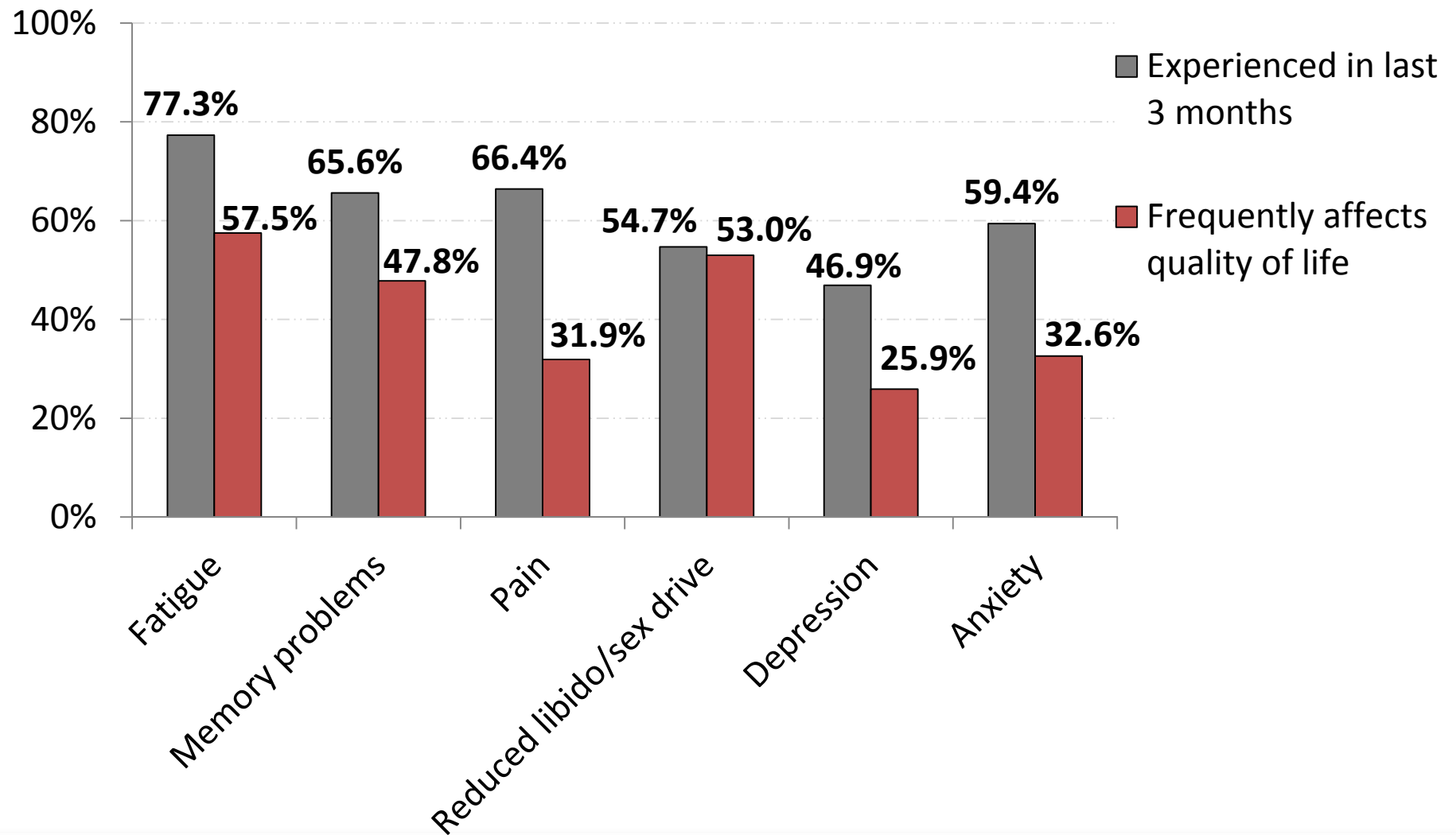
80% of respondents prefer to work together with their health care team when making treatment decisions

Impact of Cancer and Treatments

How does your cancer or related treatments interfere with your ability to do the following?



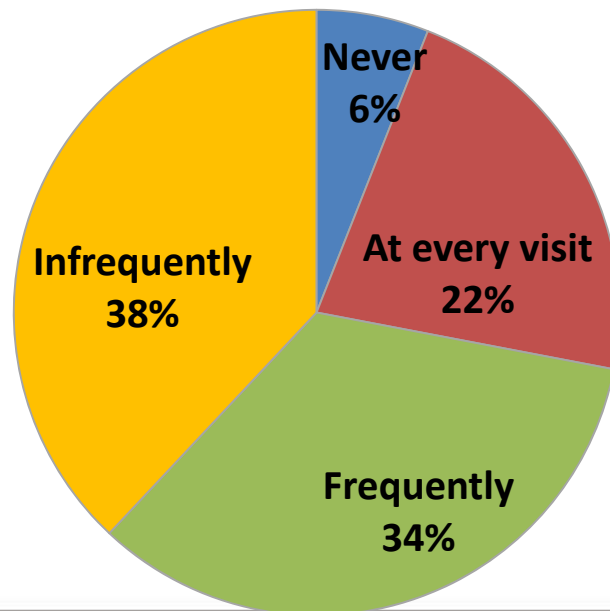
Impact of Cancer and Treatments (continued)



Discussing Concerns with Health Care Team

- While most patients report good communication with their health care team, 44% still don't share quality of life concerns regularly

Frequency of Concerns Discussed



Summary of Survey Results

- Top considerations impacting treatment decisions are:
 - effect on survival (80%)
 - impact on quality of life (71%)
- Yet respondents indicated issues with sexual function, fatigue, and cognitive difficulties
- 80% satisfied with healthcare team communication
- Yet 55% wanted access to more resources to help them make treatment decisions
- Survey informed tool and webinar

Patient Decision Making Tool

- Goal to facilitate better communication about MBC and its treatment, effects it has on one's quality of life and personal preferences

**FRANKLY
SPEAKING
ABOUT CANCER**

BE PREPARED: MAKING THE MOST OF YOUR
TIME WITH YOUR HEALTH CARE TEAM

The Cancer Support
Community (CSC)
provides support, education
and hope to people affected
by metastatic breast
cancer through its Frankly
Speaking About Cancer:
Advanced Breast Cancer
and other support
programs.

If you have advanced (metastatic) breast cancer, you know it can be scary. Many women say they feel uncertain about their future and overwhelmed by constant medical visits. But there are steps you can take to feel more in control and better able to cope. Use this worksheet to: 1) get organized before each medical appointment, and 2) write down your goals for treatment.

At each visit, bring a list of questions and be prepared to talk about:

1. What you are most worried about – use this space to write down your biggest concerns: _____

2. Your symptoms – since your last appointment, are your symptoms:

☐ Better
☐ About the same
☐ Worse
☐ Different in some way or do you have new symptoms since your last appointment
(Explain: _____)

3. How your cancer or cancer-related treatments interfere with your life – are you able to:

	not at all	occasionally	most of the time	all of the time
Work (fulfill job responsibilities)				
Sleep				
Think clearly				
Stay emotionally healthy				
Be social/enjoy hobbies				
Be sexually intimate				
Other:				

4. How you are managing symptoms/side effects:

Symptom/side effect	What are you doing to manage it?
Extreme tiredness	
Pain	
Difficulty thinking/memory	
Anxiety/depression	
Swelling	
Shortness of breath	
Reduced libido/sex drive	
Nausea/vomiting/loss of appetite	
Other:	

Ask whom you should contact if you have a problem in between appointments. Find out the best way to communicate with them (phone, fax, email, patient portal).

TEAMING UP TO MAKE TREATMENT DECISIONS THAT ARE RIGHT FOR YOU

Because of the nature of advanced breast cancer, even if your treatment is working now, you may need to reassess your options at some point. Partner with your health care team to weigh your options, including if and when to consider a clinical trial.

Take stock and map out your goals for treatment.

Think about and write down your goals. How do you hope your treatment will improve your physical health and general well-being? What about goals for your personal life and/or ability to work?

What is your main goal/what do you want to be able to do?	
Physical or general health	<i>For example: sleep better, get my appetite back, exercise or chase after my grandkids.</i>
Personal (social, family, hobbies, emotional well-being)	<i>For example: attend an upcoming family event, not be so sad anymore, be intimate with my partner.</i>
Work	<i>For example: be more present at my job, improve my concentration, limit time away from work.</i>
Other:	

OTHER THINGS YOUR HEALTH CARE TEAM MIGHT WANT TO KNOW ABOUT

- Have there been changes in your general health or well-being since your last visit?
- What you are most concerned or scared about? With whom are you able to share these concerns?
- Key questions you have related to your cancer, its treatments and/or specific options for care (check out CSC's Open to Options program to help organize your thoughts)
- Your goals for treatment – remember, these may change over time



CSC's Open to Options™ Can Help
Making decisions about cancer treatment can be overwhelming. Sometimes it's hard to know what questions to ask the doctor or how to wade through your feelings. But Open to Options – CSC's decision support counseling program – can help.

A trained specialist will help you develop a personal list of questions and concerns. You can then share this list with your providers before or at your appointment. Find out more by visiting www.cancersupportcommunity.org or call our toll free helpline at 1-888-793-9355.

Role of Allied Health Professionals

Nurses, social workers, patient navigators and other allied health professionals play a critical role:

- educating patients with metastatic breast cancer
- eliciting their concerns
- helping them focus on and weigh treatment options

All of which can greatly improve care.



Webinar for Allied Health Professionals

- Webinar aims:
 - improve awareness of the unique physical and psychosocial issues facing this population
 - promote shared decision-making
- Webinar Content
 - Speakers (Doctor, Nurse, Social Worker)
 - Discussed role in providing care
 - Offered different insights and perspectives
 - Discussed need for shared treatment decision making
- Over 100 allied health professional participated in webinar

Webinar Evaluation

- 54 respondents
- Results of survey:
 - Majority (94.5%): overall presentation ‘excellent’ or ‘very good’
 - Majority (92.7%): webinar added to their knowledge base and would help them to improve communication and promote shared-decision making
 - Most (92.6%): program inspired them to help patients share concerns and/or have greater access to treatment decision support resources/tools to better serve MBC patients

Conclusion

- MBC has become a disease that can be managed for a longer period through various treatments
- Survey results show need for improvement for resources and support available for MBC patients, particularly around treatment decision making.
- Patients' experiences provided valuable direction for development of both the patient tool and webinar for allied health care professionals.

For More Information



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