



Characterizing the metastatic breast cancer patient experience around preparing for a treatment decision

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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 and are confronted with more complex treatment decisions.
- Patient-provider communication is typically inadequate and patients are not fully prepared for communicating effectively with their doctor.
- The purpose of this research was to explore perceptions related to treatment decision-making among MBC patients.

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 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 completed the questionnaire about their experience with treatment decision making.
- The present analysis includes 572 US based registrants with completed data.



- 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

- Prior to making a treatment decision, patients reported receiving information about:
 - Their cancer type (92%)
 - Their treatment choices (78%)
 - Clinical trials (42%)
- Just over half reported they had quite a bit of knowledge about their treatment options; 22% had little or no knowledge about their treatment options.
- 39% received treatment decision support prior to making a treatment decision; 45% would have liked more support.
- 12% had little or no involvement in their treatment decision-making process.
- Nearly one-third (29%) did not feel they had a treatment choice.
- 29% reported they did not have enough time to make a treatment decision.
- Those who wrote down a list of questions prior to their first visit to discuss treatment options with their health care provider felt significantly more prepared to discuss their treatment options ($p < 0.001$).
- About two-thirds of patients were satisfied with various aspects of the treatment decision-making process:
 - Outcome of the treatment(s) received (70%)
 - Doctor's explanation of the benefits of each option (67%)
 - How they arrived at a decision (66%)
 - How much they participated in making the decision (64%)
 - Their doctor's explanation of the risks and side effects (64%)
- Patients thought it would be important to get help with:
 - Gathering information (70%)
 - Developing a written list of questions before their meetings with cancer specialists (70%)
 - Obtaining audio-recordings of appointments (48%)

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

- Although over two-thirds of these patients were satisfied with various aspects of treatment decision making, including their communication and interaction with their doctor around the decision, nearly 30% of the patients thought that they had no choice or felt rushed in making a decision.
- Those patients who prepared a list of questions prior to a consultation with the doctor felt significantly more prepared in making an appropriate decision.
- While a small majority of patients report being knowledgeable about treatment options, a significant proportion report not having enough knowledge or support to fully engage in a treatment decision.
- Further efforts are needed to address gaps in the delivery of decision support to MBC patients.

Chart 1. How knowledgeable were you about your treatment options prior to making your treatment decision?

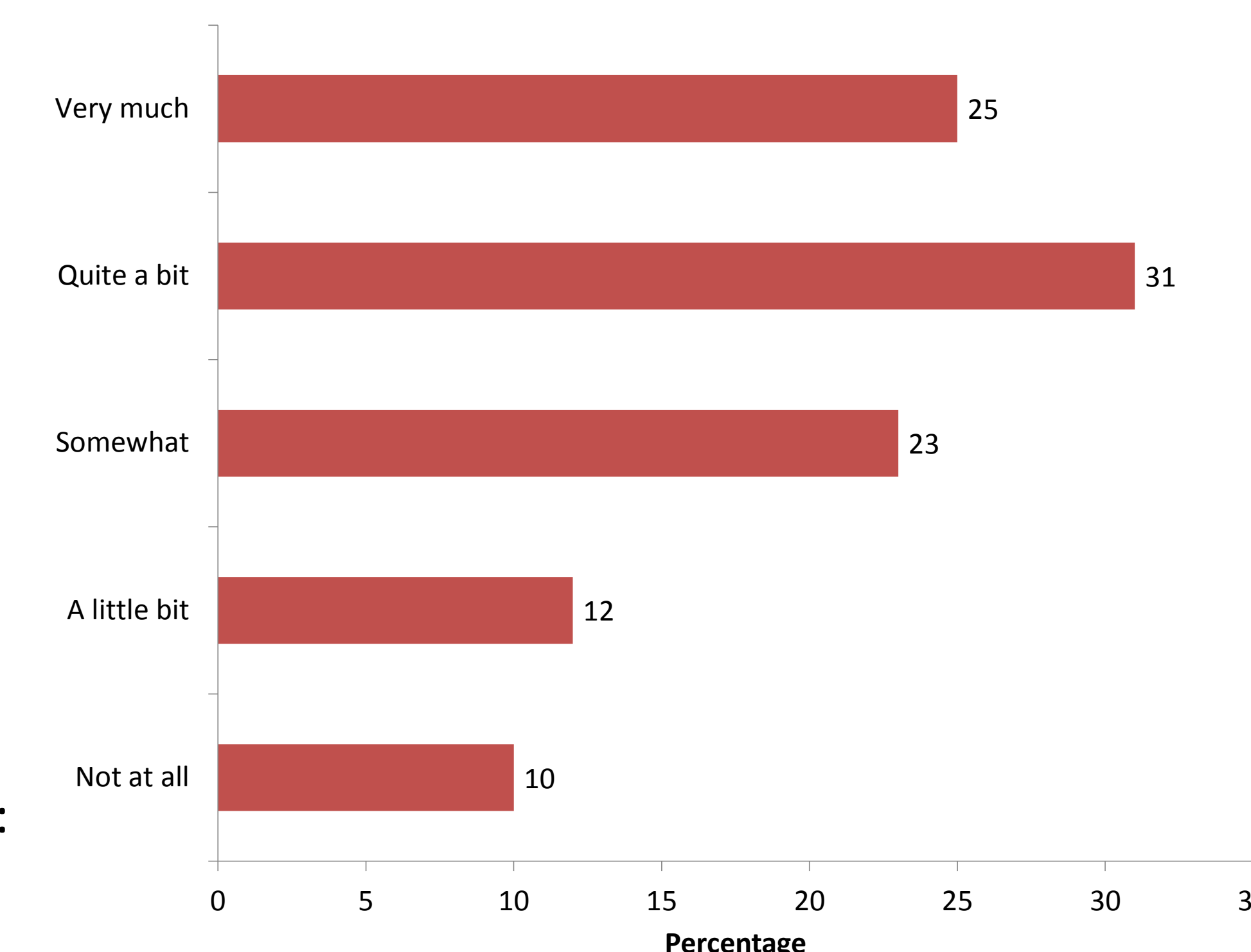
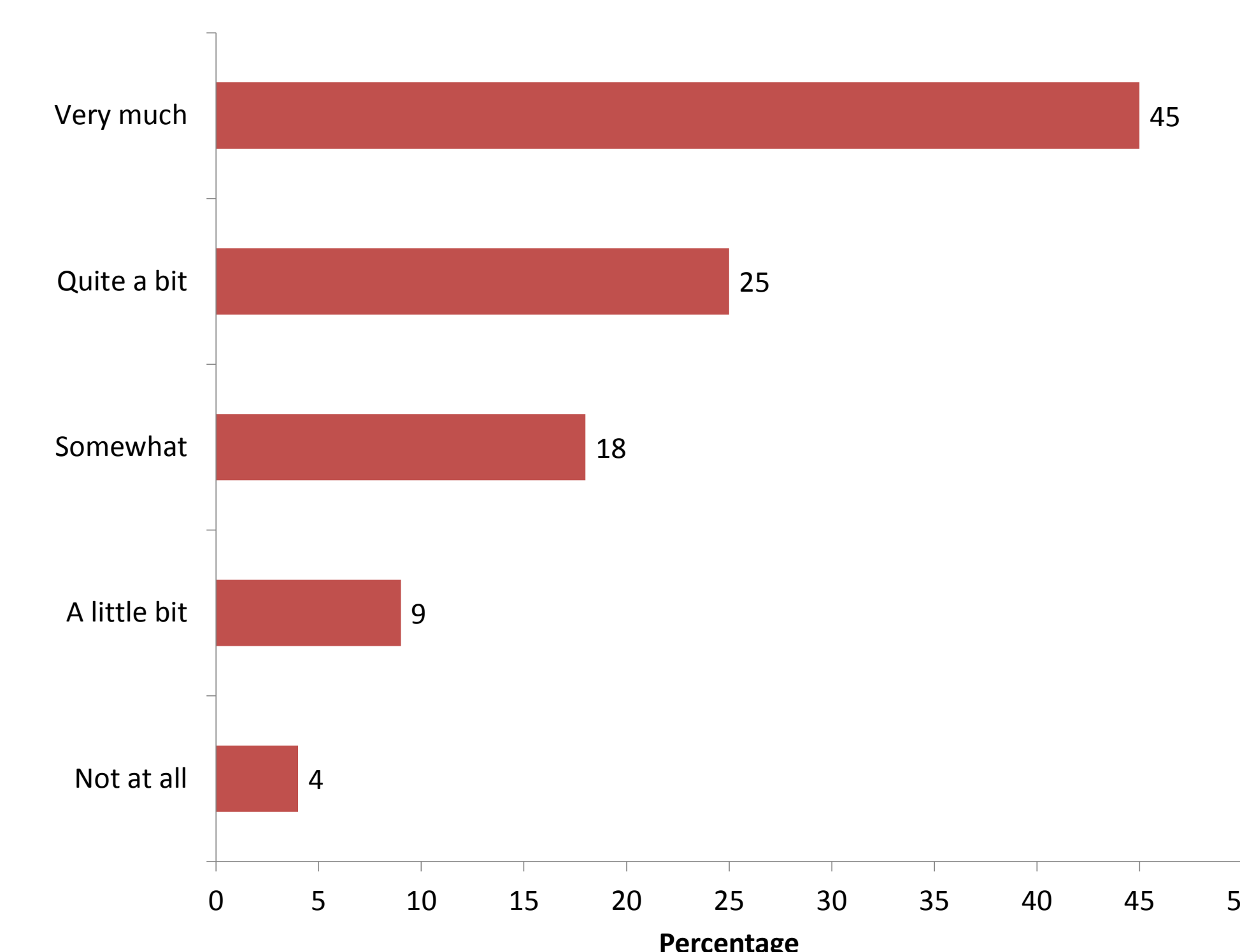


Chart 2. How involved were you in making your treatment decision?



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