

Work-related impact of metastatic breast cancer: Results from the Cancer Experience 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 US.
- With new developments in treatment, people can live with MBC for many years.
- Work is related to improved quality-of-life and health outcomes, yet little is known about the impact of MBC on work-related issues.
- The purpose of the current analysis was to understand the impact of a metastatic breast cancer diagnosis on work-related outcomes.

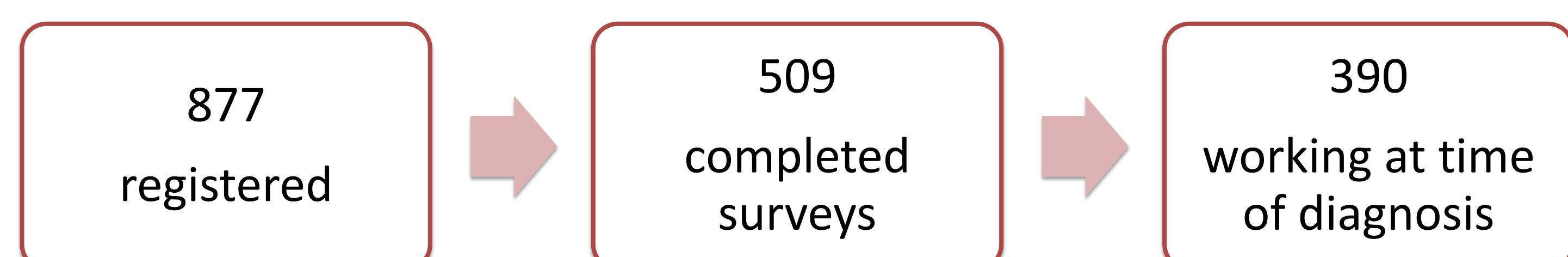
The Cancer Experience Registry

- CSC established the Cancer Experience Registry to track the immediate, ongoing and changing social and emotional experience of cancer survivors.
- The registry reaches cancer patients and survivors across the country and engages them to share their voices about issues identified by national advisors, including patient representatives, health care providers, advocates, industry representatives and researchers.
- Through the Cancer Experience Registry we are able to:
 - Garner, analyze and disseminate insights and knowledge in order to positively impact each individual's cancer experience;
 - Help inform the nation's health care systems to respond to the needs of cancer survivors; and
 - Accelerate and enhance the productivity of research to improve quality outcomes.

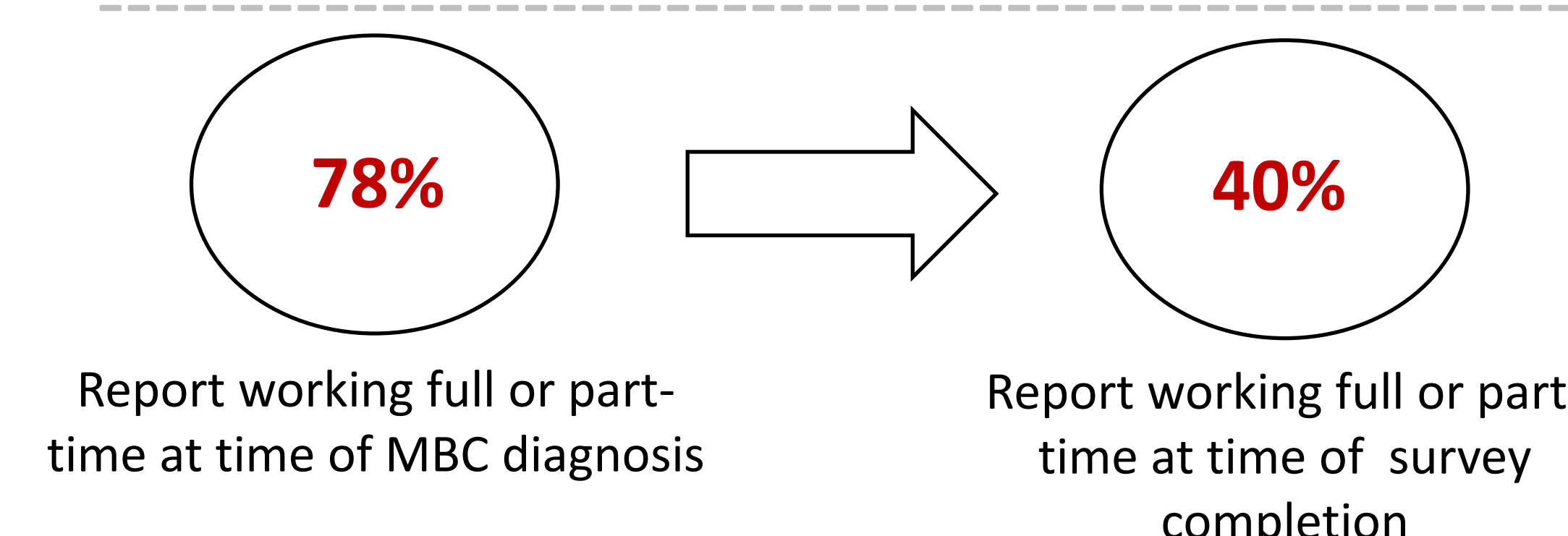
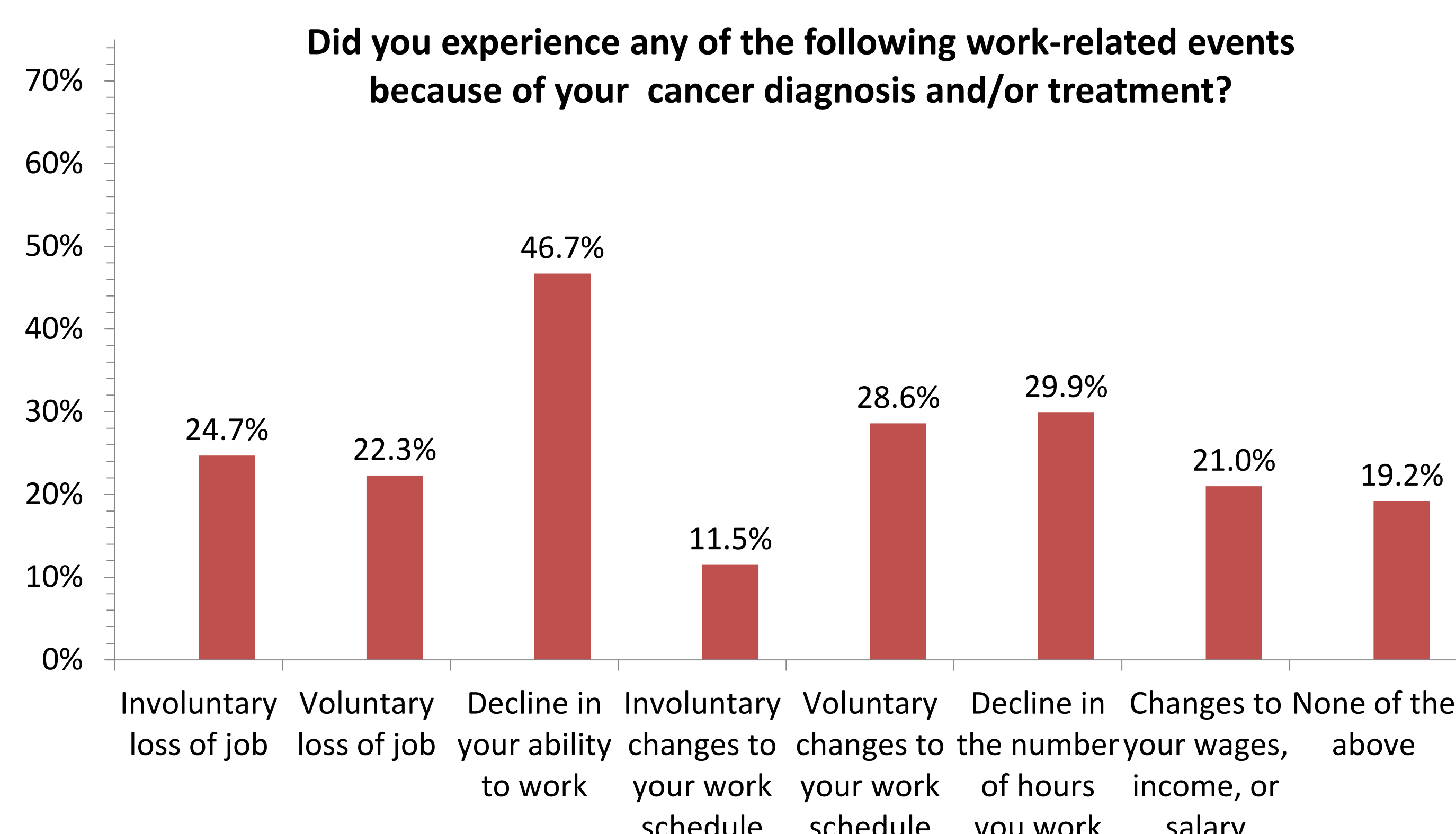
Currently, there are over 6,700 cancer patients and survivors in the Cancer Experience Registry from over 35 countries and representing more than 40 cancer diagnoses.

Methods

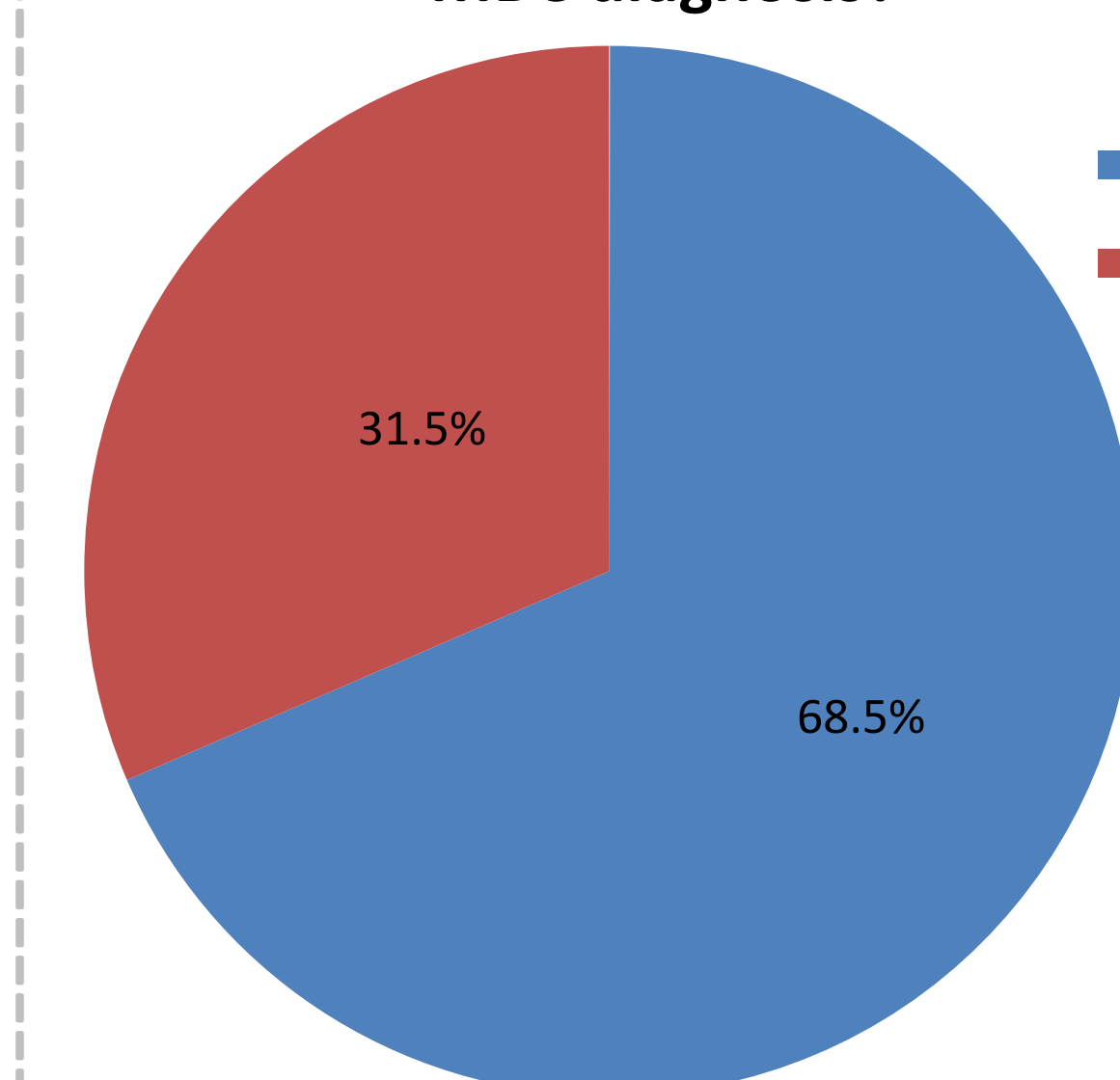
- CSC convened and engaged a National Advisory Council of MBC stakeholders and experts to generate a survey around priority topics. The National Advisory Council included members of the MBC Alliance, representing over 15 advocacy organizations.
- 877 people living with MBC joined the Cancer Experience Registry at the time of this analysis. Currently, there are over 910 people with MBC enrolled.
- 509 registrants completed the MBC survey.
- This analysis is limited to registrants who reported working at least part-time when they were diagnosed (n=390).



Results



Have you experienced stress related to the possible work related consequences of your MBC diagnosis?



Have you experienced any job discrimination because of your cancer diagnoses and/or treatment?

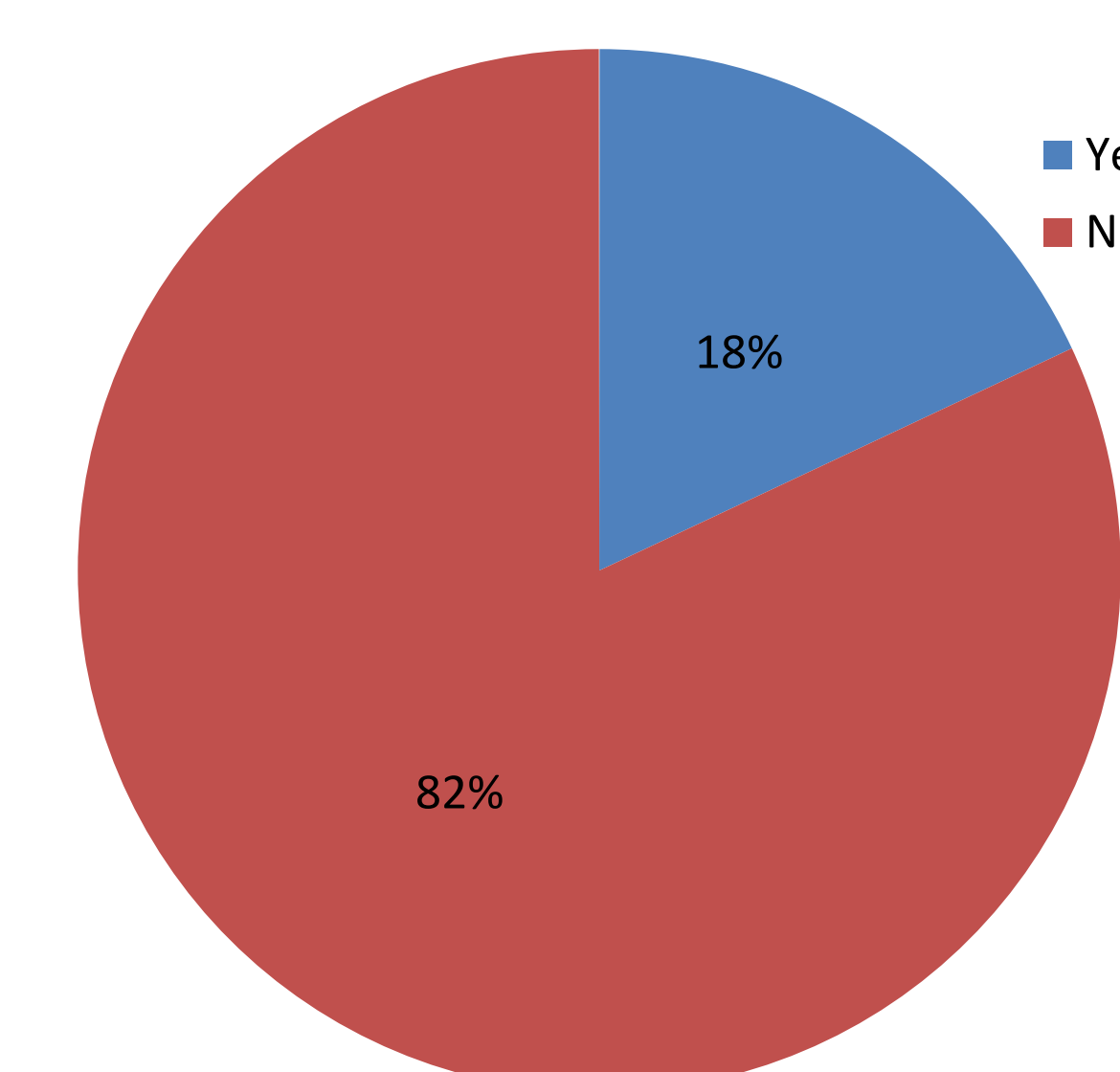


Table 1. Comparison of total distress score by reported job discrimination

Job discrimination	N	Mean	SD	t	df	p	CI
No	307	38.93	19.54				
Yes	67	47.29	20.37				
Total	347	43.11	19.95	-3.06	94.23	.003	-13.77 - -2.94

Note: Distress summary scores were calculated using a modified version of CancerSupportSourceSM (CSS), a validated distress screening tool from the Cancer Support Community. Total distress scores are out of a possible 108.

Summary of Results

- More than two-thirds (68.5%) reported experiencing stress related to possible work-related consequences of their MBC and 17.9% reported experiencing job discrimination because of MBC.
- Nearly half reported experiencing job loss (47.0%) or a decline in their ability to work (46.7%) because of MBC.
- Of those who were working at the time of MBC diagnosis, only half of respondents (49.5%) reported that they were currently working (74.3% full-time, 25.7% part-time).
- Work-related stress and overall distress levels were strongly correlated ($r=0.47$, $p<0.001$).
- Those who reported experiencing job discrimination also reported higher distress than those who did not ($p=0.003$).

Sample Characteristics (n=390)

Characteristic	Proportion
Female	99.5%
Caucasian	95.0%
Education ≥ Bachelor's Degree	72.7%
Median	
Age	54 (range: 31-76)
Time since MBC diagnosis	3 years

Conclusion and Future Directions

- Individuals living with MBC indicated that diagnosis and treatment of MBC can have a significant impact on work life and that work-related stress can substantially affect levels of overall distress.
- Future research should examine the complex dynamics of maintaining work or changes in work life and evaluate approaches to support individuals living with MBC in the workplace.



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

Acknowledgement of Funding

