

# Sexual Morbidity and Unmet Needs among Members of a Metastatic Breast Cancer Registry

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#### Introduction

As the duration of survival increases among people living with metastatic breast cancer (MBC), quality of life needs become more salient. Women treated for MBC often report adverse sexual effects, yet findings suggest that oncology providers rarely discuss sexual issues with patients. Further, the association of sexual morbidity due to MBC and depression is underexplored.

## **Objective**

- Our objective was to study the impact of MBC on sexual morbidity and its association with depressive symptoms.
- We also explored patient communication about sexual concerns with health care professionals.

## Method

- The data source for this study is the Cancer Support Community's (CSC) Cancer Experience Registry: MBC.
  - This is an online research initiative to investigate and raise awareness and improve understanding about the social and emotional experiences of patients living with MBC.
- Participants were recruited through an outreach plan that included communication from CSC affiliates and other advocacy and professional organizations.
- Since March 2013, 909 people living with MBC enrolled in the Cancer Experience Registry: MBC.
- 469 registrants completed questions about:
  - Sexual morbidity, such as: Diminished libido, vaginal dryness, feeling anxious about having sex (see Table 2).
  - Communication about sexual morbidity with health care professionals.
  - Cancer-related distress, including a depression subscale, using CancerSupportSource (Miller et al., 2014).

### Results

Table 1. Patient Characteristics (n=469)

	n	%
Non-Hispanic white	424	93
At least college degree	295	63
Income < \$40K	82	26
Recurrence	356	61
At risk for depression	250	55
Age (median)	56 years	
Time since MBC diagnosis (median)	3 years	

# Sexual Morbidity and Depression

- 71% reported MBC negatively impacted their sexual life.
- 50% reported sexual activity was a source of distress.
- 38% reported MBC changes in sexual life caused relationship difficulties.

All patient-reported outcomes listed above were significantly associated with an increased risk of depression.

Table 2. Prevalence of sexual morbidity by risk for depression

	At Risk for Depression			
	Total (n=469)	No (n=204)	Yes (n=250)	P-
Symptoms	%	%		value*
No interest in sex	80	74	85	0.014
Vaginal dryness	76	73	79	0.26
Pain during or after sex	69	65	71	0.29
Difficulty having an orgasm	64	58	71	0.020
Anxious about having sex	72	63	79	<0.01
Did not enjoy sex	64	59	68	0.10

\* Chi-square test

Having no interest in sex (p=0.014), difficulty having an orgasm (p=0.020), and feeling anxious about sex (p=0.002) were significantly more common among those at risk for depression.

Difficulty having an orgasm was more common among women concerned about body image (p=0.001).

## Results

## Communication with Health Care Professionals about Sexual Concerns

- More than half of the patients (59%) felt they could talk to a member of their health care team about sexual concerns.
- 20% reported that a member of their health care team ever asked about sexual concerns.
- 17% sought treatment for sexual dysfunction.
- 39% said they would never go to a mental health expert for sexual counseling even if it were free.

#### Conclusion

- A high proportion of these patients with MBC indicated that MBC negatively impacted their sexual life.
- Sexual morbidity was associated with symptoms of mood disorder. The direction of the association is unclear and should be studied in prospective surveys.
- More efforts are needed in oncology settings to screen for sexual problems in people living with MBC and make appropriate referrals for care. Findings might also suggest a need for clinician education and training on how to discuss issues of sexual morbidity with patients.
- Research should continue to attend to:
- Understanding the experiences of patients with MBC with respect to sexual morbidity, communication with health care professionals and desired programming.
- Raising awareness about effective treatment approaches related to sexual dysfunction and intimacy.

## Acknowledgements

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### References

Miller, M., Mullins, C., Onukwugha, E., Golant, M., & Buzaglo, J. (2014). Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. Qual Life Res, 23(10): 2855-2863.



The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers, but also includes 9 disease specific surveys including MBC.
- Findings contribute toward advancing research, care and policy.
- Over 7,600 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org