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Male Breast Cancer Has Limited Effect on Survivor's Perceptions of Their Own Masculinity: A Record Review and Telephone Survey of Patients in Johannesburg, South Africa

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Abstract

The purpose of the current study was to describe male breast cancer in Johannesburg, South Africa, and assess whether male breast cancer patients' perception of their own masculinity was affected by having a cancer commonly seen in women. A retrospective file review was carried out at two hospitals, one private and one government, of male breast cancer patients from 2007 to 2012 followed by a telephone survey of patients identified during review. Of approximately 3,000 breast cancer patients seen in the 5 years reviewed, 23 cases of male breast cancer were identified. Most were diagnosed with invasive ductal carcinoma (n = 19, 83%). Stage at presentation was from stages 0 to 3 (Stage 0 [n = 2, 9%], Stage 1 [n = 3, 13%], Stage 2 [n = 12, 52%], Stage 3 [n = 6, 26%]) and no patients were metastatic at presentation. The telephonic survey was completed by 18 patients (78%). Nearly all (n = 17/18) shared their diagnosis with family and close friends. Two thirds of patients delayed presentation and government hospital patients were more likely to present later than private sector hospital patients. Although most male breast cancer patients sampled did not perceive the breast cancer diagnosis as affecting their masculinity, Black men and those treated in government hospitals were less likely to be aware of male breast cancer, and were more likely to have their perception of their own masculinity affected.

Keywords

patient delay, sexuality, male breast cancer, oncology/cancer

Introduction

The incidence of male breast cancer (MBC) is less than 1% of all breast cancers and a rare disease when compared with female breast cancer worldwide (Czene et al., 2007; Giordano, Cohen, Buzdar, Perkins, & Hortobagyi, 2004; Goss, Reid, Pintilie, Lim, & Miller, 1999; Jemal et al., 2004), although increased incidence of reported MBC is described from Africa as up to 6% to 9% (Ndom et al., 2012; Sasco, Lowenfels, & Pasker-de Jong, 1993). In South Africa, the incidence of MBC is not well-documented but was recorded as 1.8% of all breast cancer cases according to the most recent South African cancer registry (National Cancer Registry, 2009). According to figures from other countries, the risk of developing MBC increases with age, and men tend to present later and with more advanced disease (Anderson, Jatoi, Tse, & Rosenberg, 2010; Giordano et al., 2004; Goss et al., 1999). The disease has a worse prognosis in males (Adami, Holmberg, Malker, & Ries, 1985; Heller, Rosen, Schottenfeld, Ashikari, & Kinne, 1978; Rosenblatt et al., 1991), which may be a product of the late stage of presentation rather than tumor biology which tends to be more favorable in men with a higher rate of hormone receptor positivity and less HER2 (human epidermal growth factor receptor 2) positivity

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(Bloom, Govil, Gattuso, Reddy, & Francescatti, 2001; Ge et al., 2009; Kornegoor et al., 2012; Shaaban et al., 2012).

There is a paucity of evidence surrounding the personal perceptions and psychological stressors associated with MBC survivors. MBC patients reported high levels of cancer-specific distress (Brain, Williams, Iredale, France, & Gray, 2006) and depressive symptoms related to alterations in body image are common, although studies differ as to whether they are as high as in women (Andrykowski, 2012; Brain et al., 2006; Kowalski et al., 2012). As awareness and advocacy has increased in breast cancer in Africa over the past decade, it has mimicked trends from the Western Europe and the United States becoming strongly allied with female colors and themes. Gender and the stereotyping of femininity and masculinity is a recognized to be a social construct related closely to culture (Courtenay, 2000), and research describes that there are widely shared beliefs within societies as to what these characteristics and behaviors are (Morrell, 1998; Spence, Helmreich, & Stapp, 1975). There is, however, very little reported evidence as to how men experience their breast cancer psychologically with respect to body image and female associations (Donovan & Flynn, 2007; France et al., 2000), and to the best of our knowledge there is nothing reported from non-Western countries.

This retrospective medical review and telephonic patient survey was to evaluate the experience of MBC patients undergoing treatment in terms of their emotional and psychosocial response. It was hypothesized that the strong association of breast cancer as a women's cancer would affect a male with breast cancer in terms of relationships, perception of themselves, and their own masculinity. In addition, negative emotions in these areas may contribute to delay in presentation seen.

Method

Setting

This dual center study drew participants from breast clinics in one government and one private hospital providing an opportunity to study the full spectrum of patients, with and without medical aid undergoing breast cancer care in Johannesburg, South Africa. The government hospital sees predominantly uninsured patients with between 300 and 350 new breast cancer diagnoses each year. The private center sees patients with private funding or medical insurance from all parts of Africa, although predominantly local to Johannesburg, with currently over 300 new breast cancer diagnoses per year.

File Review

All patients with a histologically confirmed invasive breast cancer (any subtype) or in situ ductal carcinoma, with a recorded gender of "male," and diagnosed between January 2007 and December 2012 were identified in both centers from clinical records and theater logs of operations (government hospital only) and included in the study. All female patients and male patients with a noncancer (benign) diagnosis were excluded.

Variables were recorded from each patient's paper-based file including the diagnosis, demographics, comorbidities, previous benign disease, family history of any cancers, and treatment. From histology reports and radiology reports of each patient the stage of disease, subtype, and receptor status were obtained. Extent of disease and treatments obtained were analyzed for each patient. Early disease represented low-volume disease confined to breast and locally advanced indicated disease that had spread to involve the regional lymph nodes or was greater than 5 cm or involving skin or muscle at initial presentation (T3 or T4). Estrogen, progesterone, and HER2 receptor status was documented for each patient according to immunohistochemistry. Florescent in situ hybridization was not routinely carried out in government practice to further determine HER2 status but was used in private patients.

Survey

The patient's contact details were recorded and contact with every patient was attempted with each patient telephonically in April 2013. If no details were available, the phone number was incorrect or unobtainable or after four unsuccessful attempts at contact, the patient was excluded from the survey. Included patients were then contacted to check and determine further management and survival. In addition, they were asked to consent to a short quantitative survey telephonically. The questionnaire was designed specifically for this study with a novel primary focus being MBC patients' perception of breast cancer and their experience of their disease including the effect on their sexual and familial relationships, feelings of masculinity, and self-confidence. Survey questions were asked and answered in English, and used 5-point Likert-type scales to quantify perceptions of disease from *strongly disagree* to *strongly agree*.

Statistical Analysis

Patient and tumor characteristics are described using frequencies, median, and interquartile range. Survey responses by patient characteristics are analyzed using Wilcoxon rank-sum (Mann–Whitney) nonparametric test for small numbers. Statistical significance was set at p value less than .05; two-sided 95% confidence interval. Binary groupings were used; patients were categorized as being aware or not aware of MBC, having delayed (≥3 months) or not delayed (<3 months) presentation after

Table 1. Male Breast Cancer Patient Characteristics, From Record Review.

Characteristic	Number	Proportion
All patients	23	
Hospital		
Government	9	39%
Private	14	61%
Age at diagnosis (years)		
Median	64	IQR: 59-72
Above or at 65 years	9	39%
Race		
Caucasian	11	48%
Black	10	44%
Other	2	9%
Family history of breast cancer		
Yes—First degree relative	7	30%
Yes—Other relative	3	13%
No	13	56%
Previous gynaecomastia		
Yes	2	9%
No	21	91%

Note. IQR = interquartile range.

noticing a breast lump, and having significantly delayed (>12 months) or not significantly delayed presentation (≤12 months). With regard to the statements about masculinity, a patient responding agreed or strongly agreed to any one of the three statements was categorized as "affected." Patient characteristics were grouped for race (Black or Non-Black), government or private sector hospital, age <65 years or ≥65 years at diagnosis, any family history of breast cancer or no family history, and relationship status (in or not in a relationship).

Ethical approval for the study was obtained from University of the Witwatersrand Human Research Ethics Committee (Protocol M130373).

Results

Patient Characteristics

Out of approximately 3,000 breast cancer patients seen during the 5-year period, 23 cases of MBC were identified: 9 from the government hospital and 14 from the private hospital. The median age of MBC patients was 64 years (interquartile range: 59-72) with 9 (39%) aged 65 years or older at diagnosis. Most patients described themselves either of "White" race (48%, n = 11) or "Black" race (44%, n = 10). Race and family history of breast cancer were correlated; only 1 of 10 Black patients had a family history documented in patient files. Further patient characteristics are summarized in Table 1.

Breast Cancer Characteristics

Breast cancer characteristics are presented in Table 2. The predominant breast cancer subtype (n = 19, 83%) was invasive ductal carcinoma. Other histology was two encysted papillary carcinomas. Two patients had "pure" in situ ductal carcinoma with no evidence of invasion, one had evidence of associated intraductal papillary carcinoma. All patients were steroid receptor positive, and most (n = 19, 83%) both estrogen and progesterone receptor positive. Three patients had tumors that were positive for HER2 overexpression, and a further three had equivocal results. One patient received anti-HER2 therapy.

Stage 2 disease was most common at presentation and no patients were metastatic at presentation. Government patients were no more likely to present with later stage disease than patients seen at the private hospital, and both were equally likely to undergo chemotherapy.

Three patients reported in the survey an episode of recurrence. All recurrences were locoregional, two to chest wall and one in the axilla. All were managed with surgery and chemotherapy and radiation if not previously received. One patient died without breast cancer recurrence.

Survey Response

Of the 23 patients identified from the record review, five (22%) could not be contacted, three were foreign visitors from other African countries without adequate local cancer treatment facilities, one was not contactable after repeated attempts, and one had died. Median time from diagnosis to survey was 34 months (range 7 to 73 months).

Only six patients (33%) were aware of MBC prior to their diagnosis. All but one patient willingly disclosed their disease and treatment to their family and friends. Race and hospital were correlated; no Black patients who participated in the survey were treated at the private hospital.

No Black patients surveyed (0 of 7) were aware of MBC; thus, being seen at the government hospital was also associated with a lack of awareness of MBC (p = .052). Patients who had a family history of breast cancer were more likely to be aware of MBC (p = .023; Table 3).

The median time between first noticing a breast lump and seeking medical attention was 7.5 months. Most (n = 12, 67%) of patients had delay considered clinically detrimental (≥3 months) in presenting for diagnosis and care after detecting the breast lump. Delayed presentation was statistically not associated with awareness or family history, but was associated with Black race and treatment at the government hospital (p = .020 and p = .052, respectively). Four (22%) patients presented after significant delay (>12 months). Patients at the government hospital

Table 2. Tumor Characteristics, From Record Review.

Characteristic	Number	Percentage
All patients	23	
Tumor status		
T0	2	9
T1	6	26
T2	10	44
T3	1	4
T4	4	17
Axillary node status		
N0	12	52
N1	6	26
N2	4	17
N3	1	4
Stage		
0	2	9
1	3	13
2	12	52
3	6	26
4	0	0
Histology grade (*n* = 21)		
1	2	10
2	13	62
3	6	29
Subtype characterization		
Luminal A	17	74
Luminal B	3	13
HER2 positive	3	13
Basal	0	0
Estrogen receptor		
Positive	22	96
Negative	1	4
Progesterone receptor		
Positive	20	87
Negative	3	13
HER2		
Positive	3	13
Negative	17	74
Equivocal (No FISH)	3	13

Note. HER2 = human epidermal growth factor receptor 2; FISH = florescent in situ hybridization.

Table 3. Telephone Survey Responses, Stratified by Patient Characteristics.

Were you aware of male breast cancer before diagnosis?	Yes	No	*p*[a]
All patients	6 (33%)	12 (67%)	
Black race	0 (0%)	7 (100%)	.020
Government hospital	1 (89%)	8 (11%)	.052
Age 65+ at diagnosis	2 (33%)	5 (67%)	.740
Family history of breast cancer	5 (62%)	3 (38%)	.023
How many months before diagnosis did you notice lump?			
Delayed presentation	<3 months	≥3 months	*p*[a]
All patients	6 (33%)	12 (67%)	
Black race	0 (0%)	7 (100%)	.020
Government hospital	1 (11%)	8 (89%)	.052
Age 65+ at diagnosis	1 (14%)	6 (86%)	.184
Family history of breast cancer	4 (50%)	4 (50%)	.192
Aware of male breast cancer	2 (33%)	4 (67%)	1.000
Significantly delayed presentation	≤12 months	>12 months	*p*[a]
All patients	14 (78%)	4 (22%)	
Black race	4 (57%)	3 (43%)	.103
Government hospital	5 (56%)	4 (44%)	.028
Age 65+ at diagnosis	4 (57%)	3 (43%)	.103
Family history of breast cancer	7 (88%)	1 (12%)	.389
Aware of male breast cancer	5 (83%)	1 (17%)	.697

[a]Two-sample Wilcoxon rank-sum test.

were more likely to have presented after 12 months than patients at the private hospital (*p* = .028).

Patient responses to statements about their masculinity and associations to patient characteristics are summarized in Table 4. Overall, patients disagreed with the statements indicating breast cancer had affected their perception of their own masculinity. Only five (17%) respondents agreed with the statement “I feel less masculine as a result of having breast cancer.” Ten patients (55%) disagreed or strongly disagreed to all three statements. No patients agreed or strongly agreed to all three statements, only three patients (17%, all Black and all at the government hospital) agreed or strongly agreed to two of the three statements.

A patient responding agreed or strongly agreed to any one of the three statements was categorized as “affected” and associations to the patient characteristics explored. Government and Black patients were more likely to be categorized as affected (*p* = .065 and *p* = .074, respectively). While only three men recorded “strongly agree” with regard to feeling less masculine, each chose to add a comment on the questionnaire (the only three to do so). These comments were “I lose my power,” “Maybe I have the genes of a woman,” “Women look at you like you fall from the moon [*sic*] . . . ”

Table 4. Responses to Statements About Masculinity, Stratified by Patient Characteristics.

Response to the following statements	Agree	Disagree, neutral	
I feel less masculine as a result of having breast cancer	5 (28%)	13 (72%)	
Breast cancer has affected my sexual relationships	3 (17%)	15 (83%)	
I am embarrassed to take shirt off in public places now	3 (17%)	15 (83%)	
Affected (agree to one or more of the statements)	**Not affected**	**Affected**	**p^a**
All patients	10 (56%)	8 (44%)	
Black race	2 (29%)	5 (71%)	.074
Government hospital	3 (33%)	6 (67%)	.065
Age 65+ at diagnosis	3 (33%)	4 (67%)	.401
Family history of breast cancer	4 (50%)	4 (50%)	.680
Aware of male breast cancer	5 (83%)	1 (17%)	.103
Delayed presentation	6 (50%)	6 (50%)	.515
Significantly delayed presentation	3 (75%)	1 (25%)	.389
In a relationship	10 (62%)	6 (38%)	.103

[a] Two-sample Wilcoxon rank-sum test.

Discussion

MBC is an uncommon diagnosis worldwide and its incidence is poorly known in Africa due to a paucity of literature and the lack of comprehensive cancer registries (Korde et al., 2010; Ndom et al., 2012). It is believed by the authors that this is the first study to describe the impact of MBC on patients' perception of their own masculinity in a Southern African patient population.

It has been hypothesized that sociocultural associations with breast cancer as a woman's disease would lead to negative effects on perceptions of masculinity for MBC patients. However, this study identifies that most MBC patients (55%) disagreed or strongly with three different statements that having breast cancer affected their feelings of masculinity, sexual relationships, or comfort in taking their shirt off in public and no patients agreed or strongly agreed to all three statements.

It had also been hypothesized that these negative perceptions and affected feelings of masculinity, would lead to a delay in presentation after noticing a breast lump. However, no relationship between affected masculinity and delays in presentation was identified. These hypotheses were determined because they are common to the literature; almost all articles on MBC make reference to the relationship between male patients and a "female" disease. Most also hypothesize that there is an association between the frequent late stage of presentation and feelings of embarrassment or emasculation (Brain et al., 2006; Bunkley, Robinson, Bennett, & Gordon, 2000; Donovan & Flynn, 2007; Farrell et al., 2014; France et al., 2000; Ruddy & Winer, 2013) and this is assumed to contribute the late stage and delay to presentation in men, despite very little evidence (Donovan & Flynn, 2007; France et al., 2000). Most other studies describe psychological distress experience by men with breast cancer but do not differentiate between general cancer-related anxiety and depression and specific problems related to perceptions of a "female" disease (Brain et al., 2006). The current study has determined that in this group of MBC patients, there was no association between issues with masculinity and delayed presentation. There was no evidence of a crisis of masculinity affecting either presentation or later coping strategies. There was also no evidence to support the existence of the often presumed relationship between delay in presentation and stage of disease. Most men with breast cancer in this study did not experience feelings of affected masculinity or alteration in sexual function and body image nor experienced feelings of emasculation by having a perceived "female" disease. They did not indicate an impact sexually or socially from having MBC. This is challenging to traditional assumptions of MBC patients and perhaps reflects that the medical professions explanation of why men present late (due to stigma) is not actually the patient's experience.

"Most men" is not all men; and it should be noted that, as evidenced in the comments recorded, although most men find their perception of their masculinity unaffected, those who do are profoundly affected. Affected patients were more likely to be of Black race and to have been treated at government hospital, suggesting some bias inherent in parts of the population.

In these affected men, there was an overlap of potential influencing factors evident with a lack of patient awareness of MBC and a lack of family history of breast cancer also seen. South Africa's complex legacy of apartheid and its persisting inequalities in health care and education mean that race, socioeconomic status, awareness of, and access to adequate health care often overlap. It is therefore difficult to determine the relative importance of education on awareness and patient's perception of their own masculinity; or the presence of more culturally specific beliefs in influencing this perception after MBC. The remarkably low prevalence of MBC makes this even more challenging.

Some work has been done to establish MBC as a separate clinical entity for patients with regard to recognizing the need for gender-specific information, improving patient access and combatting potential isolation (Andrykowski, 2012; Brain et al., 2006; Farrell et al., 2014; Kowalski et al., 2012). More work is needed among populations of MBC patients, and male breast clinic attendees, to understand problems surrounding presentation for all breast-related problems (Kipling, Ralph, & Callanan, 2014).

There are limitations to this study, as a retrospective medical review combined with a limited telephonic survey of patients at two breast cancer care sites in Johannesburg, South Africa. At the government hospital, individual medical records for all breast cancer patients were not searchable and therefore patients were identified from surgical theater records. This may have introduced a survivor bias in the government patients as patients may not have survived from diagnosis until surgery, especially if surgery was scheduled after completion of chemotherapy. Although all patients contacted readily consented to the survey, its short quantitative design would encourage further qualitative work to fully explore the findings identified here. Another limitation that should be considered is that this study was not designed to describe the occurrence of MBC in South Africa, rates of survival or risk of recurrence. Therefore, where the characteristics of MBC presented here may differ from other reported cohorts, further research is needed to identify whether these differences are significant and what are the reasons for the differences.

Conclusions

Despite beliefs in the literature that men may be adversely affected by the perception of breast cancer as a “female” disease together with a poor level of awareness and possible stigma of the disease, male patients in this study were freely willing to disclose their diagnosis to friends and family. Although three quarters of men found their perception of their own masculinity and relationships unaffected by the female associations of breast cancer, this study reports there are differences in the knowledge and attitudes of Black patients and patients receiving government hospital care. The possibility that these associations have significant impact in some concerned males remains relevant to the support of MBC patients, particularly in the government sector.

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