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RESEARCH BRIEF

Trends in Use of Risk-Reducing Mastectomy in a Context of Celebrity Decisions and Media Coverage: An Observational Study in the United States and Australia

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Objective. To examine trends in risk-reducing mastectomy (RRM) and immediate breast reconstruction in New York State and New South Wales, especially before and after Angelina Jolie's announcement of her surgery in 2013.

Data Source. Hospital discharge data, 2004–2014.

Study Design. Trends in procedures were assessed using Poisson regression and the Cochrane–Armitage test.

Data Extraction Methods. Extracted using procedure codes.

Principal Findings. There was an increase in RRM procedures after May 2013 in both regions, with a peak during late 2013–early 2014. The average bimonthly RRM procedures were significantly higher after Jolie's announcement than before.

Conclusions. In both countries, we found a substantial increase of RRM after Jolie's announcement, highlighting the impact of celebrity health care coverage on preventive surgical choice and the need for decision aids to assist patients.

Key Words. Risk-reducing mastectomy, breast cancer prevention, celebrity effect

Risk-reducing mastectomy (RRM), also known as bilateral prophylactic mastectomy, has been demonstrated to be an effective approach in reducing the risk of breast cancer in high-risk women, particularly those who are genetically predisposed to breast cancer (Lostumbo, Carbine, and Wallace 2010). In 2007, the Society of Surgical Oncology issued a position statement on RRM, with indications including genetic susceptibility, strong family history, and histologic risk factors being stated (Giuliano et al. 2007). An immediate breast reconstruction is often performed at the time of RRM, and it is known to have positive psychological effects on women undergoing the procedure, reducing

the difficulty many women experience with changes in body image following mastectomy (Dean, Chetty, and Forrest 1983).

As demonstrated by the “Kylie effect,” whereby the rates of breast imaging in women aged 25–44 years in Australia increased sharply following publicity about actor-singer Kylie Minogue’s breast cancer diagnosis, celebrity illness and treatment may generate intense media coverage and change consumer behavior (Kelaher et al. 2008). In a recent high-profile case, actress Angelina Jolie revealed through public news media her decision to undergo an RRM and a breast reconstruction with implants in May 2013, based on test results identifying a BRCA1 gene mutation (Jolie 2013). Her experience was then widely publicized globally (Berry 2013; Haynes 2013; Henneberger 2013; Hui 2013). Previous studies suggested that there was a “Jolie effect” on awareness and health care-seeking behavior (Borzekowski et al. 2014; Evans et al. 2014; Juthe, Zaharchuk, and Wang 2015; Lebo et al. 2015; Noar et al. 2015; Dean 2016; Desai and Jena 2016; Kosenko, Binder, and Hurley 2016), including increased online information searching and genetic testing and counseling.

However, there is limited evidence from all-inclusive population cohorts showing that RRM rates have been increasing and influenced by celebrity health decisions. One U.K. study examined the occurrence of RRM within a health network and reported higher rates of RRM following Jolie’s announcement (Evans et al. 2015). It was unknown whether this was a U.K.-specific or global phenomenon, warranting examination across different populations and health systems. Our primary objective was to examine trends in RRM procedures in two large states in the United States and Australia, in relation to Angelina Jolie’s announcement and subsequent media coverage, to explore the “Jolie effect” on preventive surgery use. Our secondary objective was to assess trends in RRM-associated practice patterns, including the use of immediate breast reconstruction at the time of surgery and the type of reconstruction.

METHODS

We used the New York Statewide Planning and Research Cooperative System (SPARCS) and New South Wales Admitted Patient Data Collection (APDC)

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data in the present observational cohort study. A comparison of New York State and New South Wales populations was made. Demographics and socioeconomic aspects of the two regions were similar (Table S1 in Appendix SA2).

We identified all women of age 16–80 years with no known prior history of breast cancer who underwent bilateral mastectomy between 2004 and 2014 (Australian data were not available for second half of 2014) for one of the following reasons—a prophylactic breast resection encounter, personal or family history of gynecologic malignancy, family history of breast cancer, or genetic susceptibility to breast/ovary malignancy. Detailed inclusion/exclusion process and number of women at each step are shown in Table S2 in Appendix SA2. ICD-9-CM and CPT-4 procedure codes were used to identify patients undergoing RRM in New York State from inpatient and ambulatory surgery files. As RRM is an inpatient procedure in Australia, ICD-10-AM procedure codes were used to identify patients from New South Wales APDC database (Table S3 in Appendix SA2).

Patient characteristics included age at surgery, primary insurance payer, immediate breast reconstruction, and length of stay. For New York State, Medicare and Medicaid were classified as public to align with categorization of primary payer in Australia. Type of breast reconstruction was determined using procedure codes during the same hospitalization of RRM procedures (Table S3 in Appendix SA2).

Statistical Analyses

Annual rates of RRM among women aged 16–80 years were calculated using published population estimates for New York State (U.S. Census Bureau 2016) and New South Wales (U.S. Government 2016). To adjust for differences in age structure over time, we applied indirect adjustment to standardize to the age structure of 2014 for NYS and NSW, respectively. We then estimated the number of RRM procedures per 1,000,000 women. A Poisson regression was used to assess the trends over year. Because only half-year data were available in NSW in 2014, trend by year was assessed based on projected 2014 cases for NSW with the first half year's data.

To further investigate the “Jolie effect,” data between 2009 and 2014 were analyzed bimonthly; 2009 was chosen as the starting point for this analysis as the trends in procedure numbers became steady in both states at this time. Segmented regression analysis of interrupted time series data was used (Wagner et al. 2002). A comparison of the trends before and after May 2013 accounted for any original trends in the region prior to Jolie's announcement.

An alternative start point of January 2006 was used in sensitivity analyses. Additionally, we conducted falsification tests, examining trends in the number of reduction mammoplasty and bilateral prophylactic oophorectomy procedures within the same time frame using a similar approach.

Patient characteristics were presented and compared between the two regions. Trends in use of immediate breast reconstruction and the type of breast reconstruction used were also evaluated using a Cochrane–Armitage test for trend. All analyses were performed using *SAS* v9.3 (SAS Institute Inc., Cary, NC). Statistical significance was defined as $p < .05$.

RESULTS

A total of 1,808 and 487 women of age 16–80 years underwent RRM in New York State (January 2004 to December 2014) and New South Wales (January 2004 to June 2014), respectively. The average age of women undergoing RRM was 45 years in both New York State and New South Wales (Table 1). The majority of women undergoing RRM in both regions had private health insurance (87.8 and 95.7 percent, respectively).

Overall, there was an increase in the number of RRM procedures in both regions (Figure S1 in Appendix SA2). The number of RRM procedures increased from 10 per 1,000,000 women in 2004 to 39 per 1,000,000 women in 2014 ($p < .01$) in New York State, and from 4 per 1,000,000 women in 2004 to 37 per 1,000,000 women in 2013 in New South Wales ($p < .01$).

When examining the trends of RRM procedures during 2009–2014 in the bimonthly analysis (Figure 1), there was a slight decrease in the numbers of RRM procedures from January 2009 to April 2013 in New York State ($p = .04$). During the same time period, there was an increase in RRM in New South Wales ($p = .07$). After May 2013, an increase in RRM procedures was observed in both regions ($p < .01$ and $p = .03$ for level change in NYS and NSW, respectively, Table S4 in Appendix SA2), with a peak during late 2013–early 2014. Comparing RRM procedures within 20 months before and after May 2013, the average bimonthly cases were significantly higher after Jolie’s announcement than before (before vs. after: NYS 3.3 vs. 6.3 per 1,000,000; NSW 3.6 vs. 7.1 per 1,000,000; both $p < .01$). The highest number of RRM procedures was observed from September 2013 to April 2014, reaching an average of 6.6 cases per 1,000,000 women bimonthly in New York State, and 8.4 cases per 1,000,000 women bimonthly in New South Wales. Using an

Table 1: Characteristics of Women Who Underwent Risk-Reducing Mastectomy (RRM) in New York State and New South Wales, 2004–2014

	<i>New York State (N = 1,808)</i>	<i>New South Wales (N = 487)</i>	<i>p-Value</i>
Age			
Mean (SD)	44.7 (10.3)	44.8 (11.1)	.92
<40	543 (30.0%)	171 (35.1%)	<.01
40–49	724 (40.0%)	152 (31.2%)	
50–59	391 (21.6%)	115 (23.6%)	
60+	150 (8.3%)	49 (10.1%)	
Primary payer			
Public/other	202 (11.2%)	21 (4.3%)	<.01
Private	1,587 (87.8%)	466 (95.7%)	
No cover	19 (1.1%)	0 (0.0%)	
Immediate reconstruction	1,579 (87.3%)	334 (68.6%)	<.01
Type of reconstruction			
Autologous	230 (14.6%)	57 (17.1%)	<.01
Expander	1,004 (63.6%)	172 (51.5%)	
Implant	345 (21.8%)	105 (31.4%)	
Length of stay			
Median (IQR)	2 (1–2)	5 (3–8)	<.01
<24 hours	370 (20.5%)	15 (3.1%)	<.01
1–3 days	1,237 (68.4%)	108 (22.2%)	
4+ days	201 (11.1%)	364 (74.7%)	

IQR, interquartile range.

alternative start point of January 2006, an overall increasing trend in RRM between 2006 and early 2013 was observed in NYS ($p < .01$), despite the slight decrease between 2009 and early 2013 (Figure S2 in Appendix SA2). The difference in number of RRM procedures before and after May 2013 was still prominent in both regions. Falsification tests with reduction mammoplasty and prophylactic oophorectomy cohorts did not demonstrate significant differences in number of procedures before and after May 2013 (Figure S3 in Appendix SA2).

A higher proportion of women undergoing RRM received immediate breast reconstruction in New York State when compared to those in New South Wales (87.3 vs. 68.6 percent, $p < .01$). From 2004 to 2014, there was an increase in use of immediate reconstruction following RRM in NSW (52.7 to 71.4 percent, $p = .02$) (Figure 2A). Among women who had immediate reconstructions, over half received tissue expanders to undergo a delayed-immediate reconstruction in NYS (NYS 68.4 percent) compared to only 22 percent in NSW. Over time, among those who had immediate reconstruction, the

Figure 1: Bimonthly Rates of Risk-Reducing Mastectomy (RRM) among Female Residents of New York State and New South Wales, 2009–2014 [Color figure can be viewed at wileyonlinelibrary.com]

Note. Dots—observed bimonthly procedures per 1 million women, light gray line—interrupted time series analysis with segmented regression, dashed light gray line—expected bimonthly procedures per 1 million women predicted with trends before May 2013. Results only included risk-reducing mastectomy performed for women at risk (familial or genetic) of developing breast cancer. [Color figure can be viewed at wileyonlinelibrary.com]

proportion of women receiving direct-to-implant reconstruction increased in both New York State (8.5–27.3 percent, $p < .01$) and New South Wales (13.8–37.7 percent, $p < .01$) (Figure 2B).

Figure 2: Proportionate Use of (A) Immediate Reconstruction and (B) Direct-to-Implant Reconstruction among Women Who Underwent Risk-Reducing Mastectomy in New York State and New South Wales, 2004–2006, 2007–2010, and 2011–2014 [Color figure can be viewed at wileyonlinelibrary.com]

DISCUSSION

We assessed the use of risk-reducing mastectomy in New York State and New South Wales between 2004 and 2014 and found that there was an overall increasing trend, as well as a significant celebrity effect following Angelina Jolie's announcement and its related media coverage. Along with the increasing rates of RRM procedures, we also found a high frequency of immediate breast reconstruction following surgery which was more often performed in NYS than in NSW. However, the use of immediate reconstruction was growing in NSW over the study period.

There have been studies investigating responses from the general public following Jolie's announcement, revealing its positive association with online breast cancer information searches (Juthe, Zaharchuk, and Wang 2015; Noar et al. 2015; Dean 2016) and health care-seeking behavior (Kosenko, Binder, and Hurley 2016). It has been reported in the United Kingdom, Canada, Australia, and the United States that since Jolie's announcement, there has been an increase in referrals for genetic counseling and testing (Dunlop, Kirk, and Tucker 2014; Evans et al. 2014; Desai and Jena 2016; Raphael et al. 2016; Freedman et al. 2017). In addition, a survey study in Austria demonstrated a substantial effect of media coverage of Jolie's health care choice on awareness of breast cancer surgery and reconstruction options (Lebo et al. 2015).

Most of the existing research evaluated the impact of Jolie's announcement on health care seeking and genetic testing, while only a few studies looked at downstream occurrence of preventive surgery. A U.K. study reported the impact of Jolie's announcement on RRM rates within their network (Evans et al. 2015). However, the external validity of this study, particularly on a global scale, remains unknown. While a recent U.S. study did not find any increase in overall mastectomy procedures after Jolie's media coverage, they did not evaluate the use of preventive surgery and thus it was not informative (Desai and Jena 2016). We found more frequent use of RRM procedures following Jolie's disclosure, advancing the evidence in this area. We believe that the "Jolie effect" on public awareness and health care-seeking behavior has at least partially contributed to the increase in preventive surgeries.

The increase in the number of RRM procedures may also be associated with the high usage of reconstruction surgery and the expansion of implant use as found in our study. Previous studies have demonstrated the impact of breast reconstruction following mastectomy on improving psychological

morbidities (Dean, Chetty, and Forrest 1983; Al-Ghazal, Fallowfield, and Blamey 2000), which may act as an assurance of postsurgical body image maintenance for women seeking prophylactic mastectomy as a preventive measure for breast cancer. This suggests that an increased awareness of reconstructive options might also be an important contributor to the increased rate of RRM surgery.

Our findings documenting the substantial increase in RRM rates following Jolie's announcement, combined with the previous network-wide study from the United Kingdom (Evans et al. 2015), indicate that this is a global phenomenon in English-speaking countries regardless of their health care system and may affect a large group of people. This has important public health implications. First, it highlights the significant impact of celebrity and media coverage on the use of high-risk medical procedures, such as preventive surgery, likely through the impact of increased health care information dissemination on the general public's health care-seeking behavior.

Second, the presence of celebrity effect raises the concern of whether critical medical information has been appropriately interpreted and understood by the general public. A survey study conducted in the United States found that although 75 percent of the respondents were aware of Jolie's bilateral mastectomy, fewer than 10 percent of them had sufficient information to accurately understand Jolie's risk that led to her decision to undergo RRM (Borzekowski et al. 2014). In recent years, there has been a tendency toward choosing more aggressive breast cancer treatment among women, particularly in younger age groups, possibly associated with the fear of cancer-related mortality (Jacob 2016). Similarly, those who do not have cancer but feel that they are at a high risk of developing it might make emotional decisions, especially after wide media coverage of celebrity stories. Access to medical information at the time of news release needs to be ensured to help individuals accurately interpret celebrity news and avoid irrational medical choices due to anxiety and a false interpretation of their risk level.

In light of our findings, further efforts are warranted to make sure that the risks and benefits associated with RRM can be fully comprehended by the average person. In Jolie's case, while the benefits of undergoing RRM were underscored in her disclosure, the related risks were not mentioned. There are a variety of physical and psychological consequences following RRM (Brandberg et al. 2008; Gahm, Wickman, and Brandberg 2010), as well as complications following breast reconstruction and implant use, which in some situations may require additional surgeries (Alderman et al. 2002; Zion et al. 2003; Handel

et al. 2006; Jagsi et al. 2016). It is essential that women are fully aware of the risks associated with surgery and are able to weigh the benefits and harms. For these reasons, the dissemination of medical knowledge and creation of decision aids is highly desirable to help patients in decision making.

There are several limitations to our present study. New South Wales APDC does not provide unique identifiers, and patient history can only be collected with diagnosis codes during index hospitalization. Therefore, RRM case incidence may be overestimated when history of breast cancer was not appropriately coded. However, this was unlikely to have a differential distribution over multiple years, and thus would have a minimal effect on the trend observed. NSW data were only available through June 2014, limiting the length of the study period following Jolie's announcement. The use of two regions' data may not be entirely representative of the two countries. New York State and New South Wales are both highly populated areas with high-volume facilities. Results need to be interpreted in this scope and applied to other areas with caution. In addition, because the two regions do not have consistent definitions for race/ethnicity, we were not able to adjust the trends in procedure rates by population racial composition.

CONCLUSION

Our study within two large states in the United States and Australia found an increasing trend of risk-reducing mastectomy over time, especially after a celebrity announcement of surgery. While the "Jolie effect" has important implications in health care information dissemination, it also highlights the importance of developing accurate medical information and decision aids that can assist patients in health care seeking and decision making. Partnerships between celebrities, media, and public health experts are warranted to ensure appropriate messaging.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the supporting information tab for this article:

Appendix SA1: Author Matrix.

Appendix SA2:

Table S1. Demographics of Residents in New York State and New South Wales.

Table S2. Patient Inclusion and Exclusion.

Table S3. Diagnosis and Procedure Codes Used in the Study.

Table S4. Parameter Estimates, Standard Errors and *p*-Values from Segmented Regression Model Predicting Bi-Monthly Rates of Risk-Reducing Mastectomies among Female Residents in New York State and New South Wales, 2009–2014.

Figure S1. Rates of Risk Reducing Mastectomy Surgeries among Residents of New York State and New South Wales (per 1,000,000 female residents) between 2004 and 2014.

Figure S2. Bimonthly Rates of Risk-Reducing Mastectomy (RRM) among Female Residents of New York State and New South Wales, 2006–2014.

Figure S3. Bimonthly Rates of Reduction Mammoplasty and Bilateral Prophylactic Oophorectomy among Female Residents in (A/C) New York State and (B/D) New South Wales between 2009 and 2014.