

## BREAST DENSITY LEGISLATION: THE VALUABLE ROLE OF NARRATIVES IN A SEXUALIZED DISEASE

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“It is way past time to stop giving women simplistic information. Women deserve to know everything that researchers know, even if it is not clear cut.”<sup>1</sup>

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### INTRODUCTION

During the month of October, it is impossible to avoid breast cancer signage. The use of the media to convey public health messages on the importance of screening to find breast cancer early has increased over the

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1. ANNE S. KASPER & SUSAN J. FERGUSON, BREAST CANCER: SOCIETY SHAPES AN EPIDEMIC, 235 (2000).

past few decades. However, the message on when to begin mammography and how frequently to screen continuously changes.

A woman who has been diagnosed with breast cancer may face each October with anxiety. The constant reminder of the disgusting disease depicted in feminine pink signage may not convey support but rather attention to the disease. Pink, a feminine and pretty color, attempts to mask the ugliness and scariness of the disease. Other women diagnosed may find solidarity in knowing the multitude of people that support her in the fight. Each woman's response to the various ways in which our society seeks to react to the disease may be as different as the types of breast cancer disease itself.

The reality that all women diagnosed face is that once the disease is present in the body, there is no cure. A woman who has: survived through chemotherapy, lumpectomies, mastectomy, radiation, hair loss, and dangerous illnesses as a result of poisoning her body to save her life, may be fortunate to be considered a survivor. This same cured woman might face terrifying news four, seven, or twelve years later that there are tumors forming elsewhere in her body. Cancer is complex. Once cancer is present in the body, the potential for cancer to come back never stops. The difference between remission and cure is not understood by our society. Some women may never experience cancer progression. The point is that an individual woman will experience breast cancer in a variety of ways.

With publicity and awareness created during the month of October, many women will undergo screening of their breast tissue. Breast density notification laws require physicians to notify women who have been found to have dense breast tissue, typically as a result of a mammogram.<sup>2</sup> Dense breast tissue can influence the effectiveness of screening in identifying cancer.<sup>3</sup> Currently, 27 states have adopted the notification laws.<sup>4</sup> There is a federal notification law pending which would set a minimum federal standard for the notification and recommend discussion with doctors on whether additional screening is necessary.<sup>5</sup>

The individual experience at the center of recent breast density legislation involves a woman who went from routine scanning to stage four-breast cancer, without the interim period in which the tumor can be attacked with chemo and cut out with surgery.<sup>6</sup> This terrifying narrative exposed "breast density" and gave reason for concern that mammograms

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2. Christoph I. Lee, Lawrence W. Bassett & Constance D. Lehman, *Breast Density Legislation and Opportunities for Patient-Center Outcomes Research*, 264 *RADIOLOGY* 632, 632 (2012).

3. *Id.*

4. *Legislation and Regulations – What is Required?*, DENSEBREAST-INFO, INC. (August 19, 2016), <http://densebreast-info.org/legislation.aspx>.

5. See S. 370, 114th Cong. § 3 (2015).

6. Nancy Cappello, *Nancy's Story*, ARE YOU DENSE, INC., <http://www.areyoudense.org/stories/nancy/> (last visited October 5, 2016).

might not be beneficial for particular women with denser breast tissue.<sup>7</sup> An indirect effect of this awareness transcends the benefits of mammograms for all women, as the guidelines continue to change.

The narrative at the center of breast density legislation led to the adoption of notification laws in many states. This is premised on the idea that “to withhold a woman’s breast density composition from her is denying her the right to make an informed decision about her breast health,”<sup>8</sup> “[a] screening test tries to find a disease before there are any symptoms. With breast cancer, there is a misconception that if you feel fine, don’t have a lump, and have no family history of breast cancer you’re okay. The truth is that three quarters of the women in whom we find breast cancer have no risk factors. So screening is important for everyone.”<sup>9</sup>

Storytelling policymaking, exemplified by breast density legislation, is crucial for breast cancer, a disease mischaracterized by the media due to gendered discourse and sexualization of the disease. Furthermore, these stories are particularly valuable with screening of breast cancer due to the widespread confusion as a result of changing guidelines and political influence. Although narrative policymaking focuses on individuals, which cannot be extrapolated to the community at large, when the individual experiences of those afflicted with a disease differs from that depicted in the media, expression of individual stories is vital.

Policymaking in the public health sphere requires the consideration of a variety of factors. Recently, evidence-based medicine has gained favor among public health professionals.<sup>10</sup> This approach includes making decisions with best available peer reviewed evidence, using data and information systems systematically, applying program planning frameworks, engaging the community in assessment and decision making, conducting sound evaluation, and disseminating what is learned to key stakeholders and decision makers.<sup>11</sup> A complicating factor includes the value of evidence in the medical field. Factors such as the characteristics of the patient, the patient’s readiness to undergo therapy, and society’s values can interfere with the value of evidence.<sup>12</sup> The political will to implement a particular intervention may exist before there is evidence to support it.<sup>13</sup> This runs right up against the evidence-based approach to

7. *Id.*

8. Nancy M. Cappello, *Decade of ‘Normal’ Mammography Reports – The Happygram*, 10 J. AM. COLL. RADIOLOGY 903, 905 (2013).

9. Susan Greenstein Orel, *Breast Cancer Tests: Screening, Diagnosis, and Monitoring*, BREASTCANCER.ORG (Apr. 14, 2016, 4:51 AM), <http://www.breastcancer.org/symptoms/testing/types>.

10. Ross C. Brownson, Jonathan E. Fielding & B. Christopher M. Maylahn, *Evidence-Based Public Health: A Fundamental Concept for Public Health Practice*, 30 ANN. REV. PUB. HEALTH 175, 176 (2009).

11. *Id.* at 177.

12. *Id.*

13. *Id.* at 188.

medicine. However, breast density legislation is reactionary to an intervention, mammograms, which have been shown to be fallible. Breast density legislation includes uncertainty, confusion, and anecdotal evidence, factors present in any discussion of cancer.

This article argues that the breast density legislation serves a valuable purpose through the expression of fault in current screening practices, in addition to increasing dialogue surrounding this particular uncertainty. Although breast density legislation outpaces scientific certainty surrounding cancer screening, this legislation reveals the support for action that may increase our understanding of cancer and risk, and importantly, the dialogue to the patient regarding cancer and risk. Narrative policymaking, though non-reflective of the community at large, plays an important role in pushing forward concerns of individuals who are experiencing the disease firsthand. Furthermore, those narratives are especially crucial for breast cancer, a disorder that has become an economic market with pink products and events that can distort realities of the disorder.

## I. BACKGROUND

### A. History of Breast Cancer

Descriptions of what was likely breast cancer date back to the Egyptian Pyramid Age (3000-2500 B.C.E.).<sup>14</sup> Historians characterize the history of breast cancer as an ongoing debate as to whether the disease was a systemic phenomenon or a localized process amenable to aggressive surgery.<sup>15</sup> The treatment of breast cancer up until the 1970s involved dissemination of recommendations from the physician to mostly compliant patients.<sup>16</sup> Women with breast cancer were doubly inferior to men at this time, both as patients and females.<sup>17</sup> Gendered assumptions permeated breast cancer literature, including the potential loss of sexuality and the uselessness of breasts in women who would never breastfeed.<sup>18</sup> Open discussion of breast cancer, networks of social support, access to information, and empowered decision-making would have been unimaginable.<sup>19</sup> Eventually, women in the public scene began to publish accounts of their breast cancer experience.<sup>20</sup> Personal narratives

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14. KASPER & FERGUSON, *supra* note 1, at 28.

15. *Id.* at 29.

16. *Id.* at 39-40.

17. *Id.* at 40.

18. *Id.*

19. GAYLE A. SULIK, PINK RIBBON BLUES: HOW BREAST CANCER CULTURE UNDERMINES WOMEN'S HEALTH 28 (2011).

20. KASPER & FERGUSON, *supra* note 1.

encouraged readers to view breast cancer not as a uniform disease but as an illness that varied from woman to woman.<sup>21</sup>

In 1940, approximately one in 24 women who lived to be eighty developed breast cancer.<sup>22</sup> In 1964, that changed to one in twenty.<sup>23</sup> In 2006, one in eight.<sup>24</sup> Breast cancer is now the most common cancer in women.<sup>25</sup> In the United States a woman is diagnosed with breast cancer every three minutes and a woman dies from breast cancer every eleven minutes.<sup>26</sup> Less than five percent of breast cancer patients have a familial risk of cancer due to inherited mutations in BRCA1 or BRCA2 genes.<sup>27</sup> The discovery of the BRCA genes likely contributed to a public misperception and diverted important resources away from environmental causes and prevention.<sup>28</sup>

An estimated \$17.2 billion dollars was spent on breast cancer care in the United States in 2014.<sup>29</sup> If women were to get screening mammograms every year, starting at age 40, it would cost \$10 billion a year.<sup>30</sup> This is in comparison to \$2 billion a year to screen women ages 50-69 every other year, or \$3.5 billion to scan women 50-74 biennially and screening based on personal risk factors for women under 50 and over 74.<sup>31</sup>

### B. History of Screening

There are a variety of screening mechanisms for detecting, treating, and monitoring breast cancer. Screening tests are used before there are signs or symptoms of the breast cancer.<sup>32</sup> Diagnostic tests, including biopsies, are given to individuals suspected of having breast cancer based on symptoms or the results of a screening test.<sup>33</sup> Monitoring tests are used

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21. *Id.* at 35.

22. SABRINA MCCORMICK, NO FAMILY HISTORY: THE ENVIRONMENTAL LINKS TO BREAST CANCER 13 (2009).

23. *Id.*

24. *Id.*

25. SAMUEL S. EPSTEIN, STOP BREAST CANCER BEFORE IT STARTS 19 (2013).

26. MCCORMICK, *supra* note 22, at 12.

27. KASPER & FERGUSON, *supra* note 1, at 250.

28. *Id.*

29. A Snapshot of Breast Cancer, NAT'L CANCER INST., <http://www.cancer.gov/research/progress/snapshots/breast> (last visited Sept. 28, 2016).

30. Cristina O'Donoghue et al., *Aggregate Cost of Mammography Screening in the United States: Comparison of Current Practice and Advocated Guidelines*, 160 ANNALS OF INTERNAL MED. 145, 148 (2014).

31. *Id.*

32. *What is Breast Cancer Screening?*, CTRS. FOR DISEASE CONTROL AND PREVENTION, [http://www.cdc.gov/cancer/breast/basic\\_info/screening.htm](http://www.cdc.gov/cancer/breast/basic_info/screening.htm) (last updated Apr. 19, 2016).

33. *Breast Cancer Tests: Screening, Diagnosis, and Monitoring*, BREASTCANCER.ORG, <http://www.breastcancer.org/symptoms/testing/types> (last updated Apr. 14, 2016).

once breast cancer is diagnosed in order to determine how well therapies are working and for signs of recurrence.<sup>34</sup>

The Centers for Disease Control and Prevention describe three main tests to screen for breast cancer: mammograms, clinical breast exams, and breast self-exams.<sup>35</sup> Where breast self-exams and clinical breast exams have not been found to decrease risk of dying from breast cancer, women are told “regular mammograms lower the risk of dying from breast cancer.”<sup>36</sup> The benefit of mammography is “finding the breast cancer early, [which] reduces the risk of dying from the disease.”<sup>37</sup>

Within mammograms, there are different mechanisms to observe tissue. Digital mammography has generally replaced film.<sup>38</sup> Tomosynthesis, also known as 3D mammography, is another supplemental test that benefits women with dense breasts.<sup>39</sup> Approximately 90 percent of women in a screening round have normal results and are advised to return in 1-2 years and 10 percent are called for additional imaging.<sup>40</sup>

There are screening methods in addition to mammograms used in different circumstances. Breast magnetic resonance imaging (MRI) uses magnets and radio wave instead of x-rays and creates detailed, cross-sectional pictures of the body and more clearly shows abnormal breast tissue.<sup>41</sup> However, breast MRI is only for women who are at high risk for breast cancer.<sup>42</sup> This is because MRI is expensive and more likely to find something that turns out not to be cancer, or a false positive.<sup>43</sup> Another type of screening, breast ultrasound, uses sound waves to show underlying tissue structure.<sup>44</sup> Breast ultrasound is used when breast problems are

34. *Id.*

35. *What is Breast Cancer Screening?*, *supra* note 32.

36. *Id.*

37. *Mammography: Benefits, Risks, What You Need to Know*, BREASTCANCER.ORG, [http://www.breastcancer.org/symptoms/testing/types/mammograms/benefits\\_risks](http://www.breastcancer.org/symptoms/testing/types/mammograms/benefits_risks) (last updated June 14, 2016).

38. Pac. Nw. Evidence-based Practice Ctr., *Screening for Breast Cancer: A Systematic Review to Update the 2009 U.S. Preventive Services Task Force Recommendation*, AHRQ PUBLICATION NO. 14-05201-EF-1, 5 (2015), <https://www.uspreventiveservicestaskforce.org/Home/GetFileByID/1923>.

39. *California Breast Density Law Slow to Have an Impact*, UC DAVIS HEALTH SYS. NEWSROOM (Jan. 28, 2015), <http://www.ucdmc.ucdavis.edu/publish/news/newsroom/9667>.

40. *Screening for Breast Cancer: A Systematic Review to Update the 2009 U.S. Preventive Services Task Force Recommendation*, *supra* note 38.

41. *Mammograms and Other Breast Imaging Tests: Breast MRI (Magnetic Resonance Imaging)*, AM. CANCER SOC'Y, <http://www.cancer.org/healthy/findcancerearly/examandtestdescriptions/mammogramsandotherbreastimagingprocedures/mammograms-and-other-breast-imaging-procedures-breast-m-r-i> (last updated Apr. 25, 2016).

42. *Id.*

43. *Id.*

44. *Mammograms and Other Breast Imaging Tests: Breast MRI (Magnetic Resonance Imaging)*, AM. CANCER SOC'Y,

identified during a mammogram or when a mammogram reveals dense tissue.<sup>45</sup> However, ultrasounds detect fewer tumors than mammograms and therefore are used in conjunction with mammograms.<sup>46</sup>

Breast cancer screening has been influenced politically throughout time. As early as 1985, the ACS admitted that women themselves recognize most breast cancers.<sup>47</sup> Furthermore, women who regularly performed monthly breast self-exams detected their cancers much earlier than those who failed to do so.<sup>48</sup> Despite this, the ACS still claims, “no studies have clearly shown a benefit of using BSE.”<sup>49</sup> The overwhelming majority of breast cancers are unaffected by early detection, either because they are aggressive or slow growing.<sup>50</sup> The benefits of mammography screening were based on international controlled trials, later found improperly randomized. At that point, authors of the study established that there is no justification for screening mammography.<sup>51</sup> This evidence was provided for the public through the National Breast Cancer Coalition in 2001.<sup>52</sup> The National Institutes of Health Consensus Conference did not recommend premenopausal screening, which the NCI but not the ACS agreed with.<sup>53</sup> However, under pressure from Congress, the NCI reversed its decision in favor of premenopausal screening.<sup>54</sup> At this point, with the variety of options and opinions, it is not surprising that the average woman would question the best action to take in order to protect against breast cancer.

### C. Modern Screening Issues

In the United States, certain laws require most health plans, Medicaid, and Medicare to cover early detection services for breast cancer screening.<sup>55</sup> Screening recommendations by the ACS have changed seven

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<http://www.cancer.org/healthy/findcancerearly/examandtestdescriptions/mammogramsandotherbreastimagingprocedures/mammograms-and-other-breast-imaging-procedures-breast-m-r-i> (last updated Apr. 25, 2016).

45. *Mammograms and Other Breast Imaging Tests: Breast Ultrasound*, AM. CANCER Soc’y,

<http://www.cancer.org/healthy/findcancerearly/examandtestdescriptions/mammogramsandotherbreastimagingprocedures/mammograms-and-other-breast-imaging-procedures-breast-ultrasound> (last updated Apr. 25, 2016).

46. *Id.*

47. SAMUEL S. EPSTEIN, *CANCER GATE: HOW TO WIN THE LOSING CANCER WAR*, 45 (Vicente Navarro ed., (2005).

48. *Id.* at 46.

49. *Id.*

50. *Id.* at 44.

51. *Id.*

52. *Id.*

53. EPSTEIN, *supra* note 47.

54. *Id.*

55. *See* WIS. STAT. § 632.895(8)

times since 1980.<sup>56</sup> The second most recent change in the guidelines occurred in October 2015, changing the May 2003 recommendations by eliminating breast self-exam and clinical breast exam.<sup>57</sup> The most recent change in guidelines occurred in October 2016 when the ACS suggested that women at average risk wait until 45 for their first mammogram, and then alternate years starting at age 55.<sup>58</sup>

The United States Preventative Services Task Force (USPSTF) also develops recommendations for clinical preventive services.<sup>59</sup> In 2009, the USPSTF first suggested that women not undergo screening in their 40s.<sup>60</sup> Women were directed to discuss pros and cons of mammography screening with their doctors before deciding whether to initiate screening.<sup>61</sup> This was based on increased evidence that mammograms are imperfect, less useful in younger women, and have drawbacks, including false positives, contributed to the change in guidelines.<sup>62</sup> Individual women's preferences on the balance of screening benefits versus harms are acknowledged when the individual is advised to discuss the matter with their physician.<sup>63</sup>

Critics of mammograms frequently reference false positive results as a screening harm and this influences the recommendations.<sup>64</sup> Despite concern that the negative impacts of false positive mammograms does not justify the few additional breast cancers that routine screening would confer among younger women, a recent study of 1226 women found only a transient impact of a false positive mammogram on anxiety, and no increased long term anxiety.<sup>65</sup> In fact, a woman's intention to use breast cancer screening in the future increased two fold among women who experienced a false positive mammogram.<sup>66</sup>

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56. *History of ACS Recommendations for the Early Detection of Cancer in People Without Symptoms*. American Cancer Society, AM. CANCER SOC'Y, <http://www.cancer.org/healthy/findcancerearly/cancerscreeningguidelines/chronological-history-of-acr-recommendations> (last updated Oct. 20, 2015).

57. *Id.*

58. Adam Chandler, *The Increasingly Confusing Mammogram Guidelines*, THE ATLANTIC, Oct. 20, 2015, <http://www.theatlantic.com/health/archive/2015/10/american-cancer-society-mammogram-guidelines/411538/>.

59. *Recommendations for Primary Care Practice*, U.S. PREVENTIVE SERV. TASK FORCE (Sept. 2016), <https://www.uspreventiveservicestaskforce.org/Page/Name/recommendations>.

60. *Screening for Breast Cancer: A Systematic Review to Update the 2009 U.S. Preventive Services Task Force Recommendation*, *supra* note 38.

61. *Id.*

62. *Id.*

63. *Id.*

64. Anna N. A. Tosteson et al., *Consequences of False-Positive Screening Mammograms*, 174 JAMA INTERNAL MED. 954, 954-955 (2014).

65. *Id.* at 958.

66. *Id.*

The conflicting information surrounding mammogram effectiveness is compounded by breast density. Breast density has been in the spotlight due to legislation mandating disclosure of breast density information.<sup>67</sup> Dense breasts are normal, seen in 40-50% of women undergoing mammography, but dense tissue can mask cancer and affect the sensitivity of film mammography.<sup>68</sup> Dense tissue is comprised of less fat and more fibrous and connective tissue, and thus appears white on a mammogram.<sup>69</sup> Cancer also appears white, which is why the dense tissue can mask the cancer.<sup>70</sup> Dense breasts are more prevalent in young women, athletic women, and women undergoing hormone treatment for menopause.<sup>71</sup> Women's bodies undergo tremendous change throughout potential phases of life including the menstrual cycle, pregnancy, breast-feeding, and menopause.<sup>72</sup> This leads to changes in breasts in each woman, in addition to changes between different women.

Breast cancer is diverse as well, some cancers spread rapidly through the body and appear dramatically different than the ordinary duct cells and may be considered "poorly differentiated."<sup>73</sup> This type of breast cancer is less common than those that contain some similarity to characteristics of normal breast tissue and are considered "moderately differentiated."<sup>74</sup> Breast density is only one of many confusing components to breast cancer screening, and the disease itself, however breast density lies at the center of the breast density legislation movement.

Breast density notification laws, or laws requiring physicians to notify women who have undergone mammography and found to have dense breast tissue, have been put into effect in 27 states.<sup>75</sup> Congress has introduced multiple federal breast density notification laws, most recently

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67. Priscilla J. Slanetz et al., *Breast-Density Legislation - Practical Considerations*, 372 NEW ENG. J. OF MED., 593 (2015).

68. *Id.*

69. Nancy M Cappello, *Resources, ARE YOU DENSE: EXPOSING THE BEST KEPT SECRET* (2015), [http://www.areyoudense.org/files/1814/5236/2405/JAN\\_11\\_2016.two\\_page\\_brochure.pdf](http://www.areyoudense.org/files/1814/5236/2405/JAN_11_2016.two_page_brochure.pdf).

70. *Id.*

71. Sammy Caiola, *UC study urges caution on cancer screenings for women with dense breasts*, THE SACRAMENTO BEE (May 22, 2015, 7:01 PM), <http://www.sacbee.com/news/local/health-and-medicine/healthy-choices/article21749403.html>.

72. David Plotkin, *Good News and Bad News About Breast Cancer*, 277 THE ATLANTIC MONTHLY, June 1996, <http://www.theatlantic.com/past/issues/96jun/cancer/cancer.htm>.

73. *Id.*

74. *Id.*

75. Marijke Vroomen Durning, *Breast Density Notification Laws by State - Interactive Map*, DIAGNOSTICIMAGING (May 26, 2016), <http://www.diagnosticimaging.com/breast-imaging/breast-density-notification-laws-state-interactive-map>.

on February 4, 2015.<sup>76</sup> The Breast Density and Mammography Reporting Act would set a minimum federal standard for notification and would recommend women discuss with their doctors whether additional screening is necessary.<sup>77</sup> Specifically, the patient summary required under the Mammography Quality Standards Act (MQSA) would be required to convey the effect of breast density using language from leading experts and cancer organizations.<sup>78</sup>

Controversy surrounds mandatory breast density legislation. The laws from each state differ on what is required from physicians.<sup>79</sup> Typically, all that is required is that a notice be sent to a woman whose mammogram reveals dense breast tissue.<sup>80</sup> Some states require the notices suggest a women talk with her doctor about additional screening.<sup>81</sup> Others states require health care providers to offer supplemental screening such as an ultrasound, and three states (Connecticut, Illinois, and Indiana) surprisingly require insurers to pay for ultrasound screening if a woman's breast density is above a certain threshold.<sup>82</sup> A fear expressed by doctors is women who receive a letter about breast density give up on mammograms, where mammograms serve as an infrastructure on which supplementary screening is built.<sup>83</sup> Furthermore, there are some cancers that can only be seen on mammograms.<sup>84</sup>

Lawmakers face a tension between what is best for the individual patient compared to the larger population. Policy made based on stories from select patients does not necessarily reflect what is best for the entire community. However, the increased transparency and acknowledgement of shortcoming even in this one component of breast cancer is impressive, largely due to the fact that the amount of uncertainty and confusion within the disease of breast cancer is rampant. When policymakers attempt to influence healthcare, and maximize the health of the community with finite resources, decisions must be made.

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76. *Federal Breast Density Notification Legislation Introduced*, AM. C. OF RADIOLOGY, Feb. 13, 2015, <http://www.acr.org/Advocacy/eNews/Archive/2015/20150213-Issue/20150213-Federal-Breast-Density-Notification-Legislation-Introduced>.

77. *Id.*

78. *Id.*

79. Barbara Feder Ostrov, *You have dense breasts. What does that mean?*, THE WASH. POST (June 1, 2015), [https://www.washingtonpost.com/national/health-science/you-have-dense-breasts-what-does-that-mean/2015/06/01/82f00bb4-fff5-11e4-833c-a2de05b6b2a4\\_story.html](https://www.washingtonpost.com/national/health-science/you-have-dense-breasts-what-does-that-mean/2015/06/01/82f00bb4-fff5-11e4-833c-a2de05b6b2a4_story.html).

80. *Id.*

81. *Id.*

82. *Id.*

83. Leah Small, *Law Would Improve Breast Cancer Detection*, CAP. NEWS SERV. (Feb. 6, 2012), <https://capitalnews.vcu.edu/2012/02/06/law-would-improve-breast-cancer-detection/>.

84. *Id.*

## II. ANALYSIS

*A. The change in medicine since the 1970's has corresponded with increased empowerment of women through grassroots organization with increased narratives from breast cancer patients.*

The history of women taking control of their medical care began with the landmark book on women's health and sexuality, "Our Bodies, Ourselves."<sup>85</sup> The first organized breast cancer support group was Reach to Recovery, in which a volunteer woman would visit women hospitalized with breast cancer and provide a message drafted by the ACS.<sup>86</sup> As a part of Reach to Recovery, women realized they were capable of collecting, understanding, and evaluating medical information.<sup>87</sup> Rose Kushner, diagnosed with breast cancer in 1974, demanded the ACS allow women volunteers in Reach to Recovery to share the long term physical and emotional consequences of mastectomies.<sup>88</sup> Soon, national organizations began to provide support even to those at risk of developing breast cancer and the first, Y-ME, was founded in 1979.<sup>89</sup>

The first organization with a clear political agenda was Breast Cancer Action, which demanded that activism move beyond emotional support and move into the political realm to demand a cure and effective prevention.<sup>90</sup> The founder of Breast Cancer Action suffered from breast cancer, was told she was cured, but was diagnosed several years later with metastatic breast cancer.<sup>91</sup> It would have been impossible for women earlier in our society to use personal experiences to rally support for challenging dialogue surrounding breast cancer such as use of the term "cure."

A challenge within the issue of breast cancer, compared to overall gender equality and women's healthcare (issues of information seeking and physician-patient relations), is how to handle the inherent uncertainty surrounding breast cancer. As women have experienced the uncertainties with a breast cancer diagnoses, small groups have formed to pressure for change in policy. Nancy Cappello was diagnosed with an advanced stage breast cancer though she regularly underwent mammograms for more than a decade.<sup>92</sup> She founded the public charity, "Are You Dense," an organization with the mission "to educate the public about the risks and screening challenges of dense breast tissue and its impact on missed,

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85. KATHRYN S. RATCLIFF, *WOMEN AND HEALTH: POWER, TECHNOLOGY, INEQUALITY, AND CONFLICT IN A GENDERED WORLD* 288 (2002).

86. KASPER & FERGUSON, *supra* note 1, at 326-327.

87. *Id.*

88. *Id.*

89. *Id.*

90. *Id.* at 330.

91. *Id.* at 330-31.

92. Cappello, *supra* note 6.

delayed and advanced stage breast cancer.”<sup>93</sup> The goals of the organization include not only education of the public but also to improve those diagnosed with breast cancer, advocate for changes to public policy and screening guidelines, and to support new and existing research about the causal and screening risks of dense breast tissue along with research on metastatic disease to improve quality of life, survival outcomes, and end death from breast cancer.<sup>94</sup> Although the specific narrative of Nancy Cappello is an experience unique to her, the impact and goals of her organization transcend her personal narrative.

Breast density legislation presents a challenge with different states and medical professionals potentially being required to provide information to patients without complete understanding of the next step to take. However, despite this challenge, breast density legislation provides an opportunity for physicians to provide patients with accurate information on breast density and alternative approaches to breast cancer screening.<sup>95</sup> As patient autonomy grows, and the amount of health information available to patients online increases, people are gaining access to health information at an unprecedented rate.<sup>96</sup> Nearly four out of ten cancer patients seek cancer information on the internet.<sup>97</sup> Furthermore, researchers of colorectal cancer patients found that high levels of information seeking were strongly associated with awareness and treatment using targeted therapies.<sup>98</sup> “These findings emphasize the importance of exploring patient influence on physician prescribing patterns and understanding the impact of information seeking on cancer outcomes.”<sup>99</sup>

With the confusion surrounding breast cancer screening, understanding patient knowledge and perception is vital.<sup>100</sup> The gap in understanding impacts all treatment stages, from preventative scanning to a recurrence diagnosis. For example, in a sample of women diagnosed with breast cancer in Los Angeles and Detroit between December 2001 and

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93. ARE YOU DENSE?, <http://www.areyoudense.org/about>. (last visited Oct. 6, 2016).

94. *Id.*

95. John R. Scheel, *Screening ultrasound as an adjunct to mammography in women with mammographically dense breasts*, 212 AM. J. OBSTETRICS & GYNECOLOGY 9 (2015), [http://www.ajog.org/article/S0002-9378\(14\)00628-0/fulltext](http://www.ajog.org/article/S0002-9378(14)00628-0/fulltext).

96. Press Release, Dana-Farber Cancer Institute, Patient knowledge of health information influences cancer treatment (Feb. 23, 2010), <http://www.dana-farber.org/Newsroom/News-Releases/Patient-knowledge-of-health-information-influences-cancer-treatment.aspx>.

97. *Id.*

98. *Id.*

99. *Id.*

100. Britta L. Anderson & Jay Schulkin, *Physician's Perceptions of Patients Knowledge and Opinions Regarding Breast Cancer: Associations with Patient Education and Physician Numeracy*, 6 J. BREAST CARE 285-88 (2011), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3225213/>.

January 2003, only 16% of women knew that recurrence rates were different for mastectomy and breast conserving surgery and 48% knew that the survival rates were equivalent across treatment.<sup>101</sup> Furthermore, in this case the previous explanations for these statistics, including irrelevance of knowledge to decision-making and lack of access to information were not plausible explanations in the study.<sup>102</sup>

Patient knowledge and comfort in speaking openly with a physician are vital for later stages of cancer treatment. Screening is not recommended to look out for recurrence, where cancer comes back after a period of being in remission (which may be mistaken for being cured).<sup>103</sup> This is because screening after chemotherapy and before recurrence does not increase survival.<sup>104</sup> Patients frequently go into the doctor after symptoms arise that indicate recurrence.<sup>105</sup> “The study emphasizes the importance of patient education regarding the symptoms of recurrence in the interest of a timely diagnosis.”<sup>106</sup> Patients frequently rely on stories from personal experiences. A study on the increase in mastectomies after diagnosis, despite the consensus that “breast conservation treatment is appropriate method for majority of women with early-stage breast cancer,” found that the most valued source of information for patients included stories from personal experiences of family or friends living with cancer.<sup>107</sup>

Despite the power of stories, personal stories can pose a danger to policymaking. For example, a bill in 1993 mandated Massachusetts’

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101. Fagerlin, A. & Lakhani I, et al, *An Informed Decision? Breast Cancer Patients and Their Knowledge About Treatment*, PATIENT EDUCATION AND COUNSELING 303-12 (2006), <https://www.ncbi.nlm.nih.gov/pubmed/16860523>.

102. *Id.*

103. J.L. Khatcheressian, et al., *American Society of Clinical Oncology 2006 Update of the Breast Cancer Follow-Up and Management Guidelines in the Adjuvant Setting*, 24 J. CLINICAL ONCOLOGY 5091 (2006), <http://files.imd.com/medinfo/material/6ff/4ea7c62244ae30018c1c66ff/4ea7c62344ae30018c1c6702.pdf>.

104. *Id.*

105. *Id.*

106. *Id.* at 3.

107. Andrea M. Covelli et al., *‘Taking Control of Cancer’: Understanding Women’s Choice for Mastectomy*, 22 ANNALS SURGICAL ONCOLOGY 383, 383-91 (2015), [http://download.springer.com/static/pdf/118/art%253A10.1245%252Fs10434-014-4033-7.pdf?originUrl=http%3A%2F%2Flink.springer.com%2Farticle%2F10.1245%2Fs10434-014-4033-7&token2=exp=1475788936~acl=%2Fstatic%2Fpdf%2F118%2Fart%25253A10.1245%252Fs10434-014-4033-7.pdf%3ForiginUrl%3Dhttp%253A%252F%252Flink.springer.com%252Farticle%252F10.1245%252Fs10434-014-4033-7\\*~hmac=bdface64ea448667fd15ec3472cbcc969b2964833eed3fe1efadab2b6959f721](http://download.springer.com/static/pdf/118/art%253A10.1245%252Fs10434-014-4033-7.pdf?originUrl=http%3A%2F%2Flink.springer.com%2Farticle%2F10.1245%2Fs10434-014-4033-7&token2=exp=1475788936~acl=%2Fstatic%2Fpdf%2F118%2Fart%25253A10.1245%252Fs10434-014-4033-7.pdf%3ForiginUrl%3Dhttp%253A%252F%252Flink.springer.com%252Farticle%252F10.1245%252Fs10434-014-4033-7*~hmac=bdface64ea448667fd15ec3472cbcc969b2964833eed3fe1efadab2b6959f721).

insurers to pay for bone marrow transplants for breast cancer patients.<sup>108</sup> The hearings consisted of breast cancer victims on one side, arguing that these treatments saved their lives yet the insurance companies refused to pay for the transplants because regardless of the benefits they were too expensive. With this dynamic, the fact that the treatment was causing suffering as well as saving lives did not influence the persuasion for the insurers. In this case and others, “stories can lead us down wasteful and dangerous paths and blind us to uncomfortable truths we would prefer to ignore, like the fact that there yet is no easy cure for breast cancer.”<sup>109</sup> However, storytelling and narrative are crucial to the process of policymaking. Rather than attempt to eliminate the use of narratives in contexts that are prone to confusion and dramatization, a more beneficial approach would be to increase the skill level of citizens and those who work directly with the issues so that everyone becomes intelligent consumers of stories.<sup>110</sup>

Overall, the effect of narratives in breast cancer legislation has been tremendous, as seen by the breast density movement. Breast cancer, with its popularity, has become a way for organizations to become profitable businesses and therefore is a disease most at risk for exploitation.<sup>111</sup> The way that a lived experience as a source of knowledge disrupts the dominant, biomedical knowledge constructions about breast cancer reveals the nuances of the experiences of breast cancer as well as its position within larger social structural relations in society.<sup>112</sup> Because of that, women’s voices and experiences provide a powerful critique and tool for social change.<sup>113</sup>

*B. The stories of women created the breast density legislation and challenged the patient-physician relationship, but not in the way that some feared.*

i. Impacts on the Patient-Physician Relationship

Legislation that serves to provide women with more information, in advance of their doctors’ preparation to provide that information, has the potential to confuse. However, breast density legislation has not led to

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108. J.E. McDonough, *Using and Misusing Anecdote in Policy Making*, 20 HEALTH AFFAIRS 207, 207-2012 (2001), <http://content.healthaffairs.org/content/20/1/207.full.pdf+html>.

109. *Id.*

110. *Id.*

111. Breast Cancer Action, *Stop the Distraction*, THINK BEFORE YOU PINK, <http://thinkbeforeyoupink.org/past-campaigns/stop-the-distraction>. (last visited Oct. 6, 2016).

112. L.K. POTTS, IDEOLOGIES OF BREAST CANCER: FEMINIST PERSPECTIVES 34 (2000) (the biomedical model does not take into account the role of social factors or individual subjectivity and does not consider diagnosis, which affects treatment of the patient, to be the result of a negotiation between doctor and patient).

113. *Id.*

mass confusion as some critics feared, and the goal behind the legislation is to provide further transparency to women who undergo mammography screening. Cancer is confusing. But critics who argue women will be unable to handle this information underestimate the power of informed knowledge.

Rather than focusing on the ability of women to understand a confusing statement in a notification, or the confusion behind a cancer diagnosis or misdiagnosis, attention should be turned to the way in which the medical profession presents information.<sup>114</sup> The role of doctors throughout time has changed, but doctors retain authority over analyzing scans and explaining to the patient treatment opportunities and potential outcomes. The diversity present in breast cancer alone creates a challenge in accomplishing this task.<sup>115</sup> The physical appearance of tumors varies from poorly differentiated to well differentiated, and even in situ, known to be the least severe form.<sup>116</sup> Ductal carcinoma in situ cells are cells that look like cancer but have not spread to surrounding tissue.<sup>117</sup> Although this type of breast cancer is typically non-fatal, DCIS too can occasionally grow fast and become a serious or fatal form of breast cancer.<sup>118</sup> As women are encouraged to obtain routine mammograms, more women with DCIS are undergoing treatment. Whether this treatment is necessary or not is not yet fully understood by physicians.<sup>119</sup>

Another variation that influences the treatment of breast cancer is found in whether the tumors are estrogen or progesterone receptor positive. Those tumors that have estrogen or progesterone receptors tend to grow relatively slowly and can be treated with hormone therapy.<sup>120</sup> The physician is responsible for addressing concerns of a cancer patient from screening into treatment once breast cancer is found. Along the way, multiple interpretations by the physician are required, and each one requires the physician to explain a confusing concept to the patient.

The physician is further tasked with interpreting biopsies and slides to determine the differentiation of the tumors and also the potential responsiveness to hormones.<sup>121</sup> Two different physicians may come to two different conclusions and neither be accused of making a mistake. For

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114. *Id.*

115. *See Types of Breast Cancer*, BREAST CANCER.ORG (AUG. 3, 2016), <http://www.breastcancer.org/symptoms/types>.

116. *Id.*

117. *Breast Cancer*, AM. CANCER SOC'Y 1, 84 (SEPT. 13, 2016), <http://www.cancer.org/acs/groups/cid/documents/webcontent/003090-pdf.pdf>.

118. *Id.* at 84-5.

119. *Treatment for DCIS*, BREASTCANCER.ORG, <http://www.breastcancer.org/symptoms/types/dcis/treatment>. (last visited Oct. 19, 2016).

120. *Hormone Receptor Status*, BREASTCANCER.ORG, [http://www.breastcancer.org/symptoms/diagnosis/hormone\\_status](http://www.breastcancer.org/symptoms/diagnosis/hormone_status) (last visited Oct. 19, 2016).

121. *Id.*

those women diagnosed with triple negative breast cancer, the lack of estrogen or progesterone receptors make the cancer potentially more difficult to treat.<sup>122</sup> Ensuring that the breast cancer is diagnosed accurately can open the door to additional treatments with hormone therapy that slow the growth of the cancer.<sup>123</sup>

Physicians in different geographic regions have responded differently to the mandated reporting of breast density.<sup>124</sup> Questions of effective patient advocacy are further complicated as the needs of the world change with new obligations for medical professionals.<sup>125</sup> There is already the federal requirement under the Federal Mammography Quality Standards Act, that patients be notified through summary letters.<sup>126</sup> New state laws take the process further by requiring statutorily mandated language within patient letters. The American College of Radiology has addressed the new statutes and contributed resources through their website as well as advice provided by the working group of breast radiologists who formed the California Breast Density Information Group.<sup>127</sup> Despite concern that this legislation ran ahead of physician preparedness, physicians' response, including this workgroup, reveal that with the appropriate use of technology and information sharing, physicians are equipped to handle the statutorily required language in the notifications.<sup>128</sup>

The 27 states to pass breast density legislation have also influenced the United States Preventative Task Force, responsible for the creation of mammogram screening recommendations.<sup>129</sup> The most recent recommendations cited to the legislation produced at the state level and worked in analyses of breast density with considerations of the new recommendations.<sup>130</sup> The USPSTF noted that breast cancer cannot be

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122. *Triple Negative Breast Cancer*. NAT'L BREAST CANCER FOUND., <http://www.nationalbreastcancer.org/triple-negative-breast-cancer> (last visited Oct. 19, 2016).

123. *Id.*

124. *ACR Offers Resources to Physicians on Breast Density Notification*, AM. C. OF RADIOLOGY: ADVOC. IN ACTION ENEWS, (Oct. 4, 2013), <http://www.acr.org/Advocacy/eNews/Archive/2013/20131004-Issue/ACR-Offers-Resources-to-Physicians-on-Breast-Density-Notification>.

125. CATHERINE D. DEANGELIS, *PATIENT CARE AND PROFESSIONALISM* 6 (Catherine D. DeAngelis ed., 2014).

126. AM. C. OF RADIOLOGY, <http://www.acr.org/Advocacy/eNews/Archive/2013/20131004-Issue/ACR-Offers-Resources-to-Physicians-on-Breast-Density-Notification>.

127. *Id.*

128. See Jafi A. Lipson, *Frequently Asked Questions About Breast Density, Breast Cancer Risk, and the Breast Density Notification Law in California: A Consensus Document*, CAL. BREAST DENSITY INFO. GROUP, <http://breastdensity.info>.

129. *Supra* note 4.

130. U.S. Preventative Services Task Force, *Screening for Breast Cancer: A Systematic Review to Update the 2009 U.S. Preventive Services Task Force Recommendation*, AHRQ Publication No. 14-05201-EF-1 (2015)

treated as one disease, but rather there are a multitude of factors and points at which options are provided and benefits and harms can be weighed.<sup>131</sup>

## ii. Media Influence on Dialogues

Women are not only encouraged to be skeptical of the efficacy of mammograms but additionally to question the manner in which they may choose to support those with the disease through charities and fundraising initiatives. The differing messages from the media influence women not yet affected, just diagnosed, and even those who have suffered for years. Paradoxically, women are anxious about their chances of developing breast cancer, and too hopeful about current approaches to diagnosis and treating the disease.<sup>132</sup> Thus, women believe that breast cancer is both an epidemic and that it is being cured.<sup>133</sup>

The dramatic attention focused on breast cancer contributes not only to the illusion that there is a cure, or that mammograms can save lives, but also to aspects of the disease that women living with the disease might find disturbing. Breasts have a social and sexual significance. Pictures of bowels are “not going to make the best magazine, and colostomies are hardly the sort of stuff catwalk models are going to get involved in whereas breast cancer is in the media sense and social sense a much more sexy subject.”<sup>134</sup> Breast cancer is unusual among illnesses, and among cancers, because of the specific ways that its bodily site – the female breast – is sexualized in popular representations.<sup>135</sup> Women’s health and breast cancer have received increasing coverage in recent years and breast cancer may be the most visible cancer in press coverage of health.<sup>136</sup>

Breast cancer is a unique disease in that, although more women are dying from cardiovascular disease and lung cancer, the attention brought to breast cancer each October from food labels to professional sports teams is unmatched.<sup>137</sup> With breast cancer, an entire industry of research organizations, charitable agencies, commercial ventures, and advocacy

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<http://www.uspreventiveservicestaskforce.org/Page/Document/draft-evidence-review-screening-for-breast-cancer/breast-cancer-screening1>.

131. *Id.* at 46.

132. Plotkin, *supra* note 72.

133. *Id.*

134. Jenny Kitzinger & Greg Philo, *The role of the media in public and professional understandings of breast cancer* (1999), [https://www.academia.edu/1621783/The\\_role\\_of\\_the\\_media\\_in\\_public\\_and\\_professional\\_understandings\\_of\\_bbreas\\_cancer](https://www.academia.edu/1621783/The_role_of_the_media_in_public_and_professional_understandings_of_bbreas_cancer).

135. *Id.* at 16.

136. *Id.* at 16-17.

137. *See generally* Breast Cancer Action, *supra* note 112; *See also* *Gender matters: Heart disease risk in women*, HARVARD HEALTH PUBLICATIONS, <http://www.health.harvard.edu/heart-health/gender-matters-heart-disease-risk-in-women>. (last visited Sept. 27, 2016) (“...heart disease kills six times as many women [as breast cancer] every year.”).

groups has been born.<sup>138</sup> This unusual attention given to a specific disease, influencing fewer women than other diseases reveals society's obsession with women and sexuality.<sup>139</sup> With so many different sources of information, many with questionable intentions, the benefit of smaller advocacy groups include that individual patients can seek out individuals with stories similar to her own and from individuals who more certainly have deep concerns for the seriousness of the disease.

Information on breast cancer, provided in a piecemeal approach with a focus on awareness messages, suffers from science denialism.<sup>140</sup> "Rather than acknowledging what science has confirmed about breast cancer's complexity and what it has revealed about what is yet unknown, groups like Komen divert public attention to an array of simple solutions."<sup>141</sup> The public simplification of the complex issues including the survival benefits of mammography, the multifaceted causes, and the reality that there are no guaranteed modes of prevention or treatment contribute to confusion among women who do everything they are supposed to do and yet still become breast cancer patients.<sup>142</sup>

Beyond public simplification of the complex issue, people are encouraged to take the approach of getting mammograms, participating in special programs, and purchasing pink consumer goods to contribute towards the cause.<sup>143</sup> Although these actions represent concern, promote solidarity, honor breast cancer survivors, and promote research and services, they obscure the breast cancer survivor's actual experiences.<sup>144</sup> "Metastatic breast cancer continues to strike hundreds of thousands of breast cancer 'survivors' in the U.S., and with bleak prognoses, more of them die each year."<sup>145</sup> This confusion is not unlike the confusion that Nancy Cappello felt when she was immediately diagnosed with advanced breast cancer despite following all recommended screening procedures.<sup>146</sup>

Scientific understanding lies at the heart of the controversy over screening recommendations. The mammography industry is impacted by not only scientific concerns but the political environment. The effect of political influence on the screening recommendations depends upon how science is understood.<sup>147</sup> Some see the scientific process as rational and

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138. *Id.*

139. Jessica S. Holmes, *Save the Tat-Tas, Save Women?*, HUFFINGTON POST (December 19, 2012), [http://www.huffingtonpost.com/jessica-s-holmes/breast-cancer-awareness\\_b\\_1988050.html](http://www.huffingtonpost.com/jessica-s-holmes/breast-cancer-awareness_b_1988050.html)

140. SULIK, *supra* note 19 at lxiv-xv.

141. *Id.*

142. *Id.* at 9.

143. *Id.* at 63.

144. *Id.*

145. *Id.* at xlix.

146. *Supra* note 6.

147. KASPER & FERGUSON, *supra* note 1, at 234.

objective, based on evidence and intendedly divorced from politics.<sup>148</sup> “Others believe that science is inherently political and subject to biases and special interests in the same way as any other human endeavor.”<sup>149</sup> Although the political process integrates multiple points of view, this has been interpreted as a case of science against advocacy.<sup>150</sup> Certainly, physicians should not be forced to take action ahead of scientific knowledge. At the same time, those women who have experienced the extreme cases where mammograms do not work have important narratives to share. The impact of personal stories impressively drove the state legislation on breast density notification, and the narratives carry value when considering dialogue surrounding breast cancer.

There are many urgent breast cancer and public health concerns for women in addition to breast density and the sensitivity of mammograms. Although breast cancer death rates have declined since the 1990’s, and with earlier detection comes earlier opportunity for treatment, there are still 2.5 million women worldwide who are considered breast cancer survivors.<sup>151</sup> More women are living with the disorder, yet it is twice as likely to be diagnosed in American women today as it was sixty years ago.<sup>152</sup> Negative consequences of the increased recent policymaking also include exaggerated risks of breast cancer relative to other threats to women’s health, lack of attention to nonfinancial access barriers to mammography, conflicting messages about mammography screening, and controversy on the role of consumer advocates in the policymaking process.<sup>153</sup> On the other hand, the focus on breast cancer has the potential to benefit other illnesses, particularly reproductive cancers and developmental illnesses linked to the same substances that contribute to the rise in breast cancer.<sup>154</sup>

Another potential negative effect of single-issue policymaking includes fragmentation of women’s health care services by focusing attention on one disease or body part rather than on social conditions or services that promote overall health.<sup>155</sup> For example, one approach to integrating proactive approaches to healthcare might be screening for heart disease and breast cancer at the same time. The success of breast cancer advocacy created a climate in which professionals rallied people affected by diseases to lobby for increased funding. This in turn can lead to increased resources in the short term for popular diseases, however this

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148. *Id.*

149. *Id.*

150. *Id.*

151. A.D.A.M., *Breast Cancer In-Depth Report*, N.Y. TIMES, <http://www.nytimes.com/health/guides/disease/breast-cancer/print.html>. (last visited Oct. 7, 2016).

152. Plotkin, *supra* note 72.

153. KASPER & FERGUSON, *supra* note 1, at 36.

154. MCCORMICK, *supra* note 23, at 6.

155. KASPER & FERGUSON, *supra* note 1, at 238.

approach pits diseases against each other.<sup>156</sup> As a result, certain politically popular diseases might be overfunded without regard for their prevalence, contribution to overall population health, or likelihood of scientific value.<sup>157</sup>

Despite the negative consequences of excessive funding based on popularity of disease, the mandated access to information found in the breast density legislation provides a unique opportunity to confront an inherent uncertainty in a screening procedure that most women experience. However, women are increasingly armed with information, and having the information is not enough.<sup>158</sup> To be effective with information, women need to be able to ask questions of their doctors.<sup>159</sup> This can take hard work and active patients are not the status quo.<sup>160</sup>

*C. Although breast density legislation plays an important role in the local environments where mammogram practice might be routine, federal legislation might be better off focusing on preventative measures and larger public health concerns.*

A better use of federal legislation in the realm of breast cancer would address factors that have been well known, but underemphasized. Although the narrative storytelling plays an important role in drawing attention to specific issues women with breast cancer face, there are other pressing issues surrounding breast cancer that might be better addressed by federal legislation. This includes the number of individuals who are not receiving mammograms in the first place, or individuals whose insurance prevents them from appropriately receiving follow up treatment. Breaking across the uncomfortable, sexualized nature of breast cancer, it is also time we recognize that men also get breast cancer and in fact have a lower breast cancer survival rate than women.<sup>161</sup>

Increased funding of epidemiological or data driven studies might not only lead to improved studies but also shift the focus to prevention.<sup>162</sup> This would challenge the current focus on when and how often to perform mammograms, and turn the conversation to what behaviors and products are placing women at risk in the first place. ACS strategies for mammography remain based on two myths: first, that there has been

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156. *Id.*

157. *Id.*

158. RATCLIFF, *supra* note 85, at 36.

159. *Id.*

160. *Id.*

161. *Men Have Lower Breast Cancer Survival Rate Than Women*, BREASTCANCER.ORG, <http://www.breastcancer.org/research-news/20120517> (May 17, 2012, 12:00 AM) (“Survival in the 5 years after diagnosis was: 74% for men and 83% for women.”).

162. KASPER & FERGUSON, *supra* note 1, at 253; *see also id.* at 253, 262 (“Epidemiological studies do attempt to consider or at least control for social, psychological, economic, and environmental factors... that might provide results to make consensus possible [on screening effectiveness].”).

dramatic progress in the treatment and cure for cancer, and second, that any increase in the incidence and mortality of cancer is due to aging of the population and smoking, while denying any significant role for involuntary exposures to industrial and other carcinogens.<sup>163</sup> The excessive attention breast cancer receives makes the disease a popular platform from which broader goals that impact all cancers could be addressed.

One way in which a federal breast cancer bill might prove more beneficial would be within the realm of breast cancer prevention and providing educational or awareness campaigns that address how to best present the scientific uncertainty inherent within cancer screening, and important to the widely publicized breast cancer campaigns, to the public. This would be an ambitious task, as the uncertainty within estrogen exposure, chemical exposure, and diet lead to the complication faced when analyzing potential sources. Furthermore, these interests are shared with large corporations and pharmaceutical companies. "However, a serious concern with prevention would focus our attention on a variety of environmental causes of cancer."<sup>164</sup> The main focus on the cause of breast cancer has centered on genetic causes.<sup>165</sup> Meanwhile, women are subject to conflicting messages from the media that confuse women without breast cancer, and likely offend those with it who may dig deeper into some of the campaigns.<sup>166</sup> The term "cure" has the potential to mislead women who receive the news that their breast cancer has returned after years of no news after successful treatment.

The rise in incidence of breast cancer can be explained in part by women being less likely to die young in childbirth, or of infectious disease, combined with an increase number of women in the at risk age group caused by the Baby Boom, and the growing use of mammography which allows doctors to catch cancer earlier.<sup>167</sup> However, this does not explain the entire increase, as without those factors, the chance that a woman will have breast cancer has grown steadily at one percent per year.<sup>168</sup> The age of first menstruation has gone from late teens to twelve, women have fewer pregnancies, shorter nursing times, and later menopause.<sup>169</sup> This results in the exposure of women, particularly in industrialized nations, to reproductive hormones over a much longer period than their ancestors.<sup>170</sup> The hormones at issue, estrogen and progesterone, effect the

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163. EPSTEIN, *supra* note 25, at 19.

164. RATCLIFF, *supra* note 86, at 106.

165. *Id.* at 107.

166. Plotkin, *supra* note 72.

167. *Id.*

168. *Id.*

169. *Id.*

170. *Id.*

multiplication of cells in the breast.<sup>171</sup> Just by chance, this increased cell replication increases the likelihood of genetic accidents.<sup>172</sup>

It has been accepted by many scientists that more estrogen leads to a higher risk of breast cancer.<sup>173</sup> But as early as October 1997, a variety of known and avoidable risk factors for breast cancer included: prolonged use of oral contraceptives and estrogen replacement therapy, high fat animal and dairy products that are heavily contaminated with chlorinated pesticides (that are estrogenic), exposure to petrochemical carcinogens in the workplace, carcinogenic chemicals from hazardous waste sites, exposure to indoor air pollutants, prolonged use of darker hair dyes, heavy smoking and drinking beginning in adolescence, and inactivity and obesity.<sup>174</sup> In addition to these factors, exposure to estrogen is suspected to be behind a variety of illnesses that affect both women and men.<sup>175</sup>

A significant barrier to addressing the potential causes of breast cancer and other illnesses is created by the new desirability of evidence-based medicine.<sup>176</sup> Although on average Americans are exposed to chemicals on a level never before seen, there is still difficulty proving exact causation between chemicals and the effect on humans.<sup>177</sup> This is based on the fact that it is nearly impossible to determine who has been exposed to exactly what combination of chemicals and hormones.<sup>178</sup> Uncertainty will always be a part of the discussion.

### III. CONCLUSION

Narrative policymaking has benefits and drawbacks. The attention received by proponents of the breast density legislation has increased awareness on one specific, problematic component of current screening practices for breast cancer. The legislation itself is not as dangerous or misleading as some stakeholders expressed. As seen in California, there are databases and committees whose tasks include best dissemination of mammogram results, breast density being one of many components that require explanation to the patient.

Breast cancer remains the most discussed type of cancer, and as more people live with the disease, more people are influenced by the way dialogue on the disease is expressed. More women are provided opportunities to survive this disease, but not all women do. The

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171. *Id.*

172. Plotkin, *supra* note 72.

173. McCORMICK, *supra* note 22.

174. EPSTEIN, *supra* note 25, at 25-26.

175. *Cf. The Effect of Environmental Estrogens on Men's Health*, <http://enhs.umn.edu/current/5200/estrogen/men.html>. (last visited Oct. 8, 2016); *Woman's Health and Estrogen Endocrine Disruptors*, <http://enhs.umn.edu/current/5200/estrogen/women.html>. (last visited Oct. 8, 2016).

176. *Supra* note 11.

177. McCORMICK, *supra* note 22, at 81.

178. *Id.*

differences between women and the challenge to address the most people in the most cost effective way creates a challenge for physicians, particularly as they may be required to take action that they are uncertain of, seen with breast density legislation. A more productive use of lawmakers' time and efforts might be put towards prevention of breast cancer, and the means required by researchers to pursue that path. This would positively impact all women and additionally men.

Despite the stronger need for a different type of federal legislation, the narrative policymaking that brought the breast density issue to the front of some lawmakers' agendas will continue to play a crucial role in bringing the perspective of the individual patient into the spotlight. This will remain important in order to identify failures in the current system that dramatically impact even one individual. Furthermore, the obsession our society has over women's breasts, and the spur of advocacy slogans with odd phrases such as "ta tas" is not all bad if that attention can be focused into preventing the disease in the first place. Having the narratives of women who have battled and continue to courageously battle the disgusting disease will help to remind the rest of us that it is not pretty and feminine and should not be something that anyone profits from.