

1-1-2013

A Public Health Education Initiative for Women With a Family History of Breast/Ovarian Cancer: Why Did it Take Angelina Jolie?

Jeff Nisker

Schulich School of Medicine & Dentistry, jeff.nisker@lhsc.on.ca

Follow this and additional works at: <https://ir.lib.uwo.ca/paedpub>

Citation of this paper:

Nisker, Jeff, "A Public Health Education Initiative for Women With a Family History of Breast/Ovarian Cancer: Why Did it Take Angelina Jolie?" (2013). *Paediatrics Publications*. 1496.

<https://ir.lib.uwo.ca/paedpub/1496>

A Public Health Education Initiative for Women With a Family History of Breast/Ovarian Cancer: Why Did it Take Angelina Jolie?

Jeff Nisker, MD, PhD, FRCSC, FCAHS

Department of Obstetrics and Gynaecology, Schulich School of Medicine and Dentistry, Western University, London ON

I choose not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer.

Angelina Jolie
New York Times
May 14, 2013

Angelina Jolie, whose mother died of ovarian cancer at age 56, has provided the public health education for Canadian women at hereditary risk of developing breast/ovarian cancer that Health Canada and non-governmental health organizations have failed to achieve for 20 years. Empirical evidence supporting the impact of Angelina Jolie's personal narrative on decreasing the number of deaths from hereditary early-onset breast cancer and ovarian cancer in Canada is years away, and will require engaging women about how they learned about the relationship between their family history and risk. However, the impact has already been seen in the tripling of referrals per week to our cancer genetics counselling unit and a dramatic increase in phone enquiries regarding referrals, many from family physicians who have not previously referred (Karen Panabaker, personal communication, June 14, 2013). Without Angelina Jolie's story, how many of these now-referred women would have developed advanced-stage breast cancer without appreciating that their family history put them at high risk and qualified them for MRI surveillance (that could have detected breast cancer in stage I and improved their survival rate by 70%¹), as well as genetic counselling, testing, and preventive strategies? Why is Angelina Jolie's public health education initiative the first large scale public health initiative to occur in Canada?

Thirty-six years before Angelina Jolie's story appeared, I was a resident, called to the office of a consultant, who

apologetically told me that Miriam (pseudonym), a 45-year-old woman, was being admitted for bilateral salpingo-oophorectomy because of her morbid fear that she would develop ovarian cancer like her mother and a cousin. A few hours later, I was paged by the clinical clerk who was admitting Miriam. He was terrified, and asked me to come to the ward to examine her. He introduced me to Miriam, who told me her story. When I repeated the breast examination, it was clear that Miriam would not die of ovarian cancer; she would die of breast cancer.²

Twenty years before Angelina Jolie's public health education initiative, I was boarding an aircraft filled with SOGC members going to the Annual Clinical Meeting. A gynaecologic oncologist, with whom I had discussed Miriam's story many times, excitedly handed me a photocopy of an article. "You've got to read this and we'll talk as soon as the seat belt sign goes off." An author of the paper was Canadian researcher and clinician Dr Steven Narod, who with co-investigators was instrumental in cloning the BRCA 1 gene mutation and establishing the relationship between BRCA gene mutations and breast and ovarian cancer.³

Fifteen years before Angelina Jolie's public health education initiative, the SOGC helped me bring Miriam's story, woven together with stories of Canadian women at high familial risk of breast/ovarian cancer and denied access to genetic counselling and testing, to clinicians and the general public as an educational initiative. "Sarah's Daughters"² was initially staged at an SOGC Annual Clinical Meeting and at Regional Meetings, and then produced by Genome Canada for public education in 10 Canadian cities from 2001 to 2003. The resulting research indicated that many Canadian

women at strong familial risk and many Canadian family physicians still had not heard of BRCA gene mutations.⁴ However, this theatre-based public and clinician education initiative (even with significant attention from the arts and culture media) provided information only to Canadian women and clinicians who were attracted to the theatre, conferences and arts and culture media. Also in 2003, family physician June Carroll and her co-investigators⁵ wrote: “. . . it is vital to help FPs attempting to integrate genetics into their practices by addressing their concerns, enhancing their communication skills, and developing appropriate educational tools. . . .”

Six years before Angelina Jolie’s public health education initiative, I pleaded in the pages of this journal for a national public education initiative, because responsibility for providing information to a woman about her hereditary breast/ovarian cancer risk should not rest solely with her family physician (if she is fortunate enough to have one).⁶ In 2010, Miller and co-investigators⁷ reported that Canadian primary care “providers lacked the requisite knowledge or that seemingly knowledgeable providers lacked time” to discuss genetic testing with their patients. Others had previously reported that time constraints diminish the ability of many family physicians to update their knowledge of genetics,⁸ as well as limiting their ability to take detailed and updated family histories.^{8–10}

Angelina Jolie tells us that she had been provided the information that she had an 87% risk of breast cancer and a 50% risk of ovarian cancer. This type of risk precision is possible only in women who test positive for BRCA gene mutations. In many cases the gene carried by women with families that have a strong history of breast/ovarian cancer will be different from the BRCA gene mutations currently known.¹¹ A public health education initiative would empower all Canadian women at familial risk of breast/ovarian cancer to access personal risk information, and to make choices for MRI surveillance, genetic counselling, testing, or preventive strategies.

Although the SOGC, the Canadian College of Family Practice, June Carroll, and Ellen Warner, and Ruth Heisey in a 2012 *Canadian Medical Association Journal* “primer,”¹² and previous articles have continued to prompt family physicians to take updated family histories and refer women at hereditary risk, and although websites such as that of the Ontario Ministry of Health and Long Term Care include information on hereditary breast/ovarian cancer and opportunities for MRI surveillance, clinicians must read their educational material, and women must have a certain level of education, technical ability, and concern to seek out websites.

In a justice-based democracy emphasizing personal empowerment, and a universal health system emphasizing health promotion, Canadian health policy makers ought to accept the imperative of public education so that women at hereditary high risk of breast/ovarian cancer can be empowered with the knowledge to promote their own health. For example, funding for public education was readily available for the HPV vaccine initially rolled out to prevent 350 cervical cancer deaths per year in Canada. As I have previously argued, the public health promotion money spent to prevent 350 cervical cancer deaths could have empowered the prevention of tens of thousands of deaths of women at hereditary risk of breast/ovarian cancer each year.¹³ Further, considerable funding has promoted mammography screening, including for young women, a strategy ineffective in preventing deaths in women less than 50 years of age.¹⁴ Political lobbying appears to be a more important factor in public health education initiatives than clinical common sense.

Let us build upon Angelina Jolie’s public health education initiative, so that no Canadian woman will ever develop hereditary breast/ovarian cancer without prior understanding of her individual risk and opportunities for MRI surveillance, genetic counselling, and preventative strategies.

I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices.

Angelina Jolie
New York Times
May 14, 2013

REFERENCES

1. Warner E, Hill K, Causer P, Plewes D, Jong R, Yaffe M, et al. Prospective study of breast cancer incidence in women with a BRCA1 or BRCA2 mutation under surveillance with and without magnetic resonance imaging. *J Clin Oncol* 2011;29(13):1664–9.
2. Nisker J. From calcedonies to orchids: plays promoting humanity in health policy. Toronto: Iguana Press; 2012.
3. Miki Y, Swensen J, Shattuck-Eidens D, Futreal PA, Harshman K, Tavtigian S, et al. A strong candidate for the breast and ovarian cancer susceptibility gene BRCA1. *Science* 1994;266(5182):66–71.
4. Nisker J, Martin DK, Bluhm R, Daar AS. Theatre as a public engagement tool for health-policy development. *Health Policy* 2006;78(2–3):258–71.
5. Carroll JC, Brown JB, Blaine S, Glendon G, Pugh P, Medved W. Genetic susceptibility to cancer. Family physicians’ experience. *Can Fam Physician* 2003;49:45–52.

6. Nisker JA. The need for public education: "Surveillance and risk reduction strategies" for women at risk for carrying BRCA gene mutations. *J Obstet Gynaecol Can* 2007;29(6):510–1.
7. Miller FA, Carroll JC, Wilson BJ, Bytautas JP, Allanson J, Cappelli M, et al. The primary care physician role in cancer genetics: a qualitative study of patient experience. *Fam Pract* 2010;27(5):563–9.
8. Vanstone M, Chow W, Lester L, Ainsworth P, Nisker J, Brackstone M. Recognizing BRCA gene mutation risk subsequent to breast cancer diagnosis in southwestern Ontario. *Can Fam Physician* 2012;58(5):e258–e266.
9. Carroll JC, Blaine S, Ashbury FD. Family physicians and genetic medicine: roles and challenges. In: Knoppers B, Scriver C, eds. *Genomics, health, and society: emerging issues for public policy*. Policy Research Institutes; 2006:67–82.
10. Rich EC, Burke W, Heaton CJ, Haga S, Pinsky L, Short MP, et al. Reconsidering the family history in primary care. *J Gen Intern Med* 2004;19(3):273–80.
11. Metcalfe KA, Finch A, Poll A, Horsman D, Kim-Sing C, Scott J, et al. Breast cancer risks in women with a family history of breast or ovarian cancer who have tested negative for a BRCA1 or BRCA2 mutation. *Br J Cancer* 2009;100(2):421–5.
12. Warner E, Heisey R, Carroll JC. Applying the 2011 Canadian guidelines for breast cancer screening in practice. *CMAJ* 2012;184(16):1803–7.
13. Nisker J. Vaccination against human papillomavirus. *CMAJ* 2007;177(12):1526–7.
14. Miller AB. What is the role of early detection and screening in cancer control? *J Public Health Policy* 1993;14(4):403–12.

ERRATUM

Lauren Riggin, Zipora Frankel, Myla Moretti, Anna Pupco, Gideon Koren. The fetal safety of fluoxetine: a systematic review and meta-analysis. *J Obstet Gynaecol Can* 2013;35(4)362–369.

It has come to our attention that the first author was listed as "Lauren Riggin, MSc" instead of "Lauren Riggin, BMSc." We regret the error and any distress or confusion it may have caused.