

Angelina's choice

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Abstract

This is an opinion piece on how a celebrity's personal choice to undergo prophylactic mastectomy on discovery of an aberrant gene, when publicly promoted, carries in itself the power to influence and impact healthcare trends and decisions. When celebrities advocate causes that are universally and uniformly acceptable and indisputable as the best in the realm of healthcare and cure (e.g. no smoking), it creates well-being and awareness in society at large. But those which are personal choices made out of a repertoire of other available and effective options may, because of celebrity preference, don the mantle of a norm. They thus run the danger of being blindly replicated by others without proper awareness and knowledge of the true potential of disease, risk factors, and other existing remedial or risk-reducing measures. Society should thus be encouraged to question, debate, and understand the validity, authenticity, and reason of the choices, especially those with a medical basis. This tempering of information with intelligence and rationale and making informed choices based on facts will serve humanity as a whole.

Key words: BRCA mutation, Breast cancer, BRCA mutation, prophylactic mastectomy

A friend of mine had taken an intelligent jibe at the news of Angelina undergoing a double mastectomy:

"To remove both breasts in anticipation of cancer is like killing oneself ahead of an unforeseeable accident. Mad! You can't foretell the future so how can you kill it before it happens? It would be really funny if after removing her breasts and ovaries, she dies of a heart attack!"

"That's morbid," I reacted. "Not the act as much as the person," she retorted back.

Angelina Jolie MORBID? Unreal – she has little reason to be so. A highly acclaimed international celebrity, an icon of beauty, power, and charisma, happily married, mother to a wholesome brood – this woman walks the red carpet in every sphere of her life. Furthermore, in capacity of being "Ms Jolie," she is privy to the most advanced, top of the line medical care and advice. She definitely will not be guided to make a medically unsafe or unsound choice – or encouraged to give in to an apparent morbidity on a shadowy threat. In the past too, the medical fraternity has ably aided her in her surgical choices when she decided to go under the scalpel in a quest to restructure or structure her body (breasts, lips, and nose are common public knowledge).

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In the realm of personal choices then, Ms Jolie, like any of us, is well within all justifiable rights in making or taking any decision. For the same, she is neither responsible nor accountable. However, when she chooses to validate a personal choice, she stands to be questioned – lest anyone buying into those claims decides to replicate her very individual choice and becomes vulnerable to not so perfect, even perilous, outcomes.

Angelina defends her decision as fueled by a need for being cancer free and staying alive for her kids. Kudos to her intention, most human beings would ascribe to the same sentiment. Furthermore, her reasons to go public as elucidated in "My Medical Choice" are: "I am writing about it because I hope that other women can benefit from my experience. Cancer is a word that strikes fear into people's hearts producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are susceptible to breast and ovarian cancer and take action." The media applauds her testimony and assigns her medallions of bravery and heroism.

So does Angelina's decision fulfill her goals?

Does it ensure a cancer-free life?

Does it promise longevity?

Is taking action for ovarian and breast cancer tantamount to hacking those organs?

Do all risky genes convert to cancer?

Are most at risk for having the pesky gene in the first place?

Does being diagnosed with breast cancer mean the end of life?

Is preventive mastectomy a safe and convenient procedure? Can it be universally recommended and uniformly followed? More importantly, is it the only

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alternative after discovering an aberrant gene?

Medical facts enlighten the following:

Mastectomy is not a foolproof option of eliminating the potential of being cancer free.

Secondly, there are other less drastic measures available in the advent of discovering a positive *BRCA1* and/or *BRCA2* genes, increased surveillance (regular checkups) being one of them. Others may choose estrogen-inhibiting medication which may cut the risk by half. Still some may even choose to get their ovaries removed over their breasts.

Double mastectomy is a highly specialized complex procedure involving extensive reconstruction which may be spread over months. This comes with its inherent complications of pain, infections, and changes in skin sensations. Added to this, it is irreversible. It is also very expensive and results of reconstruction vary. Angelina's "perfect breasts after mastectomy" may not be the prized possession of all.

More importantly, a negative gene test may be false negative and there could still be some other unidentified non-specific genes existent which may develop into cancer over time.

Only 1% of women are known to test positive for mutations of *BRCA1* and *BRCA2*, which signals elevated risks of breast cancer, not breast cancer itself. If these women develop breast cancer some time in their lives, it can be successfully treated with less radical treatments.

It is clearly indicated from the medical space that preventive mastectomy is not the first line of defense and certainly not the only course of action available. One also cannot take recourse in the fact that it can fully eliminate the probability of the disease.

Lastly, no individual can be completely insulated against death or disease and be ensured/insured of health and longevity.

Given the facts, figures, and discrepancies, Angelina's reason for her decision seems to fall short of coming from a purely medical standpoint. The probable reasons why she took this choice over others available finds its way to an emotional and psychological basis and bias. Women like her who chose preventive mastectomy are the ones who are unable to deal with and overcome their fear of being diagnosed with cancer. Regrettably though, even after taking such a drastic measure, they cannot be medically assured of being cancer free for life. It may even lull some into a false sense of security of never contracting cancer, in lieu of which they may play truant with the absolutely necessary periodic medical checkups. I would shudder to imagine the plight of those who, after undergoing preventive mastectomies, would face a cancer diagnosis – and there is documented evidence (albeit small) of the same. Frankly, if one needs to live with that unreliability, even after a drastic

preventive measure, then why is it so difficult to live under a potential uncertainty, without putting your physical being through stress?

At the end of the day, it is really about how effectively we are able to handle the fear of the unknown and overcome the insecurities and anxieties which float around the same. That is true empowerment.

Bravery and heroism need not only be derivatives of aggressive Lara Croft actions. They can even be attributes of a strong being, one who chooses to live without fear of the unknown, in the acceptance and joy of the "now." There is no conquest greater than the conquest of self.

Melissa Etheridge, who is a cancer survivor, has the same *BRCA* gene mutation as Jolie. On being asked to comment on Angelina's decision, she stated, "*I have to say I feel a little differently. I have that gene mutation too and it's (preventive mastectomy) not something I would believe in for myself. I wouldn't call it the brave choice. I actually think it's the most fearful choice you can make when confronting anything with cancer. My belief is that cancer comes from inside you and so much of it has to do with the environment of your body. It's the stress that will turn that gene on or not. Plenty of people have the gene mutation and everything, but it never comes to cancer; so I would say to anybody faced with that, that choice is way down the line on the spectrum of what you can do and to really consider the advancements we've made in things like nutrition and stress levels. I've been cancer free for nine years now, and looking back, I completely understand why I got cancer. There was so much acidity in everything. I really encourage people to go a lot longer and further before coming to that conclusion.*" (Washington Blade).

To my mind, this is a true reflection of active faith, belief, and positivity. Instead of giving into fear, she sends out a succinct message, "de-stress – don't distress."

Celebrity role models often cast influence on a lot of decisions including medical ones. When they promote and uphold causes like survivorship on the basis of their personal experiences, of which Michael Douglas, Lisa Ray, Manisha Koirala and Kylie Minogue are examples, they serve as beacons of strength and hope. "If these icons can survive and thrive, so can we" is the positive note which balms many a troubled heart. This encourages and inspires those who may be facing similar situations.

Caution, however, needs to be exercised on pushing issues which may promote fear and confusion, which in turn may lead to an unfounded eagerness to adopt medical practices for unwarranted situations. Care must be taken that a unique choice made by an equally unique individual is not propagated as a definite solution and becomes a norm. One person's medicine,

if not understood or weighed properly on its impact and efficacy, may well turn out to be another's poison.

Awareness and treatment should not be exchanged for over-awareness and over-treatment.

DISCLAIMER: This is purely an opinion piece and is

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Indian Cancer Congress 2013
21st to 24th November 2013
Kempinsky Ambience Hotel, New Delhi, India
alongwith

35th Annual Conference of Association of Radiation Oncologists of India (AROI)
27th Annual Conference of Indian Association of Surgical Oncology (IASO)
18th Conference of Indian Society of Medical & Pediatric Oncology (ISMPO)
15th Biennial Conference of Indian Society of Oncology (ISO)
Oncology Forum and 25 other organizations