External Breast Prostheses: Misinformation and False Beliefs

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Abstract and Introduction

This article discusses common myths associated with the use of external breast prostheses and the impact this misinformation may have on the quality of life of women after mastectomy. A review of the literature reveals that very little research has been conducted on this subject. The majority of information on breast prostheses is provided by the manufacturers and tacitly accepted by healthcare providers and the media in general. Claims regarding the medical necessity of a weighted prosthesis and the suitability of gel fillings are examined and found wanting. Widespread acceptance of these myths may be preventing women from pursuing healthy lifestyle options and restricting the development of more suitable prosthetic products. The article concludes that a rigorous, evidence-based approach to the evaluation of external breast prostheses would enhance both the development of this noninvasive and cost-effective sector of post-mastectomy care, as well as the adjustment, well being and quality of life of breast cancer survivors.

False beliefs and myths exist in the practice of medicine, extending as well to the treatment of breast cancer.[1-3] Over time, misconceptions should be subjected to critical evaluation so misinformation can be corrected. This article discusses misinformation associated with the use of external breast prostheses and the impact this misinformation may be having on the quality of life of women after mastectomy.

With the diagnosis of breast cancer, a woman must make many decisions regarding the treatment she will receive. Even if she chooses to defer the decision making to medical practitioners or other authority figures, she cannot escape the necessity of taking actions that will determine her course of treatment and her quality of life afterwards. The need to give consent to treatment requires adequate access to information upon which to make an informed decision. The process of arriving at decisions will be influenced by many factors, including the woman's personality, her use of coping mechanisms, and, importantly, the attitude of the medical team and their attitude toward her choices.[4-8]

The Internet has facilitated the search for information on which to base such life-altering decisions.[9] A woman with high information needs can find detailed information concerning her surgical reconstruction options through a variety of sources -- for example, the Web site for the US Food and Drug Administration. Such Web sites clearly outline the risks involved with surgical reconstruction either by implantation or with autologous tissue. It has been noted that women who are well informed adjust better to their treatment outcomes, and a well-informed person is more likely to engage in discussions with her surgeon about her treatment options.[10]

Having a mastectomy, however, leads to a tier of decision making regarding whether to have surgical reconstruction, wear an external breast prosthesis, or not wear anything at all to replace the amputated breast. Almost nothing is known about women who decide not to have surgical reconstruction and not wear a prosthesis, and little research has been done regarding external breast prostheses and their influence on a woman's quality of life after mastectomy.[11] "It is estimated that up to 90% of women who have had a mastectomy use breast prostheses. At present little is known about how women access information about breast prostheses.... their patterns of prosthesis use, satisfaction levels, and how the prosthesis impacts on their quality of life."[12]

The majority of information on breast prostheses is provided by the manufacturers. Women are often referred to "certified fitters" to answer their questions regarding external breast prostheses. Certified fitters are retail staff that breast prosthesis manufacturers have trained to fit and sell their products. Some, however, may not have adequate education in healthcare or oncology. "However well-intentioned fitters may be, they may not have the necessary training to adequately deal with the psychological and emotional issues many women experience."[12 ,13]

Women may not know the attitudes their primary care givers have towards external breast prostheses. Women may not be able to gather adequate information regarding external breast prostheses in an unbiased manner either from the manufactures, retailers, or their healthcare providers, in order to make an informed decision regarding their cancer care. Although the majority of women who have a mastectomy will go on to wear an external breast prosthesis,[14, 15] it is an area of a woman's post mastectomy treatment that has the least amount of objective information available to her and that has been subject to the least amount of scientific inquiry.[11]

External breast prosthesis manufacturers claim they have studied the weight and movement of breast tissue and that they can provide women with what they need.[16] Some reference books on breast care, written for the lay public, mirror this optimism and tell women that, "....there is a good prosthesis for every woman who has had a mastectomy."[17] Yet studies show that when researchers ask specific questions of women who wear a breast prosthesis, there is a list of complaints.

Objective and open discussion of the complications arising from surgical reconstruction provides an impetus for further research and improvement in surgical outcomes. This type of objective measurement and critique of practice does not occur in the breast prosthetic industry. One could argue that this is not necessary, because wearing an external breast prosthesis is not invasive and does not have the same attendant health risks associated with autologous tissue reconstruction or prosthesis implantation and therefore does not merit the same scrutiny. However, surgical articles state that the most common reason for choosing reconstruction is to not wear the external prosthesis.[18] Given the continuum of choices a woman must navigate throughout her cancer treatment, one could argue that there is a hypothetical link between her dissatisfaction with external breast prostheses and the physical consequences she encounters with surgical reconstruction -- if she chooses to have the surgery out of dissatisfaction with her external breast prosthesis. Therefore, the lack of evidence-based information concerning external breast prostheses, and the problems arising from wearing a prosthesis, may well have more of an impact on women's health than believed at first glance.

Over 30% of women are dissatisfied with their external breast prosthesis.[12] Journal articles note that many women find breast prostheses to be hot and heavy, to limit a woman's choice in clothing, and to become displaced with movement.[18-21] Many women wear the prosthesis only when they are outside the home, and many continue to wear the lightweight foam shells, meant to serve as a temporary prosthesis, many years after their mastectomy.[22] In addition to the physical discomfort associated with wearing a prosthesis, a gel-filled prosthesis may emit a noise when struck.[23] Many gel-filled prostheses are designed with a hollow cavity in the back to decrease the weight and minimize contact with the uneven contours of the chest wall. Suction can form when the prosthesis is pressed against the chest by the bra. When this suction is broken with physical activity, a sound can be created. Adhesive-retained prostheses attempt to mitigate the creation of noise in prostheses.[20]

Because information on external breast prostheses is largely presented to women by the manufacturers and vendors of these prostheses, it is understandable that they may overstate the virtues of their product and not refer to difficulties that some women experience with them. Additionally, some of the Web sites that women access for general information on breast cancer and its treatment are, in fact, maintained by external breast prosthesis manufacturers. It stands to reason, therefore, that misinformation and false beliefs regarding external breast prostheses are reinforced and perpetuated.

The National Cancer Institute (NCI) estimates that about 1 in 8 women in the United States (approximately 13.3%) will develop breast cancer during her lifetime. According to the National Alliance of Breast Cancer Organizations, more than 200,000 new breast cancer cases are diagnosed each year in the United States; there are more than 2 million breast cancer survivors. One report has estimated that the number in the United States may increase to 400,000[24] annually due to the increased number of people born after 1945 entering the age group when cancer is most likely to occur. Forty-eight percent of the cases of breast cancer occur in women older than 65 years, and 30% occur in those older than age 70.[25] Older women are more likely to choose a breast prosthesis over surgical reconstruction after a mastectomy.[18] Therefore, the number of women seeking an external breast prosthesis for their nonsurgical restoration after mastectomy can be expected to increase as the incidence of breast cancer increases in the aging population.

The impact of breast cancer on a woman's physical, social, and psychological well being is undeniable. When adapting to life after cancer, a woman may want to re-engage in previous behavior and seek to re-establish the life she led before having become a "breast cancer patient." Alternatively, the occurrence of cancer may spur the individual to make positive changes in her life,[26] such as changing jobs or being more attentive to good nutrition and exercise.

Have we identified the features in external breast prostheses that facilitate an optimal quality of life after mastectomy? Conversely, do we know enough about those features that have a negative impact on a woman's life after mastectomy?

"Shoulder Drop" and the Myth of the Weighted Breast Prosthesis

Women are told they must wear a "weighted" breast prosthesis to simulate the weight of the missing breast in order to "restore balance." Advertisements tell women that the consequence of not doing so may result in them developing "a problem with their balance," "spinal problems," and "shoulder drop." Women with breast cancer who are reading this material are already in a state of heightened anxiety over their health and even more vulnerable to false claims regarding their well being. Unfortunately, the claim that women will develop problems with their skeletal alignment or balance by not wearing a prosthesis that replaces the weight of the missing breast is not evidence-based. It is not supported by any scientific study of the posture of women after a mastectomy.

The clinical-sounding term "shoulder drop" is only used in the marketing of external breast prostheses. A Google search of "shoulder drop" linked with "breast prosthesis" resulted in 60 hits, all of which were selling various brands of external breast prostheses. "Shoulder drop" does not appear in the NCI cancer dictionary or in any other medical dictionary. A PubMed literature search of "shoulder drop" linked with "breast cancer" produced no results. A PubMed search of "shoulder drop" alone resulted in articles on topics unrelated to breast cancer, such as peripheral nerve injuries and lesions of the spinal accessory nerve. A Medline literature search using the key words "posture," "skeletal alignment," "balance," and "back pain" shows that these physical problems develop as a result of a variety of causes. Not one study was found that made reference to these complaints being associated with women not wearing a weighted external breast prosthesis after mastectomy. Instead, these complaints are attributed to factors, including the structure of the skeleton the woman was born with; stress; occupational factors; lifestyle choices such as wearing high heels; diseases such as osteoporosis, diabetes, or arthritis; and the loss of muscle mass, to name but a few.[27-37]

The majority of breast cancers are seen in women at middle age and older. These women will begin to show the general effects of aging and have physical complaints arising from life-long habits, disease, and occupational wear and tear. It stands to reason that a certain number of women, at middle age and beyond, will be found to stand at rest with one shoulder lower than the other. Some of these women will have aches in their back. A percentage of these women will also lose a breast to cancer. What is being noticed perhaps is a correlation, but there is no evidence of a causal relationship between the loss of the breast and any skeletal symptomatology.

One consequence of using the pseudo medical term "shoulder drop" as a marketing tool is that it may in fact impede a woman as she searches for the optimal adjustment to her post treatment life. "Physical activity promises to be one modifiable risk factor through which women can reduce their risk for breast cancer. Clinicians can now advise women that reducing risk for breast cancer may be one additional reason to adopt an active lifestyle."[38] Women who exercise reduce their risk of breast cancer by preventing weight gain or by lowering their weight.[38-41] It remains unclear whether exercise may also reduce the risk of a recurrence of breast cancer. Excess weight and obesity are associated with increased levels of estrogen, and physical activity decreases the exposure of breast tissue to estrogen, a growth stimulant. This could possibly also have an influence on the likelihood of a recurrence in a secondary site just as it may stimulate the growth of cancer cells in a new primary site. Added to the benefits of reducing the risk of cancer, physical activity is associated with reduced mortality in general,[42, 43] including a reduced risk of heart disease,[44, 45] a lower risk of diabetes,[46] and proven effectiveness at lowering stress and anxiety.[47]

Clearly, one of the most important aspects to be investigated in external breast prostheses is the impact the prosthesis has on a woman's level of physical activity after mastectomy. Physical exercise is an important contributor to a woman's quality of life, her psychological well being, her physical health, and even possibly to her survival. If women continue to wear a weighted breast, due to fear of the medical consequences of not doing so, then this false claim may well be a myth that is effectively preventing women from pursuing true healthier lifestyle options.

Do Gels Really "Move and Feel" Like Breast Tissue? Are There Better Materials?

Are there other reasons to wear a "weighted" external breast prosthesis? The most common filler material used today in external breast prostheses, meant for long-term wear, is gel. Most of the variation and choice in contemporary external breast prostheses appears to be in the design of the prosthesis. Dow Corning, one of the developers of silicone, held the patent on silicone gel and introduced gel-filled breast prostheses as an implantable device in the early 1960s. In the late 1960s, Dow Corning collaborated with a large prosthetic company to market gel-filled external breast prostheses.[48]

Advertisements for breast prostheses claim that gel "moves and feels like breast tissue." How a real breast moves or feels may be subjective and will probably vary depending on the age of the woman, whether she has had children, and other factors such as having dense breast tissue. Moreover, when trying to simulate a breast, one must take into consideration that the breast, real or prosthetic, will most likely be contained within a bra. The type of bra a woman chooses to wear will also contribute to the feel of the breast that the prosthesis is intended to simulate.

The weight of a gel is similar to breast tissue (tissue being mostly water and the weight of gel being close to that of water). This single similarity, however, does not mean that gels mimic the breast in all regards, and it has not been demonstrated that weight is the feature that women benefit from most. An implanted gel-filled breast prosthesis may indeed feel like a real breast, but the implant is held in place behind skin and/or muscle. In fact, with capsular contraction, it may be too well held in place. External breast prostheses must be secured in place with adhesives and Velcro attachments or by a sticky-back surface. However, many wearers have a skin reaction to the glues -- particularly after radiation therapy -- and they do not work well in hot weather or with menopausal symptoms.[49, 50]

Given the negative attributes of gel-filled prostheses, such as noise and displacement as a result of its weight, one can question whether gel really is the most appropriate material. Gel may be too literal a translation of the concept of breast tissue. In fact, a conviction that a weighted gel-filled prosthesis is necessary for medical reasons may curtail the

development and application of new materials and different designs.

Studies on the satisfaction levels of women who wear a breast prosthesis compared with those who chose surgical reconstruction never define the physical characteristics of the prosthesis the women were wearing.[18, 19, 11] This implies that contemporary breast prosthesis manufacturers can only employ 1 type of design and use only 1 type of material, which is not the case. Could it be that women who are dissatisfied with breast prostheses are in fact dissatisfied with only certain properties of the prosthesis that could be altered?

As of June 1999, the US Patent Office listed 178 patents for the design and manufacturing of external breast prostheses.[51] The first patent for the design and manufacture of a breast prosthesis was granted in 1874. In the past century, breast prostheses have been available through mail order, as a store-bought stock item, and as a custom-made device. The basic design of a prosthesis with an outer casing forming the skin of the prosthesis with an inside filling was patented early in the past century. Down, cotton, and different types of foam and fiber have been used in the past to create the missing breast. This demonstrates that there are, in fact, many choices in materials and options in the design and delivery systems.

In light of the cost of surgical reconstruction and the risks involved for what is essentially an elective surgery, women who desire to wear an external breast prosthesis should have options that are just as complex, variable, and well researched as their surgical alternatives. There should be an option for women that is not as invasive as surgery but is as individualized as the surgical options. Given the cost of surgical reconstruction to the public healthcare system and to private insurers, better prostheses that satisfy the needs of women could ultimately result in savings. More important, however, is that women need choices in all aspects of their cancer care and this extends to the design, weight, and material used to create a prosthetic breast which is meant to replace a part of their own body.

Is It Just About Attractiveness and Beauty?

Similar to the practice of medicine, the practice of creating body prostheses is grounded in the prevailing culture and evolves along with it. The field of prosthetics displays the material culture of the time period, and body prostheses have become an area of interest to historians and scholars in cultural studies. Some texts have commented on the manner in which breast prostheses are marketed to women. It has been noted that advertisements for external breast prostheses tend to emphasize attractiveness and the physical beauty of women in their publicity along with the use of pastel colors and similar "feminine" attributes, to reinforce cultural stereotypes of women.[48]

The stereotypes of "femininity" that have been commented upon as being characteristic of the manner in which breast prostheses are advertised may inadvertently trivialize the authenticity of a woman's need for restoration by casting it as gender specific; ie, a female (and therefore possibly a vain or neurotic) response. In the case of breast cancer, the breast is often linked to issues of sexuality. However, both genders confront issues with body image, self-esteem, and sexual dysfunction when presented with a diagnosis of cancer and or disfigurement.[52, 53]

It is important not to minimize the significance of the loss of a body part nor minimize the efforts one makes to overcome the loss. Disfigurement goes beyond the superficial concern of attractiveness and touches much more profound issues regarding the presentation of self in society, illustrated eloquently in research on stigmatization conducted by the sociologist, Erving Goffman. He distinguished between the "discredited" -- those with visible disfigurement -- and the "discreditable," whose concealed disfigurement leaves them vulnerable to stigmatization.[54]

Many patients do not wear their prosthesis at home and are comfortable with family and friends knowing of their disfigurement. However, the prosthesis becomes an important tool in mitigating discreditability when interacting with the outside world. The breast cancer survivor does not want to lose control of social interactions and have people's attention diverted to their physical disfigurement as they strive for mastery over their illness. The wearing of a prosthesis becomes a vital means of restoring a woman's social credibility and the sense of personal well being that she enjoyed before her disfigurement.[55]

Would All Women Benefit From Surgical Reconstruction?

There will always be a need for external breast prostheses. Articles that look at why women decide to delay or not have surgical reconstruction list that they are anxious about additional surgery, do not want anything foreign in their body, are dissatisfied with the expected cosmetic results, or feel they are too old.[18, 56] Additionally, the majority of breast cancers occur in older women who may have other age-related circumstances and comorbidities that prevent them from having surgical reconstruction. Women with metastatic disease and those who smoke or are obese may be excluded from surgery. Some women will have failed attempts at surgical reconstruction, and others may wish to delay their decision to have surgical reconstruction and want to wear a breast prosthesis in the interim.

Plastic surgeons looking at the results of their work seek to quantify the benefits women obtain from the different types of surgical reconstruction. Studies have compared the psychological benefits between delayed versus immediate reconstruction and compared the physical and psychological outcomes between the different types of reconstructive surgery.[57-59] There has been a tendency in this literature to extrapolate the results and assume that since the majority of women with surgical reconstruction benefit from it, then all women with a mastectomy will benefit. For obvious ethical reasons it is impossible to test many of the assumptions regarding the benefits of surgical reconstruction after mastectomy through a double-blind clinical trial with a control group. However, women who decide to have surgical reconstruction are self-selecting. Many could have reported satisfaction with their surgery either because they had a prior psychological necessity to receive the benefits resulting from the surgery (some of which cannot be achieved through other means) or, if not fully pleased with the results, could have been motivated in retrospect to rationalize and justify their decision to undergo the surgery.

In general, breast reconstruction is intended to provide psychological benefits, but evidence suggests that the question of who benefits from reconstructive surgery is far more complex than surgeons have supposed. A review of the literature concerning the psychological aspects of breast reconstruction found, "...methodological flaws with much of the existing research in this area, in particular the reliance on retrospective designs and the inappropriate use of randomized controlled trials." It concludes that, "...the widespread assumptions regarding the psychological benefits of reconstructive surgery remain largely unsupported by sound research evidence."[60]

Whether a woman undergoes surgical reconstruction is influenced by such factors as her age, her tumor type and characteristics, stage of disease, family income, insurance status, ethnicity, geographic location, and type of hospital where she received treatment.[61]

Additionally, a woman's use of coping styles, such as positive problem solving, escape/avoidance, and seeking social support, shape her behavior and ultimately the decisions she makes. Other important influences are the opinions of the oncologist and healthcare team members and the quality of the patient/doctor communication.[6]

In plastic surgery literature, breast reconstruction is claimed to be a viable option for the majority of women with breast cancer. The rate of surgical reconstruction is considered to be too low and reconstruction is seen as an underused option. Articles call for the need for greater physician and patient education on the benefits of surgical reconstruction.[16, 61]

A call for better advocacy in relation to external breast prostheses was not found in the literature. In fact, an article in a clinical psychology journal states that "...women with reconstruction do , indeed, experience what many report as the main benefits of reconstruction -- greater ease in clothing style and convenience -- and the escape from wearing a prosthesis."[62]

In a study of women with lumpectomy, mastectomy alone, and mastectomy with reconstruction, a majority of women in both mastectomy groups -- those wearing a prosthesis and those with reconstruction -- were satisfied with their method of restoring their premastectomy appearance. It seems that women in both groups made choices based on their individual needs and were, as a result, content with those choices.[14] However, in another study, more of the women who had chosen surgical reconstruction after mastectomy felt cancer had had a negative impact on their sex life.[63] Additionally, another study established that although some studies report a mastectomy having a negative impact on measurements of body image, quality of life encompasses more than body image, and studies of quality of life have shown that women who have a mastectomy alone report a greater quality of life.[64]

Literature on breast cancer demonstrates that the experience of breast cancer is multidimensional. A woman's response to the loss of a breast is individual and predicated by many factors. No one method of restoring the missing breast is suitable for all women. Accordingly, it is incumbent on researchers to subject women's experience of external breast prostheses to the same rigorous and detailed examination that occurs in surgical reconstruction and other breast cancer-related fields. It is unfortunate that -- due to the absence of sound, applied research and development -- an external breast prosthesis is currently viewed by many in the medical community as an inferior choice or an option that women choose despite its many shortcomings.

Conclusions

External breast prostheses are an important adjunct to the treatment of breast cancer in women. Although the majority of women wear a breast prosthesis after mastectomy, very little independent research has been done to clarify which properties in an external breast prosthesis benefit women and have a positive impact on their quality of life. Healthcare professionals are an important source of information for women with cancer and, as a result, the information they give must be as accurate as possible. Many of the claims regarding external breast prostheses, such as the need to wear a weighted prosthesis or the suitability of gel, are not evidence based, yet remain unchallenged and are perpetuated by the manufacturers, retailers, healthcare professionals, and the general literature on breast cancer. These false claims may be having a negative effect on women as they enter their post treatment life. It is clear in a review of studies that included women wearing external breast prostheses that there are, in fact, a number of complaints with external breast prostheses and that some women may be choosing surgical reconstruction because of their dissatisfaction with the limited range of available prosthetic products.

Precisely because of their noninvasiveness and cost-effectiveness, external breast prostheses can and should be subjected to more rigorous scientific evaluation than has been done to date. Research concerning the psychosocial adaptation of women after mastectomy should also include tests of the characteristics of external breast prostheses that contribute most to the optimal quality of life of women after cancer treatment. This would establish the validity of the information presently being given to women regarding prosthetic rehabilitation. Research objectively outlining the needs of women who seek prosthetic restoration would establish benchmarks that manufacturers need to achieve, and would undoubtedly result in a better and broader range of products.

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