Non-Reconstruction Following Mastectomy

This document is intended to help educate physicians and laypersons in the option to live flat, without reconstruction, following mastectomy (whether unilateral or bilateral), from the patient's point of view and studies available. Over half of women (approximately 58%) live without breast reconstruction post mastectomy and it is felt that the option of non-reconstruction should also be addressed with all mastectomy patients so that they are fully informed of their choices at the onset of their treatment discussions.

By law, women are entitled to full disclosure of all options. In the event of breast cancer, women are also entitled to reconstruction or symmetry of their chest, which in some cases would include a prophylactic mastectomy.[1] A full treatment plan should be known by women prior to deciding on options regarding reconstruction, including irradiation, chemotherapy, and other adjuvant therapies.

When faced with cancer or a positive genetic mutation, women need time to assimilate all of the information and new challenges. It has been shown that most of what is discussed with the patient after hearing she has cancer is not retained and may need to be re-explained. This includes surgical options.

It should also be discussed with the patient that she may choose no reconstruction at this point, and that months or years later, she may change her mind if she is in good health. Furthermore, women should be fully advised of the myriad of all short and long term complications that can result from reconstruction. Women should also understand that the loss of their breasts does not make them less of a woman, or a social outcast - the end result being to reduce the risk of cancer occurring or recurring.

Current state of understanding the non-reconstruction option

A recent study reported in JAMA Surgery[2] cites the reasons for women not having reconstruction as follows: options not explained thoroughly to women or they don't understand them, black women and those less educated, women who have other major health problems, chemotherapy, could not take time off of work, lack of insurance - primarily citing lack of education as the reason. It is unknown where geographically this

[1] Women's Heath and Cancer Rights Act of 1998
[2] JAMA Surgery, Aug. 20, 2014

data was obtained, if randomized, or using which parameters. What is known is that it does not clearly reflect the reasons given by the majority of women who have chosen no reconstruction.

The vast majority of women are unequivocally given adequate information when it comes to their option of surgeries, including lumpectomies or reconstruction choices and options by their breast oncology surgeons and general surgeons. There is a wealth of information at most plastic surgeon's offices, as well as on the internet. Very little is ever mentioned to women about the option of no reconstruction – if at all. There is no opposition to a woman having the choices outlined regarding reconstruction, but the opinions of those who have not been reconstructed, or have had to have deconstruction, are not routinely heard or reported upon.

Overall, women are not guided by Hollywood standards, in our choices for surgery. They do, however, look closely at the psychosocial aspects of what it means to have a mastectomy, as well as individual physical needs and limitations.

Non-reconstruction can result from several scenarios

Unsuccessful reconstruction can be related to infection, obesity, irradiation, vascular issues, as well as numerous other complications. It is difficult to find any published data on how many reconstruction surgeries overall result in failure, or deconstruction, but some small studies have been done.[3],[4],[5]

There may also be a delay in reconstruction due to further necessary or prophylactic surgeries, chemotherapy, infection, irradiation, and other commitments by the patient. A patient may also change their mind after having reconstruction and decide that they wish it reversed.

Reasons for non-reconstruction

After careful consideration and informed choices, a patient may wish to not undergo reconstruction based on the following concerns: increased pain, lengthier recovery time, additional surgical risks such as anesthesia, infection (including nosocomial), intolerance of pain medications, increased risk of lymphedema, seromas, further loss of sensation, flap or total flap failure and/or loss, fat necrosis, surgical site weakness, extrusion, no guarantee of bra cup size, deep venous thrombosis and pulmonary

[3] Ann Plast Surg 2013 Sept; 71(3):286-91 "Long-term outcomes of failed prosthetic breast reconstruction."
[4] Clin Breast Cancer. 2012 Dec; 12(6):428-32 "Failure rate and cosmesis of immediate tissue expander/implant breast reconstruction after postmastectomy irradiation."
[5] www.breastcancer.org

embolus, fat grafting pulmonary embolus, systemic complications or foreign objects in the body[6],[7]

Other considerations are failure rate of implant-based reconstruction (having a 50% failure rate at 7 years), and women not comfortable with the look of reconstruction results, such as coldness in the chest, potential dimpling and displacement, rupture or leak of implants, the potential of needing multiple surgeries and further revisions, or ultimate failure of the surgeries.

Many women are not comfortable with tissue mounds on their chests meant to resemble breasts, which will never feel or look the same as what they naturally had. Others do not wish to sacrifice other body parts or areas to obtain breasts, or further compromise muscle strength or range of motion. Women may have small children at home and/or employment where more recuperation time is not possible to manage, and they need to step back into their lives as quickly as possible. They do not have the time for further surgeries and procedures required whether for implants or autologous reconstruction to complete the process. Some are fearful of losing their employment and/or insurance coverage.

Women who have aggressive cancers wish to more easily detect a new lump or recurrence, which could be hidden or obscured by reconstructive surgeries. Those with inflammatory and lobular breast cancers also do not have the screening surveillance assurances of mammograms and ultrasound. Many women do not desire a lumpectomy which would result in weeks of radiation and its inherent risks, are unable to take that much time off of their job and provide for childcare, and would also require a lifetime of further surveillance with the issues related to that option. Still others may live alone and have no means of support or help. Prophylactic surgeries based on genetic mutation status, or higher than average familial risk, are chosen to reduce lifetime risk and increase survival rates up to 88%[8]

Some women choose prophylactic bilateral mastectomy due to hereditary factors. Others choose to have the non-cancerous side removed for symmetry, ease of fitting clothing, to avoid discomfort of prosthetic bras, for emotional healing, and to remove the anxiety from further scans, mammograms and surveillance of breast tissue. Still others choose to leave the unaffected breast intact and remain asymmetrical. The reasons given are varied and wide-ranged, but are informed choices suited to individual needs.

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[6] www.drmarga.com/specific-surgical-breast-surgery-complications.html

[7] www.cancerresearchuk.org "Possible problems with breast reconstruction."

[8] British Medical Journal, Feb. 11, 2014 "Contralateral mastectomy and survival after breast cancer in carriers of BRCA1 and BRCA2 mutations: retrospective analysis."

After researching all options independently - having thoroughly accessed the risks versus benefits - most women will make an educated and informed choice with regard to lifestyle and personal needs.

Results desired when choosing non-reconstruction

There is a strong consensus on wanting to obtain the best results possible - primarily for the chest to be smooth and flat. Emphatically, women choosing non-reconstruction want mastectomy completed and devoid of “dog ears”, extra tissue left or skin sparing, large indentations and with minimal nerve, muscle and lymph damage. Women would like the scars to be straight, smooth, and as low as possible to accommodate for varying necklines in clothing yet allowing for various swimwear options without having to reveal scars, including bikini tops.

If the breast or general surgeon is not able to give these results, then optimally women wish a plastic surgeon to assist, and give the same care as if reconstruction were chosen, as they will be living with the results for the rest of their lives. Women respectfully ask for, and will insist upon, a scar or scars which are not bumpy, erratic, or leave unnecessary tissue.

Support for the option of non-reconstruction

The experiences of many women have shown that when given a choice and non-reconstruction is chosen, there appears to be a strong negative bias from the medical professionals, not observed with those choosing reconstruction. Studies have indicated that those choosing no reconstruction and those undergoing reconstruction have the same level of satisfaction with the choice many years down the road if the surgery or surgeries are successful.

Support can be given by discussing all options – reconstruction and non-reconstruction. Some women may not realize there are others who have chosen not to reconstruct, including this option will open the lines of communication and give her an opportunity to share what she desires.

Women want their surgeon’s support during this difficult time. Support includes acknowledging she is in charge of her body and knows what is best for her. Verbalize the desire to support her in this difficult time of having her breasts removed and attempting to achieve the results desired in choosing to be flat. Discuss whether a unilateral or bilateral mastectomy is an option and support her decision if this includes prophylactic removal of non-cancerous breast. Verbalize that the goal is her satisfaction with the end result.

Women do not like to be asked repeatedly if they are sure that they do not wish reconstruction, as that tends to invalidate their choice. In some countries, as well as a minority of oncologists or surgeons in the U.S., a psychiatric or psychological evaluation is required to determine if this choice is appropriate - which is biased when a person who receives reconstruction is not required to have such an evaluation.

Women do not wish to hear that they will be less of a woman without breasts, clothes will fit better with reconstruction, and that society will be more accepting of their appearance. Women do not wish to equate a body organ with their femininity. These organs threatened their very existence, therefore they see no need to recreate them. Many do not wish to replace a body part that could potentially have caused death, or increased odds of metastasis and Stage IV. Most women wish to have no part in the sexualization of their disease and challenges.[9], [10], [11], [12]

Conclusion

Women facing the difficult path of mastectomy need to be presented with all viable options – both for reconstruction and non-reconstruction. During this time, women look to their doctors, surgeons and other medical professionals as the experts and want to enter into a partnership to achieve the best possible outcomes.

Women who choose non-reconstruction have often been misunderstood and given the perception they are in the minority. At this time, the reality is that they are in the majority. By openly supporting and helping these women achieve the results they desire, the path to non-reconstruction will be brighter and healthier.

[9] www.breastfree.org "The Alternative to Reconstruction"
[10] www.breasthealing.com "No Reconstruction"
[11] www.facebook.com/groups/FlatANDFabulous - a closed group of women living with contralateral or single mastectomies, deconstructed, or those seeking information prior to making a decision
[12] www.flatandfabulous.org