

Breast Reconstruction Practices in North America: Current Trends and Future Priorities

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ABSTRACT

The Women's Health and Cancer Rights Act (WHCRA) became federal law on January 1, 1999, mandating health care payer coverage for postmastectomy breast reconstruction. Despite passage of this legislation, breast reconstruction rates in the United States remain low. The Surveillance, Epidemiology and End Results (SEER) database for mastectomy patients in 11 regions across the United States show overall rates for immediate and early delayed reconstruction (performed within 4 months of mastectomy) of 15.4% for 1998 and 18.0% for 2000. Reconstruction rates vary significantly by region as well as by patient age, race, and income. The paper examines potential etiologies for low utilization of breast reconstruction and outlines possible remedies.

KEYWORDS: Breast reconstruction, breast implant, TRAM, SEER

After years of lobbying by women's health advocates and amidst much fanfare, the 1998 Federal Breast Cancer Reconstruction Law (also referred to as the Women's Health and Cancer Rights Act of 1998 or WHCRA) was signed into law by President Bill Clinton. Passage of this legislation marked the culmination of intensive lobbying efforts by breast cancer survivors, clinicians, researchers, and policy makers to ensure coverage by health care payers of breast reconstruction following mastectomy. In the two decades preceding passage of the WHCRA, a growing body of research demonstrated significant psychosocial and quality-of-life benefits for breast reconstruction.¹⁻³ Largely as a consequence of these studies, provider and patient perceptions evolved away from viewing breast reconstruction as a "cosmetic" procedure. Instead, health care professionals and consumers concluded that creation of a new breast following mastectomy was a reconstructive operation and, for many women, an important element in breast cancer recovery. Despite these changing attitudes,

some health care payers had failed to include breast reconstruction among their covered benefits, steadfastly maintaining that these operations were cosmetic in nature. With passage of the WHCRA, this barrier was removed. The law mandated that health plans include breast and nipple reconstruction as well as contralateral breast symmetry procedures among their benefits afforded to mastectomy patients.

The WHCRA was a significant milestone in several respects. It was a tangible sign that breast cancer had become a prominent issue in health care politics and that breast cancer advocacy had evolved into a potent lobbying force on the national political scene. The new law also signaled that breast reconstruction had become widely recognized as an important element in breast cancer treatment rehabilitation. Finally, the WHCRA demonstrated the power of consumers to impact health care policy on a national level.

At the time of this writing, the WHCRA has been the law of the land for almost 5 years. What have

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been the effects of this and other factors on practice patterns in breast reconstruction? Given current trends, what should our future priorities be? This article will examine available data in an attempt to address these questions.

WHAT DO WE KNOW ABOUT BREAST RECONSTRUCTION RATES IN THE UNITED STATES?

Measuring the current rate of breast reconstruction may seem like a straightforward proposition. In fact, determining recent rates of postmastectomy reconstruction in the United States presents a daunting challenge, largely due to the fragmented nature of clinical databases in this country. Although many other developed countries have nationalized health care systems with comprehensive patient databases, the U.S. system, with its hodgepodge of public and private payers, does not currently possess a single data clearinghouse for the entire patient population. Researchers seeking to evaluate national trends for health care utilization are forced to rely on databases that include only segments of the treatment population. Results from such studies are severely limited in their generalizability. For example, the Medicare database contains a nationwide sample of patients, but is largely restricted to those over 65 years of age. Because breast reconstruction is relatively uncommon in the elderly, using Medicare data to study reconstruction rates for the general population would not be appropriate. Medicaid databases are similarly flawed, as they are mainly limited to patients within a narrow socioeconomic spectrum.

Our best estimates for breast reconstruction utilization have been obtained through analyses of the Surveillance, Epidemiology and End Results (SEER) database, which was created by the National Cancer Institute.⁴ The SEER Program is the most comprehensive source for national cancer incidence and outcome data in the United States. Although the program covers only 14% of the U.S. population, the 11 regional registries that contribute data provide a fairly representative sample of the nation as a whole. Inclusion of diverse socioeconomic, geographic, ethnic, and age groups greatly enhances the generalizability of the sample to the general U.S. population.⁴

To date, most published studies on breast reconstruction utilization have relied upon the SEER Program. Although the SEER database mainly includes patient-specific information on breast cancer staging, treatment, and outcomes, the registry also records basic details on mastectomy reconstruction. The database tracks reconstructions performed at the time of the mastectomy (immediate procedures) or within 4 months following mastectomy (early delayed procedures).⁴ Delayed reconstructions performed later than 4 months

after mastectomy are not recorded, a deficiency that constitutes the database's greatest limitation in analyzing reconstruction rates. However, information on types of reconstruction (i.e., implant versus autogenous tissue) are included.

Two published reports have used the SEER program to analyze rates of breast reconstruction. In a study published in 2000, Polednak analyzed SEER data for 1988 through 1995.⁵ Overall rates for mastectomy patients receiving reconstruction rose from 4.3% in 1988 to 10.8% in 1995. Polednak also examined regional variations in these rates: over the entire study period, the registry with the largest proportion of women undergoing reconstruction was Atlanta (16.0%), and the lowest was Hawaii (3.3%). Region was a statistically significant predictor for breast reconstruction in all age categories. Income level also had a significant effect on reconstruction rates, with the two lowest income quintiles having less likelihood of receiving reconstruction.

In a more recent study (2003), our group evaluated patients from the 1998 SEER database.⁶ Within the immediate to early delayed period, the overall reconstruction rate for the 10,406 women in 1998 with mastectomy was 15.4%. Among all reconstructions, 41.8% used autogenous tissue (muscle flaps), 24.0% were tissue expander/implant, and 11.5% utilized combined flap/implant procedures. Several sociodemographic variables were found to have significant effects on the rate of reconstruction. Compared with women ages 45 to 54 years, those 35 to 44 years were significantly more likely to receive reconstruction (OR = 1.52, $P < 0.001$). Those 55 to 64, 65 to 74, and 75 years and older were significantly less likely to undergo reconstruction (OR = 0.42, $P < 0.001$; OR = 0.16, $P < 0.001$; and OR = 0.29, $P < 0.001$, respectively).

In addition to patient age, ethnicity also had a significant effect on the likelihood of postmastectomy reconstruction in the SEER population. Compared with Caucasian women, African-American patients were significantly less commonly reconstructed (OR = 0.48, $P < 0.001$). Similarly, Hispanic and Asian-American women were significantly less likely to receive breast reconstruction (OR = 0.45, $P < 0.001$ and OR = 0.29, $P < 0.001$, respectively).⁶

Our analysis also found large regional variation in rates of postmastectomy breast reconstruction.⁶ Although the Atlanta registry reported the highest rate (33.6%), Hawaii recorded the lowest (7.6%). Thus, the proportion of mastectomy patients receiving reconstruction showed a fourfold variation among the regions. Controlling for potential confounding variables (patient age, race, disease stage, marital status, and use of adjuvant radiotherapy), regression analysis found that 6 of 10 regions had significantly different rates of reconstruction compared with the reference rate (San Francisco). Choice of procedure type also showed considerable

regional variation: for example, 83.2% of reconstructions in Atlanta used autogenous tissue, compared with 53.5% in San Jose-Monterey and 53.5% in Iowa.

Evidence of low utilization of breast reconstruction also was reported in a statewide study by Polednak (2000).⁷ Using the Connecticut Office of Health Care Access and Connecticut Tumor Registry databases, he analyzed reconstruction rates for mastectomy patients diagnosed between 1992 and 1996. An overall rate of 12.5% was observed for the entire study period, ranging from 8.8% in 1992 to 15.6% in 1996. As in his earlier SEER study, Polednak also found that economic status was a significant predictor of reconstruction. In two of three age categories analyzed, low-income patients were significantly less likely to receive reconstruction.

WHAT ARE THE CURRENT TRENDS IN BREAST RECONSTRUCTION RATES?

Based on review of the SEER data described in the preceding section, it appears that breast reconstruction experienced slow but steady growth in the United States from 1988 through 1998. This trend likely reflected increasing awareness and acceptance of postmastectomy reconstruction by patients, providers, and payers. With passage of the Women's Health and Cancer Rights Act in 1998, it would seem reasonable to expect that the trend would continue or even accelerate, due in part to the law's removal of financial barriers to reconstruction for many women.

Although determining current trends for breast reconstruction with complete accuracy remains an elusive target, it is possible to draw some conclusions based on available, but (as we discussed earlier) imperfect databases. To date, the SEER Program provides reconstruction data up to the end of the year 2000. Overall reconstruction rates for the 11 registries were 16.8% for 1999 and 18.0% for 2000. Choice of procedure types also showed minor changes compared with 1998: For 1999, 55.7% of patients received autogenous tissue reconstructions, 27.0% underwent expander/implant techniques, and 17.3% had combined flap/implant procedures. In 2000, the rates were 54.9, 29.3, and 15.7%, respectively.

The American Society of Plastic Surgeons also provides data on trends in breast reconstruction.⁸ Information is self-reported by plastic surgeons across the country. Although these statistics may be subject to sampling error, the ASPS database still represents one of the more comprehensive and up-to-date sources of information on reconstructive procedures. According to these data, a large increase in the number of breast reconstructions occurred between 1992 and 1998 (from 29,607 to 69,683 cases, respectively). Between 1998 and 2001, there was an additional rise in case volume to 81,089. However, for 2002, the total declined to 73,026.

In summary, the case volume for postmastectomy reconstruction remains relatively low compared with the number of women still undergoing mastectomies each year in the United States. Despite the passage of the WHCRA in 1998, breast reconstruction utilization continues to rise at the extremely modest rate of slightly more than 1% per year, roughly the same rate seen during the decade prior to 1998. These findings raise a variety of health care delivery and policy issues, some of which we will address in the text that follows.

WHY ARE BREAST RECONSTRUCTION RATES SO LOW?

Given the extensive efforts by patient advocates and providers over the past 20 years to promote reconstruction for women undergoing mastectomy, the low utilization and small rate of increase reported for this procedure are disappointing. In light of these somewhat surprising results, it is tempting to focus on the weaknesses of existing research and to simply maintain that breast reconstruction is underreported. This may be the case with the SEER database, because it does not track reconstructions performed more than 4 months following mastectomy. The ASPS database indicates that 39 to 42% of reconstructions performed by its members are immediate,⁸ leading one to speculate that SEER data may overlook a substantial proportion of reconstructions performed in the delayed setting. However, even if the "true" rate (including both immediate and delayed reconstructions) is twice that reported in the SEER analyses, only about one in three mastectomy patients are receiving reconstruction. In reality, this estimate is probably overly generous: Polednak's study of the Connecticut databases for 1992 to 1996 included both immediate and delayed procedures and still reported reconstruction rates in the range of 9 to 15%.⁷

The low utilization reported for breast reconstruction may be attributable to patient preferences. Perhaps the vast majority of mastectomy patients simply do not want reconstruction. In a single-center, single plastic surgeon retrospective study, Finlayson and coworkers found that only 21% of women undergoing mastectomy chose immediate or delayed reconstruction, despite the opportunity for preoperative consultation with a plastic surgeon and receiving what the authors describe as "specific preoperative counseling about post-mastectomy breast reconstruction."⁹ Given the questionable generalizability of these findings and the lack of additional studies which address the issue of patient preference, we can only speculate about the "right" rate for reconstruction (i.e., the rate at which well-informed patients, with access to appropriate care, would choose breast reconstruction).

Although we know little about preferences for reconstruction among mastectomy patients, the wide

variations in rates of reconstruction across demographic variables such as locality, race, and income level suggest that barriers to reconstruction still exist, despite passage of the WHCRA. For example, both Polednak and our group have observed four- to fivefold variations in regional rates of breast reconstruction.^{5,6} Although it is not inconceivable that patient preferences play a major role in accounting for these differences, it seems somewhat far-fetched that women in Atlanta are three times more likely to want reconstruction than women in Los Angeles (controlling for age, race, and disease stage).⁶ A more likely etiology for this variation is a series of flaws in our health care system, which still limit patients' access to reconstruction (and to other health care resources).

WHAT BARRIERS REMAIN FOR WOMEN SEEKING BREAST RECONSTRUCTION?

Due to a current shortage of research on utilization of postmastectomy reconstruction, we can only speculate about the potential barriers that still exist for women seeking these procedures. However, based on what little we do know, several factors appear to limit access: (1) ongoing financial barriers, (2) race-based inequalities in health care, (3) lack of patient knowledge about options for reconstruction, and (4) geographic variations in access to reconstructive services. We will examine each of these issues in the following paragraphs.

Financial Barriers

As noted earlier, the WHCRA mandated coverage of postmastectomy reconstruction by all health care payers as of January 1, 1999. Passage of the WHCRA was widely perceived in the lay press as a virtual guarantee that no patient would be denied reconstruction based on financial status. As patients and plastic surgeons have discovered (much to their disappointment) in the last 5 years, the WHCRA is riddled with loopholes. Due to the lack of provisions addressing payer compliance and enforceable penalties for infractions, the law has more bark than bite. In essence, the current law depends on payers' good will to ensure its implementation. Attempts to amend the WHCRA, adding penalties for noncompliance, died in legislative committees during the 107th Congress. As of October 2003, this legislation had been reintroduced in the 108th Congress as H.R.295 Kelly and S.AMDT.567 Biden (amendment to the 2004 tax bill S.1054) and was pending before a House-Senate Conference Committee. In the meantime, health care payers remain on the "honor system" to fund reconstruction for their mastectomy patients.

Another weakness in the WHCRA is its failure to address physician reimbursement. Although the law mandates that payers include breast reconstruction as a

covered benefit, rates of physician reimbursement are not specified. To assess the impact of this oversight, a discussion group of 15 plastic surgeons from six states was initiated by the first author in December 2003. Academic and private (solo and group) practices were all represented. Time in practice ranged from 2 years to 27 years. After a presentation on current rates of reconstruction, participants were queried about barriers to breast reconstruction observed in their geographic areas. Overwhelmingly, reimbursement was the most common factor identified by the practitioners. Although several of the surgeons stated that they accepted third-party reimbursement as payment in full for their services, the majority of the group did not participate in health care plans for breast reconstruction. Among those declining managed care and third-party plans for reconstruction, the primary reason given was inadequate reimbursement. As a method of coping with low reimbursement, some of the surgeons still participating in health care plans tended to choose less time-consuming options, such as tissue expanders, rather than more complex autogenous tissue procedures. The experiences related by these surgeons are probably not atypical. In its 2002 member survey, the American Society of Plastic Surgeons found that the issue with the greatest impact on members' practices was declining reimbursement.¹⁰

Finally, the WHCRA also overlooks the 44 million Americans who lack health care coverage of any kind. Uninsured women must either pay out of pocket for reconstruction or forego an important quality-of-life-enhancing procedure. Given the extremely limited economic resources of this patient population, "no insurance" probably means "no reconstruction."

Race-Based Inequalities in Care

Disparities in utilization of health care resources between racial/ethnic minorities and Caucasians have been well documented in many areas of medicine. Compared with Caucasians, African-Americans often receive less medical care, receive less aggressive treatment interventions, and are diagnosed at later stages of disease.¹¹⁻¹⁴ The 1998 SEER data echo this trend, as race was a significant predictor of postmastectomy reconstruction.⁶ Compared with Caucasians and controlling for the other variables such as age, treatment location, and stage of disease, the odds of reconstruction for African-Americans, Hispanics, and Asians were significantly lower. African-American and Hispanic women were approximately half as likely and Asian woman were approximately one third as likely to be reconstructed.

Teasing out the etiologies for disparity in our health delivery system is a monumental task. However, the easiest target upon which to focus is money. Since the classic Whitehall study of the 1960s, the disturbing relationship between social class and health status haunts

our society.¹⁵ Financial status could partially explain the lower rates of reconstruction in the minority populations. One could also postulate that financial status affects the type of reconstruction a woman chooses. Expander-implant techniques may be less popular in a financially disadvantaged group due to concerns regarding transportation and time away from work. The provision of mandated insurance coverage for reconstruction only removes one small fraction of the financial barriers women in lower socioeconomic classes confront. Other financial burdens, such as childcare, transportation, and lack of sick leave from employers, limit “non-lifesaving” health provisions such as reconstruction.

Financial barriers cannot account for all of the discrepancies found in the delivery of postmastectomy breast reconstruction. The cultural value of women’s breasts may differ across ethnicities. In our experience, Asian women often receive similar health care services as Caucasians, but Asian women in the SEER database were significantly less likely to receive breast reconstruction compared with Caucasians.⁶ In addition, each subculture of our society has varying levels of trust in the health care system, which impacts health care choices. The African-American culture has historically been distrustful of the traditional health care system, partially born out of the Tuskegee syphilis experiments. This inherent distrust in the health system may explain the lower likelihood of breast reconstruction in African-Americans compared with Caucasians.

Inadequate Knowledge about Breast Reconstruction

Imperfect information can also act as a barrier to health care. Although the WHCRA requires payer coverage, it does not mandate public knowledge. The postmastectomy patient may not be aware that (1) breast reconstruction is a safe option, (2) this procedure is covered by insurance, or (3) the benefits of reconstruction extend beyond aesthetics.

Information regarding reconstructive options is generally provided by either the treating physician or the media. Historically, the health profession has had marginal success in presenting unbiased health care choices to patients. Breast cancer is no exception. The option of breast-conserving therapy has not always been provided to women by their physicians, which triggered governmental intervention. Physicians were mandated to provide information on both mastectomy and breast-conserving treatment options.¹⁶ Similarly, referring physicians may be biased against postmastectomy reconstruction. The option for reconstruction may not be presented to all patients or may be provided to different patient populations. An underlying cultural assumption is that breast reconstruction is for the young and sexually active.¹⁷ This cultural bias may influence physicians’

referral patterns for reconstructive surgery and may contribute to the significantly lower rates of postmastectomy reconstruction in older women, as previously discussed.

On the other hand, women may know that reconstruction is available but may not be aware that it is a financially viable option. Often the public perceives plastic surgery as a “cosmetic” operation performed for “vanity.” Breast cancer patients may also have the misperception that breast reconstruction is not covered by insurance. A heightened awareness of the benefits of the WHCRA, directed both at the general public and referring physicians, is an absolute necessity for the potential benefits of the legislation to reach fruition.

In addition to the need to highlight the benefits of WHCRA, general information about the psychosocial and quality-of-life benefits of reconstructive surgery should be disseminated to both the general public and the medical community. Outcomes research on postmastectomy reconstruction is inundated with data supporting the psychosocial benefits of these procedures. Women who choose postmastectomy reconstruction have significantly improved emotional health, general mental health, social functioning, and body image post-operatively.¹⁻³ The effects of reconstruction extend beyond “cosmetics,” but awareness of these benefits may be limited outside of the plastic surgery community.

Geographic Variations in Access to Reconstruction

The geographic variation in breast reconstruction rates noted earlier is hardly unique to this procedure. As early as 1986, Chassin and coworkers observed at least three-fold differences in the rates of 67 of 123 medical and surgical procedures studied among Medicare beneficiaries in 13 large service areas across the United States.¹⁸ More recently, Birkmeyer and colleagues reported up to 10-fold variations across regions in the rates of 11 common surgical procedures in the 1995 Medicare population.¹⁹ Speculation over potential etiologies for these variations is widespread in the current health services literature. Some investigators, such as Carlisle and coworkers, maintain that geographic variation in utilization of surgical services is significantly associated with differences in ethnicity and socioeconomic status across regions.²⁰ Other researchers, including Birkmeyer and colleagues, point to physician factors as the likely sources for regional variation in surgery rates.¹⁹ Providers may disagree about the effectiveness of health care interventions, including breast reconstruction. Chassin theorizes that geographic differences in the use of health care may be attributable to variations in the prevalence of physicians who are “enthusiasts” for particular interventions.²¹ In the case of breast reconstruction, areas with higher rates may be populated with physicians who are

knowledgeable about reconstruction and who actively promote this operation among their mastectomy patients. If this is so, efforts to educate providers, particularly oncologists and primary care physicians, about the benefits of reconstruction might encourage more practitioners to consider this procedure as an option for their patients.

Variation in the availability of local plastic surgeons may also account for some of regional differences in breast reconstruction rates. The relationship between the number of surgeons who perform a particular procedure and the number of these operations performed in a geographic location has been examined previously for other types of surgery. For example, Leape and coworkers found that regional rates for carotid endarterectomy were, in part, linked to the number of surgeons performing the operation in the area.²² Similarly, the relatively low rates of breast reconstruction observed in our study of the SEER regions may be attributable (in part) to limits in the availability of plastic surgeons (or of those offering breast reconstruction) in some communities. Efforts to improve the outreach of existing reconstruction centers or to initiate new programs may increase availability and utilization of breast reconstruction. New technologies, such as telemedicine, also may offer some assistance in this regard.

WHERE SHOULD WE GO FROM HERE?

We need a clearer understanding of current reconstruction rates across the country and about patient and provider variables that impact these rates. To this end, more work is required in several research areas. We need to continue development of nationwide cancer treatment databases (such as SEER) that capture clinical information on large and diverse populations of patients. A national database will greatly enhance the generalizability of research findings, allowing investigators to evaluate utilization and the impact of care on a wide variety of demographic groups. Better understanding of breast reconstruction utilization will not only require database research, but will also necessitate survey research to study the decision-making processes of patients and providers making reconstructive choices. This information will help us determine (in the words of health services researcher Jack Wennberg) "what rate is right?"¹⁹

If additional studies demonstrate that breast reconstruction is underutilized (as we suspect), plastic surgeons must partner with patient-advocates and health care policy makers to remedy systemic flaws that block access to reconstruction. Strengthening the WHCRA, educating our patients and colleagues, and addressing infrastructure and provider needs all may contribute to achieving the "right" rate of breast reconstruction on a

national scale. In the years to come, we certainly have our work cut out for us.

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