

# Closing the Breast Cancer Loop: Barriers and Perceptions of Breast Reconstruction among Rural Women

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**Background:** Despite policies such as the Women's Health and Cancer Rights Act (WHCRA) and Breast Cancer Patient Education Act, rates for breast reconstruction vary and are especially low for some subpopulations of patients, especially rural women. In order to better understand patient perceptions, qualitative analysis using focus groups is an underutilized tool for obtaining patient perspectives regarding health-related issues and access to care. Our aim was to better understand patient perceptions using qualitative analysis.

**Methods:** Three focus groups were held in rural counties within West Virginia in order to better understand patient perceptions, knowledge, and beliefs regarding breast health, breast cancer, access to breast reconstruction, and how to disseminate and educate this patient population regarding their right to accessing breast reconstruction.

**Results:** Major themes analyses revealed perceived barriers to care related to lacking care coordination, lack of insurance coverage and other resources, as well as issues related to transportation. Participants consistently discussed avoiding breast screening care due fear and denial in addition to pain. Few patients were aware of their right to accessing breast reconstruction per the WHCRA, and many were concerned about follow-up burden, complications, and general fear related to breast reconstruction. Themes related to dissemination of information to promote the option of breast reconstruction included social media, patient counseling by their referring physician, and other means of intervention in clinics and other points in the care coordination chain.

**Conclusions:** Rural women have important, unique viewpoints regarding access to and perceived barriers from obtaining breast reconstruction. Plastic surgeons must work diligently to educate, disseminate, and improve care coordination among this population in order to improve access to breast reconstruction among rural breast cancer patients. (*Plast Reconstr Surg Glob Open* 2020;8:e2638; doi: [10.1097/GOX.0000000000002638](https://doi.org/10.1097/GOX.0000000000002638); Published online 20 February 2020.)

## BACKGROUND

Breast cancer is a pervasive disease in the United States, affecting >12% of all women.<sup>1</sup> Those with breast cancer may elect to undergo breast reconstruction, which can be considered an important step in the continuum of treatment for breast cancer. In fact, the impact of reconstruction has been shown to improve patient satisfaction, psychosocial stressors, and provide an overall survival

benefit for patients.<sup>2-6</sup> Recognizing the importance of breast reconstruction in breast cancer treatment, the Women's Health and Cancer Rights Act (WHCRA) was passed in 1998, which mandated universal insurance coverage for breast reconstruction as part of the medical and surgical treatment of breast cancer.<sup>7,8</sup>

Although the policy framework and insurance support now exist for breast cancer patients to receive breast

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reconstruction, rates for this intervention still vary. In fact, in the years immediately following the WHCRA, breast reconstruction rates remained unchanged.<sup>9</sup> Unfortunately, rates are particularly low for select patient populations throughout the country. The source of variations in reconstructive rates has been linked to age, geography, insurance status, race/ethnicity, socioeconomic status, education level, and access to a plastic surgeon.<sup>10–13</sup> Although breast reconstruction rates have trended up in recent years, the majority of breast cancer patients are still left without reconstruction.<sup>14</sup> Some have postulated that patients lack awareness of breast reconstruction as part of their treatment paradigm, which inspired the Breast Cancer Patient Education Act in 2015. The purpose of this policy was rooted in patient education, with the intention to inform women of breast reconstruction availability and their right to undergo reconstruction, if so desired.<sup>15</sup>

Rural states, such as our state of West Virginia, tend to be fraught with poverty, medical comorbidities, and inadequate access to health care services which logically makes breast reconstruction particularly challenging for many patients. In fact, based on our previous study, as little as 13% of providers participating in our West Virginia Annual Breast Cancer Conference reported being aware of the WHCRA.<sup>16</sup> This information may corroborate why, anecdotally, many women in West Virginia seem to be largely unaware of breast reconstruction as an option in their breast cancer treatment. Understanding knowledge and perceptions within this population, as it relates to breast health and breast reconstruction, may lend well to intervening and mitigating such challenges.

Focus group-based qualitative analysis is an underutilized tool for obtaining patient perspectives regarding health-related issues and access to care. Such open-ended methodologies are effective in obtaining accurate reflections of patient knowledge, beliefs, and perceptions regarding various health issues.<sup>17</sup> Given the existent barriers to care and perceptions related to breast reconstruction in rural areas such as West Virginia, a qualitative study to obtain better understanding is warranted.

After recognizing the clear benefits of breast reconstruction and continuing issues surrounding patient knowledge, perceptions, and utilization of this procedure, we performed a qualitative, focus group-based, study. The purpose of our study is to identify patient barriers to breast care, perceptions of breast reconstruction, and how to improve access to information to subsequently bridge the knowledge gap in a rural underserved patient population.

## METHODS

### Subject Recruitment, Consent, and Compensation

This qualitative study was approved by the West Virginia University Institutional Review Board. Through partnership with the Cancer Prevention and Control outreach group at West Virginia University’s Cancer Institute, a

sample of 28 women were recruited to participate in 3 different focus groups to take place in 3 different rural counties throughout the state of West Virginia: Hampshire, Preston, and Webster. Specifically, women were recruited by local entities associated with the county health department and WV Cancer Prevention and Control outreach group. Eligible participants included all women who were ≥25 years of age. All consented women who took part in the focus group and completed the questionnaire were compensated with \$20 gift card for their participation. Informed consent was obtained from all participants before focus group meetings and questionnaire completion in accordance with the Health Insurance Portability and Accountability Act. Prospective participants were informed that they could terminate their involvement in the study at any time as part of the informed consent process.

A script of the discussion was designed to assure that all counties would discuss similar topics in breast health including mammogram, access to care, understanding of breast reconstruction, and how to improve the dissemination of information. Talking points for facilitators are summarized in Table 1.

### Focus Group Meetings

Each of the 3 focus groups that were held took place in the community settings within each of the 3 West Virginia counties: Hampshire, Preston, and Webster. The specific location of the meetings was local churches and community centers. Two focus group facilitators moderated and guided each focus group meeting. Importantly, the focus group facilitators were not physicians or familiar health care providers but rather women familiar with the local community that are part of the WV Cancer Prevention and Control outreach group. This was done in an effort to promote comfortability and participation among focus group members.

**Table 1. Summary of Facilitator Talking Points for Focus Groups**

General Topic	Specific Talking Points
General community health issues	General at large health issues in their communities Comfortability with and perspectives on finance and cost of care Determinants of health care issues Experiences in accessing health care (positive and/or negative) Barriers to health care Benefits and challenges associated with health insurance coverage
Breast health	Discussion of knowledge on testing and examining breast health Prevalence of clinical breast examinations during annual visits
Breast reconstruction	Knowledge of mandatory coverage for breast reconstruction by insurance companies Awareness of WHCRA and/or BCPEA Types of breast reconstruction available Decision-making factors in opting for or against breast reconstruction Methods for effective communication for availability of breast reconstruction

BCPEA, Breast Cancer Patient Education Act; WHCRA, Women’s Health and Cancer Rights Act.

**Table 2. Summary of Focus Group Participant Demographic Information**

	25–39	40–49	50–64	>65	—	—	—
Age range	25–39	40–49	50–64	>65	—	—	—
Participants (n = 28)	0	3	10	14	—	—	—
Household income range	<\$10,000	10,000–25,000	25,000–40,000	40,000–65,000	65,000–80,000	80,000–100,000	>100,000
Participants (n = 28)	2	5	5	9	3	0	3
Education level	Completed <9th grade	Some HS	Completed HS or GED	Some college	Completed college	Masters or higher	—
Participants (n = 28)	0	4	7	9	2	5	—
No. occupants in the home	1	2	3	4	5	—	—
Participants (n = 28)	7	15	4	1	1	—	—

GED, General Education Developments; HS, high school.

Each focus group session consisted of a welcome and introduction followed by a round robin of introductions for the focus group participants and facilitators to get to know one another. Following this, a general discussion regarding health status, experiences with the health care system, access to care, and health insurance ensued. Subsequently, a lengthy discussion of breast health took place where participants were asked to comment on breast cancer, mammograms, breast reconstruction, and how information related to these subjects could be better communicated to the West Virginian population. After this, the discussion was summarized by the group/moderator and additional questions from the focus group participants were addressed. The talking points from scripts used by the facilitators can be seen in Table 1. After the focus groups, participants filled out a demographic questionnaire for information related to age, race/ethnicity, socio-economics, education level, and whether or not they are currently up to date on their recommended breast cancer screening.

After the data were collected, a detailed content analysis was conducted to extract key themes and anecdotes from each focus group. Descriptive statistics from quantitative survey data were run using STATA (STATA – Release 15; StataCorp LLC, College Station, Tex.).

## RESULTS

### Study Population

Across the 3 focus groups held, a total of 28 women elected to participate. Study participant demographics are summarized in Table 2. All women who participated were above 40 years of age, with half being elderly (> 65 years of age). More than 75% of participants' household incomes were ≤\$65,000. All participants completed at least some high school, whereas most women (16, 57.1%) completed some college or higher. A large majority of focus group participants (22, 78.6%) lived in either single-person or 2-person households.

Participant responses regarding their current health care utilization status are summarized in Table 3. Most women in this study had their own primary care physician, were currently enrolled in a health insurance plan at the time of the study, and had received mammogram screening within the prior 2 calendar-years. Despite participants' documented access to care (Table 3), the vast majority of study participants (23, 82.1%) were unaware

**Table 3. Summary of Focus Group Participants' Survey Data Regarding Access to Health Care Services**

Health Care Access Metric	No. Participants (%)
Participant has a PCP	26 (92.9)
Participant has health insurance	27 (96.4)
Participant has received mammogram in past 2 calendar-years	24 (85.7)

PCP, primary care physician.

of the WHCRA; the law providing a right to breast reconstruction for all breast cancer patients.

### Focus Group Major Themes Analysis

Major themes and selected supporting quotes are summarized in Table 4. Participants outlined numerous barriers to care access.

*“Where do they have to travel next? How expensive is it gonna be for the traveling? Who’s gonna take ‘em? There’s all those different issues, so some women just say, “I don’t want to deal with it.”*

#### Transportation Limits Access

Specifically, focus group participants cited transportation being uniquely prohibitive for patients living in rural locales. Both distance to physician and cost of transportation were factors which became barriers to care for participants.

*“If you live back in the mountains somewhere, actually getting out and getting to those services...is hard.”*

#### Lack of Social Support

Participants emphasized the pervasive issue of a lack of social support in seeking healthcare. They gave examples of prolonged preauthorizations, long distances among physicians, lack of coordination of care among physicians, lack of health education by providers, and sparse support groups to illustrate their perception that the healthcare system does not support them.

*“If you’ve been told you have a lump...and you want to get this checked as soon as possible. However, you gotta wait four to six weeks...for pre-authorization.”*

*“We’re so isolated [here] that, in order to get the [health-care] information, you almost have to do the research yourself.”*

**Table 4. Summary of Major Themes Analysis and Supporting Quotes from All Focus Groups Held**

Themes	Supporting Patient Quotations
Barriers to accessing medical care/breast reconstruction	“Where do they have to travel next? How expensive is it gonna be for the traveling? Who’s gonna take ‘em? There’s all those different issues, so some women just say, “I don’t want to deal with it.”
1. Transportation	Lack of Transportation Preventing Care “If you live back in the mountains somewhere, actually getting out and getting to those services...is hard.” “With transportation, being in a more rural area, having to travel like you said to Winchester or Morgantown...is a hardship.”
2. Cost	Health care Costs Preventing Care “The sad thing is, people don’t get any health care because it costs so much money...” “I don’t have any insurance for that [medication]. And I’m single and 74 years old and I’m still working.”
3. Lack of social support	Lack of Community Healthcare Resources “And if they have family, then the family has to do everything. And if they don’t have family in the area, then they may or may not get any help.” “Well but we don’t have any resources...I mean, when my son had testicular cancer, I mean, there was nothing here.”
4. Age	Age Preventing Care “Yeah, I was 61. If I’d have been in my 40’s, I may have made a different choice [regarding breast reconstruction].” “I think if I’d of been younger, I would have probably got a [breast] reconstruction.” “I was asked if I wanted to have [breast reconstruction] and I said no, not at my age, I’m not having it done.”
Perspectives on breast reconstruction	Impact of Word of Mouth “Horror stories from everybody else.” “I just heard these horror stories and I just thought... ‘Being cut from here to here. I can’t go through that now.’” “I was too scared because I had heard so many horror stories about [breast reconstruction]. And I was too scared to have it done.” Information Gathered by Patients “Because they cut your stomach, and there is a vein in there...and if you have ever smoked, they won’t do it anyway.” “I don’t know if they do everyone, but they brought my muscle from my back.” Reasons for Reconstruction “I thought...I don’t want to...be reminded that I had breast cancer. I want to just get through this thing and forget it.” “I think that’s why a lot of women do [breast reconstruction]...because they don’t want to be reminded, they don’t want to see the scars and the ugliness.” “Well I couldn’t look at myself. I mean, I was so horribly disfigured.”
Proposed education materials	“If it’s [educational materials] too technical, women are just gonna glance over it and that’s gonna be it.” Need for Pre-emptive Education “I just think we need to get the information out to everybody before they even have the situation [breast cancer].” “I think it should just be common knowledge [breast reconstruction]. Just common knowledge.” Television/Video as a Method “They can put it [breast reconstruction educational materials] on their information television if you’re in the specialist’s office.” “Put it [breast reconstruction educational materials] on TV.” Social Media as a Method “What about Facebook and Twitter and using social media?” “I would think for the younger generation, social media would be the way to go.”
Positive impact of plastic surgeons on the community	Role for Surgeons Remains “She has made me feel pretty again. Like, I couldn’t even look at myself [before].”

**Cost as a Barrier to Access**

Cost of care and the reality of the consumer-opaque cost structure is a clear barrier to care in this rural community. Participants also mentioned the gap in insurance coverage resulting from Medicaid income regulations as a serious issue within their community.

*“That’s the sad thing is, people don’t get any health care because it costs so much money until they’re very, very ill, and sometimes it’s too late to get help.”*

**Age Misconceptions Prevent Care**

Interestingly, an overlapping theme from all three focus groups was the role that age played as a barrier to

accessing medical care and breast reconstruction. Many older women tended to forego breast reconstruction, citing their advanced age as their rationale.

*“Yeah, I was 61. If I’d have been in my 40’s, I may have made a different choice [regarding breast reconstruction.]”*

**Impact of Community on Perceptions of Breast Reconstruction**

When considering participants’ perspectives on breast reconstruction, they were largely influenced by word of mouth and other gathered information. Much of what participants reported hearing regarding breast reconstruction was negative and fear-invoking.



*“I just heard these horror stories and I just thought...  
Being cut from here to here. I can’t go through that now.”*

#### **Evidence of Patient Education**

Focus group participants also detailed specifics of breast reconstruction, including surgical approaches (ie, latissimus flaps), microvascular reconstruction, and comorbidity identification and counseling.

*“Because they cut your stomach, and there is a vein in there...and if you have ever smoked, they won’t do it anyway.”*

*“I don’t know if they do everyone, but they brought my muscle from my back.”*

#### **Suggestions to Solve Existing Educational Gaps**

Consistent themes also emerged when participants were prompted to provide suggestions for education regarding the availability of breast reconstruction. Three themes most commonly uncovered were as follows: (1) the need for preemptive education; (2) the utility of visual learning for patient education; and (3) social media as an educational tool for certain patient populations.

Early education for women regarding breast reconstruction was also highlighted in all 3 focus groups. Focus group participants largely agreed that knowledge regarding breast reconstruction should be widely dispersed and accessible to all.

*“I just think we need to get the information out to everybody before they even have the situation [breast cancer].”*

The use of video emerged as a specific approach to breast reconstruction education. Specifically, women discussed the use of educational videos in both physician offices and on television.

*“They can put it [breast reconstruction educational materials] on their information television if you’re in the specialist’s office.”*

*“Put it [breast reconstruction educational materials] on TV”*

Finally, social media was highlighted as a medium for breast reconstruction education and further communication.

*“I would think for the younger generation, social media would be the way to go.”*

#### **Impact of Plastic Surgeons on the Community**

Although patient perspectives influenced by word of mouth were often negative and fear-invoking, focus group participants who underwent reconstruction themselves tended to recognize its importance. These opinions reaffirm the important role that plastic surgeons play in the surgical management and overall care of breast cancer.

*“She has made me feel pretty again. Like, I couldn’t even look at myself [before].”*

## **DISCUSSION**

### **Assessing Access to Health Services**

A popular framework for understanding and gauging access to health care services was initially described by Penchansky and Thomas<sup>18</sup> in 1981. The framework comprised of 5 “A’s” that include accessibility, affordability, availability, accommodation, and acceptability. Accessibility to the relationship between provider supply and patient location, also accounting for transportation, is a potential barrier. Availability refers to appropriate supply in the volume of care needed for a given population. Affordability describes concordance (or lack thereof) among consumers’ financial status, socioeconomic status, insurance status, and price for health care services. Accommodation describes the level to which services have been built to accept patients (eg, walk-in clinics, insurance preauthorizations, appointment scheduling systems) and the level to which patients are able to adapt to these systems. Acceptability refers to the positioning and relationship of a patient and their health care providers regarding the personal characteristics of one another. Key “A’s” from the framework by Penchansky and Thomas<sup>18</sup> that emerged from the focus group data include accessibility, affordability, and accommodation.

Focus group participants repeatedly cited accessibility, long distances to their physicians as reasons for not presenting for care. Due to poverty within the area, access to transportation is not a given, leading patients to go without care. This issue is exemplified by the solution of the traveling mammogram bus which delivers care to patients in their communities. “The bus,” as it has come to be known, was the most frequently mentioned existent solution to the pervasive issue of care accessibility.

Unfortunately, affordability was another common theme which emerged throughout the survey participants. Participants frequently highlighted the heavy burden which costs of care have weighed on their families. Specifically, one participant mentioned that a family member’s current costs of care has prevented her from seeking breast care. These stories are not uncommon, and we postulate, after speaking to study participants, that they play a clear role in the lack of overall breast health within West Virginia. Commentary from the group regarding copays, prescription charges, and lack of charge visibility all come together to show the importance which affordability of care has on this rural community.

Accommodation, the extent to which healthcare has been “built” to serve patients, was also an issue emphasized by participants. Participants touched on preauthorizations from their insurance companies as barriers to care even after being diagnosed with a “breast lump.” Other issues, including a lack of overall social support in the way of disease support groups and home support that would allow women to leave their household and children to care for themselves, also highlighted accommodation of the healthcare system as an issue in this rural community. Moreover, our focus groups brought forth a sentiment many have previously described, which is that patients feel unsupported in their health care journey. As surgeons in

the community, we must be able to appreciate the barriers to care that these patients experience and make a concerted effort to support them from diagnosis to recovery.

Falling outside of the aforementioned Pechansky framework, but a critical insight from our analysis, was the impact which the community had on participant's views of breast reconstruction. Two key themes, which clearly were not perpetuated by the healthcare system, emerged. The first theme was the impact of word of mouth on perceptions of breast reconstruction. Repeatedly, we heard study participants (most of which had never experienced the procedure themselves) highlight "horror stories" of breast reconstruction, citing complications, poor care, and abandonment. Regardless of whether these stories are a form of confirmation bias, physicians must do better to educate this population of their options, potential risks, and complications which will thus dispel the fear which underlies breast reconstruction procedures.

The second theme not encompassed by the Pechansky framework was the importance of age on perceptions of breast reconstruction. We found many participants citing their age as a reason for not considering breast reconstruction. This sentiment was pervasive in the focus groups and, considering the current literature regarding safety of breast reconstruction in the elderly,<sup>19,20</sup> should be dispelled in this rural community.

#### Access to Breast Reconstruction

Studying access to breast reconstruction has long been a research topic for plastic surgeons,<sup>21</sup> especially in the wake of important policy actions such as the WHCRA and Breast Cancer Patient Education Act. A recent systematic review by Retrouvey et al<sup>22</sup> assessed access to breast reconstruction by evaluating nearly 100 qualitative and observational studies. By applying a modified version of the framework by Pechansky and Thomas<sup>18</sup>, adding a sixth "A" to include awareness, the group further described barriers related to breast reconstruction access. Unsurprisingly, availability varied based on hospital size, type, and provider base. Patients who reside in nonmetropolitan and rural areas or were required to travel greater distances to plastic surgeons were largely found to have decreased accessibility. Furthermore, accommodation was associated with decreased access to breast reconstruction when plastic surgeons were limited in their operating room time. Affordability influenced by payer type and was adversely impacted by women who have lower median household incomes. Finally, acceptability was influenced greatly by physician characteristics, physician beliefs, and patient factors. These findings suggest that breast reconstruction access is inherently complex and there is much work to be done to ensure sufficient and equitable access to reconstruction.

Numerous studies have assessed and quantified access to breast reconstruction for rural women in the United States.<sup>23–26</sup> An important limitation of the existing literature, as it relates to breast reconstruction access, is the lack of qualitative focus group-based studies. As a result, few studies have sought to obtain rural patient's true perspectives regarding access and knowledge of breast

reconstruction. Understanding women's beliefs and perceptions directly from the populations of interest in the form of qualitative-based focus groups uniquely permits physicians to design targeted interventions to mitigate barriers in access to care, dispel myths to more positively influence perspective, and appropriately educate the patient population in a way that they deem as being helpful and appropriate.

After extensive review of the literature, this is the first qualitative, focus group-based study to assess perspectives and barriers to access to breast reconstruction in a rural patient population. Although some of the themes uncovered in our study are reflective of other challenges to access (including cost and patient age), more unique barriers such as lacking access to adequate transportation to reach specialized health services were also realized.

Moreover, no studies have queried this population for potential-specific interventions that could be undertaken by providers for the improvement of access and knowledge regarding reconstruction. The key themes of lacking access to breast reconstruction described here by our focus group participants included lacking transportation, cost, social support, societal misperceptions, and patient age. Perspectives related to breast reconstruction were largely formed and influenced by word of mouth and information gathered by women themselves from external resources. Unfortunately, focus group participants' perspectives did not seem to be influenced from education by health care providers. Potential means by which awareness and knowledge may be increased, according to focus group participants, included preemptive education, audiovisual education through television and videos, and social media educational campaigns.

#### LIMITATIONS

Despite the important findings discussed, there are inherent limitations associated with the methodology of qualitative focus group-based studies including potentially limited generalizability and definitive obtainment of theme saturation to comprehensively understand patient perspectives. Additionally, this was a convenience sample of women who willingly participated in our focus group, and perspectives of this participant population may not be representative of female breast cancer patients or female patients who have undergone breast reconstruction. Finally, based on the health care access metrics assessed in the survey component of the study, most of the focus group participants had a designated primary care physician, had health insurance, and had received a mammogram in the past 2 years; again, this may not be representative of the larger rural West Virginia female population.

#### CONCLUSIONS AND FUTURE DIRECTIONS

Rural women from West Virginia have unique and important perspectives concerning breast reconstruction related to accessibility, accommodation, affordability, and other themes outside of established frameworks. Ability to obtain transportation to seek specialized health services that come with breast reconstruction, prohibitively large

costs, lack of social support, and potential adverse viewpoints from word of mouth may all contribute to unique reconstruction barriers for this population. Further, these women have specific suggestions for mitigating a lack of breast reconstruction knowledge including preemptive education through social media and video formats. Based on the findings from this study, we intend to work with rural communities and physicians to implement focus group participant suggestions and improve knowledge to address barriers to breast reconstruction for rural women. Our overarching aim is to promote equality in access to reconstruction.

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